Understanding Care Transitions from the Perspectives of Persons with Dementia and Their Caregivers: A Grounded Theory

by

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AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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ABSTRACT

Introduction: The proportion of the Canadian population living with dementia is rising. Since persons with dementia are intensive health care service users, they have many contact points with various health care providers and settings. Consequently, they may be required to navigate through an often-fragmented care system. Transitional care, which involves the coordination and continuity of care for patients moving within or between care settings, has the potential to improve transitions for persons with dementia and their caregivers. Despite being recognized as a policy and research priority, transitional care for persons with dementia and their caregivers is poorly understood.

Objective: This study aimed to fill gaps in the understanding of care transitions from the perspectives of individuals with dementia and their informal caregivers through the development of a theoretical framework outlining factors that contribute to the processes care transitions in this population. Research questions addressed what was important to persons with dementia and their caregivers as they moved throughout the health care system as well as the challenges that they faced during health care system transitions.

Methods: Constructivist grounded theory methods were used to build an understanding of the care transitions of persons with dementia and their caregivers. Individual or dyad interviews were conducted, recorded, and transcribed verbatim. Through initial and focused coding, themes and relationships between themes emerged and framework development began. Data collection and analysis occurred iteratively until saturation was reached.

Results and Discussion: A three-part theoretical framework outlining the context, processes and influencing factors of care transitions emerged from the data. Elements of context included the existence of multiple realities and goals among those involved in transitions, the broader community, and the parallel experiences of others navigating the system. Phases of transition processes experienced during the dementia journey were a transition into the dementia care system, a continuous process of management and follow-up, and the adjustment to a new home. Four categories of influencing factors were described by participants: catalysts (causes of transitions), buffers (intermediary actions to ease future transitions), facilitators (factors that help transitions), and obstacles (factors that hinder transitions). This study suggests that transitions are complex; there is no single, simple remedy for the challenges of transitions. However, gaining an in depth understanding of the care transitions of individuals with dementia is an important step in improving transitions for this population.

Knowledge translation and significance: The results of the study may be useful in the creation of recommendations for improving the care transition experiences of individuals with dementia and their caregivers. Furthermore, the consultations contributed to dementia strategy development in Ontario. Transitional periods represent a time of risk for adverse events and a high level of caregiver stress; therefore, this study has the potential to improve the quality of care and quality of life of persons with dementia and their informal caregivers.

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Overview

Persons with dementia represent a growing population of intensive health care service users in Canada (Alzheimer Society of Canada [ASC], 2010; Gill et al., 2011). Those with dementia and their informal caregivers have many contact points with various health care services (British Columbia Ministry of Health, 2007; ASC, 2010; Gill et al., 2011) and may be required to navigate through multiple sectors of a fragmented health care system during the processes of diagnosis, treatment and care management (ASC, 2010; Callahan et al., 2012). Persons with dementia experience more transitions than other older adults and may face unique barriers while navigating the health care system (Callahan et al., 2012; Change Foundation, 2012).

Care transitions are significant because inadequate transfers of information and medication errors may put patients at risk for adverse outcomes (McMurray, et al., 2013; Forster, et al., 2003; Moore, et al., 2003; Kripalani et al., 2007). Transitions may also cause stress, grief and exhaustion in caregivers and unnecessary costs to the health care system (Afram, Verbeek, Bleijlevens, & Hamers, 2014; ASC, 2010). Transitional care, a term which encompasses any actions taken to ensure the coordination and continuity of care for individuals moving between or within care settings, has the potential to improve care transitions for individuals with dementia (Coleman & Boult, 2003). Currently, there is no consensus on how transitional care should be provided (Manderson et al., 2012).

Although transitional care and system navigation have been identified as policy and research priorities (ASC, 2010; Stolee et al., 2011), there remains a gap in the literature on how

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to best provide transitional care to those with dementia and their caregivers (Piraino et al., 2012).

This study aimed to a) illuminate factors that were important to individuals with dementia and

their caregivers as they transitioned throughout the health care system and b) examine the

challenges they faced while moving within or between health care settings. The primary

objective of the study was to use this information to fill gaps in knowledge by developing a

theoretical framework outlining care transitions from the perspectives of persons with dementia

and their caregivers.

Constructivist grounded theory methods enabled the development of a theoretical

framework for care transitions that was built upon the views of those living with dementia and

their caregivers. Interviews with persons with dementia and their caregivers, conducted either

individually or in dyads (depending on participant wishes), were recorded and transcribed.

Coding processes, consisting of initial and focused coding, allowed the researcher to draw out

themes, sub-themes, and interactions. Throughout the research process, memoing and reflexivity

helped the researcher remain true to participant voices and aided in the process of theory

development (Charmaz, 2006). The theoretical framework was developed emergently and

iteratively; the processes of sampling and analysis were carried out simultaneously until no new

ideas emerged from the interviews.

A three-part theoretical framework describing the context, processes, and influencing

factors of care transitions from the perspectives of individuals with dementia emerged from the

iterative process. The transition context aspect of the framework consists of three components:

the conflict or harmony of multiple sets of realities and goals, broader community and social

support for persons with dementia and their caregivers, and the parallel experiences of others

navigating the dementia care system. The transition processes are comprised of three main phases that are linked to stages of the dementia journey: a transition into the system that was signified by a diagnosis of dementia, a continuous process of management and follow-up that was facilitated by coordination and continuity efforts, and a transition into long-term care that required an adjustment to a new home. A perceived 'final transition' occurred at different points for caregivers, including the transition out of the home or the death of an individual with dementia. Finally, four types of influencing factors emerged from the data. First are catalysts, or factors that lead up to or cause transitions. Second are buffers, which are intermediate influences that can ease future transitions. The final two types of influencing factors are facilitators and obstacles, which help and hinder transitions respectively.

Gaining an understanding of important aspects of transitions from the perspectives of those with dementia and their caregivers is important because it will allow providers to view transitions through a lens that has often been overlooked. Although the creation of specific recommendations for improving care transitions in this population was not the aim of this study, the results do have several implications for health care practice. Furthermore, some of the knowledge that was generated through consultations persons with dementia and caregivers has informed the creation of strategies for integrated dementia care in Ontario (Geriatric Health Systems Research Group, 2015). The results have the potential to influence health care policy and practice, thus improving the care transition experiences and quality of life of individuals with dementia and their caregivers.

Chapter 2

Background and Literature Review

2.1 Introduction

The term 'dementia' refers to a number of disorders wherein brain damage leads to a progressive decline in cognition and memory (ASC, 2010). These disorders are often irreversible and ultimately fatal, as in the case of Alzheimer's disease, in which damage to links between brain cells results in cell death (ASC, 2010). Alzheimer's disease and vascular dementia are the most common dementias, constituting approximately 83% of all Canadian cases (ASC, 2010). Other less common forms of dementia include mild cognitive impairment, frontotemporal dementia, Lewy body dementia, and Parkinson's dementia (ASC, 2014).

Although the clinical presentation of dementia varies according to type, some common symptoms include memory loss, poor judgement and reasoning, mood changes and alterations in communication abilities (ASC, 2010). Dementia is often accompanied by behavioural disturbances and depression, which have implications for the ability of individual with dementia to perform activities of daily living (ADL) (Cipher & Clifford, 2004). ADL dependence is a significant consequence of dementia due to its association with poor quality of life among persons with dementia as well as depression among informal caregivers (Andersen, Wittrup-Jensen, Lolk, Andersen & Kragh-Sorensen, 2004; Covinsky et al., 2003).

The complexity of the dementia experience is further intensified by a high prevalence of comorbid conditions in those with dementia (Naylor, Hirschman, Bowles, Bixby, Konick-McMahan & Stephens, 2007). In a sample of 3,013 American patients, Schubert and colleagues (2006) found that individuals with dementia had an average of 2.4 chronic conditions and were

prescribed 5.1 different medications. Furthermore, Bynum and colleagues (2004) found that the likelihood of having over four select chronic conditions was three times higher in persons with dementia compared to those without dementia. An international scoping review conducted by Bunn and colleagues (2014) revealed a high prevalence of specific conditions such as diabetes and stroke in populations with dementia. Ten of the 11 studies examined in the scoping review compared receipt of treatment or services in those with and without dementia and found that quality of care or access to services was worse for those with dementia compared to those without a dementia diagnosis (Bunn et al., 2014). Although comorbidity indicates an advanced level of medical complexity and need for support, this support is not always provided.

Approximately 1.5% of the Canadian population has a diagnosis of dementia, and this proportion will nearly double over the next 30 years (ASC, 2010). A similar increase in the prevalence of dementia is expected within Ontario specifically (Hopkins, 2010). Due to a projected constraint in long-term care (LTC) bed availability, there will be an accompanying 10% increase in the number of individuals with dementia living at home and accessing support through community care services (ASC, 2010). Compounding the severity of the situation, there is evidence that the aging baby boomer generation is unprepared for this rise in Alzheimer's disease and dementia; a survey of Canadian baby boomers indicated that approximately one quarter of participants could not cite any early signs of the disease (ASC, 2011).

The rise in community-dwelling dementia patients will place an increasing burden on both informal and formal health care systems (ASC, 2010). Annual unpaid informal caregiving hours are expected to increase from 231 million to 756 million hours over the next 30 years (ASC, 2010). The formal health care system will also incur a considerable increase in economic burden,

including a ten-fold increase in the direct health care costs of dementia (ASC, 2010). These projections, in conjunction with evidence suggesting that persons with dementia are an inadequately served and complex population, highlight a need for the effective coordination of health care and community support services for individuals with dementia and their informal caregivers (Bunn et al., 2014).

2.2 Dementia and Health Care System Use

Due to the complexity of dementia and a high prevalence of comorbid conditions in this population, those with dementia and their caregivers contact various sectors of the health care system at multiple points during the continuum of care (Gill, Camacho & Poss, 2011). Points of contact may include care coordination services, community support services, primary care, and acute care (ASC, 2010; Alzheimer Society of Ontario [ASO], 2012; Gill et al., 2011; Ontario Association of CCACs [OACCAC], 2013).

Persons with dementia have greater contact with the health care system than other older adults; a study assessing health system use among frail seniors found that community-dwelling older adults with dementia "were more intensive users of health care services across the spectrum…than older adults without dementia" (Gill et al., 2011, p. 68). Specifically, hospital and emergency department visits, length of hospital stay, alternative level of care (ALC) designations, physician visits and use of home care services were all more common in persons with dementia (Gill et al., 2011).

A majority of older adults with dementia (73%) will be hospitalized at least once during a given year (Callahan et al., 2012). Individuals with dementia have nearly four times greater odds of hospitalization than those without dementia (Bynum et al., 2004). Gozalo and colleagues

(2011), in a study assessing end-of-life care in nursing home residents with cognitive issues, found that 8.1% of the sample had multiple hospitalizations in the last 90 days of life. The high rate of hospitalizations among those with dementia is particularly significant given that hospitalization in the previous year is associated with an approximate twofold increase in risk of death (Aneshensel, Pearlin, Levy-Storms & Schuler, 2000).

Not only are hospitalizations common among individuals with dementia, but they are also more likely to wait for appropriate care than other patients once hospitalized (CIHI, 2012). Alternate Level of Care (ALC) designations signify individuals who remain in hospital past the point at which they require acute care services (CIHI, 2009). The Canadian Institute for Health Information (CIHI, 2012) found that dementia was among the most common reasons for admission of ALC patients in Canada. Over half of hospitalizations that cite dementia as the primary diagnosis had at least one ALC day between 2007 and 2008 (CIHI, 2009). Furthermore, ALC length of stay was higher if an individual was admitted for dementia-related reasons, indicating that persons with dementia wait longer for appropriate care than other individuals (CIHI, 2009).

Specialist consultations also contribute to high levels of health care use among persons with dementia. The majority of individuals with dementia (87.3%) will visit a specialist at least once during a given year (Gill et al., 2011). Qualitative data further illuminate the frequent use of specialist consultations, indicating that many family physicians limited confidence in their diagnostic abilities and are even less self-assured when it comes to care management, reporting a reliance on specialist referrals and specialized services (Turner et al., 2004; Heckman, et al., 2011). Primary care providers in North America have indicated that difficulties in managing

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dementia are a product of health care system issues rather than deficits in their own abilities (Koch & Iliffe, 2010), suggesting that their roles might be facilitated by health system supports and strategies.

2.3 Care Transitions in a Fragmented System

Because older adults with dementia frequently access a wide range of health care services, they will experience transitional periods during which they will be required to navigate through an often-fragmented health care system (Hollander & Prince, 2002; Manderson, et al., 2012). A health care transition can be defined as "the movement patients make between health care practitioners and settings as their condition and care needs change during the course of a chronic or acute illness" (Coleman, 2011, para. 1). Significant transition points in an individual's condition, and thus in his or her care needs, may include initial diagnosis, loss of independence (e.g., the ability to drive), changes in residential environment, and the need for end of life care (British Columbia Ministry of Health, 2007). Despite a wide range of health care and support services available to persons with dementia and their caregivers at these transition points, service providers and patients have criticized service delivery as disorganized and poorly integrated (ASC, 2010; Forbes et al. 2008; Hollander & Prince, 2002; Smale & Dupuis, 2002).

Modern medicine in Canada is largely organized according to organ systems, resulting in a high degree of specialization in the health care system (Hogan, 2007). Health care specialization influences the provision of health care in that it necessitates the movement of patients from provider to provider or setting to setting in order to meet different health needs. Fragmentation of care for older adults remains an important issue due to the growth in formal and informal services available to the aging community (Clarfield, Bergman & Kane, 2001). The

wide array of services may cause confusion and difficulty in navigating the system among older adults. The Change Foundation (2012) assessed the health care system navigation experiences of seniors and their caregivers in Ontario and found that only about one third of participants believed that they could easily navigate to the next step in the treatment process.

Issues with health care fragmentation are particularly significant for individuals with dementia given the number of transitions they experience. Callahan and colleagues (2012) found that those with dementia had more care transitions per person-year of follow-up and more total transitions compared to subjects without a dementia diagnosis. Aaltonen and colleagues (2012) discovered a similar trend; persons with dementia experienced 4.2% more total transitions than those without dementia.

In addition to experiencing more transitions than other older adults, persons with cognitive difficulties may face unique challenges as they navigate through the health care system. Participants of a study investigating factors that contribute to successful transitions from the nursing home to the emergency department identified compromised cognition as a "unique challenge" in effective transitions due to an increased need for family involvement (Robinson et al., 2012, p. 421). Similarly, participants of the Change Foundation's (2012) study on the system navigation experiences of seniors noted that seniors with cognitive deficits, such as those with dementia, might face additional barriers as a result of stigmatization and a greater reliance on caregiver assistance.

2.4 Informal Caregivers: An Important Consideration during Care Transitions

As indicated by the comments made by participants of the Change Foundation's (2012) study, informal caregivers are central to the health care transitions of individuals with dementia. Ward-

Griffin and colleagues (2012) found that, in Canada, informal care is commonly regarded as inexhaustible and primary, whereas formal care is viewed as scarce and supplementary. These findings indicate an extreme reliance on informal care. Furthermore, caregiver characteristics (e.g., age and caregiver burden) may predict the occurrence of certain transitions among those with dementia, such as nursing home placement (Yaffe et al., 2002). The close linkage of person with dementia and caregiver outcomes was well articulated by Bloomer and colleagues (2014) in their suggestion that "[the] care process must consider the dyad of carer and patient, as they are often tightly entwined" (p. 9). As such, it is important to examine the informal caregiver's needs, feelings and opinions alongside those of persons with dementia during both transitions and the study of those transitions.

Informal caregivers of individuals with dementia have emotional, informational and relational needs during care transitions, which are overlooked in many cases (Afram et al., 2014). For example, Kelsey and colleagues (2010) found that a majority of caregivers were inadequately informed about policies for transferring persons with dementia to memory care units in assisted living facilities. These unmet needs, among other factors, contribute to stress, grief and exhaustion among informal caregivers of persons with dementia (Afram et al., 2014). A failure to attend to the needs of informal caregivers during transitions may be attributable to a lack of understanding of caregiver needs by formal care providers (Singh, Hussain, Khan, Irwin & Foskey, 2014).

Although these findings indicate a need for increased attention to informal caregivers during the health care transitions of individuals with dementia, there is some evidence that the presence of an informal caregiver may result in the neglect of the views of those with dementia

during decision-making (Sury, Burns & Broadaty, 2013). That said, caregivers can provide important information to consultations that might not be possible to obtain by speaking with individuals with dementia alone. For instance, in a study exploring transfers of persons with dementia from acute to sub-acute care, Digby, Moss and Bloomer (2012) found that only three of eight participants with dementia were able to recall the transition at all. Consequently, during the occurrence and study of transitions, providers and researchers must balance their consideration of person with dementia and caregiver views. This balance of perspectives will allow for a better understanding of the needs of and challenges faced by both individuals with dementia and their informal caregivers while navigating the health care system.

2.5 Significance of Care Transitions

The challenges of care transitions have significant consequences for quality of care and quality of life. Transitional periods represent a time of increased patient vulnerability and risk (Coleman, 2003). For example, Bookvar and colleagues (2004) found that at least one medication was altered in 86% of transitions from nursing homes to hospital and 64% of transitions from hospital to nursing homes. One fifth of these bidirectional transfers were associated with an adverse drug event (Boockvar et al., 2004). Such medication errors and other adverse events during transitions may compromise patient safety (Forster, et al., 2003; Moore, et al., 2003).

Gozalo and colleagues (2011) defined the concept of a "burdensome transition" through consultations with health care providers and family members with lived nursing home transition experiences. According to this definition, a transition can be considered burdensome if a) it occurred in the last 3 days of life, b) there was a lack of continuity of nursing homes before and

after hospitalization, or c) there were multiple hospitalizations in the last three days of life. Estimates of the proportion of LTC residents with cognitive issues or dementia who experience burdensome transitions range from 9.5 – 19 percent (Gozalo et al., 2011; Aaltonen et al., 2014); however, studies on burdensome transitions among Canadian persons with dementia have not yet been conducted. Although the definition of a burdensome transition is setting-specific and relatively narrow in scope, these statistics suggest that a significant proportion of those with impaired cognition experience transitions that could be detrimental to their quality of life.

A higher risk of burdensome transitions among persons with cognitive deficits is associated with communication and care planning issues (e.g., lack of advanced directives, do not hospitalize orders, or do not resuscitate orders) (Gozalo et al., 2011). Direct communication between acute and primary care physicians often does not occur, and discharge summaries frequently miss important information (Kripalani et al., 2007). These inadequate transfers of information are common (McMurray, et al., 2013) and may negatively impact quality of care and subsequent outcomes (Kripalani et al., 2007).

Although unmet care needs are a large source of potential issues associated with transitions, factors that are less directly related to the actions of physicians and other formal care providers can also cause problems during transitional periods. For example, feeling abandoned by family and a perceived lack of control can contribute to the poor adjustment of persons with dementia during the transition into a nursing home (Sury, Burns & Brodaty, 2013). These findings suggest that the challenges associated with transitions are complex and, thus, require a multifaceted response. Effective transitional care can help resolve issues related to care transitions.

2.6 Transitional Care and Related Concepts

Transitional care can be defined as "a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location" (Coleman and Boult, 2003, p. 556). In order to fully grasp the concept of transitional care, its two main concepts (i.e., coordination and continuity of care) must also be understood. There is no singular, agreed upon definition of care coordination; however, the general goal is to provide appropriate care to people when and where they need it (McDonald et al., 2007). Key elements include role clarity, information exchange, and integration of care activities between multiple individuals (McDonald et al., 2007). Continuity is related to how individuals experience care over time (Reid, Haggerty, & McKendry, 2002). If efforts to ensure coordination are successful, then patients will experience care as continuous rather than fragmented (Reid, Haggerty, & McKendry, 2002). When combined, these concepts can result in successful transitional care. It is likely that improved transitional care could have significant benefits for individuals with dementia and their caregivers, including improved patient satisfaction and quality of life; however, there is a lack of consensus on the best model for providing this integrated care (Manderson et al., 2012). Existing care coordination, care continuity, and transitional care interventions and models can provide insight into common approaches to supporting individuals through transitions in care.

2.6.1 Providing coordinated care

In a support-based intervention proposed by the Alzheimer Society of Canada (ASC), all persons diagnosed with dementia would be assigned a system navigator to provide them with care coordination (ASC, 2010, p. 33; Naylor & Van Cleave, 2010). It is expected that this

intervention would reduce the economic burden of dementia, delay long-term care admissions and reduce caregiver burden (ASC, 2010). These outcomes are particularly significant given preferences of older adults to remain in their homes and communities and emphasize the importance of care transition support in terms of the quality of life of persons with dementia and their caregivers (Dye, Willoughby & Battisto, 2011).

The creation of system navigator roles similar to those proposed by the ASC has proven effective in different disease-specific groups. For example, an evaluation of a Cancer Patient Navigator role implemented in Nova Scotia found that patient navigators were particularly beneficial in dealing with emotional, informational and logistical needs (Cancer Care Nova Scotia, 2004). Similar needs are evident in experiences of persons with dementia in primary care (Prorok, et al., 2013); therefore, it is likely that these roles will be useful for persons with dementia.

Judge and colleagues (2011) described an example of an existing care coordination intervention for individuals with dementia called Partners in Dementia Care (PDC). Major aspects of the intervention include formal partnerships between community organizations and primary care, multidimensional assessment and treatment, ongoing monitoring and relationship formation, and a computerized information system (Judge et al., 2011). Since care coordinators reported experiencing few barriers, it was determined that the intervention was feasible and acceptable. However, the views of persons with dementia and their family members were not considered in the development or evaluation of the intervention; it was developed based on the Chronic Care Model and evaluated using a care coordinator survey (Judge et al., 2011). Thus, it

is unclear whether the model actually addresses aspects of transitions that are important to those with dementia and their caregivers.

2.6.2 The concept of continuity

A systematic review conducted by Reid and colleagues (2002) identified three concepts of care continuity: informational, relational, and management continuity. Informational continuity involves using information from past health care encounters to connect and inform current and future care. In order to achieve relational continuity, an ongoing relationship must be formed between a patient and one or more health care providers. Finally, management continuity is defined by a shared management plan that facilitates appropriate service provision (Reid et al., 2002).

In another systematic review, Servellen, Fongwa and D'Errico (2006) examined the extent to which continuity of care was associated with quality of care for individuals with chronic conditions. It was noted that the literature supports relationships between continuity and patient satisfaction, early diagnosis, compliance, and reduced use of resources (Servellen, Fongwa, and D'Errico, 2006). However, the results indicated that continuity of care was often considered as one of many contributors to quality of care, suggesting that it does not function alone. Furthermore, many of the interventions described in the review aimed to improve care coordination and transitional care; continuity was either conceptualized as an aspect of these constructs or a more secondary result of interventions (Servellen, Fongwa, and D'Errico, 2006). This idea aligns with this study's focus on transitional care, which encompasses both coordination and continuity of care.

2.6.3 Transitional care models

Transitional care interventions and models have been established to develop system navigation skills among patients, families, and providers. Two models of transitional care that have been proposed are the Care Transitions Intervention (CTI) and the Transitional Care Model (TCM) (Coleman, Parry, Chalmers & Min, 2006; Naylor & Van Cleave, 2010). The CTI is based on four pillars that represent patient and caregiver values identified through qualitative research: medication self-management assistance, a patient-centred record that is owned and maintained by the patient to facilitate information transfer, timely follow-up, and knowledge of "red flags" that signify worsening conditions coupled with response instructions (Coleman et al., 2002; Coleman, Parry, Chalmers & Min, 2006). The primary aim of the CTI is to provide patients and caregivers with support as well as the tools to participate more actively in their care transition. Though it has proven useful in reducing hospital readmission rates in older adults, it has not been tested with persons with dementia and their caregivers (Coleman, Parry, Chalmers & Min, 2006).

Unlike the CTI, the subjective experiences of patients and caregivers were not considered in the development of the TCM; instead, it was developed on the basis of an existing framework, then tested using randomized controlled trials (Naylor et al., 1999; Naylor et al., 2004; Brooten et al., 2002). The TCM was developed to promote early discharge in high-risk patients using a transitional care program facilitated by Advanced Practice Nurses (APNs), now also referred to as transitional care nurses (TCNs). The essential elements of the TCM include a nurse with advanced knowledge and skills in the care of older adults serving as a care coordinator, collaboration with team members, regular home visits, continuity of care through follow-up, a holistic focus on the goals and needs of the patient, active patient engagement and early

identification of and response to risk (Naylor & Van Cleave, 2010). Qualitative research conducted by Bradway and colleagues (2012) indicated that the TCM may have value in populations of cognitively impaired older adults; however, it was recommended that "future research should explore patient and caregiver perceptions of the challenges and facilitators to transitional care" for comparison to this TCM-specific study (p. 405).

2.6.4 Important aspects of care transitions: Common elements among existing models

The elements of transitional care, care coordination, and continuity of care identified in the models presented in this section serve as a representation of some important aspects of care transitions. These existing models can be included within the category of sensitizing concepts, which were described by Blumer (1969) as general concepts that researchers begin with in order to provoke them to ask certain types of questions of their participants. Some common elements among a dementia-specific care coordination model (the PDC), a conceptualization of care continuity (concepts of continuity) and two transitional care models (the CTI and TCM) are presented in Table 1. Only one of the models presented (the PDC) was dementia-specific, and it was not developed based on the views of individuals with dementia. The only model that directly considered patient views in its development (the CTI) has not been tested in individuals with dementia. Therefore, before recommendations can be made regarding the use of these models or roles in populations with dementia, a better understanding of the important aspects care transitions from the perspective of persons with dementia and their caregivers is required.

Table 1. Common Elements among Existing Models

Common Element	Care Transitions Intervention (Coleman, Parry, Chalmers & Min, 2006)	Transitional Care Model (Naylor & Van Cleave, 2010)	Partners in Dementia Care Model (Judge et al., 2011)	Concepts of continuity (Reid, Haggerty & McKendry, 2002)
Self-management	Medication self-management assistance	Managing symptoms, educating/ promoting self-management	Self-management of dementia	(N/A)
Patient-centeredness	Patient-centred record	Holistic focus on patient-needs	Consumer directed philosophy	Importance of knowledge of patient as a person
Follow-up	Timely follow-up, home visit	Regular home visits, telephone support	Care coordinators make ongoing follow-up calls	Ongoing relationship with providers
Identification of "Red Flags"	Identification of "red flags" and instructions	Early identification and response to health risks and symptoms	(N/A)	(N/A)
Professional collaboration and information transfer	Encourage patient to share personal health record with primary care provider and/or specialist	Physician-nurse collaboration	Formal linkages between community organizations and primary care	Informational continuity
Engagement	Patient understandings and manages a personal health record	Active engagement of patients and caregivers	Coordinators empower dyads to manage their care	(N/A)

Arguably, a well-integrated health system might obviate the need for programs or services

for the specific purpose of helping a patient navigate the system (The Change Foundation, 2013).

Such an ideal system is unlikely to be realized in the near future, however, and in the meantime,

patients and families dealing with complex health conditions such as dementia would benefit from improved care transition support.

2.7 Transitional Care in Ontario: An Overview of Available Services

A specific transitional care role (e.g., a system navigator) has not been established within the dementia care system in Ontario; however, services that aid in care management and coordination do exist. For example, many Alzheimer Society chapters in Ontario offer First Link programs, which aim to connect individuals with dementia and their caregivers to dementia-specific information and services within their communities (ASO, 2012). An Alzheimer Society representative reaches out to individuals who have been diagnosed with dementia in order provide them with information and support. Follow up contact is maintained in order to keep the individual with dementia and his or her caregiver well informed about the disease, planning for the future, tips and services (ASO, 2012). An evaluation of the First Link program conducted by McAiney and colleagues (2012) found that the program has been largely successful in achieving its objectives, including enhancing connections between the Alzheimer Society, primary care practitioners and other care providers.

In 2006, the McMaster University Centre for Family Medicine Family Health Team (FHT) in Kitchener developed a primary care-based memory clinic to address challenges in the dementia care system and to promote interdisciplinary management of dementia through a focus on collaborative care (Lee et al., 2010). More recently, the Alzheimer Society of Ontario partnered with some memory clinics with the goal of improving the system of care for persons with dementia. Alzheimer Society representatives have been embedded in some care teams in order to fill various gaps in the dementia care system, and results to date are promising. Lee and

colleagues (2014) found that the partnership between memory clinics and the Alzheimer society has increased initial referrals to the Alzheimer Society of Ontario and improved the integration of primary and community care services.

The Integrated Geriatric Service Worker (IGSW) initiative had similar goals. It was developed by The Waterloo Wellington Geriatric Services Network and Trellis Mental Health and Developmental Services in order to enhance senior care by providing integrated services for seniors in the Waterloo Wellington area (McAiney & Hillier, 2012). An evaluation of the IGSW program illuminated its impacts including improved system navigation and improved care coordination/integration across health care sectors (McAiney & Hillier, 2012).

Finally, the mission of Community Care Access Centres (CCAC) is to provide individuals with care coordination services to ensure smooth transitions through the health system. CCAC case managers provide information about available services and develop care plans to address individual needs (OACCAC, 2013). Though CCACs are not a service that is specific to individuals with dementia, they do provide transition support to the general home care population, which includes those with dementia. Some seniors have criticized the care coordination provided by CCACs, suggesting that they remained confused about available services even after accessing help from a CCAC (The Change Foundation, 2012); however, partnerships between CCACs, First Link and FHTs have been cited as beneficial in helping older adults with dementia navigate the health care system (McAiney et al., 2012).

Although some of these transition support services have been evaluated independently (Lee, et al., 2014; McAiney & Hillier, 2012; McAiney, et al., 2012), it is unclear which approaches might be most useful in which situations, and how various services might be

coordinated (McAiney, et al. 2012). Gaining an inductive understanding of care transitions from the perspectives of persons with dementia and their informal caregivers will help build knowledge regarding which services are most useful for individuals with dementia and their caregivers as they navigate the health care system.

2.8 Summary and Implications

Models and interventions for transitional care, care coordination, and continuity of care exist and have potential value in improving the transitions of individuals with dementia. However, the provision of transitional care to persons with dementia and their caregivers cannot adequately address the needs of this population in the absence of an in depth understanding of those needs. Given that there is evidence that individuals with dementia a) are more intensive users of the health care system, b) experience more health care transitions, and c) may face additional challenges while moving through the health care system than those without dementia, it is important that their experiences of transitioning throughout the health care system are understood. Gaining an understanding of person with dementia and caregiver perceptions of transitional care is the first step in the process of creating an integrated and coordinated system of care that best suits their needs. Given the association of transitional periods with risk and adverse events as well as caregiver stress, improved transitional care may translate into improved quality of life for individuals with dementia and their caregivers

Chapter 3

Study Rationale and Objectives

3.1 Research Gap on Care Transitions of Persons with Dementia and their Caregivers

Although dementia-specific system navigation and transitional care have been recognized as priorities for provincial dementia strategies (ASC, 2010; British Columbia Ministry of Health, 2007), for research (Stolee, Hillier, Cook & Rockwood, 2011), and for performance measurement (Institute of Medicine, 2006), there remains a lack of understanding of how these transition challenges might best be addressed for persons with dementia. In a systematic review of transitional care programs, Piraino and colleagues (2012) identified a research gap in the area of transitional care support for individuals with cognitive impairment and dementia. It was found that some studies purposefully excluded dementia patients from their samples; therefore, the generalizability of existing transitional care models to individuals with dementia is questionable (Piraino, Heckman, Glenny & Stolee, 2012).

Chick and Meleis (1986) proposed that the phases of transitions are continuous rather than discrete. Although the idea of continuity in health care transitions has been echoed in more recent publications (i.e., Coleman et al., 2002), there remains a large focus on specific transitions (e.g., hospital-to-home or home-to-LTC) in the literature. This study aimed to move beyond the idea of transitions as singular or discrete entities in order to understand care transitions of individuals with dementia and their informal caregivers more broadly. As such, the term *care transition* is used to describe any kind of transition in the health care system and the term

transitional care is used to describe the care and support provided to individuals moving throughout the health care system.

3.2 Study Objectives and Research Questions

This study aimed to fill gaps in the understanding of care transitions from the perspectives of individuals with dementia and their caregivers. Gaining this understanding is important because one cannot assume that the views and needs of persons with dementia and their caregivers during transitions are the same as any other older adult.

Chick and Meleis (1986) acknowledged the importance of transition theory in the field of health care, suggesting that a conceptualization of transitions "offers a key to interpreting person-environment interactions in terms of their actual and potential effects on health" (p. 239). The primary objective of the study was to develop a theoretical framework outlining the factors that contribute to processes of health care transitions from the perspectives of persons with dementia and their caregivers. In line with this objective, the following research questions were addressed:

1) What is important to persons with dementia and their caregivers as they transition through the health care system?

2) What challenges do persons with dementia and their caregivers face as they transition through the health care system?

3.3 Addressing the Research Gap

A qualitative methodology that encouraged an in depth consideration of participant views throughout the research process was ideally suited for this research topic. By obtaining direct accounts of health care transitions from person with dementia and their caregivers, the research

method illuminated voices that had often been missing from previous related studies. As such, this study addressed the current knowledge gap surrounding the perceptions of those with dementia and their caregivers regarding transitional care. The constructivist grounded methods that were chosen to meet the study objectives are further described in Chapter 4.

Chapter 4

Methods

4.1 Study Design and Rationale for Approach

Constructivist grounded theory methods were chosen to fulfill the study objective of developing a theoretical framework that outlines the factors that contribute to health care transitions from the perspectives of persons with dementia and their caregivers. Charmaz (2006) asserts that the purpose of grounded theory is to develop theories or frameworks in order to understand "the worlds we study," or topics of interest (p. 10). Rather than attempting to understand the essence of the experiences of care transitions, as one would in a phenomenological study, this study aimed to understand and develop a theoretical framework for care transitions from a dementia-specific perspective. Thus, grounded theory was an appropriate method for this topic.

4.2 Philosophical Assumptions

In line with a constructivist approach, the researcher assumed the ontological perspective that both the researcher and participants exist within the "world we study" and consequently, within the data that are collected (Charmaz, 2006, p. 10). Furthermore, the researcher acknowledged the existence of multiple realities, including the reality of each participant and the reality of the researcher. Therefore, throughout the research process the researcher remained dedicated to authentically representing the meanings of the participants' views rather than attempting to discover a universal truth (Ritchie, Lewis, McNaughton-Nicholls & Ormston, 2013). From an axiological perspective, the researcher assumed that the individual values of persons with

dementia and their caregivers were important and should be respected throughout the research process.

The researcher adopted the constructivist epistemological assumption that individual experiences inform reality; thus, knowledge about the topic of investigation was co-constructed by researchers, persons with dementia, and caregivers during the course of the study (Charmaz, 2006). An awareness of the social construction of data and analyses means that reflexivity and recognition of pre-existing assumptions were important at each stage of the research process. Such assumptions included knowledge of the benefits and challenges of transitional care for older adults that have been attained through prior reviews of published literature. The researcher acknowledged that the care transition experiences of those with dementia could be unique; therefore, no concrete assumptions about the emergent theory were made prior to the data collection and analysis processes. Rather than taking an objectivist stance and removing herself from the research process, the researcher acknowledged, noted, and described her role throughout the process using reflexive journals and memos.

Finally, the researcher went into the study with the methodological assumptions that the principles of grounded theory would guide the data collection and analysis procedures. Specifically, it was assumed that the process of research would be inductive, iterative and emergent in design and that the processes of theoretical sampling, theoretical sensitivity, theoretical saturation and constant comparative analysis would guide framework development (Charmaz, 2006; Creswell, 2007). These processes will be described in more detail in sections 4.4 and 4.5.

4.3 Sampling and Recruitment

In line with a grounded theory, only individuals who were "excellent" or "expert" participants, or those who had experienced the process that was being explored, were recruited for the study (Bryant & Charmaz, 2007, p. 231). Therefore, inclusion criteria for the study sample consisted of the following: a) participants must have been diagnosed with or care for someone who has been diagnosed with dementia, b) participants must have undergone any type of health care system transition since the dementia diagnosis. There were no explicit exclusion criteria for the study sample based on diagnosis or stage of dementia or type of care transition experienced.

4.3.1 Sample rationale

Both persons with dementia and their caregivers were included in the study due to the present and growing importance of informal caregivers for persons with dementia (see Section 2.4). Caregivers were also able to provide information about the transitions of those with dementia who could no longer communicate effectively.

This study did not focus on a specific transition (e.g., hospital to home); instead, it aimed to build an understanding of the experiences of persons with dementia and caregivers while moving throughout the health care system more broadly. Coleman and colleagues (2002) suggested that patients and their caregivers experience care in a continuous matter, irrespective of specific health care divisions. Furthermore, unlike hospital to home transition studies associated with traumatic events such as hip fractures (e.g., Toscan, Mairs, Hinton & Stolee, 2012), there is no natural starting or ending point for a transition associated with dementia. By taking a broad approach to the idea of care transitions in the interviews, participants could

comment on a range of different transitions as well as provide information about how they experienced the journey through the system as a whole.

4.3.2 Recruitment processes

To locate persons with dementia and their caregivers who were willing to participate in the study, Alzheimer Society of Ontario (ASO) Chapters and FHTs were used as gatekeepers. In qualitative inquiry, a gatekeeper is an individual or group who serves as an "initial contact for the researcher" in order to direct the researcher to suitable and willing participants (Creswell, 2007, p. 125). The ASO and FHTs were chosen as appropriate gatekeepers for several reasons.

ASO chapters are located throughout Canada, including 37 Alzheimer Societies across Ontario (ASO, 2014). The ASC guiding principles and values extend to chapters across the country; therefore, using the ASO as a gatekeeper has the potential to enhance the generalizability of the study's results. FHTs, although less standardized than ASO chapters, currently serve approximately one fifth of Ontario's population and are located in over 200 communities (Ministry of Health and Long-term Care, 2014). Using both the ASO and FHTs as gatekeepers allowed the researcher to gain access to a large number of individuals with dementia living in their communities as well as through primary care.

The ASO and FHTs were also chosen for feasibility reasons; namely, the research team had existing connections with ASO chapters and FHTs. It is possible that persons who are linked with their local ASO chapters are more connected to supports within their communities than other individuals. Similarly, persons who receive primary care through FHTs may have access to a more integrated system of care (see Limitations, Section 6.4). However, it was concluded that the benefits of using the ASO and FHTs outweighed the potential costs.

Eight ASO chapters and one FHT were contacted by phone or e-mail about helping

identify persons with dementia who would be willing to participate in the study (see Appendices

A, B and C). Recruitment locations were situated within the Waterloo-Wellington, South West,

and Central East Local Health Integration Networks (LHINs). ASO chapter representatives and

FHT physicians were asked to send or hand out a short invitation letter to potential participants.

This letter provided a brief description of the project purpose and what would be involved if they

chose to participate (see Appendix D). Interested participants were asked to contact the

researcher directly. When this contact was made, face-to-face interview were set up at a time and

place that was convenient and comfortable for the individual with dementia and/or the caregiver.

Most often, interviews were conducted in the homes of participants. Scripts for contacting a) the

Alzheimer Society chapters and b) participants via telephone once the ASO has made initial

contact were used (see Appendices A and E).

4.3.3 Theoretical sampling

Initially, a convenience sample of persons with dementia and caregivers who had undergone any

care transition since the dementia diagnosis was identified (see Section 4.3.2). Snowball

sampling, during which current participants helped to recruit new participants, was also used to

build this initial convenience sample, which consisted of two dyads and two informal caregivers.

When feasible, further sampling throughout the study was purposeful and theoretical: since the

data collection and analysis processes were iterative and occurred simultaneously, some

participants were chosen based on ideas that arose and according to the needs of the emerging

theory (Bryant & Charmaz, 2007). For example, early interviews pointed to the importance of

the dementia diagnosis in the care journey; thus, participants who had different types of

diagnoses were sought out. Ongoing partnerships with gatekeepers facilitated this theoretical

sampling due to their in depth knowledge of client/patient characteristics. Theoretical sampling

is often used to refine and elaborate on categories that emerge during analysis (see Section 4.5).

A very broad range of theoretical categories emerged from the data; sampling for these ideas was

difficult because it was not immediately clear from patient characteristics whether their stories

would support emerging categories. Instead, probing questions (see example in Appendix L)

were used during interviews to delve into specific aspects of experiences and further refine

categories (Charmaz, 2006; Creswell, 2007).

4.4 Data Collection

There are unique challenges associated with including individuals with dementia in

qualitative research; however, to gain a complete understanding of their perceptions of

transitional care, it was necessary that the researchers found ways to overcome these challenges

(Hubbard, Downs, & Tester, 2003; Reid, Ryan & Enderby, 2001; Wilkinson, 2002). Hubbard

and colleagues (2003) emphasized the importance of tailoring research strategies to individual

participants with dementia. Since those with dementia have a range of communication abilities

and may experience different levels of anxiety, this study customized specific qualitative

methods to the preferences of the individuals recruited for the study (Cheston, Bender, & Byatt,

2000). Preferences for individual (including a person with dementia OR a caregiver) or dyad

interviews (including a person with dementia AND a caregiver) were ascertained and respected.

All persons with dementia that were recruited preferred to be interviewed in the presence of a

family caregiver, and several caregivers were interviewed on their own. Caregivers are

recognized as both useful collaborators in research as well as, in some cases, a potential

challenge to research. It is possible that a caregiver might care more about protecting the individual with dementia from pain and grief than about providing a truthful response to a question (Wilkinson, 2002). Consequently, this study considered transparency as a key priority. By asking individuals with dementia and their caregivers ahead of time whether they might have any concerns with being interviewed in a dyad, potential response issues were reduced.

4.4.1 Interview rationale

In order to develop a framework for understanding transitional care from the perspectives of individuals with dementia and their caregivers, detailed and "rich description" was required (Bryant & Charmaz, 2007). Agar and MacDonald (1995) suggest that individual qualitative interviews elicit the most detailed information. Using individual or dyad interviews rather than group interviews allowed participants to delve more deeply into their individual experiences and provide the researchers with information-rich data. Furthermore, it was expected persons with dementia might have become confused if others in the room were talking about unrelated experiences. The focus on individual experiences fit within the constructivist paradigm that the researcher adopted, which acknowledges the existence of multiple realities corresponding to each participant and researcher (Creswell, 2007). Charmaz and Belgrave (2012) suggested, "when researchers use focus group interviews as the sole method for data collection for grounded theory studies, they often relegate grounded theory methods only to data analysis" (p. 354). This statement further supports the idea that individual or dyad interviews were an appropriate collection method for this grounded theory study.

4.4.2 Interview procedures

Each individual who agreed to participate was given an information letter (see Appendices F and G). The letter contained information about the purpose of the study, the participant's role in the study, the risks and benefits of participation, voluntary participation, withdrawal rights, confidentiality and security of the data, and researcher contact information. At the beginning of the interviews, the information letter was reviewed and a consent form was given to the person with dementia and/or the caregiver (see Appendix H). Questions used to determine whether an individual with dementia could provide consent were asked (see Section 4.8), and consent was obtained from both the individual with dementia and the informal caregivers. Proxy consent was not required in any of the interviews including individuals with dementia; each individual interviewed was able to provide his or her own consent. Furthermore, the researcher completed a brief background information form (see Appendix I) using verbal information provided by either the person with dementia and/or their caregiver. This information was used for sample description purposes. Consideration was given to completing a cognitive assessment solely for sample description. The researcher decided against this option for the following reasons: a) the researcher is not trained to deal with the potential stress induced by the assessment, and b) rich information for the sample description can be gathered by talking to the participant.

With the consent of the participants, the interviews were audio-recorded. Initial interviews included both open-ended questions about experiences while moving from setting to setting or from provider to provider as well as more structured questions that were developed using four current transitional care, coordination or continuity models (see Appendix J and K for interview guides and Table 1 for model elements). However, due to an observation that the structured

questions broke up the individuals' stories, caused some confusion, and did not significantly add to participant descriptions, they were removed after the first four interviews. They were replaced with further open-ended questions that aimed to delve deeper into the context of transition experiences (see Appendix L for the revised interview guide).

Interview techniques such as remaining active in the interview as well as being aware of and asking questions about participants' language were used in order to obtain rich data from the interviews (Charmaz & Belgrave, 2012). Some types of questions that the student researcher considered during data collection included, a) whether "the data reveal[ed] what [lay] beneath the surface" and b) whether the researcher "gained detailed descriptions of a range of participants' views and actions" (Charmaz, 2006, p. 19). Interviews were conducted between October of 2014 and April of 2015, constituting a very large proportion of the study timeline (see Appendix M). Time between the interviews, along with the completion of verbatim transcriptions after each interview, facilitated the simultaneous processes of data collection and analysis. After each interview was analysed (see Section 4.5), the results were used to inform further theoretical sampling as well as any alterations to the interview guides required in order to saturate the emergent theory (Charmaz, 2006).

4.5 Data Analysis

Background information provided by participants was summarized to provide sample description and context for the results of the study. NVivo 10 (QSR, 2012) qualitative data analysis software was used in conjunction with coding procedures outlined by Charmaz (2006) to analyse data. The goal of coding was to synthesize the data and begin the process of interpretation in order to build a "story" and, eventually, a theoretical framework (Creswell,

2007, p. 160; Charmaz, 2006). Interview transcripts were first read through for familiarization. Subsequently, two stages of coding were used to analyse the data: initial and focused coding.

4.5.1 Coding process

In initial coding, data were closely examined using a procedure known as incident-by-incident coding. Short, action-focused codes, or gerunds, were assigned to each small piece of data. Using actions in coding (i.e., words ending in –ing) prevented the researcher from "making conceptual leaps" prior to more in depth analysis (Charmaz, 2006, p. 48). Furthermore, *in vivo* codes were used to preserve participant voices (Charmaz, 2006). Sample codes (both gerunds and *in vivo* codes) can be found in the summary table of results presented in Appendix N. A constant comparative method was used, meaning that segments within and between interviews were compared throughout the data collection and analysis processes (Charmaz, 2006).

In focused coding, the most frequent or most significant codes from the initial coding were used to synthesize the data into a more coherent story (Charmaz, 2006). Categories and subcategories were developed and relationships and links between categories were suggested. Again, codes and data were compared with each other in order to focus the emerging theory. Examples of steps taken during reconstruction and synthesis can be found in Appendix O. Throughout the coding process, the researcher ensured that there were clear connections between the codes and the data so that the resulting theory was actually grounded in the data rather than shaped by the researcher's preconceptions (Charmaz, 2006). The simultaneous data collection and analysis procedures occurred until the point of theoretical saturation.

4.5.2 Theoretical saturation

Theoretical saturation was reached when no new concepts arose during the interviews and/or when "no new properties emerge[d]" within the categories formed during analysis (Charmaz, 2006, p. 96; Creswell, 2007). A review of 50 grounded theory studies conducted by Thomson (2005) indicated that the average sample size in grounded theory studies was 24 participants. Furthermore, McCracken (1988) suggested that most studies reach saturation between eight and 24 interviews and that saturation will depend on the conceptual size of the study topic. In a grounded theory investigating the experiences of spousal caregivers during transitions from geriatric rehabilitation to home, researchers used a sample of 18 caregivers (Byrne, Orange, & Ward-Griffin, 2011). Another study investigating a similar topic conducted by Reuss, Dupuis and Whitfield (2005) reached saturation after 21 interviews. Since this study also aimed to create a framework for care transitions, it was predicted that a similar number of participants would be required to reach saturation.

It is important to recognize the possible implications of using both dyad and individual interviews for the process of reaching theoretical saturation. This study aimed to understand the concept of care transitions from the perspectives of persons with dementia and caregivers rather than the subjective experiences of these transitions alone; thus, the views and perceptions of persons with dementia, caregivers, or a combination of both contributed to a set of common conclusions about care transitions. Since persons with dementia often move through the health care system along with their caregivers, it was expected that they would have complementary and related experiences (Bloomer et al., 2014). Therefore, rather than attempting to reach

saturation in each group individually, the researcher collected data to the point of theoretical

saturation of the topic under investigation (care transitions).

It was initially expected that between 15 and 25 interviews would be required; however,

ultimately 29 interviews were conducted in order to reach theoretical saturation. In practice,

theoretical saturation was determined by noting a point in the coding process at which no new

codes were required to explain the meanings behind participants' stories; codes could easily be

selected from an existing list on NVivo 10. To ensure confidence in saturation, five further

interviews were conducted after this point.

4.5.3 Theory development: Addressing the research objective

When theoretical saturation was reached and confirmed, a framework was developed and

refined to describe care from the perspectives of persons with dementia and their caregivers and

to fulfill the study's primary objective. Since the study has been situated within a constructivist

framework, the resulting theory is interpretive. An interpretive theory recognizes the existence of

multiple realities rather than universal truth; thus, the theory focuses on how participants

"construct and act on their view of reality" (Charmaz, 2006, p. 127). Furthermore, the

researchers acknowledge that theory development requires interpretation and that the emergent

theory is situated within a particular context shaped by the participants' and researchers' values

and assumptions (Charmaz, 2006, Creswell, 2007, p. 65). Diagramming was used throughout the

data collection and analysis process to visually represent emerging categories and relationships.

A sequence of diagrams that emerged throughout the analysis process is included in Appendix O.

The emergent framework of dementia-specific transitions has also been represented

diagrammatically (see Results, Chapter 5). In line with a constructivist perspective, theory

development and diagramming avoided reductionism and respected the flexibility and complexity of reality (Charmaz, 2006).

4.6 Memo-writing and Reflexivity

Memo-writing is an integral part of grounded theory methods (Charmaz, 2006). Memo-writing was used to record and develop the thoughts and ideas of the researcher throughout the entire research process. This step was important because it kept the researcher actively engaged in the analysis process and was useful in the process of creating focused codes and comparisons of data (Charmaz, 2006). Memos were spontaneous and informal; they were used to inspire ideas, think about categories and relationships, note frustrations, discover gaps, and begin report writing (Charmaz, 2006). Memos were instrumental during the theory development process as they served as a method of refining categories; some memos have been included in the results to explain ideas that arose during the interviews.

Memos also provided a record of the research process and the researcher's analytic procedures. In this sense, memos served as a tool for reflexivity. Creswell (2007) considers reflexivity to be a key feature of any qualitative inquiry, meaning that all qualitative researchers should reflect on their role and the participants' roles in the study. The process of reflexivity began early on in the development of the research plan by clarifying philosophical assumptions (see Section 4.2). Other methods of reflexivity were employed throughout the research process including the use of reflexive journaling, which allowed the researcher to write out emotional responses to the interviews, as emotions may affect interpretation (Mauthner and Doucet, 2003).

4.7 Ensuring Quality and Rigour

Criteria for evaluating grounded theory outlined by Charmaz (2006) were used to ensure that the methods were rigorous. The criterion of credibility assesses whether the researcher is familiar with the context and topic, whether there are clear links between data and analysis, and whether there is enough data to support claims (Charmaz, 2006). Credibility was ensured by gathering rich data during interviews. Furthermore, data were transcribed verbatim, and initial coding stayed as close to the data as possible through the use of gerunds and *in vivo* codes. A senior member of the research team read through codes to ensure that the student researcher was staying true to the data. Finally, data were collected until no new information arose from the interviews; thus, ensuring that claims were based on a sufficient amount of data.

The criterion of originality refers to whether the categories are fresh and the ways in which the study extends current ideas (Charmaz, 2006). A gap in the literature in the area of transitional care for persons with dementia was identified; therefore, the study's results extend current knowledge of care transitions to include the perspectives of those with dementia and their caregivers. More detailed information about how this study extends current knowledge can be found in the discussion section (Chapter 6).

The idea of resonance pertains to whether the theory that is developed makes sense to the participants (Charmaz, 2006). To ensure resonance, individual member checks were conducted with participants after the theory was developed in order to confirm that the theory matched their actual experiences. Participants were asked to sign a re-contact agreement form at the time of their initial interview so that the researcher could ensure that the participants were willing to provide their input again at the completion of the data analysis process (see Appendix P).

Participants were contacted by telephone and asked whether the framework in general and/or specific aspects of the framework aligned with their experiences. The script that guided the member check process is included in Appendix Q and the results of the member check process are presented in Section 5.7.

Finally, the criterion of usefulness assesses whether people will be able to use the results in everyday life, whether the study may spark further research, and whether it contributes to knowledge (Charmaz, 2006). During the member checks, the researcher ascertained whether the participants believed that the framework was useful. Furthermore, the emergent framework was compared to existing models of transitional care, care coordination, and continuity of care to determine what specific knowledge it contributes to the literature. Finally, some of the results were used to inform the creation of regional dementia strategies for the South West and Waterloo Wellington LHINs, indicating that they have value that extends beyond the individual participants of the study.

4.8 Ethical Considerations

There are ethical concerns associated with involving those with dementia in research, including the issue of informed consent. Persons with dementia and their caregivers have a unique ability to provide details on their experiences while moving throughout the health care system because they are often the only common element among all transitions. Therefore, it was considered necessary that those with dementia be included, even in cases wherein they could not provide their own consent. The researchers did not encounter this challenge, as all those with dementia who agreed to participate in interviews were able to provide their own consent. To determine whether an individual had the capacity to provide consent, the researcher ascertained verbally

while reviewing the information letter whether the individual 1) understood the nature of the research, 2) appreciated the consequences of participation in the study and 3) understood the alternative choices. An assent form was available at all interviews to ensure that those with dementia participated as much as possible in the consent process in cases wherein they could not provide consent, but this form was never used (see Appendix R).

The consent or assent provided by an individual with dementia at the beginning of the interview does not necessarily hold true for the entire interview due to the variable nature of the disease (ASC, 2014). Therefore, the researcher verbally reconfirmed agreement to participation throughout the interview process by periodically asking whether the individual with dementia was still comfortable answering questions. This ongoing amendment to consent ensured that those involved in the study fully understood their rights as a research participant at all times. Those with dementia who were interviewed were in the early stages of the dementia journey, and were all comfortable answering questions.

To ensure anonymity and confidentiality of the data, all information provided during interviews has and will continue be held in confidence. Information is kept in a locked filing cabinet and accessed only by members of the research team. Participants' names do not appear on any of the data. Electronic files containing study data are password-protected and will be destroyed after 5 years. Audiotapes, transcriptions, background information sheets and data files will remain anonymous. Each participant was assigned an identification number for organization purposes and a pseudonym for presenting quotations. A list of pseudonyms can be found in Appendix S.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee.

Chapter 5
Results

5.1 Sample Description

In total, 29 interviews were conducted in 15 cities or towns within Ontario, spanning three different Local Health Integration Networks (South West, Waterloo-Wellington and Central East). Approximately 40% of the interviews were conducted with dyads consisting of a person with dementia and their caregiver; the other 60% were conducted with caregivers only. Therefore, a total of 41 individuals participated in the interview process (12 persons with dementia and 29 caregivers).

The vast majority of caregivers were wives of persons with dementia (n=21; 72.4%), followed by daughters (n=4; 13.8%), husbands (n=3; 10.4%) and sons (n=1; 3.4%). As such, there was a heavy representation of females among the caregivers interviewed (n=25; 86%). The persons with dementia represented by the interviews (i.e., the 12 individuals who were interviewed plus those represented by the voices of their caregivers) were primarily male (n=23; 79%). The ages of these individuals with dementia ranged from 55 to 94; four caregivers also represented the views of persons with dementia who had passed away. There was a heavy representation of persons with dementia in the 75 to 84 range (41.4%). Caregivers ranged in age from 35 to 84, with a majority in the 65 to 74 range (51.7%).

Participants (persons with dementia and/or their caregivers) represented seven different types of dementia. In order from most prevalent to least prevalent among study participants, these were: Alzheimer's Disease, Vascular Dementia, Mixed Dementia, Mild Cognitive Impairment (MCI), Fronto-temporal Dementia, Parkinson's Dementia, and Dementia with Lewy

Bodies. Over 25% of participants also reported a non-specified or unclear diagnosis. Individuals received their dementia diagnoses from a variety of providers including geriatricians (37.9%), primary care physicians (27.6%), physicians at memory clinics (20.7%), neurologists (10.4%), and one doctor in a care home (3.4%). Finally, apart from the dementia, those represented in the interviews had an average of 2.07 self-reported chronic conditions. Tables including all sample description data can be found in Appendix T.

5.2 Framework Overview

In speaking with those with dementia and their family members about their movement within the health care system, it became clear that their transition experiences involved much more than the direct health care-related actions and resources provided to ensure high quality transitional care. That is to say, their care transitions did not occur in a vacuum; they were situated within communities and support structures, and were influenced by the relationships between the realities and goals of participating parties. Participants' transitions represented aspects of the journey through the dementia experience and care system. Rather than discrete instances of movement from setting to setting, transitions were experienced as continuous and linked to each other and to the dementia journey. They could be gradual or sudden; precipitated by crises or events; buffered by proactivity and preparation; and facilitated or hindered by patient, provider, and system level factors. The theoretical framework presented here respects the complexity of the transition experience by illustrating the context of care transitions; the processes encountered while moving through the dementia care system; and factors that can influence these transitions.

5.3 The Theoretical Framework

Figure 1. A three-part theoretical framework outlining the context, processes and influencing factors of care transitions from the perspectives of individuals with dementia and their caregivers
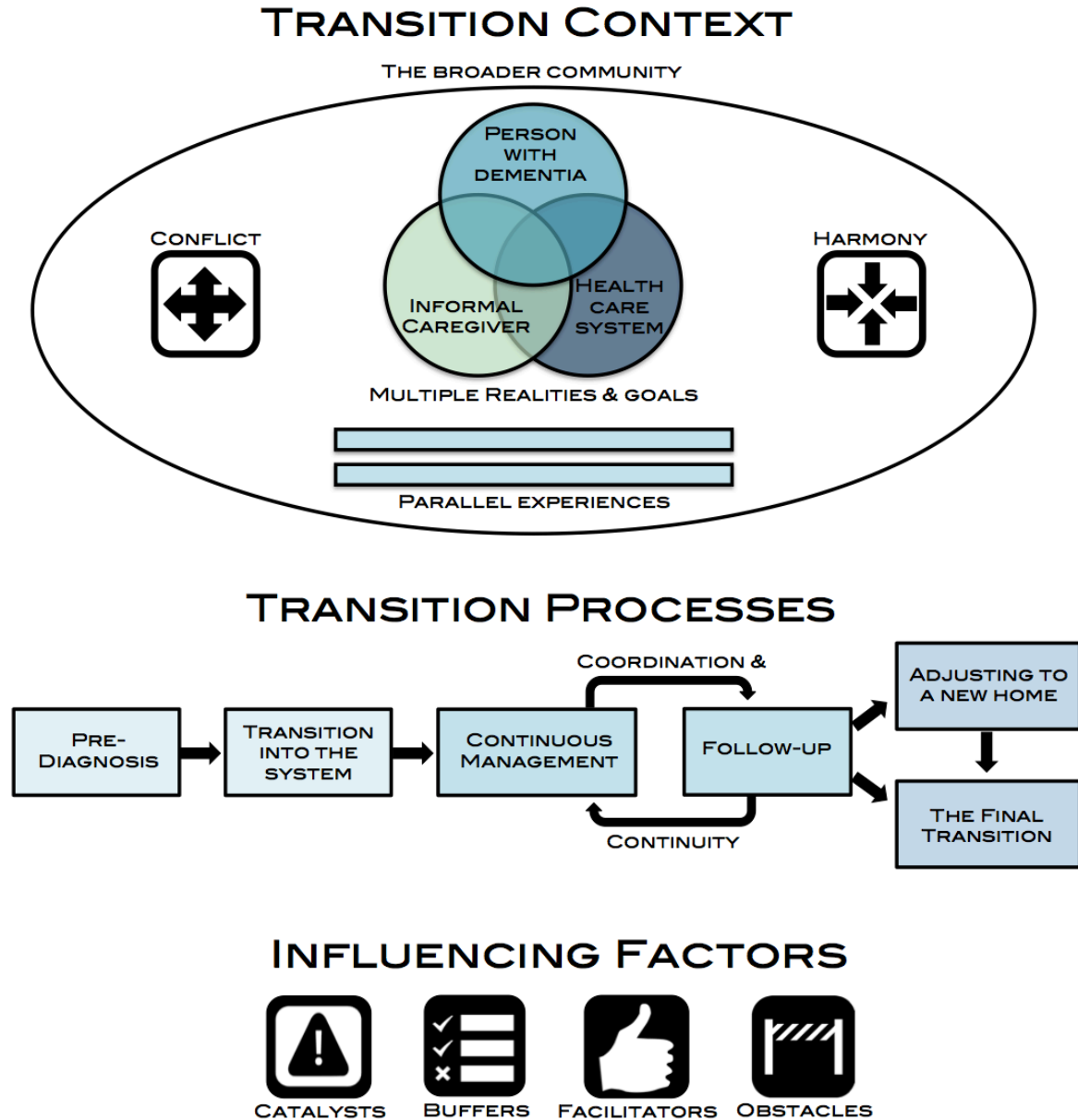
5.4 Transition Context

> "As far as care transitions, it was great. It was just the transition for him, not being at home, and I guess trying to figure out why I would've left him at the hospital when he should be home in his mind."
>
> – Margaret (Caregiver*)*

The quote above illustrates the idea that a transition in care may be different from an individual's experience of that transition. In other words, the context of a transition may influence the perceptions of those involved, regardless of the quality of care provided. Transition context consists of broad factors that must be considered in order to fully understand perceptions of transitions. In the case presented here, it was not the actions of the health care system that made the transition from home to hospital difficult for the individual with dementia; rather, it was dealing with the fact that his wife had left him there and he did not know why. This was his perception of reality; the caregiver's view of reality was that the care that her husband received was "great." Thus, when considering the context of a transition, one must take note of those involved in that transition and how their goals and realities might interact. Others aspects of context include broader community considerations and the potential influence of the parallel experiences of others navigating the dementia care system. These discussions of context, although not always directly related to care transitions, set the stage for individuals' stories about their health care system navigation.

5.4.1 Multiple realities and goals: In conflict or in harmony

As described in the methods section (Chapter 4), a social constructivist perspective guided both the design and analysis of this study. This perspective proposes that reality is not an objective, external concept; instead, individuals construct reality based on their interactions. In the words of

Bryant and Charmaz (2007), "social constructivists study what people at a particular time and place take as real." The researcher's assumption of the individuality and multiplicity of reality allowed her to acknowledge and respect all views presented during the interviews, even when perspectives were deemed *"out of reality"* by others (terminology taken from caregiver, Beth).

The idea that it is important to consider the often-unique realities of persons with dementia began to surface early on in the data collection and analysis process. Included below is an excerpt from an initial memo:

> The reality that a person with dementia experiences may be very different from what the informal caregiver or care provider experiences. When someone has dementia, their view of reality may be distinctive; however, this does not mean that their view of reality should be discounted. Their realities can provide valuable information about strategies for allaying their fears as well as contribute to care plans, regardless of whether their view of reality matches any other person's reality.

The existence of multiple, differing realities was illustrated by the quote presented in the transition context description; the reality experienced by the person with dementia contrasted with the view of the care transition as described by the caregiver.

In addition to perceiving different realities, those involved in health care system transitions also often have different goals. Stolee and colleagues (1999) suggested that "patient care typically includes many goals, and not all goals will be relevant for every patient" (p. M641). In other words, goals are an individualized construct, and there may be a disconnect between patient and system care goals. The perspective adopted for this study regards both realities and goals as constructs that are subjective and distinct to individuals. It is argued here that the realities and goals of different individuals or groups may interact to produce instances of conflict and harmony.

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Three distinct sets of realities and goals emerged from the data. Two are those of the participant groups: persons with dementia and their caregivers. The perspectives of those with dementia were attained by either speaking with them directly in interviews, or through the stories relayed to the interviewer by their caregivers. A third reality arose from participants' descriptions of their health care experiences: that of the health care system. Although this third perspective was not attained directly through interviews, it was clear that it was an important consideration in theorizing about transitions. Thus, this perspective is comprised of the system-level goals, processes, and constraints described by participants. In this section, instances of conflict and harmony between each intersecting pair of realities and goals are examined.

5.4.1.1 The dyad: The intersecting perspectives of persons with dementia and their caregivers

The importance of the dyad was clearly supported by the data. Caregivers play a vital role in the lives and care journeys of those with dementia. Participants described the increase in caregiver involvement and responsibility that occurred as a consequence of the dementia diagnosis. Anita suggested that her husband Rick now required her presence at all health care encounters:

> "Now, going into see the doctor, I have to be there to make sure
> that everything is said that needs to be said, even if I send a list in
> that doesn't work. And then if there's instructions, I have to hear
> them, because Rick will understand it at the time, but then he
> won't remember. So that's changed…he doesn't have the same
> privacy that he used to have… That probably doesn't bother you
> now, because we've been together so long."

As such, the dyad becomes a team that navigates the system together. Laura eloquently illustrated the importance of recognizing the union of a person with dementia and their caregiver in saying, *"I think the compassion that people have for the couple. Whether it's the parent and the child, whether it's a spouse. I think…that goes a long way."* Although the dyad often acts as

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a team, there are cases of conflict between patient and caregiver realities or goals. In part, this conflict arises from communication difficulties or differences in memories of certain events; however, more powerful instances of conflict can emerge from feelings of perceived abandonment among persons with dementia.

Some caregivers expressed struggles in understanding their loved ones' points of view, reasoning, or cognitive processes. Laura described this notion in stating, *"It's just...when someone doesn't have the thought process to properly explain what they're thinking, that's tough on all of us because we don't know what they're thinking either."* Another caregiver, Britney, reflected upon a specific occasion when she could not discern why her husband Marshall was angry: "*He was mad, and we don't know why, but maybe it was part of the dementia then the whole, 'What's wrong with me? Why am I going crazy' that was another sentence that he would say."* During these instances of communication problems, caregivers felt that they were responsible for accurately representing the needs of their loved ones. Britney struggled with this responsibility, suggesting that she may not always know the answers: "*I'm supposed to know everything and answer to what he can't think right? Sometimes that's hard, because I could be 10 fields out you know?"*

There were also occasions during dyad interviews during which each individual remembered details of the dementia journey differently. For example, when Alexia and Martin were asked about his dementia diagnosis, Martin relayed that he had been diagnosed *"recently"* whereas Alexia indicated that he had been diagnosed years ago. Similarly, during a conversation with Melissa and Matthew, Melissa believed that her dementia symptoms were much less severe than the others in her day program group; however, Matthew suggested that they were *"all about*

the same level." These cases of differing realities were relatively harmless; they did not lead to

any outward conflict between participants. However, when combined with transitions, such as

the movement into long-term care, differing realities and goals can lead to anger and resentment

and, consequently, more negative perceptions of the transition experience.

Interview data strongly supported the difficulty that caregivers experienced in

relinquishing care to hospitals or long-term care homes. Susan relayed this idea in stating, *"it's*

such a big step when you do put a loved one on the list to go into long-term care." Caregivers

often experienced an internal battle between feeling guilty for leaving their loved one and

knowing that their loved one should be in a place where they will receive adequate care.

Geoffrey offered the following description of his internal conflict: *"You go through that range of*

guilt and 'I'm responsible,' but in the end, because I had no other support, the best thing to do

was have her put in a home." In this case, the caregiver's reality consisted of this internal

conflict followed by the realization that long-term care could provide better support for his wife.

The goal of ensuring that their loved ones receive the best care possible was a common goal

among caregivers.

There were several instances wherein the reality of the individual with dementia during

these transitions did not reflect the desire of the caregiver to do what was best for both of them.

Instead, they felt abandoned and angry. Margaret told the following story about her husband

Allan's transition into hospital, which portrays the disconnect between caregiver intentions and

the perception of the person with dementia:

> "My husband was very, very angry when he went into the hospital.
> He never was an angry person, we never fought, but he felt that I
> was throwing him away… And then he told everybody that I had a
> boyfriend and that's why I had thrown him away… and we had

been married 53 years… It took several months of him being away to stop telling people that I had abandoned him. Although I went every day to the hospital to spend time with him, it didn't seem to make any difference in the first ten months. And, like I said, it was heartache because you've been together for 53 years and then all of a sudden accusations that were not him. But that did pass. So I guess the transition for him was difficult."

Allan's perception that he had been abandoned resulted in him viewing the transition very negatively. Due to the fact that his belief of abandonment conflicted with Margaret's goal of doing what was best for him, she felt that these statements were accusatory. This conflict had an adverse effect on Margaret's transition in the sense that she felt *"heartache"* due to his accusation of her having *"thrown him away."* Britney echoed the idea that she sometimes had to take on the role of the bad guy stating, *"Sometimes the spouse becomes the bitch. You're the bad person."* Gaining an understanding of these conflicts and their effects on perceptions can provide important information about the context of individuals' care transition experiences.

Harmony between the realities of caregivers and persons with dementia occurred during instances of mutual understanding and respect. In most of these cases, the person with dementia acknowledged that they had memory and cognition issues and required assistance from others in their lives. Participants with dementia expressed gratitude for the support provided by their care partners. For example, Martin expressed his appreciation for his wife Alexia in saying, *"Good thing I'm married to a nurse who knows all the answers."* Similarly, Rachel was thankful for her daughter's involvement in her care. During the interview she voiced this gratitude: *"I'm so glad that I have her."* Another individual with dementia, Daniel, echoed this sentiment in stating, *"I'm where I am because of Leanne. If she wasn't here I would still be in my apartment and I would be a mess."*

When both parties appreciated the partnership between patient and caregiver that often accompanies having dementia, then their realities were more closely linked. Maria illustrated the mutually beneficial relationship between her and her husband with dementia: *"So we, you know, we complement each other, and everything is fine."* Lynne spoke of the relationship between caregiver and patient realities suggesting, *"If it's better for me then it's better for him."* Karen also described the linked lives and realities of her and her husband Brad in her declaration that they were *"in this boat together."*

Caregivers often desired to work with rather than for their loved ones to ensure that they received appropriate care, suggesting a desire to attain a balance with rather than to supplant their realities and goals. Laura suggested that she would like to be involved with, but not take over, decision-making: *"The more involvement that the caregiver can have in…understanding and in helping to make decisions about the care, the better it is. I mean you don't want to take over the decision-making, but I think they have to be involved."* She wanted to understand the system and her husband in order to bridge any gaps occurring between them because of his dementia. Likewise, Fran said that she wanted to go with her husband to appointments in order to help him better relay his feelings: *"I sit in with him all the time too. So that helps a little bit. I can try and communicate a little more… what he's feeling."* Beth, who said, *"I want to be an advocate for someone who has no voice,"* articulated a similar sentiment. In these cases, caregivers wanted to be involved in order to help express the goals of their loved ones when they were not fully able to do so themselves. This type of involvement does not preclude the occurrence of conflict; however, it does suggest that the dyad can work together to ensure that the realities and goals of both the person with dementia and the caregiver are represented.

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5.4.1.2 Caregivers and the health care system: Navigating a position within the care circle

Due to health care system constraints, informal caregivers assumed much of the responsibility for providing care to persons with dementia. Jennifer, who is a caregiver for her mother Rachel, described the responsibility placed on informal caregivers:

> "I think a lot of the onus goes onto a family member or whoever is looking after it. You have to keep on top of it, because you won't get people calling you. You don't often get a follow up on things. I can't say that we've never had one… but generally speaking you have to stay on top of it. And unfortunately that's the way it goes with the health care system today."

Heather further communicated the importance of informal care in stating, *"They know darned well that they're balancing a ball on the back of the caregiver."* Caregivers wanted to help their loved ones, and there is a clear need for them in the care circle of persons with dementia. However, they did not always feel included or consulted to the extent that they thought they should be. Therefore, conflict arose between the informal and formal care systems about how to best provide care.

The biggest problem voiced by caregivers regarding their relationship with the health care system was the fact that they did not always feel heard by those involved in the care of their loved ones. When providers did not listen to their points of view, they felt that they could not help their loved ones and, consequently, felt powerless. The caregivers interviewed illuminated several instances of this failure of the system to listen to their goals and input. Heidi explained how not being heard by the system delayed her husband's entry into the dementia care system: *"There were weeks where you would forget he was sick and other days I was absolutely sure of it that something serious was going on. But I couldn't seem to get anyone to listen to that."* Lynne

described how she felt powerless when her knowledge about her husband was not considered during his transition into long-term care:

> "Our first year and several months has not been pleasant, and the
> one thing that I will continually say is that any form of dementia is
> hard enough without the negative attitudes being added on…
> Without being made to feel that what you know about your loved
> one, and could help contribute to his care, is negated."

Caregivers felt that the health care system should listen to them because they knew their loved ones best and could provide insight into their needs. Emma felt upset when her doctors dismissed her concerns: "*He dismissed what I was saying, and I felt very upset about that.*" She noted, *"if they're not listening to family members who deal with this all the time, then there's something lacking there,"* indicating that the system is at a loss when it does not consider caregiver insight.

Another related source of conflict between the caregivers and the health care system emerged from caregivers' fear of speaking out due to concerns about how it might influence their loved ones' care. If caregivers do not voice their concerns, then the health care system cannot accurately ascertain their goals. Beth expressed her fear of providers generalizing negative views from her to her husband:

> *"I want to have good relations with everybody there and have
> Charlie have good relations with everybody there. I don't want to
> extrapolate from me to Charlie – if they don't like me, maybe they
> won't like Charlie."*

Lynne had the opportunity to view the reports written about her husband in long term care. She noted that concerns like Beth's were validated by what she saw in this report.

> "The one common thread from talking to other loved ones that
> come in is 'Oh Lynne we're so glad you're speaking out! You go
> for it!' Well, 'Why don't you?' 'Because I'm afraid they'll take it
> out on my dad, or my husband…' And… after reading John's

report I really feel those comments are validated. That if I've said too much, then there's been a big issue made afterwards about John's agitation or whatever. We should be able to express our concerns without feeling that there's going to be negative repercussions."

Not only did the system often fail to ascertain the goals of caregivers; at times, the goals of the system directly opposed and outranked the goals of caregivers. Beth again described her conflict with system-level goals in the following story about booking home care support through CCAC:

"Trying to book these, these events, the woman that I had to book through in London, her goals were different than mine. Mine were to make Charlie happy with the people that came, to try and make it as few, few new faces as possible…For me to be able to get out, I know and understand that need for the caregiver to get out and about and do what they like and it was winter and I liked to ski and snowshoe… Her goal was to have you be specific about the exact times that you would want those PSWs, and to have it a regular weekly booking. And to make sure that you're underneath the 60."

Rather than taking into account caregiver wishes, system timelines and constraints were imposed during the assessment for home care services. Maria described a strict time constraint in stating, *"The CCAC came and interviewed William… and we had 3 months to call them if we needed their services… and if not, then we'd have to apply again."* Strict timelines also caused several caregivers to feel rushed when making decisions about transitioning to long-term care. Beth experienced this source of conflict and described the rapid progression of the long-term care process:

"Eight days later, in the middle of a winter storm, I got a call for a bed at… the local long-term care facility, where he now is. And I had to make the decision within 2 days and then he had to be admitted within 5 days. So you have 48 hours to phone that decision in. I had only had 8 days."

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Jim also felt rushed by the long-term care transition; he made note of the need to consider the difficulty of the decision for caregivers.

> "The other thing that I didn't know until I got the call, but basically when a position became available at [the long-term care home]… I had 24 hours to make a decision. And sometimes that's difficult, you know, when you've been together for 40 years. Just to say 'I'm going to put her in a home.' So I don't know whether that could be sort of altered."

In these cases, rather than accommodating or negotiating with caregiver goals, the health care system forced it's reality on caregivers. When the health care system *did* make the effort to accommodate caregivers, they had more positive experiences. Alexia described an instance that illustrates this idea: *"They didn't have rules. They had ways of, rather than a rule, they had a way of giving me support. They found a way."*

Conflict with the health care system caused caregivers to feel like they were not respected, even when the care received by their loved one was adequate. Margaret illustrated this point in the following statement: *"I think that he was looked after well. I have no complaints about, you know, how he was looked after. I think my biggest complaint with them was that the caregiver wasn't given any respect."* This quote suggests that caregivers might have a negative perception of a transition despite the provision of high quality care. On the other hand, when providers within the health care system acknowledged the needs and goals of informal caregivers, they felt heard and respected. Anita provided support for this idea in stating, *"They were respectful and they listened and took their time, and it was nice."* Heather also felt that her husband's geriatrician respected caregivers because *"she knows that the whole system is being held up by the caregivers."* In cases like this, the emotional reactions of caregivers to the ways they are

treated in the health care system can significantly influence their perceptions of health care experiences.

5.4.1.3 Persons with dementia and the health care system

Sometimes persons with dementia constructed a view of reality that was unique. For example, in Section 5.4.1.1, beliefs of abandonment and betrayal by caregivers that did not match the caregiver's view of reality were described. Persons with dementia also often had distinctive views of their health and health care experiences. Beth described a particularly interesting view of reality that her husband perceived after having his driver's licence taken away:

> "Charlie's picture of that right now in his head is that he was there with the doctor and the doctor came into the room with a stick with his driver's license on the end of it and dangled it in front of him and then said, 'we are taking your license away.' That's how he views it."

Even though it is not likely that a physician would taunt an individual with dementia with his driver's license, Charlie's reality included this memory, which caused him to resent his provider. In another case, Kevin believed that the providers in the hospital were trying to punish him; he would wander and, therefore, was physically restrained. His daughter, Bonnie, described Kevin's state of mind while in hospital: "*He couldn't figure out why everybody was so angry with him and punishing him. So it was really not a very nice scene.*"

Another caregiver, Heidi, explained how her husband Geoff's view of reality did not line up with her view reality in her assertion that "*his opinion of what he is capable of and reality is not always the same.*" She felt that Geoff's differing view of reality caused a safety problem because it made him seem more capable than she believed he was during an assessment for home care. In cases like this, a person with dementia may provide inaccurate information to providers.

Susan's father was a good example of this: *"At one point he was on 20 to 22 prescription drugs per day, but you'd ask him, and he'd say, 'No I don't take pills.' "* She perceived this misinformation as *"fooling"* the system: *"They're very good at fooling people. And that the health care system gets fooled so easily."* Steven was simply expressing his view of reality; however, Susan perceived his actions as purposeful. Regardless of the intent of the actions, caregivers often felt that the health care system was not getting the information required to properly assess the needs of the person with dementia. Beth provided further support for this notion:

> "Towards the end, you know, he would say the right thing like, 'I understand that it's really difficult for Beth to look after me…but I do need her help…' When she asked him specifically, 'do you think that you could be on your own in the home?' He said 'Oh yes, I certainly could do that, I'd be fine, I'd look after [the dog]' and it was just so obvious that that was not the case, that he could not be on his own and he really was not clear in his head about that piece of it. That it was almost, you know, out of reality."

Considering the possibility of these conflicting views of reality would allow the system to adjust practice accordingly. Monica suggested that persons with dementia often feel like they are being accosted, triggering them to react in a way that causes them to be labeled as aggressive.

> "They constantly think they're being accosted, dementia patients, if you go up to them too quickly or something they will just go like this, and once they do that, if they ever strike out they're labelled as aggressive or they're medicated, or confined or whatever."

This story provides an example wherein a failure to recognize the potential effects of a person with dementia's unique view of reality negatively influenced his care.

When individuals were taken seriously, treated like people, and included in health care decisions, then they sensed that the system was trying to work with them in order to provide the

best care possible. Betsy explained how she and her husband valued being included in the care process.

> "We've been included in everything at [geriatrician's] office and maybe we're lucky with our CCAC person, but she very much talks to Paul and talks to me sort of on the side the conversation is with Peter and if he sort of can't answer then she talks to me so that we're really included in in everything."

Martin, an individual with dementia, found that his providers were *"very cooperative in in discussing things with [him]. Not saying you must do this."* These individuals felt that their views and opinions were valued, and thus, had better care experiences. In this sense, it can be argued that patient and family engagement is an appropriate method of achieving a balance of multiple, sometimes conflicting, realities (See Facilitators, Section 5.6.3).

Although not every story presented in this section was directly related to care transitions, they illustrated of the types of conflict that can arise when multiple individuals or groups with distinct realities and goals try to manage together in a system. Since transitions in care often involve the person with dementia, informal caregivers, as well as multiple providers, accounting for these intersections of individual realities and goals is important.

5.4.2 The broader community

Since this study has adopted a broad perspective of care transitions, many of the transitions discussed actually happened while individuals were at home, residing in their communities. Thus, their communities provide important information about the context of these transitions. Several participants discussed the importance of having understanding communities and neighbours, as well as supportive social circles, while navigating through the dementia care system.

Social interactions were an important part of individuals' experiences with dementia. For example, Alexia noted:

> "They're really inclusive, which is good… Martin and I are often out. We've maintained a fairly good social life. And get out for dinner…go out with people things like that. Yeah it's good that way."

Rebecca also felt that maintaining a social life was *"good"* for her and her husband Gregory: *"Everybody has been very good, and we try to go out as much as possible too. I think that's good to go out and see people."* William, who has dementia, was very fond of his day program because of the social interaction it provided. He expressed this in stating, *"Everybody is very sociable sorta thing there. We joke around and that sort of thing."* The importance of these social interactions was further supported by Melanie, who spoke of a social program that was developed by couples dealing with dementia in the Waterloo-Wellington area. She explained, *"It's a social thing. It's all the people that I know from Alzheimer's Society. All of the men go there. So… you know, we're amongst friends."*

When persons with dementia and their caregivers had social interactions, they felt supported by others; however, several of those interviewed did not have the same level of support from their communities. Heidi believed that a lack of understanding of dementia produced fear: *"I was going to say I honestly don't think people understand. I think it frightens some people."* Anita had a very similar view, suggesting that people do not understand dementia; therefore, they avoid those with dementia and their caregivers:

> "I think that's it, because a lot of people don't really have an understanding of what it is, they hear that word and they think that's the end of your life, or they think that now you can't do anything at all, and you can, you can still do lots of things for

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many years. So people tend to sort of back away from me sometimes when they hear that."

Because of this avoidance, persons with dementia and their caregivers struggled with social isolation. Laura described the difficulty she experienced socially: *"It's the social part that I find is very difficult to deal with. So there's a great deal of social isolation for him and for me."* Feelings of social isolation also resonated with Margaret, who described how having dementia changed how people felt while interacting with her husband.

"People who had known him and who were neighbours, but with the dementia… people didn't want to come back, because… sometimes he didn't… he had lost boundaries, he would say something that didn't even make any sense, and the people would feel uncomfortable… whereas if he had just had Parkinson's and didn't have dementia they would've sat with him and played cards and done something… It's just the isolation I think as a caregiver that you have with the dementia patient. And that's a big thing."

When family and friends failed to provide support to persons with dementia and caregivers, they felt lonely and stressed. In these cases, caregivers often felt solely responsible for their loved ones. Heidi explained how those in their lives reacted to her husband's dementia diagnosis: *"We've had a lot of friends pull back…even family pull back… It's a pretty lonely road at times."* Beth also described a particularly difficult time during which she had no support from family:

"During that time there was only one daughter in law who was sort of tuned in to the idea of dementia and helping and… understanding that it was difficult. And she sort of fell off the map during this time too, during this 7 to 8 month time period where I had absolutely no contact for several months… You know you always worry about, 'what have I done, what have I said.' So that became a huge worry for me at that time… and so really there was nobody else but me to look after him."

Transitions in the context of non-supportive communities and families are difficult for caregivers

due to these feelings of sole responsibility. In Beth's case, she ultimately realized that she was

unable to manage with her husband at home on her own. This realization hastened her husband's

transition into long-term care, illustrating how caregiver support can influence the care

transitions of those with dementia (See Catalysts, Section 5.6.1).

By being honest and helping those within her community better understand her husband's

dementia, Laura believed that she was able to create her own dementia-friendly community. She

described this sentiment in saying,

> "I think that I created my own dementia community…dementia
> friendly community… Being honest about the situation helps to
> create community. Helping people understand how to deal with it
> creates community. I think… giving people responsibility creates
> community."

Creating knowledgeable and supportive communities can help individuals with dementia and

their caregivers better manage at home. Given the fact that many older adults, including those

interviewed, desire to stay at home as long as possible, managing at home is a significant aspect

of their health system navigation.

Supportive communities helped relieve caregiver stress and responsibility. Susan explained

the idea of a supportive neighbourhood: *"The neighbours are very much involved… and quite*

often have to go out looking for her, because she does wander." Furthermore, Lynne described

how her supportive community helped her manage: *"It made his life easier. It made my life*

easier. I didn't have to be the…what do you call it? Helicopter mother? Or wife…. When he was

out walking I knew I had eyes on the street." Knowing that others in the community were

looking out for the interests of her husband gave Lynne peace of mind. Rita who, along with her

father, cared for her mother Ruby further supported this idea. She felt that involvement of more family members helped relieve the burden on her father: *"I think in the involvement of like more family… like more people who know what's going on and what should happen…not all the burden on my dad to decide everything."*

When community or family support is not available, it is important that the health care system is aware in order to provide people with the formal support that they require. While Monica's husband was transitioning out of hospital, her provider asked her about her home support system. Since she did not have any informal or formal help, her physician decided to keep her husband in hospital until she received the support that she needed. Her description of this experience was as follows: *"She noticed how he was and she said to me, 'what help do you have at home?' And I said, 'I don't have any.' And she said, 'you just take him right upstairs and say you're not going home until you get help.' "* By taking the initiative to understand the community and family support systems in place for persons with dementia and caregivers managing at home, providers can better understand the context of their care of transitions.

5.4.3 Parallel experiences

> I have found that my participants describe and experience their own realities through relationships, communication, and interaction with others…People often describe the experiences of others when asked about their own experiences. This tendency was nearly universal - not often did individuals *only* talk about their own experiences in an interview.
>
> Through avenues such as caregiver support networks or groups, people learn about others' experiences…The ways that they take in and make sense of those experiences are by relating them to or comparing/contrasting them with their own experiences.
>
> – Jessica Ashbourne (Excerpts from two memos)

The memos presented here explains how individuals with dementia and their caregivers often

construe their own health care experiences in relation to the experiences of others. This idea has

been labeled 'parallel experiences' because the experiences happen at the same time; however,

they do not necessarily directly intersect. People hear about them second hand from others.

Nevertheless, they have an important influence on the ways in which people think about their

own care. Four distinct aspects of these parallel experiences arose from the data and are

described in this section: seeing the future in others' experiences, feeling fortunate in

comparison, helping and learning from others, and comfort in knowing others are going through

similar experiences.

5.4.3.1 Seeing the future in others' experiences

> People recognize that others have different experiences and thus,
> different issues. If differences are related to the stage of
> dementia/stage of the journey, then participants recognize that the
> experiences that they are hearing about might resemble their own
> future experiences.

- Jessica Ashbourne (Memo)

When comparing their experiences to those of others, participants acknowledged that differences

might be due to the stage of their journey. They valued hearing from others at different stages

because they were able to learn about an array of issues. Leanne described this notion: *"Some*

people there already had their relatives in nursing homes, so it was all different levels. So I think

because of that we were able to talk about a whole broad range of fears, and that was really,

really good."

Hearing about the problems that others further along in the journey faced while

transitioning through the system allowed participants to better understand what might happen to

them later on. Fran explained how she learned about what might lie ahead through her caregiver

support group: *"The caregivers that we have, there's different stages. So you kind of get an*

understanding of what might be down the road. Which is very nice to get feedback from them."

Laura expressed a similar sentiment, using phrases like, *"I'm sure we'll eventually get there"*

and *"I see probably a need for that in the future"* when describing what she had heard from

others. Others spoke of services that they might need to access in the future based on what others

have used. Maria discussed CCAC assessments, saying, *"the time will come, but not just yet"*

and Anita noted, *"a lot of this stuff, we're not really there yet"* when talking about getting on the

list for long-term care. Karen suggested that earlier stages come along with a *"glow"* – her

experiences early on were relatively good, but she believed that they would likely get more

frustrating as her husband's dementia progressed:

> "I think because we're at the early stages, the glow is still there.
> Like I said, I think as we move forward in the disease it will get
> more frustrating dealing with CCAC and bodies like that, because
> they are stretched."

In cases like these, people used their interactions with others to formulate expectations for

the future. These expectations may, in turn, influence perceptions of transitions when they do

occur. In the following section, entitled 'feeling fortunate in comparison,' the ways in which

expectations informed by others can influence perceptions are explored.

5.4.3.2 Feeling fortunate in comparison

It became clear after the first few interviews that people who had positive experiences navigating

the system felt fortunate. The following memo was created early on in the data collection and

analysis process:

> The idea that individuals feel lucky or fortunate for experiences that are positive in the system seems to be coming up in the interviews… Even when they have good experiences, they don't believe that their experiences are the norm.

People explained their own experiences in relation to specific stories that they had heard from others. Beth described how she had heard of others waiting much longer to get into long-term care homes: "*The thing that is really great about our area is that we don't have a huge waiting list as they do in other places. I've heard of people waiting 2 years or 3 years.*" Melissa explained how her twin, who also had dementia, did not have access to the same resources as she did: "*But no, they've been really great. Absolutely, because my twin in BC, she doesn't get any of those resources and she has Alzheimer's.*" Regarding CCAC assessment processes, Emma noted, "*I mean I usually hear bad things, but our experience with them was very good.*" Geoffrey compared his experience with the nursing home to what he had heard: "*I've heard in the Alzheimer's group that I go to, other stories about battles with staff in nursing homes et cetera, et cetera…I've never experienced any of that.*"

When people compared their experiences to the less positive experiences of others, they reported feeling fortunate or lucky. In order to clearly portray how common this notion was, nine different instances of the use of the terms 'fortunate' or 'lucky' are included here.

> "We have been very **lucky**…cause I've heard some horror stories."
> – Betsy

> "We have been very **lucky** that once we got to that stage where we were talking about long term care, we have had a consistent RN who has come up and done the interviewing." – Betsy

> "We really haven't had any big need for the health care system, which has been **fortunate**…so far things have been good. But I know that there must be a lot of need for improvements by what I hear from what other people are complaining about." - Emma

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"I was surprised when I do meet people and they seem to have all these challenges. We were just very **fortunate**… I've heard horror stories. But never from my point of view." - Jennifer

"Some people were not as **fortunate** as we were." – Melanie

"Actually we've been very **lucky.**" **-** Jessica

"We were very **lucky.**" – Melissa (person with dementia)

"I was very **lucky** with the doctor and with medications." - Monica

"I think by and large we've been **fortunate** that we've had fairly positive experiences." – Karen

This idea that people feel fortunate for experiences that are better than others' experiences is very closely linked to the social constructivist view of reality that asserts that individuals perceive their own realities through social interactions. This link was described in a memo:

> Social construction of reality is important to understanding how people construe and experience care transitions. It means that interactions and relationships with individual people are extremely important to perceptions. Furthermore, expectations that are informed by the experiences of others can influence how people perceive their own experiences.

Hearing about others' *"horror stories"* may influence expectations for health care; therefore, when individuals have experiences that are not as bad, they view them in a more positive light. These feelings may arise without regard to what is done by the health care system to ensure good care, further supporting the notion that a health care transition can be highly influenced by context, irrespective of provider or system actions.

5.4.3.3 Helping & learning from others

Not only did communicating with others about their parallel experiences influence expectations and perceptions; it also allowed individuals to help and learn from others. Some participants

believed that sharing their own health care system experiences and dementia journey could help

others prepare for or avoid certain situations in the future. Karen explained this notion:

> "That's why Brad and I agree to take part in any studies that we
> can, because we can't do something about what's going to happen,
> but we can do something about maybe providing information for
> people at a better stage so that they don't go through similar
> frustrations. Or hopefully they learn from it."

Jim also believed that his experiences could be useful to others. He explained how his motivation

for going to support groups was influenced by this desire to help:

> "The reason I go is because I try to tell them about the negative
> things I've come across, you know? Because you don't want
> people getting to this stage where they're having to care for
> somebody and then coming across all of these problems."

Several participants reported getting ideas and learning from people like Karen and Jim. Betsy

described how she learned from the others in her support group: *"You get ideas from the other*

grumblers about what or how you can manage…and things you can do…you know getting ideas

from other people." Rebecca also found hearing from others helpful in terms of learning coping

strategies: *"Once a month you go and sit around and gab and talk about things that have*

happened and understand how other people are coping, I think it's very good." Laura reiterated

this idea, noting, *"That was very valuable in giving me some strategies to keep Bill calm and on*

task and so on." These stories suggest that hearing from others can help people learn to better

manage.

Since recruitment of participants was conducted through Alzheimer's Society chapters,

most of those interviewed had access to a group where they could learn from others going

through similar experiences. Presumably, not everyone moving through the system has this

opportunity. Thus, considering the level of peer support for persons with dementia and their

caregivers is an important part of understanding the context of their health care experiences,

including care transitions.

5.4.3.4 Comfort in knowing others are going through similar experiences

The final aspect of parallel experiences that emerged from the data was that people with

dementia and their caregivers are comforted in discovering that others are going through similar

experiences. In Sections 5.4.3.1 and 5.4.3.2, the important impact of *differences* in parallel

experiences was described. However, seeing *similarities* between one's own experiences and the

stories of others can also significantly influence one's perceptions. Specifically, knowing that

others were facing similar struggles helped individuals with dementia and their caregivers feel

connected throughout their health care journeys. Geoffrey eloquently described how his peer

support group helped him:

> "I've been going to the support group now for two years, and it has
> been invaluable. And one of the things it's taught me is how
> important it is to make those connections. They're almost social
> connections… beyond the professionals, with people who are
> going through similar situations. So you can share those
> experiences, you learn to laugh, you learn to… you learn a respect,
> you also learn that you're not alone. And for me… those kinds of
> supports will be necessary I think for a while. Long after I need a
> whole lot of health professionals."

Both caregivers like Geoffrey and persons with dementia felt connected to the experiences of

others through peer support. Caregiver Rebecca and her husband Gregory explained this

sentiment together during their interview:

> Rebecca: It was excellent, I think, because you know, as frustrating
> as it was, there were other people in the same situation.

Gregory: That was the best thing. Not always, but it was good to
hear the others that want to get around.

Other individuals with dementia who shared this view included Melissa, who said, *"It's nice to see that there's other people,"* and Brad, who told the following story about his peer support:

"So we have 4 of us. We're all about in the same boat. And so we
kind of talk about it and go through some of the latest stuff that's
gone on… and you know, see what everybody is experiencing and
all that. It's kind of like a comfort zone thing you know? You've
got some people that are in the same boat as you."

When people heard that others had gone through similar struggles and survived, they felt encouraged to continue on their own journey. Andrew described how others who shared the dementia diagnosis encouraged him: *"There was a couple of other people with Alzheimer's or dementia who have encouraged me… Attitude is contagious, so that helps you. It helped me, anyways."* Andrew's statement suggests that seeing others retaining positive attitudes during difficult health care experiences can help individuals stay positive as well. Again, this notion indicates that the parallel experiences of others can influence peoples' perceptions of their own experiences; therefore, they are an important consideration when thinking about the context of care transitions.

5.4.4 Transition context summary

In this section, important aspects of the context of care transitions were described. First, the realities and goals of each individual involved in a transition may conflict or align; whether one's realities and goals are accounted for or respected by others can influence one's perceptions of health care experiences. Second, the presence or absence of community and family support for those with dementia and their caregivers can provide important information about their ability to manage at home. Finally, communicating and interacting with others who are also navigating the

system can influence one's attitudes and perceptions about one's own experiences. Each aspect of context described here lends support to the notion that perceptions of care transitions involve much more than the direct actions or supports provided by the health care system.

5.5 Transition Processes

Participants were asked very general questions about their care transitions during the interviews (e.g., can you tell me what has gone well for you while moving or navigating through the health care system?). As such, participants relayed stories about several types of care transitions. During the focused coding process, codes that were related to specific types of transitions were grouped, and categories were refined. Relationships between these categories were suggested and clarified. Finally, a sequence of transitions through the health care system that aligned with experiences of the dementia journey emerged.

Transition points that emerged included pre-diagnosis and the transition into the system, wherein individuals were beginning to make contact with the dementia care system. System entry could be gradual or sudden, each of which possesses its own set of issues. During the processes of continuous management and follow-up, people began to accept and cope with their diagnoses. Transitions were frequent and involved many different settings and professionals. As such, care coordination and continuity efforts helped to connect the numerous transitions occurring during this time. Moving to long-term care stood out to participants as a distinct transition; it represented a turning point in the dementia journey due to both the emotional and physical implications of the move. Finally, caregivers who had experienced the loss of a loved one with dementia discussed the idea of the final transition, which represented a transition out of a caregiving role for family members.

5.5.1 Pre-diagnosis and the transition into the system

Several participants suggested that their transitions into the dementia journey and care system

began long before a diagnosis was received. Some of the persons with dementia represented by

the interviews had been declining cognitively for years prior to the diagnosis. Emma explained

her husband Edward's pre-diagnosis experience with health care system:

> "His family doctor for about 3 or 4 years had been following his
> cognitive state…and had been performing tests…showing that
> probably, you know, there was something going on…and with also
> my input and his children's input…it just all came together that
> something was going on."

Another caregiver, Lauren, began her contact with the dementia care system even before her

husband did due to her concerns about his memory and cognition:

> "I mean I had gone to my family doctor for a couple of years about
> it before we actually had Andrew go… Even before [the
> diagnosis], quite a few years before, I had taken a course on
> Alzheimer's when I expected that this was the issue."

For people like Edward, Andrew and their caregivers, the transition into receiving care for

dementia was gradual. It progressed slowly and eventually led to obtaining a diagnosis. The

diagnosis was not a shock, due to the process of ongoing decline. Susan explained this notion in

relation to her father's entry into the dementia care system: *"It wasn't actually a diagnosis as*

such. Umm, it was such a slow progression, so it started off very slowly, just not remembering

things."

For some individuals, this slow progression eased the transition into the system; they knew

it was coming, so they had been mentally preparing for years. However, for others, this gradual

transition represented a failure of the health care system to address their needs in a timely

fashion. Alana felt that her doctor did not take her concerns about her husband's memory

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seriously: *"He said, 'well if you go out for a walk can you find your way home?' Well yes he could but… 'Oh you're okay then' He said, 'don't worry about it.' "* Several caregivers felt that they had to push for their loved one's diagnosis. Lauren noted: *"it took… a long time to convince [the family doctor] that Andrew had memory issues."* Likewise, before her husband Geoff was diagnosed, Heidi felt like she *"had been asking [to be assessed] for too long and it felt like [they] were getting nowhere."*

In Heidi's case, she believed *"it took too long to get Geoff into the system."* Lynne also experienced a delay in access to specialist services for a diagnosis:

> "The negative to that was, it took our family doctor a few years
> before he would actually send us to a specialist. And I feel, that if
> they feel, the doctor feels it's an issue of Alzheimer's or some
> form of dementia, we should have been sent at that time, and
> known exactly what we were dealing with."

As Lynne expressed, persons with dementia and their caregivers wanted to know what was going on. In this sense, a diagnosis could give them peace of mind. Lynne further explained this idea: *"The only thing I can say is, as his spouse and caregiver, I would have felt better understanding more of what was happening to him."* Participants recognized that a delay in diagnosis or an uncertain diagnosis would not necessarily change the treatment options; however, it could delay the feeling of reassurance that comes from knowing that everything that can be done is being done. Heidi explained this sentiment: "*I don't know if knowing two years in advance would have made any difference except…I think I would have felt he was in a safer place and that his problems were being addressed."* Likewise, Karen wanted to ensure that her husband's symptoms were not the result of something treatable:

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> "When you first see the signs of something beyond normal aging,
> and you're worried, 'is this a brain tumour, what is it?' And you're
> waiting a year or a year and a half to get in to access the service
> that might be the diagnostic tool… it's kind of frustrating."

When individuals did not have a prompt, clear diagnosis, they felt like they were waiting for a crisis to occur. Betsy noted: "*Of course it didn't take terribly long before there was a major accident and we'd been sitting here waiting for it to happen. You know? And that's a very difficult transition isn't it?*" However, when those crises did occur, people were *"propelled into the care that [they] needed"* (Heidi, Caregiver). Many participants spoke of specific incidents that clarified the need for dementia care. Britney described an episode when her husband became very angry:

> "I thought that he would hit [my daughter] or I, you know? I
> thought that… cause he was furious, you could see it in his eyes.
> So anyways… I guess that I would say that was beneficial, because
> that helped us get right to the bottom of things, and I didn't need to
> go through that again."

Bonnie spoke of a fall that accelerated her father's decline and began his journey with dementia:

> "It started with an onset of my father falling. Had a dizzy spell
> when he was getting out of the car – driving the car. He had
> brought it into the garage and when I got out he fell and hit his
> head… So then it seemed that things moved along really quickly
> from then on, and I don't know whether the fall aggravated it,
> or…made it rear its' ugly head more?"

Events like these, which trigger the onset of transitions, have been labeled 'catalysts' and included as a major influencing factor for transitions (see Section 5.6.1). In the case of transitions into the system, these catalysts may help gain clarity about the cognitive state of the individual in order to obtain a diagnosis. In some situations, these crises followed a period of waiting for a diagnosis; however, in other cases the diagnosis was sudden and a surprise. For Margaret, *"it*

came as a shock when [Allan] was diagnosed." Garry and Melanie also experienced a sudden

transition into the system:

> Melanie: I think he was diagnosed very fast.
>
> Garry: Yeah, diagnosed very quickly.
>
> Melanie: Yeah. He was… he was diagnosed within three days.

Garry and Melanie considered his prompt diagnosis as a very positive aspect of their transition

into the health care system. That being said, during a sudden transition into the system,

individuals do not have very much time to prepare for the diagnosis, which is why it may come

as a shock. For some this shock may be so overwhelming that they do not seek out the help that

they need right away. Leanne described the need for support at the time of diagnosis: *"There*

needs to be a way that as soon as a diagnosis is made, somebody picks it up. Because I think

families are often in shock at that time, so there isn't a follow up, and then nothing happens."

Stories about transitions into the system suggest that the perceptions of those entering the

dementia care system can be highly influenced by the way in which they receive a diagnosis.

People want to know what is going on; therefore, when concerns are respected and care is

provided promptly, then they have an easier transition into the system. This transition sets the

stage for the rest of the journey through the dementia care system, because once they are

diagnosed they can start receiving the support they need. Lynne noted: *"John was diagnosed on*

a Friday, I called them on the Monday, and by Thursday there was a First Link[1] coordinator at

our house… she's been by our side every step for the last six years." The diagnosis allowed

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[1] See Section 2.7 for a description of the role of First Link

Lynne and John to begin the process of continuous management and follow-up that comprises a large part of the dementia journey for many people.

5.5.2 Continuous management and follow-up

Transitions in care after the initial diagnosis and entry into the system were often viewed as a process of continuous management and follow-up. Many participants specifically noted the continuous nature of their post-diagnosis transitions. For example, Geoffrey described the *"seamless"* care his wife received in several settings after she transitioned into the care system:

> "Once I started to involve the doctor and then the memory clinic…
> I mean all of that seemed to go kind of seamlessly, and then the
> Alzheimer's society, and they made it happen with the CCAC, and
> then the CCAC came back and… it was all very gentle and very
> seamless."

Emma echoed this view:

> "I mean our transitions have…from one thing it seems to be…on-
> going…I don't think that's ever going to be at a standstill. Because
> of age and because of the…some of the medical diagnoses…it's
> always going to be a continuous transition."

Regarding his mother's care experiences, Bobby suggested that *"it all flows together."* Moreover, when Gregory, who has dementia, was asked about his care transitions, he noted that his care consisted of *"just visits to the doctor's office, or the hospital, whatever comes first."* This statement indicates that Gregory viewed his care experiences as a series of indiscriminate visits to different physicians. Betsy felt that her husband's transitions were so intimately linked that she was *"almost barely aware of the transitions."*

Betsy continued on to say, *"I mean they, things unfold and you adapt and you don't really think, 'this is a transition.' "* The notion that individuals deal with or adapt to health care

experiences as they arise formed the basis of the management portion of the 'continuous management' category. Many care transitions may occur during the course of a journey with dementia; however, these are not often considered discrete instances of movement from provider to provider. They are perceived as individuals' reactions to changes in the dementia symptoms, in their needs, and in their lives. People learn to cope and manage. Britney illustrated this point: *"I just cope with things. That's all you can do."* Maria expressed a similar idea in saying, *"whatever comes… we'll deal with it."* Bobby felt like he was just waiting to see what came next in his mother's care journey: *"I'm sort of waiting… okay, you know… what's the next part?"*

During these continuous transitions and adaptations, participants desired regular follow-up by those involved in their care; they wanted to know that someone was checking in on how they were managing. When people received consistent follow-up they were happier with their experiences. Betsy said, *"I think maybe it's just nice to be able to have that professional support fairly regularly."* Rebecca felt that the Alzheimer Society did a particularly good job at following up with her and her husband with dementia: *"Alzheimer Society usually checks in and gives a phone call every so often, and say how are you doing and do you need something, and that means a lot. I think they're very good here."*

Some individuals did not receive much follow-up from their providers, which negatively influenced their perceptions of their health care. Daniel experienced this lack of follow-up with one of his physicians: *"He was at the hospital in [city], and he took me in one of the rooms, checked my bowels, said I was fine and then I never heard another word from him."* In another case, due to a clinic's lack of follow-up with her father, Bonnie described it as *"of absolutely no use,"* indicating how important follow-up was to her perception of the care her father received.

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Leanne believed that it should be the responsibility of providers, rather than the patients or caregivers, to provide this follow-up: *"I think that they need to be the ones that are following up, and checking maybe every six months to see where things are at."*

5.5.3 Coordination and continuity

During the process of continuous management, persons with dementia and their caregivers often visited and required follow-up from many different providers. Geoffrey listed some of those he had been in contact with: *"I met with a series of health professionals, social workers, psychiatrist, doctor, Alzheimer's Society, Mental health ward nurse."* Jessica also explained how having multiple conditions apart from the dementia caused her husband to require care in several settings:

> "He was not going only for his shoulder, but he has also Fabry's Disease, which is a genetic disease… so… we were going to Toronto, to the Clinic for that too. And so… it was like… Okay. You know. Just to keep everybody straight as to where, what, why."

In this quote, Jessica described how difficult it was to differentiate between the professionals that her husband had come across without writing everything down.

Since these individuals often saw several health care professionals during the course of their experiences with dementia, efforts to ensure coordination and continuity of health care helped (or in some cases failed to help) connect the continuous transition processes. Aspects of coordination that were important to participants included clear referrals to appropriate services, professional collaboration, and information transfer. Participants felt that it was the responsibility of their health care providers to refer them to other providers and services; however, referrals did not always occur. A failure to suggest other services reinforced perceptions of the

disconnectedness of the health care system. Bonnie spoke about her experience in hospital near the time of her father's diagnosis; she did not feel like anyone was taking the initiative to provide her with information:

> "In our hospital we've got administrators, administrators'
> assistants to the assistants. All these doors that used to be rooms….
> Everybody has their own office. And of all those offices there
> wasn't one person who approached Dad about… 'now that your
> dad has dementia, here are some of the things you can look into for
> helping.' "

Daniel illustrated a similar point in speaking about his experience after his diagnosis with dementia: *"Pretty well all they did for me was make sure that I had a bracelet. Umm… They didn't talk about any programs."* He felt like his providers did not help him access services that he could have benefited from. Heidi did not receive adequate information from her husband's providers:

> "[The doctor] and some of the staff at the study would say things
> like 'you may want to consider that,' but no one really sat down and
> kind of laid out what they had to offer and why it was good. I sort
> of had to find out on my own."

In the cases presented here, persons with dementia and their caregivers could have benefited from increased provider-provider or provider-service referrals. Provider awareness of and communication with other providers and services in the community could help to ensure that individuals receive appropriate care.

Not only was there a perceived need for providers to be aware of and refer to each other; participants also believed that providers should actually work together to meet their needs. In other words, participants observed a need for professional collaboration. One type of professional collaboration that was described in about 20% of the interviews was that within

primary care memory clinics. People described how they valued having multiple providers addressing their concerns at the same time. Gregory appreciated the opportunity to hear each provider's point of view at one time: *"I thought it was good to hear what goes on from everybody."* However, the majority of participants did not have the opportunity to experience care in a memory clinic. Moreover, many of them perceived collaboration problems. Fran described this lack of collaboration among providers in her area: *"Well, a lot of them up there… they're all, on their own… each one… so they got their own controls. I think it's the biggest thing here."* She viewed her providers as disconnected rather than as a team of individuals working together. Bobby also viewed his mother's providers as separate entities: *"everybody sort of nibbles at the sides…but there's no one concerted effort."* He felt that *"there [was] no one coordinated effort going through"* the health care system, indicating that his mother's experiences could have been improved through increased collaboration.

The final major aspect of care coordination described by participants was the importance of information exchange, which emerged primarily from stories about deficits in transfer of information. For example, Alana noted that her husband's providers did not always communicate: "*Some of the others in between there was a lack of communication between them.*" Jennifer also described a failure in information transfer between two of her mother's providers:

> "There sometimes isn't a communication from one doctor to the other… which is what we're having right now with her arthritis doctor. I have to make sure that the medications that she's taking for this are now being decreased… so it's little things like that, or making sure she's getting foot care, or… just little niggly things that I have to do."

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She felt like she had to take the initiative to check whether the required information had actually been transferred. Alexia also felt that information would not always be communicated without the patient or caregiver taking the initiative to ensure its transfer:

> "Every once in a while I say, 'did you send that to [the family doctor] because he's I see him as a real focal point and when he's the GP…Then I made sure that [the geriatrician] got the notes on his stent surgery, so that she had all that stuff you know… But we made sure ourselves. We didn't just trust them because, and it didn't all just fall into place… They didn't do it the way they said they would. So I just said, 'well then we'll get it' then they'd phone and get it."

When information did not get transferred, participants perceived that health care became repetitive. Emma expressed this sentiment in stating, *"You're constantly repeating the same thing to every person that you see."* Likewise, Betsy noted: *"Being batted around and having to tell your same story over and over to you know four or five people is not helpful."* The consequences of coordination issues during transitions are noteworthy in that they can compromise patient safety. Leanne described an encounter during which a specialist changed her husband's medication, but the information was never relayed to the family doctor, who continued prescribing that medication.

> "The gerontologist told him to start taking a specific drug, and… somehow that never got relayed to the family doctor, and he kept prescribing it. And it wasn't until I think we got to our new doctor that it was taken care of… It was a medication that could cause some serious health issues."

It follows that a commitment to coordination through referrals, collaboration and information transfer can improve patient safety.

Continuity of care is a construct that is very closely related to care coordination; however, it focuses more on experiences of care overtime (Reid, Haggerty, & McKendry, 2002). The goal of care continuity is to connect distinct care experiences in order to create a more coherent pathway through the system. Providers having an overview of an individual's care experiences and provider consistency are elements of continuity that were discussed by participants. The following quote from Beth explains the consequences of a lack of overview:

> "Nobody really knows what's going on when there's a pattern developing… I'm thinking that most people are just…it's just happening without anybody really paying much attention to patterns. Who knows the patterns?"

She went on to say that she would like to see, *"one person responsible…could be a person to contact when they are there, who would know Charlie and would know everything about him medically."* Given that persons with dementia often experienced care in a variety of settings from a range of providers, it was important that someone had a broad outlook on the entirety of an individual's care journey. Maria explained this notion regarding her husband William's care: *"Having a doctor see William every 6 months… I know that someone has his journey on paper."* Consistent follow-up with the same physician enabled the creation of record of all information regarding William's care. The idea that a single provider should act as the nexus of care arose in several other interviews. Jessica felt that she and her husband with dementia could have avoided repetition in assessment if her doctor had possessed all of the necessary information:

> "Okay, are we doing this testing over and over? Did you… And I think I asked, 'are these things from the Alzheimer's Society, the tests, are they going to the doctor?' … There's different ones where it does and others where it doesn't. I didn't understand it totally, like to me all of this stuff should go to the doctors so that they have anything that might pertain."

When overview happened, people felt that their care or their loved one's was better managed. Laura explained:

> "But as soon as their spouse was diagnosed with Alzheimer's, the CCAC was there, they managed the whole care. You know it wasn't piecemeal; it was sort of one person in charge of that person's care. And they didn't fall through the cracks in any way, at least from the spouse's point of view."

Having one person responsible for managing her husband's care helped him receive care that was not fragmented.

Provider consistency was the second major aspect of continuity that emerged from the interviews. Participants indicated that, whenever possible, maintaining consistency in providers caring for persons with dementia was preferable. Laura explained: *"I also think the consistency in any kind of health care is important."* Betsy described how consistency made the CCAC assessment process easier: *"If you have somebody who's been here three times before, she's familiar with your file and she glances at her computer and she starts here and didn't have to start down here all over again. You know?"* Beth noted that her goal with the CCAC was *"to make Charlie happy with the people that came, to try and make it as few, few new faces as possible,"* indicating how important provider consistency was to her. However, she and her husband were not often able to experience this consistency due to strict regulations:

> "If I particularly liked this one person…and would like to book [her] as much as possible, I was not allowed to talk to her and say… 'What would be the best time that would work for us?' She wanted me to go in, to phone in the times and not try to arrange it any other way. She would send who comes."

Participants described how adjusting to new people when one has cognitive and memory problems could be very difficult; thus, they felt that continuity was particularly important for

those with dementia. Bonnie illustrated this notion: *"You need a little bit of continuity here with these poor people who don't even know who they are themselves."* Daniel, who has dementia, felt as if changing doctors would be confusing to him. When his wife was talking about how they have to switch doctors due to their family doctor's retirement, Daniel said, *"Yeah, that's going to screw me up all completely."*

The analysis has revealed that the processes of continuous management and follow-up constituted a large part of the care journey for persons with dementia and their caregivers. Types of care received during this time included but were not limited to follow-ups with family physicians, trips to the hospital, consultations with specialists, and management through CCAC. Several aspects of coordination and continuity helped make the transitions between these providers and settings more coherent for those navigating the system. However, participants did not feel that this series of continuous experiences lasted for the entire care journey; permanent environmental shifts (i.e., into long-term care) represented a distinct transition for participants, as they signified the need for adjustment to a new home.

5.5.4 Adjusting to a new home and the final transition

For many interviewees, the movement to long-term care represented a distinct and difficult transition. Betsy, whose husband Peter had not yet moved to a long-term care facility, labeled it *"the big transition"* and further noted:

> "If there's a crisis and lets say Peter really needs long-term care, that is a frightening point because honestly, I know people who've been told you're at the top of the list, pack your bag and be ready cause we're going to call you…and then they've waited 2-3 months… I do know that that is a very difficult time."

Likewise, Susan called it a *"big step"* and Britney noted that *"it's no easy route."* Both of these individuals recognized that the lengthy and taxing long-term care processes contributed to the difficulty of transitions. Karen also supported this view stating, *"You want to be able to have a few decisions, manage it, and do it in a timely fashion… but you know that's like… you've heard that I'm sure, that that process is extremely difficult."* Lynne had a very hard time with the long-term care process suggesting that it *"dragged [her] to the limit of what [she could] take."* Furthermore, Bobby suggested that his mother's movement to a retirement home was difficult because, for her, it represented a loss of hope that she would get better:

> "I took a day off of work and went through it all and set it all up,
> and brought her down to it… and she… started screaming at me,
> 'No! You don't do that! You don't take that out of my house! You
> put it all back!' And what it was… was the fact that she was
> clinging on to every bit of hope that once her head was healed…
> she could go back home. And that's the difficulty with the
> transitions."

These instances represent the procedural and emotional difficulties that result from transitions into long-term care. Further examples of emotional turmoil and conflict due to perceived abandonment and caregiver guilt were described in Section 5.4.3.1. Feelings of a loss of control among caregivers also contributed to the emotional significance of long-term care transitions. Lynne illustrated this perspective: *"It's also overwhelming to be in a position where you have to face the fact that you cannot do it, and you have to turn his care over to somebody else."*

Participants also described the physical significance of the move to long-term care. Jim supported the idea that moving to long-term care was difficult due to the environmental disturbance it caused for his wife: *"I think she was having real problems, because you know… she'd recognize me in the home, but if we were outside or someone else she had difficulty, when*

it was a different environment." When Susan's father moved into long-term care, the environmental shift was a major stressor for him as well:

> "He took a dive bomb as far as… understanding things, being able to… he had no idea he was in [city]. Like, 'when are we going back home'… like he just dive bombed horribly and stayed that way for many, many days."

The significance of changes in physical environmental resonated with Rebecca who noted: *"It's different surroundings and sometimes when you take a person out of their own surroundings it makes a difference."* Rita indicated that she wanted to keep her mother out of long-term care because she believed the disruption would cause her to decline more rapidly: *"It would be better to keep her out of one as long as possible…because I don't think she would get the same care or she would go into a faster decline."* These stories provide support to the notion that the long-term care transition stands out, in part, due to environmental or physical disruptions.

Familiarization with the long-term care environment prior to the transition was suggested as a method to ease the environmental shift. Heather described this idea in suggesting, *"there might be some advantage to having him in [respite care] there because as the thing progresses he will be stabilized in a place that's familiar."* Leanne also illustrated this benefit of respite care: *"That was kind of the same thing where they could stay in the respite bed there…it was good because it was a familiar place to the people at the home."* Susan expressed how having her father in a day program housed at his future long-term care home was helpful:

> "It was actually CCAC that suggested that he go to day away the day he'd be moving into the long-term care centre. And the [day program] just happened to be at the same facility… So it worked out really well."

When transitions to long-term care went smoothly, persons with dementia began to adjust and consider the facility their new home. The staff in Bonnie's father's home treated her father as if it was his home in order to ease his transition and help him adjust: *"They insist and they say, 'it's his home now. So he needs to be treated like he was in his home.' So it's all great that way."* Like many caregivers, Jim was skeptical of the idea of living apart from his wife, but her positive interaction with the staff allowed it to become her home:

> "I wasn't going to go with her you know, because… you feel a bit guilty, but what it was… the people that said, 'Well you've got several choices… You can put her in, it doesn't have to be permanent, and at some point later on if you need to take her out you can… and the other thing is you can visit her whenever you want to.' So… I did that, and actually… it's become her home. You know… she's… she doesn't have a lot of interaction with me, but she has a lot of good interaction with the staff there."

Ultimately, people want to know that their needs will be met. Garry sought input into the long-term care home decision before his dementia advanced to ensure that he would get placed somewhere that would take care of him: *"I'm still able to choose where I want to go, you know, because we've visited quite a few nursing homes. And… umm… they're not all good. So… I'd like to go to a place where I know that I'll be well taken care of."* Geoffrey, although he felt a range of emotions including guilt and uncertainty in his decision to move his wife into long-term care, resolved that it was the best option for her to receive sufficient support: *"I'm glad she's here. Because she is getting the help she needs."*

A progression of dementia symptoms and the move to long-term care marked the beginning of the caregiver's transition out of the caregiving role. Geoffrey regarded this transition as the *"final transition:"*

> "I think once that final transition is made, so Amanda is where she is, and she will be there presumably till she dies… then you… the transition is different, because it's… you're not going to have any of those gut wrenching changes anymore… it's just watching that decline."

Participants described how, in many cases, this final transition actually began before the death of an individual with dementia due to the concept of ambiguous loss: the idea that someone is still alive but is not the same person that they used to be. Bobby explained how he had begun the transition out of his role, even though his mother was still alive: "*She's just sort of continuing on… but she's not the same person that raised me, that brought me into the world … So in my mind… I've already had a funeral for my mother.*" Margaret also felt the ambiguous loss of her husband before he passed away: "*That person is still there, but it's not your husband anymore, and you still love them very deeply… but they are almost like a stranger.*"

At the transition into long-term care, caregivers mentioned having to alter their lives and mindset. Lynne had trouble knowing what to do when she no longer had the full-time job of taking care of her husband: "*What am I supposed to do with this time?*" Geoffrey described the process of his transition into a new role and learning how move on without his wife:

> "So now my transition is… the challenge for me transitioning as an individual, is how do I re-orient my life. I'm an employment councillor so I'm constantly dealing with someone who's lost their job at 63, and their whole life expectation for retirement has changed… we had all these plans about what we'd do in retirement… but they all went out the window. So now I have to re-orient my life, and I put all that on hold for a couple of years… but now I'm beginning to shift it back into, 'How do I go forward?' "

Bobby spoke of a woman in his support group whose mother had passed away and did not know what to do with her time:

"Well now she's having a hell of a time dealing with, the time!
You know? Because for years… everything was focused on
dealing with her mother and dealing with the [retirement home],
and dealing with [the long-term care home] and dealing with the
CCAC and… she wrapped everything in her life up along that…
and now that her mother is gone, it's like, 'Oh my god, what do I
do?' "

Similarly, after her husband passed away, Margaret had trouble transitioning from doing things

together to doing things alone: *"We always discuss this together. I've got to make a decision all*

by myself... I've heard that other people say that all of a sudden, 'I'm just alone.' "

Although the final transition often occurred at a point where the individual with dementia

had endured significant cognitive decline, it was perceived as essential that caregivers and

providers maintained a focus on the person with dementia's personality and wishes. Beth noted

how consideration of her husband's love of music eased his transition into long-term care: *"He*

was a singer and music has played a tremendous role in helping him through all of this

transition." When Alana's husband learned that he did not have much time left, her provider

looked to him for his preferences for end-of-life care: *"So...the doctor said to him what's your*

final wish. And he said, 'to go home.' "

5.5.5 Transition processes summary

The evidence that emerged to inform the transition processes section indicates that transitions

through the health care system are primarily continuous rather than discrete; however, the

beginning and end of the journey stood out to participants as requiring a unique set of

considerations. At the beginning, the manner in which a diagnosis was received coloured

individuals' initial perceptions of dementia care. In the middle, whether actions to ensure

coordination and continuity of care were taken influenced transitions between or within various

settings in the health care system. At the end, the emotional and physical significance of the transition into a new environment affected perceptions of long-term care. Finally, caregivers perceived loss of control and transition out of caregiving were major aspects of the idea of 'the final transition' that emerged from the interviews.

5.6 Influencing Factors

Several types of factors that may influence transitions surfaced during the interviews. The category of catalysts includes factors that precipitate transitions, including incidents such as falls as well as changes in ability to cope. Transition buffers are actions taken to ease future transitions. Lastly, the categories of facilitators and barriers occur at the time of transitions to either help or hinder the process.

5.6.1 Catalysts

When talking about their movement through the health care system, participants often described the factors that led up to their transitions. In some cases, these were sudden and directly triggered a transition; in others, there was a slow progression of changes that eventually led to the need for a different level or type of care. As such, two main types of transition catalysts emerged from the interview analysis: precipitating events or crises and changes in patient and/or caregiver coping abilities.

In some cases, a sudden event or crisis caused an immediate change in care needs. Several participants described how falls led to transitions in care. Susan noted how her father's fall led him to require rehab, and subsequently caused a consistent downward spiral:

> "He fell, when he was at long-term care… it wasn't the hip that
> broke… it was the pelvic wall… then they eventually start into

> rehab and getting you up…They did get him to the point where he
> was walking from his room down a couple of rooms to the
> restaurant, the dining room. But…he just kept going down from
> there."

Jessica described an incident wherein her husband fell, causing him to require care in hospital:

"He had a fall in December of 2012… he fell down the basement steps and was in hospital for a week. He hit his head, fractured his collarbone and some ribs and whatever." Margaret's husband Allan also suffered a bad fall; he required even more time in hospital: *"When he fell and hit his head, he had a hematoma and was in the hospital for over 3 years before he passed."* Other types of incidents that precipitated transitions in care included overdoses, heart attacks, surgeries for cancer, and major behavioural problems. For example, Rebecca's husband Gregory had a heart attack that worsened his dementia symptoms, causing him to require care outside of the home for a period of time: *"When he had his heart attack, that spikes his dementia, and he was really confused and didn't know where he was and what day it was and I could not bring him home in that condition."* Alana's husband Lucas transitioned into and back out of the hospital due to a bone cancer that required surgery:

> "They finally took a bone scan and discovered that he had a cancer
> in his leg. So, the doctor said to him… 'I want you in the hospital
> tomorrow morning and I'm coming in Saturday to do the surgery
> in your leg and put a steel rod in because the leg is about to break
> any minute'… So he had the surgery. He was in hospital for 3
> weeks."

Events and crises in the lives of caregivers also precipitated transitions for persons with dementia. In one case, surgery was required for Britney, which led to a transition for her husband Marshall due to her inability to manage at home during her recovery: *"So then it came to the point where I got a knee problem. Pain! So then I was booked for surgery. So then we decided*

that we'll book him for the nursing home, because our four girls, they all work." Jim's health

also reinforced the need to transition his wife to long-term care. He was diagnosed with cancer,

causing him and others to question his caregiving abilities:

> "Is shortly after that I was diagnosed with cancer. So the thing is
> that… there were some questions about my capability about
> looking after Angela. And then what came forward was a full term
> position at [a long-term care home] in [town]. So I actually put her
> in there on the xxth of December 20xx, and she's been there ever
> since."

Not all transitions were preceded by major events or crises; patient and caregiver ability to

manage at home changed over time, in some cases leading to different care requirements. For

example, Heidi noted a change in coping, which led her to call CCAC to have her husband Geoff

assessed for at home support: *"we were getting to the point that we weren't coping very well,*

which is why I made the call." Lynne also saw the need for further support when she realized

that she could no longer manage her husband at home:

> "When it became obvious that it was beyond my capabilities,
> patience, the rest of it, physical ability, and he was going to go into
> long-term care, then you get extra help. I had help in the morning
> to get him up, and bathed and dressed, I had help at night to get
> him into bed."

When Beth's husband Charlie went into respite care, she realized that she could not imagine him

coming home again. She noted, *"I thought about where I was at, and I knew it was beyond me to*

have him come home from there." Having him away from home helped her realize the toll her

caregiver role was taking. Similarly, Heather began to have an increasingly difficult time with

her husband's eating problems, leading her to reach a tipping point: *"I thought, well, I'll take*

him home and tomorrow I'm going to call her and tell her I can't do this anymore, I just, I've

reached the end… I said I can't face more of this vomit and I can't make the portions any

smaller."

Caregiver burnout and exhaustion heavily contributed to the need for transitions in care.

Heidi explained how burnout could influence the health of the caregiver: *"Caregivers are going*

to burn out and then you're going to have two patients instead of the one you used to have."

Laura indicated that she was getting tired; therefore, she felt like she needed extra care in home:

"I did call CCAC a second time… They did come out because I was trying to figure out if there

were some supports they could help with because I was getting tired." Bonnie also recognized

that she needed help for her own wellbeing: *"I called and said this is the situation that I had this*

morning, and I'm just wondering what I can do…if I can get some help. I was getting kind of

tired too from being with him!" Many caregivers felt guilty or overwhelmed when they realized

they could not manage anymore. Lynne described this feeling in saying, *"It's also overwhelming*

to be in a position where you have to face the fact that you cannot do it, and you have to turn his

care over to somebody else." These stories suggest that caregiver support may play an important

role in reducing the frequency of care transitions among persons with dementia.

5.6.2 Buffers

> "I'm convinced that if you… if you're able to step back and take
> steps like getting the powers of attorney, adjusting the household
> arrangements. Letting the family members know, checking out the
> credit cards… removing anything where she could do damage…
> that in fact you become much more resilient, and that that
> resilience cushions you against the next change in her, the next part
> of that transition."
>
> - Geoffrey (Caregiver)

The quote presented above summarizes the idea that pre-transition proactivity and preparation can provide an emotional buffer for care transitions. Geoffrey found that taking necessary steps and preparing for the future allowed him to become resilient to the transitions to come. The concept of a transition buffer can be conceptualized as an intermediary action that is taken in between the time that one perceives that a transition is coming and the transition occurrence. It serves to lessen the physical and emotional burden associated with transitions. Participants described two primary types of transition buffers: patient and caregiver proactivity, and preparation through avenues such as patient and caregiver education.

Persons with dementia and their caregivers recognized the reality of health care system constraints such as lack of time and insufficient staff. As such, many participants reported having to be proactive and advocate for their own care while moving throughout the system. The importance of patient and caregiver proactivity was described by several participants, including Jennifer who noted:

> "It's like anything else…if you go out and look for the support systems and look at what's happening and whether you need help at the CCAC, then you can go after it… you have to be on top of that. Because if you let stuff slide, they don't necessarily get in touch with you… They don't knock on your door and say 'Well here we are! Do you have any issues, do you need any help?' "

Matthew also felt that, as a caregiver, he played an important role in ensuring that his wife received appropriate care. He expressed problems that arise when individuals do not engage in the health care process: *"If you're just going to sit and do nothing… then you're not going to get anywhere."* Daniel supported this notion from the perspective of an individual with dementia in stating, *"You have to be aggressive, and if you're not an aggressive type person then you'll miss out on those things. You'll just go by."* Betsy had heard of many people who did not take the

initiative that she did: *"It is surprising I think how many people sit at home and wait for the system to come to them."* One of these individuals was Alexia who noted, *"I find that a bit of an issue, but I have to go along with what the system is saying now."* She had experienced a problem but brushed it off as a system issue that could not be resolved.

Lauren noted how lack of proactivity is, in part, a personality or generational issue. She described an interaction with older individuals that she came in contact with while caring for her husband:

> "I can see that for someone like them where they are more timid and they're 80, then they're not the type of people who are going to take the initiative to find out. I'm the type of person that will… I just realized that it is very hard to get that help when you don't have that type of proactive personality."

Emma suggested that in cases like these, people might not be aware of their rights to engagement:

> "They think that they don't have the right or the knowledge either to ask certain things… You can't sit back and just let things happen. You have to…be alert and know what's out there…and know what your rights are."

Jennifer asserted that people might avoid asking for help due to a lack of knowledge about where to start with their questions: *"I think people are afraid to ask because they don't know what questions to ask."* Knowledge about one's rights to active engagement in care is an important transition buffer because it can help ensure that care is centred upon the needs of persons with dementia and caregivers. The provision of appropriate care, a major aspect of care coordination, is dependent on the knowledge of patient and caregiver wishes. As such, transitional care can benefit from patient and caregiver proactivity.

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Emma illustrated the connection between self-advocacy and the need for patients to be educated and prepared for health care encounters in stating, *"We've definitely got to be our own advocates when we go to the doctors. You've got to know a little bit about some stuff."* When people were not educated about dementia or about the health care system, they were confused and did not know where to seek out help. Heidi expressed a desire for *"more information and more in depth information"* so that she could have accessed support earlier. Fran was also having difficulty finding out about programs in her area: "*I don't know what's out there, like what programs are available. Maybe it needs to be more… forthcoming or something?"*

When people did receive the explanations and education that they felt they needed, they had more positive outlooks on the journey. Rebecca said that her doctor *"explained things that I didn't know what was going on"* and called him *"terrific."* Bonnie also noted that her provider *"explained all of that and… I couldn't have asked for anything better."* Types of information that people desired included information about the stages of dementia, the steps that might need to be taken, and health care system processes. Jim believed that it was important to acquire some knowledge about the disease:

> "I think one of the things relative to Alzheimer's Disease is getting some sort of formal knowledge. And what I did, I went to the Care Essentials, which is put on by the Alzheimer's Society to teach about the different stages of Alzheimer's and the care… and I think that was a really good thing."

Geoffrey thought it was useful to have information about the steps that he needed to take:

> "I met with them individually, and they took me through a number of steps in terms of things that I should look into doing. Prior to that… I had been advised by my doctor to get powers of attorney and powers of personal care, and to see about switching her name out of various accounts."

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Lauren was grateful to know her options when it came time to think about the process of long-term care placement:

> "We'd learn about the different kinds of residence that you could go to, and all the day programs and all that kind of stuff. And this one was… like if you just feel like you're in a crisis and you just emotionally can't handle it anymore…. You can go together or separately or whatever… and I thought that that was a really nice option to know that you had that."

Margaret explained how an increased understanding of the journey eased transitions: *"I started to get educated and could understand what was happening. Because if you don't understand what is happening as a caregiver… ya it does make it easier if you understand what is happening."* Karen suggested that her knowledge gave her an advantage in the system: *"Knowing what the process is, and how lengthy it is, and knowing some of the little techniques to put yourself in a better advantage… umm… that's what these information sessions are good for."* Daniel also spoke about the perceived benefits of system knowledge: *"I think I have a bit of an advantage over other people because I have Louise who knows all of the ins and outs of the care system."*

By gaining a better understanding of dementia and the health care system, participants were able to prepare for future transitions. Lauren planned ahead of time in order to feel more prepared for the future: *"I knew I didn't need anything at the time, but I just wanted to make sure that I had all of my research and homework done. So that when I do need assistance I have someone to call and I'm already in the system."* In a related comment, Karen noted:

> "We always plan as much in advance as we can. I'm not going to be one of those people that's in my group that… if it gets to the point where 24-hour care is required, that's not something I can

provide. You know? And keep myself healthy. So I won't wait
until that. I'll get help in the house. However I have to get it."

There were also situations when people felt unprepared, causing feelings of surprise or shock at
the time of a transition. Susan felt unprepared for her father's assessment with CCAC; she felt
like the process was too blunt and sudden. She believed that her experience would have been
improved *"if the CCAC person could warn the family, and say, 'This is the way it's going to be,*
this is what I'm going to say…. It's going to come across as being rather harsh and brutally
honest.' " Jim also felt unprepared for his wife's transition into long-term care due to a lack of
awareness that he would have a very limited time to make the decision when a bed was available.
He suggested that providers should *"just give some sort of warning that there may be a position*
available in so many months, just so people could prepare." Thus, feeling prepared helped
alleviate some of the emotional difficulties that often accompanied transitional periods.

5.6.3 Facilitators

The facilitator category consists of attributes and actions of providers, the health care system,
and persons with dementia or caregivers that contributed to the success of transitions from the
perspectives of the participants. The major themes that arose included: positive views of provider
attributes and actions, patient and family engagement, and person- and family-centred care.

5.6.3.1 Positive views of provider attributes and actions

Participants often had very positive views of the people that they came in contact with while
receiving care for dementia, even in cases of more negative system experiences. Geoffrey noted
that he had *"nothing but praise for the… health professionals that dealt with [his wife]. Both at*
the hospital, in the mental health ward, they were superb… police, doctors, everyone…"
Rebecca also expressed praise for those working in the health care system in stating, *"I can't say*

enough about the people. They were excellent, just excellent." Lynne had some very difficult

experiences during her husband's transition into long-term care; however, she still valued the

people that she came in contact with:

> "It's really hard to try to pinpoint a negative in the aspect of the
> people you were dealing with… [they] were doing their best, and
> doing as much as they can, so I can't put any negative
> there…We've been met with a lot of kindnesses from doctors, and
> nurses, and… community, and staff at long-term care."

Despite the problems that she experienced, she respected the fact that her providers were

working hard within the context of system constraints.

Participants particularly respected and appreciated providers who were understanding and

compassionate while at the same time professional and skilled. Lynne noted that the providers

who treated her husband in hospital *"were very compassionate, very understanding"* of the

dementia and willing to take time to ensure that John was comfortable throughout his time there.

Melissa and Matthew noted that their providers were *"very understanding at every stage"* and

"compassionate," but also that they had *"done it before, they know what's going on"* and they

were *"probably the best in the country."* It was common for participants to accompany

comments about provider attitudes with statements about provider professionalism and expertise.

Regarding her husband's physician in the memory clinic, Maria noted that he was *"a very gentle*

man and he always has time for you," but also that "*he's the one who calls the shots,"*

suggesting that she valued both his attitude and his expertise. Similarly, Margaret noted that the

nurses in hospital *"were very kind to both he and I"* and that *"they seemed to understand the*

dementia;" again, the placement of these statements together indicates that her appreciation for

providers emanated from a combination of their attitudes and knowledge or skills. Geoffrey

proposed that provider compassion is intrinsically linked to their professionalism; the former giving rise to the latter:

> "It's that patience, that professionalism… and while I think it's a genuine compassion - that compassion may be born out of the professionalism. But it strikes me as something that you don't find in everyone, so clearly these people chose this profession because it suited who they are."

That said, perceptions of provider compassion and professionalism were not universal; an explanation of perceived issues with provider knowledge and education can be found in Section 5.6.4

Certain actions of providers contributed to participant perceptions of provider compassion and professionalism. These include: going above and beyond for persons with dementia and their caregivers and explicitly considering caregiver needs. When participants felt like their providers made the time to address their concerns, they felt supported through their care journey. Betsy's geriatrician stood out to her as being particularly good at making time for her and her husband with dementia:

> "She would say, 'if you have a crisis and you need to talk to me, call and I'll come in at say 8:00 or quarter to 8 and I'll see you in the morning. You know. I'll see you. I'll fit you in somehow.' Which… I think twice we took advantage of that and I thought that was so much above and beyond. You know, cause she has so much responsibility."

Alexia supported the importance of her geriatrician's willingness to make time for her: *"She's there for us whenever we need to come and see her."* Bonnie had a comparable view of the physician in her father's long-term care home, suggesting that the doctor was diligent in ensuring the process was well-understood by both Bonnie and her father, Kevin: *"I'm very happy with the*

fact that they have a doctor that's on site who cares enough to call and take the time out of her

day, with all the people she has to see, to explain things so well." Furthermore, Heidi was

grateful that her physician made extra time to address her concerns about her husband's care:

"He's taken time to answer a lot of my questions outside of normal visits."

In a similar vein, participants were also thankful when providers inquired about how they

were managing. Rebecca noted: *"Alzheimer Society usually checks and gives a phone call every*

so often, and say, 'how are you doing and do you need something,' and that means a lot. I think

they're very good here." Another caregiver, Margaret, had a very similar experience with her

local Alzheimer Society:

> "Contacting me, you know, in between the… our meetings to just
> see how I'm doing, and some counseling… not really counseling,
> but, 'How are you?' And if I had any questions they would get
> back to me about things as well."

Both of the cases presented above were described by caregivers; thus, these quotes also provide

support for the perceived importance of explicitly considering caregivers needs. Caregivers'

perceptions of their providers were improved when providers cared for them and helped them

receive the support that they needed. Laura described how her geriatrician helped her first make

contact with the CCAC so that she could receive more in-home support: *"[The geriatrician]*

called them and said he wanted Bill to… be enrolled in the day care…day program because I

needed help." Lynne also illustrated her provider's consideration of her needs in addition to her

husband's: *"At one point, [he] decided care for just John wasn't enough, and that I needed*

respite, so they put someone in the house for two hours every week." The nurse at Bonnie's

hospital also thought of her needs as a caregiver when she was willing to take Bonnie's father

into the hospital for the night in order to provider her with an opportunity to sleep:

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> "I got one of the nurses that had been there for years and knew my mom, and knew me, so I explained the situation to her and she said, 'Bonnie, we don't have any rooms but if you can't go through another night like this, so if you want to bring him down we can keep him in emerg for the night and give you some rest"

Gregory also appreciated a periodic shift in focus from the person with dementia to the caregiver; he stated:

> "I think it was one of my doctors who said, 'We know what her concern is, now we have to concentrate on you.' And that's great. In other words not, 'How's Amanda doing…how are you doing?' Very reassuring."

Caregiver support is particularly important given the fact that caregiver coping ability was one of the primary transition catalysts discussed in Section 5.6.1.

The actions of providers that caused participants to perceive them as compassionate and professional also contributed to the formation of patient- and caregiver-provider relationships. Several participants described how they formed special relationships with certain providers. For example Susan described her *"favourite nurse"* who *"joked with [her father]… and he just loved that! Fed his ego. Which was very important to him."* Monica had a particularly good PSW. She explained why her relationship with this woman was so special in stating, *"she's very understanding, she has a way of, just an instinct of how to deal with people who have confusion."* Anita also described the special relationship that her husband Rick formed with one of his support workers, *"that worked out really nicely because she was coming in here for two or three hours in the morning and I could go off and do errand and her and Ron developed a nice relationship."* These relationships were fostered through patient and family engagement and the provision of patient-centred care.

5.6.3.2 Patient and family engagement

Participants recognized that the development of a working relationship with a provider required two-way effective communication. A caring relationship is not simply the delivery of care from one party to another; rather, both parties work as a team to ensure that the needs of the person with dementia and their caregiver are met. Jennifer described this two-way communication:

> "I think it's all in the matter in how you approach people sometimes as well… If you go in and yell and scream you're not going to get anywhere with them. I think they just put up a wall and… you're not going to get anywhere."

Betsy reiterated this notion:

> "I know people who they go beyond advocating and take a run at the system. And if you take a run at the system I think you put get put to the bottom of the list you know? Nobody wants to call you back because they got yelled at last time."

Effective communication enables patient and family engagement, wherein users of the health care system are included as partners in all care decisions. Martin described how his providers included him along with his caregiver in the decision-making process, stating that they had been *"very cooperative in discussing things with us. Not saying you must do this."* Betsy also felt like she and her husband Peter were engaged during all of their health care encounters:

> "I think that umm we've been included in everything at [the geriatrician's] office and maybe we're lucky with our CCAC person, but…she very much talks to Peter and talks to me sort of on the side the conversation is with Peter and if he sort of can't answer then she talks to me so that we're really included in everything."

The fact that the providers always tried to direct questions and information to the individual with dementia, Peter, was a particularly salient component of Betsy's perception of their health care engagement.

Engagement in the case of dementia is distinctive in the sense that the individual who is declining cognitively will often have a family member act as power of attorney. Both before and after they reach that point, persons with dementia still want to contribute to their health care decisions. Daniel described the engagement-related mantra of a dementia advisory group within the Waterloo-Wellington region: "*You know, you're not doing stuff for us, you're doing stuff with us.*" He believed that the fact that he had dementia should not influence his engagement in his own care. Melanie suggested that people with dementia, especially in earlier stages, should be given the right to choose their own future (e.g., participate in long-term care placement decisions): "*So for the few that really are able to choose, I think that they should let them.*" Alana described an instance of complete lucidity in her husband before he passed away: "*But he knew exactly what he wanted and his memory he just, he just knew exactly he didn't ask anything. He said I want [this].*" In order to ascertain the wishes of someone with dementia, providers need to ask them directly; participants viewed attempts to ascertain the wishes of the person with dementia very positively. For example, Susan noted: "*They try to direct as much of the conversation to Dad as possible. So that's good.*"

Engagement of persons with dementia and their caregivers in their care can facilitate positive perceptions of transitions because people feel respected. Engagement through discussion can also provide those navigating the system with a better sense of the health care system and its processes, thus reducing confusion during transitions. Finally, engagement can help prevent coordination and continuity problems by encouraging people to take ownership of their own care by following up with and questioning their providers.

5.6.3.3 Person- and family- centred care

The concept of engagement is very closely linked to the notion of person- and family-centred care. Codes related to this concept were some of the most commonly referenced in the interviews; there were approximately 90 references to aspects of person-centredness within the 29 interview transcripts, an average of approximately three per interview. The following memo portrays the importance of understanding of a person with dementia as an individual:

> When caregivers describe the needs of their loved ones, they often make reference to how that person used to be. Their personality traits, as well as their previous jobs and hobbies, tell the caregiver how they would want to be treated, even in cases wherein they cannot explain their desires themselves. These aspects of an individual's life should be made readily available to professionals, because they can dictate the type of care that would be best suited to an individual. Furthermore, they might provide insight into things that the person with dementia would be sensitive to – e.g., a man who has taken pride in his appearance and personal hygiene would be very strongly affected by the idea that someone has to help him bathe and stay clean.

When asked about their loved ones' experiences navigating the health care system, caregivers often focused their conversations on the person with dementia's personality and past; in other words, they described who they are/were as a person. Britney said, *"I think in every dementia you see a little bit of everybody."* She further explained how her husband's characteristics influenced her care goals for him: *"The idea is that I want Marshall clean. That's my aim. Because he was always a very clean person, well dressed, you know? Well groomed, you know?"* Other caregivers felt that certain personality features of an individual with dementia made the transition into receiving care from others very difficult. Laura noted: *"You're talking about someone who has always looked after himself. Or was very good about keeping his image, his public image up. And then to have someone come in…"* Susan had a very similar view: *"Very*

proud man! Extremely proud. And he had his own business, he had a bunch of stuff, he dealt with all of the big wigs in the city here and in Toronto…. So, for me to have to get Red Cross in…" Beth explained how her husband's love of music influenced his care: *"He was a singer and music has played a tremendous role in helping him through all of this transition."*

Caregivers suggested that it was important that the health care system viewed persons with dementia in the same way that they are viewed by their loved ones: as people with individual desires and needs. Bonnie, for example, wanted providers to be aware that *"they're still people"* and Leanne thought that it was *"important to see the person as the person instead of as the disease."* Matthew expressed the importance of this notion, suggesting that relying on numbers alone would not give providers a sufficient amount of information about the person: *"Two people are not the same, you can't go on the test results alone."* Furthermore, Betsy believed that rather than having rules, the system should accommodate individual needs: *"I think that they should be able to look at that and…make it work for individual people."* Bonnie suggested that conversations with staff about an individual with dementia are important in order to let the staff know *"who this person is"* as well as *"who this person was:"*

> "I think letting the staff know who this person is… if they know something about the person they can talk about something that you've done or accomplished or… whoever you are. And that conversation is important. I think that often… it's not anything that'll happen. Is that there's not enough time for the nurses to have conversation with them, and if the patients don't have family who come in… it's very difficult for the nurses to know anything about this person. And I think it's really important that the staff know something about who this person was."

There were several cases in which the system succeeded in providing this person-centred care. Matthew noted how his wife's providers generally responded to her needs as an individual

rather than her needs as part of the category of individuals with Mild Cognitive Impairment: *"I don't think they respond categorically. They just see that person and respond to that."* Concerning the staff in her father's long-term care home, Susan remarked: *"They make it their business to know what that person did in their life and what's important to them."* Heidi explained an example of her husband was respected as an individual:

> "The rec leaders really get to know what the individuals' interests are. And they focus on those and then they just kind of have general physical activities that keep them active. And they do…depending on their level of functioning, they'll do anything from trivial pursuit questions to simple word definitions. You can just see what really works to stimulate them in the areas that they need."

Bonnie also described how her father's background was considered in planning activities in his long-term care home:

> "Because of his musical background… one day we went and they had music, which they have for anyone in these homes… but they had my father up by the piano, with his spoons, he also plays the spoons. And they had got him spoons and let him play! And he was so pleased! He said, 'Well, I have a band.' And for a few days after that he was still carrying the spoons in his pocket. And if he heard music and you saw him you'd see him clanging away on these spoons."

Bonnie's father was made happier and more comfortable in long-term care due to a focus of the staff on his interests. Person-centred care can facilitate transitions by helping people feel at ease during new care experiences (e.g., the transition into long-term care).

5.6.4 Obstacles

The final type of influencing factor in the theoretical framework is the idea of transition obstacles, which are system, provider, or patient-level features that may hinder transitions from

the perspectives of those with dementia and their caregivers. Four subsections of the transition

obstacle category were identified during the analysis process: system complexity and constraints,

issues with provider knowledge and education, information and communication problems, and

denial and depression in persons with dementia.

5.6.4.1 System complexity and constraints

Transitions can be impeded by the complexity of the health care system and the resulting

confusion among persons with dementia and their caregivers. As noted in Section 5.5.3,

participants received care in several different settings by several different providers. For many,

this caused a great deal of confusion. Jessica talked about the complexity of her husband's health

care system navigation: *"It's kind of sometimes… umm…. It can get kind of confusing."*

Similarly, Fran found the system *"a little confusing,"* but she noted, *"I guess once I get to know*

the system it'll be alright." Confusion can lead to transition problems because persons with

dementia and their caregivers will not know where to go for help. Jennifer described this notion

in stating, *"Sometimes it's a little difficult to navigate your way through the system in terms of*

who to call."

In addition to being complex and confusing, the health care system is also constrained by

factors such as time, money, and strict regulations. There were several stories about system goals

and mandates conflicting with the needs of persons with dementia. The system constraints

described by participants included rules against "double-dipping," or using more than one

government-funded resource at one time; a focus on the bottom-line; strict referral policies; and

time constraints. Susan described how double-dipping policies caused her father to lose access to

a program that he loved, even though it could have eased his transition into the long-term care

home that housed the program.

> "Dad went to day away, which was his be all and end all in that
> period… that was everything he looked forward to… absolutely
> loved it. I found out that once dad was accepted into long-term
> care, it would be like double dipping. You could no longer attend
> day away. Because both of them are government funded. So as
> soon as you go into long-term care, day away stops. Even though it
> was in the same building, he could no longer have anything to do
> with day away."

Another caregiver, Jennifer, explained how her mother could not receive help from CCAC

because she was residing in a retirement home with nursing staff who could, for a fee, provide

care to her mother.

> "I had a couple of mixed messages, that CCAC said if you can
> have someone at the retirement home give her assistance - because
> if there's nursing staff there, then they were not going to give us
> any help… I know that when my mother was in the hospital a year
> ago, in February, and she had a really bad fall and CCAC was at
> the hospital. Before they release you they come in, and I had said
> to them at that point, 'Are we going to get some help?' and they
> said 'No.' Flat out. If you have assistance at the retirement home,
> because there's nursing staff there… then you will not get any help
> from CCAC."

In situations like these, the system did not prioritize the needs of the individual with dementia;

instead, system regulations outweighed their needs.

A similar lack of consideration for the needs of individuals was clear in stories about a

system focus on the bottom line. Heidi noted:

> "There's always the bottom line in health care and the needs
> always outweigh the funds. But I honestly feel that if they don't
> have a little bit more of a support system implanted, like, to be
> honest if I burn out my whole family will go under and we'll all be
> torn down."

In this quote, she recognized that funding is a major consideration for the health care system; however, she believed that support systems should be prioritized to ensure that both the caregiver and the person with dementia are adequately supported. Retirement homes and long-term care homes were viewed as moneymaking institutions by some of the participants. Susan believed that retirement homes cared more about money than people. An individual who worked for the retirement home in which Susan's father resided was fired because she helped him get on a list to move to long-term care, meaning that the home lost a client:

> "To fire a nurse because she saw that the person was beyond the care level that could be provided… and needed to get into long-term care. She's fired because of that, because it's affecting their bottom line. That's pretty sad."

Likewise, Jim felt as though his wife's long-term care home cared more about money than people: *"I may be negative, but I think some of the places are just being run like big businesses…It's a business that is making money, and not necessarily looking after the people itself."* He felt that a focus on the business aspect of health care detracted focus from the patient care in nursing homes.

Strict referral policies represented another source of conflict between the needs of persons with dementia and the goals of the health care system. Having to go through CCAC rather than attaining referrals to services directly through family doctors or geriatricians was seen as a barrier to transitioning into programs. Betsy suggested that frail older individuals might find the process of speaking to CCAC disheartening, which might prevent them from attending programs or accessing helpful services.

> "If you go to the CCAC there's like a gateway person. Well what do you need? Well that might be that person or this person or that

person. And so I think that's off putting and if you're already frail a lot of caregivers are a lot older than I am right. There's obstacles, there's gatekeepers…there's obstacles in the way, preventing transitions almost. You know they don't mean to, but they're just steps that you have to go through… You know, if [geriatrician's] office could persuade people this VON day program is terrific, 'I can have my nurse send a form you know by e-mail today.' Except for but now it has to be referred through the CCAC."

Heidi described this referral process as a barrier as well: *"You can`t do the intake at the day program until you have a CCAC recommendation."* She believed that the intake process with CCAC did not emphasize her goal of getting her husband Geoff into a day program; instead, it focused on questions about his activities of daily living. She described this perceived misdirected attention in saying, *"They actually sent out...an occupational therapist just to evaluate how Geoff was doing in the house. Like could he bathe himself? And things like that. Those were never the issues!"* Those behind these stories felt like the referral process was not intuitive. Referral guidelines, rather than contributing to improved care coordination, took focus away from individual needs.

Finally, some stories illustrated how system time and staffing constraints influenced care for individuals with dementia. For example, Beth felt that more should be done to keep people continent in long-term care; however, the home put all individuals in adult diapers in order to simplify work for staff:

"Everybody turns out wears diapers, no matter what in a long-term care. Whether you can go yourself or not, everybody wears diapers. And I understand that it's, it's easier for the staff… in the long run, but I also think that if a person is continent, every effort should be made to make that person continent."

In another case, Emma felt that her presence at the hospital was necessary in order for her

husband to receive adequate care because she felt that provider time constraints led to patient

neglect:

> "I was up there…from morning until evening. I found it
> necessary. Otherwise he would not have had the care that I wanted
> him to have. And it had nothing to do with the people there…were
> neglecting him – they just don't have time… I know the load that
> they carry and it's not…they cannot do the things you want for
> your loved one in the hospital. There's just no way."

People like Emma recognized and understood the constraints of the system, but did not believe

that they should be used as an excuse to take focus away from those being cared for. Other

examples of participants acknowledging these constraints are included below:

> "I think that the problems at the CCAC, they're run off their feet."
> - Betsy
>
> "I'm sure she was hugely stressed and I could not imagine, she was
> the only single person booking for this whole area. How one
> person could manage that?" - Beth
>
> "CCAC is amazing. I don't know how those people do what they
> do." - Susan
>
> "We all understand that they're short staffed, we all understand
> they can only allow so much time per resident, we don't have a
> problem with that if our loved one is, for lack of a better word,
> maintained, regularly." – Lynne
>
> "They've got funding issues, staffing issues, they're going on
> strike, there are not enough beds… I think they are doing the best
> they can." – Karen

These system constraints can delay transitions due to long wait times. Many participants had

experienced long wait times; even when the care they received was perceived positively, wait

times were perceived as an important issue. Maria had a positive perception of the people

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involved in her husband's care, but noted a problem with having to wait for care: *"They're all very nice. Ya. The only problem is that you have to wait."* Others expressed their concerns about waiting for specialist care once a referral was made. For example, Karen called the process of getting a referral to a specialist *"simple, but then you wait."* Daniel and Leanne also experienced delays in transition to a specialist due to a long wait time. Leanne noted, *"The only bad part of transitioning has been the 8 month wait after our referral."* Again, the system, rather than the people working within it, caused a problem.

5.6.4.2 Provider knowledge and education

Although in many cases, providers within the system were viewed in a positive light, there was a clear perceived need for increased knowledge and education of providers among some participants. For example, Lynne remarked, *"I think that as time goes on it is an area where more training is going to be needed with all staff. Because more and more of this is coming."* Bonnie was also a proponent of increased training about dementia among nurses:

> "It's a huge, a huge thing for a young nurse, or any nurse... the young ones can learn it, where it seems like these older ones are too tired to do it. That's the impression we get it's like, 'Been here long enough, don't need to...' But you do! If you're going to be in those facilities, you can't not be involved."

Monica extended this notion to PSWs: *"I think it will have to be mandated that the frontline workers, PSWs have to be trained, have to take a certain amount of training. And it should be mandated across the province."* Bobby believed that a problem with training could lead to mistaking the symptoms of dementia for signs of normal aging:

> "I find that unless a doctor is a specifically trained in how to handle dementia... They tend to sort of 'pooh-pooh' it, and it's

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like… 'Well you know, you're getting old… and that's it, and that's the way it is.' "

This error could significantly delay access to support services for those who need them.

Some caregivers also expressed a perceived lack of training on rarer forms of dementia. Bonnie's father Kevin has Lewy Body dementia; she noticed that the training that providers do have is usually Alzheimer-specific: "*I feel that they do have some training in….but more so it seems to me that it's more of an Alzheimer's training.*" Margaret's husband Allan had Parkinson's dementia; she described how his transition into dementia care was delayed by a lack of understanding of this specific type of dementia within the health care system: "*So they didn't really understand…. Like Allan had had it for a long time, and I didn't even know that Parkinson's dementia existed. Nor did they.*"

Participants also acknowledged lack of provider knowledge about services available to persons with dementia in their communities. For example, Fran did not believe that her family doctor had sufficient knowledge to refer her husband to other services: "*She just, like… you know, she's in her field, and that's what she deals with. And she can suggest things, but she doesn't really know maybe what is really available.*" Rita found that her CCAC case manager did not have enough knowledge to provide her mother with services in her area: "*The CCAC guy… he doesn't know what services are in the Wellington region.*" A knowledge deficit about available services can prevent persons with dementia and their caregivers from accessing support.

5.6.4.3 Information and communication problems

Participants felt that their ability to successfully navigate the health care system was hindered by information or communication deficits. They described different types of informational issues. For example, the explanation that Lynne received about her husband's dementia was subpar: *" 'Oh, he has dementia, well… take him home, he can't work.' Not really much other explanation."* Alana also wanted to know what was going on with her husband; however, her providers *"don't contact [her] with any results."* Heather even felt like her providers were purposefully withholding information from her: *"So that's what I mean by not always lying but just holding information in. And I got that feeling all the time that it was all private information and I had the bloody nerve thinking I should be entitled to stuff."* She felt like her providers portrayed medical information as owned by the system rather than by the person navigating the system, which is contrary to the facilitator of person-centred care. When participants' providers did not provide them with enough useful information, they felt like they had to go looking for it themselves, which contributed to their stress. Laura explained, *"You have to go searching and that's just one more thing in the day."*

Communicating information in the manner that is preferred by the person with dementia or caregiver could help address the obstacle of information problems. However, appropriate communication did not always occur. Beth noted that she and her husband *"wanted to be able to communicate differently"* with the woman who booked her homecare appointments but they *"weren't allowed to"* due to the strict booking procedures. Engagement of many persons with dementia is also dependent on an appropriate communication style. Daniel could not always fully understand his providers when they attempted to communicate with him: *"They've got the words*

that you don't know what they're saying." Given that information allows people to prepare for transitions (See Buffers, Section 5.6.2), information problems and communication difficulties leave persons with dementia and their caregivers at a disadvantage. Thus, providing persons with dementia and their caregivers with sufficient information in the format that they desire would help improve their transitions.

5.6.4.4 Denial of diagnosis and depression among persons with dementia

Psychological concerns that could impede the transitions of persons with dementia include denial and depression. In some cases of dementia, individuals either deny their diagnosis or avoid the issue entirely. Jessica, the wife and primary caregiver of her husband Rob, described this denial in stating, "*People… sometimes they don't realize that that's what's going on with them…so they just avoid."* Denial and avoidance can influence several aspects of health care experiences. Jim described the delay in access to services that may arise from denial: *"They're in denial, and by the time they see any symptoms, they've had dementia for maybe 5-6 years."* Geoffrey indicated that his wife's reluctance to admit her diagnosis kept her from going to the doctor:

> "Her reluctance to go to the doctor was because she didn't want…
> she would never admit to this. To this day the word dementia… we
> never discussed it. We never had that discussion. She never used
> the word about herself, she never expressed any concern about
> whether she might have dementia, whether it might be passed
> down to the next generation… her generation… now I wonder
> whether that was buried so deeply, but it inhibited her from going
> to the doctor."

After the diagnosis was made, concerns about navigating the system with a person with dementia in denial remained. Betsy expressed this concern in stating, "*How do you move the system with an unwilling participant?"*

Participants also considered depression in the individual with dementia as an important influencing factor. Depression at the beginning of the journey was common. Lauren, caregiver of her husband Andrew, described how his diagnosis of dementia influenced his mental health in stating, *"Well… it is depressing, there's no question. Knowing that you have dementia is depressing."* Andrew echoed this idea: *"It sunk in. I was like 'Woah…' You know? I folded up like a balloon, and I had to pump myself back up again."* Heather expressed the significant effect that depression could have on entry into the system and dementia management:

> "He seemed to me to be sleeping a lot during the day and to be generally depressed and I took him to [doctor] who's a gerontologist…She prescribed a medication which he refused to take… and continued sleeping through the afternoon and so on and so we went back I made another I waited almost a year"

Her husband Frank's depression influenced his first interaction with a geriatrician and medication adherence. These psychological considerations are important to consider when planning transitional care; addressing the denial and depression of persons with dementia could help improve their care transitions.

5.6.5 Influencing factors summary

In this section, the factors that directly influenced participants' perceptions of their transitions were described. Crises or gradual changes in coping served as catalysts for transitions. Proactivity and preparation eased future transitions, acting as transition buffers. Facilitators such as positive perceptions of provider attitudes and actions, patient and family engagement, and person-centred care, lead to improved perceptions of transitions. On the other hand, factors such as system-level constraints, lack of provider knowledge, information and communication problems, and denial and depression among persons with dementia served as obstacles to

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successful transitions. Considering these factors, along with the context of transitions, is important to understanding transition processes.

5.7 Member Check Results

The results of the study were brought back to those who were interviewed in order to ensure that the elements of the theoretical framework actually matched the experiences described in the interviews. Out of the 29 interviews conducted, representatives from 13 of the interviews agreed to participate in member checks (a response rate of nearly 45%). An overview of each section (i.e., context, processes and influencing factors) was provided to participants (see Appendix Q for the member check guide). Every individual that participated in the member check agreed that the framework accurately and comprehensively described their experiences. Support for this notion was provided by detailed notes taken during the phone calls.

Participants tended to expand upon those aspects of the framework that resonated with them. One caregiver noted, *"the context that you mentioned is so important."* This caregiver also remarked that the researcher was *"right to highlight peoples' expectations based on anecdotes."* Likewise, another caregiver expressed her understanding of the parallel experience aspect of the framework, suggesting that those going through similar situations are *"closer than family."* Regarding the provider consistency aspect of continuity, one participant noted: *"it's difficult to jump to hospital – everybody changes and it's frightening."*

Others voiced overall comments about the comprehensiveness of the theoretical framework including the following:

> *"I related to everything you've talked about."*
> *"You've grasped the whole experience."*

"You've touched on basically everything."

Finally, regarding the usefulness of the study, participants noted that the study was *"timely"* and could *"provide knowledge"* that could be useful in *"training people accordingly."* Thus, it can be concluded that the theoretical framework meets the rigour criteria of resonance and usefulness.

Chapter 6
Discussion and Conclusions

It is clear from the diversity of the information that arose from the interviews that developing a conceptualization of care transitions from the perspectives of persons with dementia and caregivers is not a simple task. Transitions cannot be purely described by a series of actions taken to ensure that an individual moves gracefully from one setting in the health care system to another; transitions are not often viewed as discrete and influencing factors are not easily listed. The theoretical framework presented in the results section aims to distill a multifaceted topic while still respecting its complexity. Thus, it was necessary to describe not only the factors that have a direct influence on perceptions of care transitions, but also the contextual influences: overarching elements that are not easily altered but can provide important information about how individuals make sense of their experiences. Recognizing the complex nature of transitions does not necessarily complicate the provision of transitional care; many of the features of existing transitional care models and interventions are very relevant to the results of this study. Taking into consideration the different dimensions of transitions can give health care providers a better insight into the perceptions of those they care for.

In this chapter, themes within the three divisions of the framework (i.e., context, processes, and influencing factors) are discussed in relation to potential implications for health care practice. Next, the ways in which the theoretical framework addresses gaps in knowledge are considered. Furthermore, the theoretical framework that emerged from the data is reviewed and discussed with reference to existing transitional care, care coordination, and continuity of care models. Finally, the strengths, limitations, and challenges of the study are outlined.

6.1 Key points & Their Significance for Practice

Although it was not a direct aim of this study to create best practice guidelines or definitively change the health care system, the results of the study may be used to inform improvements to the care transitions of individuals with dementia and their caregivers. Therefore, it is important that aspects of the framework are situated within the context of health care practice.

6.1.1 Transition context

The transition context division of the framework consists of factors that, when considered by health care professionals, can elucidate the circumstances surrounding transitions for persons with dementia and their caregivers. Since several sets of realities and goals may be competing during care transitions, openness and honesty through engagement and the formation of relationships can help to ensure that all realities are respected. This result also points to the potential value of validation therapy during care transitions. Validation is defined as "the acceptance of the reality and personal truth of another's experience" (Neal & Wright, 2009, p.2). Validation therapy is very closely linked to person-centred care in that it requires empathy and recognition of individual needs. Engagement and relationship formation can be coupled with validation therapy to ensure that realities are understood and valued.

The use of Goal Attainment Scaling (GAS) with both persons with dementia and their caregivers during transitions is another possible method of ascertaining and meeting the goals of both parties. GAS is "an outcome measurement approach that accommodates individualized measurable patient goals" (Hartman, Borrie, Davison, & Stolee, 1997, p.111). There is evidence that goal setting is an appropriate tool for engagement through shared-decision making (Schulman-Green et al., 2006); GAS is a goal-setting and measurement approach that has been

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used in populations with dementia (Rockwood, Stolee, Howard, & Mallory, 1996; Hartman et al., 1997, Rockwood, Graham, & Fay, 2002; Bouwens, Van Heugten, & Verhey, 2008). Furthermore, Mills and colleagues (2013) included GAS as an element of their toolkit to evaluate transition planning from nursing homes to community. This evidence, when combined with the importance of considering multiple sets of unique goals that has emerged from the present study, indicates that GAS may be a useful tool to promote the consideration of person with dementia and caregiver goals during transitions.

The transition context results also indicate that individuals transitioning through the health care system during the process of continuous management must be considered in the context of their communities and social support systems. Dementia-friendly communities and supportive friends and family help to relieve the responsibility placed on caregivers. Since a caregiver's inability cope can precipitate transitions, this support is fundamental to the transitions of persons with dementia. Public education about dementia can help improve awareness and support. Education and awareness-building can be very individual (e.g., a neighbourhood or group of friends); however, there are initiatives that aim to help communities become more broadly supportive of persons with dementia. For example, in October of 2014, a small town in the Central East LHIN called Bobcaygeon piloted a campaign called *Living Well with Dementia,* during which businesses around the community were educated about dementia in order to better meet the unique needs of those with cognitive and memory problems. A pin depicting a blue umbrella identifies those with dementia. Those in the community will learn to recognize this pin, allowing them to provide any required support (Alzheimer Society of Peterborough, 2014).

Further expansion of programs like this one may help provide a more supportive community context for the health care transitions of individuals with dementia.

The parallel experiences aspect of the transition context section has less obvious implications for practice. Essentially, the data revealed that individuals often compared their own transition experiences to those of others going through similar situations, causing them to form expectations that influenced perceptions of their own experiences. The stories of others also helped participants prepare for future experiences and gave them a sense of comfort and connectedness. Further encouragement of peer support for persons with dementia and their caregivers can help promote the helpful aspects of these parallel experiences (i.e., learning and comfort). However, it is possible that listening to the stories of others can lead to the formation of expectations that are inappropriate given a dyad's specific circumstances. Thus, it is vital that providers, persons with dementia, and their caregivers have open conversations about expectations to ensure that all those directly involved in the transition are on the same page.

6.1.2 Transition processes

The transition processes section of the results indicates that individuals experience many of their transitions as a continuous set of related health care encounters caused by evolving care needs. Transitions that did stand out to persons with dementia and their caregivers as unique were those that signified important steps in the dementia journey. First, many individuals specifically spoke about their transitions into the dementia care system, which was defined by receiving a diagnosis. The ways in which individuals obtained their diagnoses influenced their initial perceptions of dementia care. Participants desired prompt, clear information about their health. When their diagnoses were delayed, participants felt that their needs were not being met.

Approximately half of those with dementia represented in the interviews were given a diagnosis by a specialist (i.e., a geriatrician or a neurologist); when individuals experienced a delay in obtaining a diagnosis, they were often waiting for access to specialists. Increasing the capacity of primary care to diagnose and manage dementia could help address problems related to slow entry into the system of dementia care. Further expansion of primary care memory clinics (e.g., Lee et al., 2010) across Ontario could help address some of the problems that persons with dementia and their caregivers experience while transitioning into the system.

During the processes of continuous management and follow-up, persons with dementia received care in several settings from numerous providers. Coordination and continuity are the primary aspects of transitional care as defined by Coleman & Boult (2003). They have independently emerged from the interviews as important to maintaining smooth transitions throughout the processes of management and follow-up. Existing transitional care, care coordination, and continuity of care models often aim to address this phase of transition processes. However, they are often only relevant to a particular type of transition (e.g., hospital to home, home to long-term care). Table 2 compares some of these models to the theoretical framework that was developed here; further explanation of similarities and differences between the frameworks and models can be found in Section 6.3.

Some of the services in Ontario that were presented in the literature review as being potentially useful in providing transitional care (Section 2.7) may aid in the coordination and continuity of care for persons with dementia. First Link could help address problems experienced by participants related to receiving appropriate referrals to community organizations and to awareness of existing services (ASO, 2012). Alzheimer Society representatives in memory

clinics could help ensure communication between community supports and primary care, which could aid in care coordination (Lee et al., 2010). The goal of the IGSW initiative is similar in that it aims to integrate services for geriatric populations (McAiney & Hillier, 2012). Only one of these services (First Link) was actually mentioned by participants during the interviews. Participants did not refer to the other services when describing their transitions, indicating that the potential for these services to help coordinate transitional care for persons with dementia may not yet be realized. On the other hand, nearly all participants had at least some contact with CCAC, another organization mentioned in Section 2.7; however, many participants did not view CCAC as a care coordinating organization. Rather, CCAC assessment was often perceived as a formality or even a barrier to receiving appropriate care. The results indicate that many of these services have missions that match the needs of persons with dementia and caregivers during transitions; however, it remains unclear how they can work together to provider coordinated, continuous care.

Finally, adjusting to a new home (i.e., the transition into long-term care) stood out to participants as being a particularly significant transition due to its emotional and physical significance. Provider awareness of the emotional effects of the transition can help them better support individuals going through the long-term care process. Engagement and person- and family- centred care are particularly important during this transition because people often desire input into how they or their loved ones will be looked after in their new home. Getting to know the individual is vital in the planning of long-term care recreational activities, and setting up the room with familiar items may help with both the emotional and physical stress of the move.

6.1.3 Influencing factors

The influencing factors aspect of the framework has perhaps the most explicit implications for health care practice. These are elements of transitions that had a direct impact on the occurrence and success of transitions of participants. Due to the rising prevalence of dementia in Canada and limits to long-term care bed availability, delaying or preventing transitions into long-term care will be a significant priority for the health care system (ASC, 2010). Furthermore, hospitalizations and ALC days among those with dementia represent significant costs to the health care system. Consideration of transition catalysts could be useful in preventing unnecessary transitions. Preventative medicine (e.g., fall prevention, physical activity) can play a role in preventing some of the precipitating crises that may lead to transitions into hospital and long-term care. It is also important that caregivers are adequately supported and that their health is considered as central to the care for those with dementia, because many transitions occur due to changes in caregiver coping abilities.

There are also steps that can be taken by persons with dementia and their caregivers to ease future transitions; these have been entitled transition buffers because they are an intermediary action that protects individuals with dementia and their family members against difficulties associated with impending transitions. The Alzheimer Society played an important role in preparing persons with dementia and their caregivers for their transitions through patient and caregiver education sessions and encouragement of peer support. Physicians can also play an important role by empowering patients and families to take control of their health and become more proactive; communication and conversations about their rights to engagement can help support this.

Engagement was also identified as an important direct facilitator of transitions. During a member check conversation with Jennifer she noted that she was unsure of how much to tell her mother with dementia about her health care. A person-centred approach would require that both individuals with dementia and their caregivers should be engaged and valued as central to the continuum of care. Brooker (2004) conceptualized person-centred care in dementia as a sum of four elements: "valuing people with dementia and those who care for them, treating people as individuals, looking at the world from the perspective of persons with dementia, and a positive social environment in which the person living with dementia can experience relative wellbeing" (p. 216). These aspects of person-centred care encompass several other features of the theoretical framework, including explicitly considering caregiver needs, respecting the realities of those with dementia and the importance of a broad community perspective. Thus, person-centred care acts as more than a direct facilitator; it can indirectly influence other parts of the framework.

The final set of influencing factors included in the framework were obstacles to successful transitions, which included system complexity and constraints, provider knowledge and education, problems with information and communication, and denial and depression in the individual with dementia. Some of the mentioned facilitators and buffers have potential to address these problems. For example, preparation and proactivity can help people with dementia and their caregivers handle system complexity. A commitment to respecting realities of individuals with dementia and providing person-centred care can help to ensure that system constraints do not overshadow patient needs. Denial and depression are individual considerations that would be identified and acknowledged in care plans developed using person-centred care

approaches. Information and communication problems can be relieved through engagement and relationship-formation.

Deficits in provider knowledge are a barrier that would not necessarily be addressed by the facilitators mentioned in the framework. These would be best addressed through improvements to the education of health care providers. In a 2008/2009 survey of 16 Canadian medical schools, Heckman and colleagues (2013) found that the mean number of geriatric education hours was 82 compared to over 300 hours spent on pediatrics. Improved geriatric education was also proposed as a goal in Sinha's (2012) Senior's Strategy for Ontario. Provider education has also been included as a major goal in both regional and provincial dementia strategies (Geriatric Health Systems Research Group, 2015; Manitoba Health, 2002; The Newfoundland and Labrador Department of Health & Community Services, 2002; Saskatchewan Provincial Advisory Committee of Older Persons, 2004; Quebec Ministry of Health, 2009). The importance of improved geriatric and dementia-specific provider education is being increasingly recognized; related efforts may help to address the obstacle of provider education that was expressed by participants.

6.2 Filling a Knowledge Gap

Two major knowledge gaps were described, indicating a need for this study. First, persons with dementia and their caregivers had often been excluded from studies about transitional care. Therefore, there was a gap in knowledge regarding what is important to them as they move throughout the health care system. Obtaining their perspectives is not always easy, and their views do not always match those of their caregivers or their health care providers (Arlt et al., 2008). The researcher chose to adopt an outlook that respected the realities and perspectives of

persons with dementia. The constructivist philosophy of this study ensured that the analysis appreciated the validity all perspectives presented. The idea that their realities must be considered, even when they do not match caregiver or system realities, was central to the transition context aspect of the framework.

This study did not attempt to compare the transitions of persons with dementia to those of individuals without dementia. However, some key findings were particularly relevant to the dementia experience indicating that their voices cannot simply be conflated with those of other older adults. The dyadic experience of health care (Section 5.4.1.1) stood out as particularly important in the case of dementia. Although informal caregivers are not unique to dementia, an extreme reliance on caregivers was viewed by many participants as distinctive to the dementia experience. Cognitive and memory problems often necessitated caregiver involvement during care encounters and transitions. Therefore, supporting and balancing the goals and realities of those with dementia as well as of their informal caregivers can facilitate transitions.

Participants often associated their transitions with stages of the dementia journey: the diagnosis signified a transition into the system; when they were managing at home, transitions were continuous and interrelated; and, when the dementia had progressed significantly, a transition into the long-term care was required due to precipitating crises or difficulty coping. This finding indicates that learning about the dementia journey from the perspectives of those with dementia and their caregivers is important to understanding their movement through the health care system. Weirsma and colleagues (2014) have identified some of complex processes and events that define the dementia journey by speaking with persons with dementia across

Ontario. An increased understanding this journey among providers could facilitate a more holistic understanding of transitions.

The final major factor that was particularly relevant to the experiences of persons with dementia was the possibility of denial during transitions. Mograbi and colleagues (2012) conducted an international, population-based study on unawareness of dementia diagnoses, which could range from minimization to complete denial. Prevalence of unawareness among those with dementia ranged from 63% to 81%; however, the numbers were influenced by social and cultural factors (Mograbi et al., 2012). Although percentages of those denying their diagnoses in Canada or Ontario specifically are unknown, these data suggest that unawareness of diagnoses is a common feature of dementia. Furthermore, the results of the present study indicate that denial can significantly influence willingness to seek out support, thus influencing transitions into the system. Considering individuals' acceptance or denial of the diagnosis can provide important information about the best way to provide them with assistance.

The second gap identified in the literature was the lack of information on broader transitions through the health care system. Research on transitions has primarily focused on specific transitions; for example, many studies focus on transitions between hospital and home. This study provides support for the idea that transitions throughout the health care system are experienced as a continuous series of changes in care needs. The broad perspective of transitions adopted for this study facilitated the development of a theoretical framework that elucidates aspects of several types of transitions while respecting the continuous nature of transition experiences.

6.3 Comparing the Framework to Existing Models

Four models were presented in Section 2.6 to represent important elements of transitional care, care coordination, and continuity of care that have been identified in the literature. Common elements of these models were initially used as sensitizing concepts in the interviews to spark discussion and ascertain whether these elements extended to those with dementia; however, they were removed as specific questions because participants were repeating what they had already expressed during the open-ended interviews. Instead, aspects of all four models presented in the literature review have been compared to the elements of the theoretical framework developed in the present study. Table 2 represents an initial comparison of these models. Future research may investigate differences between models in greater detail. Furthermore, this list of models is not exhaustive; it serves as a representation of some key aspects of care transitions as identified in previous literature in order to situate the current study within the context of prior work.

Table 2. Comparison between the elements of the present study and previously existing models

	The present study	Transitional Care Model (Naylor & Van Cleave, 2010; Naylor et al., 2007)	Care Transitions Intervention (Coleman et al., 2006; Parry et al., 2003)	Partners in Dementia Care Model (Judge et al., 2011)	Concepts of continuity (Reid, Haggerty & McKendry, 2002)
Acknowledgement of multiple realities and goals					
Consideration of community and social support networks					
Acknowledgement of the influence of others with comparable experiences					
Timely diagnosis					
Continuous management					
Follow-up					
Clear referrals to appropriate services					
Professional collaboration					

Information transfer	blue		purple	green	orange
Provider overview/ coordinator role	blue	pink	purple	green	orange
Provider consistency	blue	pink			orange
Considering the emotional significance of long-term care transition	blue				
Considering the physical significance of the long-term care transition	blue				
Precipitating crises or events	blue	pink			
Changes in patient and caregiver coping abilities	blue				
Patient/caregiver proactivity	blue		purple		
Patient/caregiver preparation (e.g., education)	blue	pink	purple	green	orange
Views of/ relationships with providers	blue			green	orange
Patient and family engagement	blue	pink	purple	green	
Person- and family-centred care	blue	pink	purple	green	orange
System complexity and confusion	blue	pink	purple		
Provider knowledge and education	blue	pink	purple	green	
Patient-provider communication/ information exchange	blue	pink	purple	green	orange
Considering denial and depression in person with dementia	blue	pink		green	
Decision support				green	
Early identification of and response to risks		pink	purple		
Self-management		pink	purple	green	

To determine what this study adds to the body of knowledge on care transitions, facets of

the theoretical framework that were not covered by previous models have been identified.

Although the CTI, TCM and PDC recognized patient goals, none of the models explicitly

expressed the importance of considering and respecting multiple sets of realities. Only two

models considered patient support systems and none considered the influence of the parallel

experience of others. These findings suggest that consideration of context outside of direct health

care system or provider actions during transitions could be improved upon in other models.

Although the concept of context is not entirely unique to this study, the results suggest that it

should be considered as central to conceptualizations of transitions; it is currently not a central aspect of any of the models.

The CTI and TCM both focus on acute episodes of care (i.e., hospitalizations) and the PDC focuses on coordination between community services (i.e., Veterans Affairs) and primary care (Coleman et al., 2006; Naylor & Van Cleave, 2010, Judge et al., 2011). The concepts of continuity model is the only one that provides information about care over multiple transitions or conceptualizes the transition experience as continuous (Reid, Haggerty, & McKendry, 2002). As stated in Section 6.2, a consideration of multiple transitions was identified as a knowledge gap. This study addresses this gap by including multiple transitions (including a consideration of the emotional and physical significance of transitions into long-term care) within one framework. In doing so, the framework provides an overview of how transitions are experienced more broadly as individuals with dementia and their caregivers navigate the dementia journey.

The CTM was the only model that acknowledged transition catalysts by considering reasons for hospitalization; similarly, only the TCI recognized the buffer of patient proactivity by coaching patients and family members to be self-advocates. Catalysts are important to the goal of preventing transitions and buffers acknowledge the important role that persons with dementia and their caregivers can play in their own transitions. The CTI, TCM and PDC all recognized the importance of self-management during transitions or while coordinating care; this is a concept that did not arise explicitly in participant stories, but is closely related to the buffer category. Thus, the patient role was acknowledged as generally important; however, the specific importance of proactivity was not expressed many other models.

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Finally, two of the models failed to recognize the importance of considering

psychological factors such as denial and depression. The only model that considered denial of

the diagnosis as an important barrier, the PDC, was the only dementia-specific model used in the

comparison. The TCM considered the barrier of depression, but only in a study testing the model

in a population with dementia. These observations provide support for the possibility that these

may be more common barriers to transitions among individuals with dementia.

There was no single model that considered every important aspect of transitions that was

expressed by those with dementia and their caregivers in this study; however, most aspects were

considered by at least one model. This finding is promising, as it indicates that many of the

important aspects of other models are relevant to this population. No other model fully respects

the complex and multidimensional nature of transitions throughout the health care system, but

each model might be very useful in certain situations.

6.4 Strengths, Limitations and Challenges

The most notable strength of this research is the important contribution it makes to care

transition literature by extending current knowledge to include an in depth account of care

transitions from the perspectives of individuals with dementia and their caregivers. Furthermore,

care transitions are not over-simplified in the results of this study; the theoretical framework does

not assume a one-size-fits-all model of transitional care. Instead, transition complexity is

respected and described throughout the presentation of the study results.

The rigorous methods of the study ensured that the researcher did not make assumptions

about the experiences of individuals with dementia and their caregivers. Although it is

recognized that the results are constructed by the researcher and the participants throughout the

process, reflexivity allowed the researcher to note her role and maintain a focus on participant voices. Transparency was maintained by making use of quotations in the written document as well as by including sample codes and data reconstruction diagrams in Appendices N and O.

The research process was also accompanied by several challenges and limitations, which were addressed as much as possible throughout the research process. First, Charmaz (2006) described the idea of "the disputed literature review" (p. 165); many qualitative researchers assert that a literature review should be conducted after the data collection and analysis process has been completed. In the case of this study, the requirement of a formal thesis proposal made it impossible to delay the literature review. However, the researcher remained reflexive throughout the process in order to minimize influences of previous knowledge on the analysis. Furthermore, conducting a literature review before the interviews gave the interviewer insight into the experiences of transitions that allowed her to engage with participants and encourage them to delve deeper into their descriptions, thus providing the study with richer data.

The second major limitation of the study is the possible influence of the recruitment method on the results of the analysis. Recruiting through Alzheimer Society Chapters and Family Health Teams may have led to the recruitment of individuals who are more connected to community supports and already have access to a more integrated system of care. However, problems with access to services and coordination were still described by many participants. Those who do not have access to the Alzheimer Society or to a Family Health Team will likely experience even more problems with these aspects of transitions, suggesting that recommendations for improvement of these areas based on the results of the study may in fact

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offer help to those who do not have the same connections even more than those who were interviewed.

Thirdly, there was an overrepresentation of female caregivers and males with dementia among those interviewed, despite the fact that, in Canada, the prevalence of dementia is higher in females compared to males (ASC, 2010). However, Xie and colleagues (2008) found that women are more likely than men to be widowed and there is also evidence that females are more likely to be caregivers than males (Cranswick & Dosman, 2008). Therefore, it follows that wives taking care of their husbands are more likely to be living at home with a spouse and accessing support through the Alzheimer Society and Family Health Teams. It is hard to say whether the high prevalence of female caregivers and men with dementia skewed the results in any way. There did not appear to be any gender differences in themes; therefore, it was not viewed as necessary to theoretically sample male caregivers or females with dementia.

Finally, during the data collection process, caregivers often carried more of the conversation than those with dementia. The interviewers attempted to minimize this by addressing all questions to the individuals with dementia. Despite these efforts, persons with dementia often directed questions back to their caregivers. It is possible that individuals with dementia become accustomed to their caregivers answering questions related to health for them. Certainly, in the interviews it was clear that caregivers played an important role during health care appointments and assessments. In this sense, the interview process mimicked a health care encounter. The research has included the direct views of persons with dementia wherever possible; however, their perspectives were also inferred indirectly from stories told by their caregivers.

6.5 Knowledge Translation and Dissemination

Initial results of the study have been presented at the Canadian Association on Gerontology conference and the International Conference on Integrated Care. Further presentations at academic conferences are expected. The results will also be submitted to a peer-reviewed journal for publication. Initial feedback has been provided to participants through the member checking process. Participants were asked about the format in which they would like to receive feedback, and from these discussions it was determined that feedback regarding the final results will be disseminated to the participants of the study in the form of a summary document (similar to the member check guide included in Appendix Q); this will be sent along with a standard feedback letter (see Appendix U).

Furthermore, the consultations with persons with dementia and their caregivers conducted for this study have been used to inform the creation of a dementia strategy for the South West Ontario Local Health Integration Network (Geriatric Health Systems Research Group, 2015), and also supported the development of a strategy for the Waterloo-Wellington Local Health Integration Network. Additional consultations with health care providers and administrators contributed to the creation of recommendations and strategies for improving the care system for individuals with dementia and their caregivers in these regions.

6.6 Conclusions

Transitions are far from straightforward. Perceptions of transitions are influenced by much more than the actions of health care providers. They are influenced by the experiences of others, they occur in several phases related to aspects of the dementia journey, and they are situated within the context of multiple realities and broader communities. There is no prescription that can

definitively improve a transition. This study respects the complexity of the transition experience and offers a conceptualization of the concept of care transitions from the perspectives of those with dementia and their caregivers. The goal of this interpretive theoretical framework is to provide understanding rather than explanation (Charmaz, 2006). Gaining this understanding is important in its own right. The perspective of those with dementia is important, but often excluded from research about care transitions. This theoretical framework provides readers with an opportunity to view transitions from the vantage point of individuals with dementia and their caregivers. Future research can build upon this conceptualization to begin the process of providing more concrete recommendations to improve dementia care for individuals with dementia and their caregivers. Given the significance of transitions for patient safety and caregiver stress, improving care transitions may in turn improve the quality of care and quality of life for individuals living with dementia.

Appendix A
Alzheimer Society Chapter Script

Hello, my name is Jessica Ashbourne, a Masters student from the University of Waterloo School of Public Health and Health Systems. My supervisor, Dr. Paul Stolee, and I would like to discuss with you the possibility of partnering with you to locate persons with dementia who might be interested in participating in a research study that we are conducting. We are looking for persons with dementia and their caregivers who have had some kind of care transition experience since their diagnosis of dementia. We hope to better understand transitional care, or the coordination of care for individuals moving between or within settings in the health care system, from the perspective of persons with dementia and their caregivers. This study involves taking part in individual interviews, consisting of either a person with dementia or a caregiver of a person with dementia, or dyad interviews, consisting of both a person with dementia and their informal caregiver. Personal preference for individual or dyad interviews will be respected. The interviews will last approximately one hour and will be scheduled based on the availability of interested participants. The interviews will be held in a private setting of their choice. The decision to participate is completely voluntary.
This study has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee.

Would you be interested in aiding in recruitment for this study?
If Yes:
With your permission, we would like to ask if we can send you an invite letter with a short project description for you to send out to persons that you think would agree to participate in the study. Based on your preferences and protocols, you could subsequently send names of interested people or continue as a gatekeeper, making arrangements for interviews at the local chapter. Do you give consent for researchers from the University of Waterloo to contact you regarding recruitment for this study?
Do you have any questions?
Also inform them of the following:
- Participants may decline to participate in any part of the interview and may terminate the interview at any time.
- The interview will be audio-recorded to facilitate collection of information, and later transcribed for analysis.
- All information provided will remain confidential, will be stored in a secure location, and will be destroyed after 5 years.

If No: Thank you for your time.

September 8, 2014

Dear [family health team representative]:

This letter is a request for the [family health team name] assistance with a project I am conducting as part of my Master's degree in School of Public Health and Health systems at the University of Waterloo, Ontario, under the supervision of Dr. Paul Stolee. The title of my research project is "Transitional care for persons with dementia and their caregivers." I would like to provide you with more information about this project that explores the experiences of persons with dementia and their caregivers during health care transitions between or within settings.

The purpose of this study is to develop a framework for understanding transitional care [the coordination of care while moving within or between health care settings] from the perspective of persons with dementia and their caregivers. Knowledge and information generated from this study may help inform recommendations for the future development of transitional care for persons with dementia and their caregivers.

It is my hope to connect with persons with dementia and caregivers who have undergone a transition experience since their dementia diagnosis to invite them to participate in this research project. During the course of this study, I will be conducting interviews with persons with dementia, caregivers and dyads consisting of both a person with dementia and their caregiver to gather their stories about moving throughout the care system.

What I intend to do, is provide the [family health team] with invitation letters to be distributed in-person by the [family health team] at their discretion. Contact information for me and my advisor will be contained in the letters. If an individual is interested in participating they will be invited to contact me directly.

Participation of any person with dementia and caregiver is completely voluntary. Each potential participant will make their own independent decision as to whether or not they would like to be involved. All participants will be informed and reminded of their rights to participate or withdraw before any interview, or at any time in the study. Patients will receive an information letter including detailed information about this study, as well as informed consent forms. This study will follow the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (2010).
To support the findings of this study, quotations and excerpts from the stories will be used labelled with pseudonyms to protect the identity of the participants. Names of participants will not appear in the thesis or reports resulting from this study. Participants will not be identifiable, and only described by gender and as parent/child.

If the [family health team] wishes the identity of the organization to remain confidential, a pseudonym will be given to the organization. All data collected will be retained locked in my office and in a secure cabinet in the School of Public Health and Health Systems at the University of Waterloo. All paper notes and electronic data will be confidentially destroyed after five years. Finally, only myself and my advisor, Dr. Paul Stolee in the School of Public Health and Health Systems at the University of Waterloo will have access to these materials. There are no known or anticipated risks to participants in this study.

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. However, the final decision about participation belongs to the family health team and the persons with dementia and caregivers. If you have any comments or concerns with this study, please feel free to contact Dr. Maureen Nummelin, the Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

If you have questions about the research or about your role in the study, please feel free to contact Dr. Paul Stolee by phone at (519) 888 4567 x 35879 or by e-mail (stolee@uwaterloo.ca) or Jessica Ashbourne by phone at (519) 888 4567 x 35879 or by email (jashbourne@uwaterloo.ca).

I hope that the results of my study will be beneficial to the [family health team], to persons with dementia and caregivers, as well as the broader research community. I very much look forward to speaking with you and thank you in advance for your assistance with this project.

Yours sincerely,
Jessica Ashbourne
Master's Candidate
School of Public Health and Health Systems
University of Waterloo

Dr. Paul Stolee
Associate Professor
School of Public Health and Health Systems
University of Waterloo

Appendix C

Alzheimer Society Chapter Letter/E-mail

September 8, 2014

Dear [Representative];

This letter is a request for the Alzheimer Society of [chapter name] assistance with a project I am conducting as part of my Master's degree in School of Public Health and Health systems at the University of Waterloo, Ontario, under the supervision of Dr. Paul Stolee. The title of my research project is "Transitional care for persons with dementia and their caregivers." I would like to provide you with more information about this project that explores the experiences of persons with dementia and their caregivers during health care transitions between or within settings.

The purpose of this study is to develop a framework for understanding transitional care [the coordination of care while moving within or between health care settings] from the perspective of persons with dementia and their caregivers. Knowledge and information generated from this study may help inform recommendations for the future development of transitional care for persons with dementia and their caregivers.

It is my hope to connect with persons with dementia and caregivers who have undergone a transition experience since their dementia diagnosis to invite them to participate in this research project. During the course of this study, I will be conducting interviews with persons with dementia, caregivers and dyads consisting of both a person with dementia and their caregiver to gather their stories about moving throughout the care system. At the end of this study, we hope to conduct a webinar and discussion with Alzheimer Society representatives to talk about next steps in the development of care transition experiences for persons with dementia and caregivers.

What I intend to do, is provide the Alzheimer Society of [chapter name] with invitation letters to be distributed by the Alzheimer Society of [chapter name] at their discretion. Contact information for me and my advisor will be contained in the letters. If an individual is interested in participating they will be invited to contact me, you can provide me with their information for me to contact them with their permission, or you may choose to continue to serve as a gate keeper in setting up the interviews at your local chapter.

Participation of any person with dementia and caregiver is completely voluntary. Each potential participant will make their own independent decision as to whether or not they would like to be involved. All participants will be informed and reminded of their rights to participate or withdraw before any interview, or at any time in the study. Parents will receive an information letter including detailed information about this study, as well as informed consent forms. This study will follow the Alzheimer

Society of Toronto's Ethical Guidelines for Participation in Research and the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (2010).

To support the findings of this study, quotations and excerpts from the stories will be used labelled with pseudonyms to protect the identity of the participants. Names of participants will not appear in the thesis or reports resulting from this study. Participants will not be identifiable, and only described by gender and as parent/child.

If the Alzheimer Society of [chapter name] wishes the identity of the organization to remain confidential, a pseudonym will be given to the organization. All data collected will be retained locked in my office and in a secure cabinet in the School of Public Health and Health Systems at the University of Waterloo. All paper notes and electronic data will be confidentially destroyed after five years. Finally, only myself and my advisor, Dr. Paul Stolee in the School of Public Health and Health Systems at the University of Waterloo will have access to these materials. There are no known or anticipated risks to participants in this study.

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. However, the final decision about participation belongs to the Alzheimer Society of [chapter name] and the persons with dementia and caregivers. If you have any comments or concerns with this study, please feel free to contact Dr. Maureen Nummelin, the Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

If you have questions about the research or about your role in the study, please feel free to contact Dr. Paul Stolee by phone at (519) 888 4567 x 35879 or by e-mail (stolee@uwaterloo.ca) or Jessica Ashbourne by phone at (519) 888 4567 x 35879 or by email (jashbourne@uwaterloo.ca).
I hope that the results of my study will be beneficial to the Alzheimer Society, to persons with dementia and caregivers, as well as the broader research community. I very much look forward to speaking with you and thank you in advance for your assistance with this project.

Yours sincerely,
Jessica Ashbourne   Dr. Paul Stolee
Master's Candidate   Associate Professor
School of Public Health and Health Systems   School of Public Health and Health System
University of Waterloo

Appendix D

Invitation Letter

September 8, 2014

To whom it may concern:

This letter is being sent to you on behalf of Dr. Paul Stolee and Jessica Ashbourne in order to provide you with information about a study that they are conducting in the Geriatric Health Systems research group at the University of Waterloo School of Public Health and Health Systems.

They are hoping to have discussions with individuals with dementia and their caregivers about their experiences while moving from one health care setting to another or from one provider to another within the health care system. They hope to better understand transitional care, or the coordination of care for individuals moving between or within settings in the health care system, from the perspective of persons with dementia and their caregivers. Your participation in the study would involve taking part in an interview (either one on one or in a pair consisting of a person with dementia and a caregiver). The interview would last approximately one hour and would be held in a private setting of your choice. In appreciation of your time commitment you will receive remuneration in the form of a $10 gift card to either Chapters or Tim Hortons. Your decision to participate is completely voluntary.

The data collected during interviews will contribute to a better understanding of the experiences of persons with dementia and caregivers while moving between providers and settings in the health care system. **These findings will assist in creating recommendations for improving and developing the care provided to persons with dementia and caregivers while they transition from provider to provider or setting to setting within the health care system.**

If you are interested in participating in the study, please contact Jessica Ashbourne and Dr. Paul Stolee at 519-888-4567 ext. 35879 or jashbourne@uwaterloo.ca to let them know that you are interested. Dr. Paul Stolee and Jessica Ashbourne will set up an interview at a time and place that is convenient to you. This research has received clearance through a University of Waterloo Research Ethics Committee
Sincerely,

Jessica Ashbourne
University of Waterloo
School of Public Health and Health Systems
Telephone: 519-888-4567 ext. 35879 Email: jashbourne@uwaterloo.ca
Website: https://uwaterloo.ca/geriatric-health-systems-research-group

Appendix E

Participant Recruitment Script

Hello, my name is Jessica Ashbourne, a Masters student working under the supervision of Dr. Paul Stolee in the Geriatric Health Systems research group at the University of Waterloo School of Public Health and Health Systems. I understand that you have expressed interest in participating in a research study that we are conducting.

To review how you would contribute to our study: we are hoping to discuss your experiences during periods of time when you have moved from one health care setting to another or from one provider to another in the health care system. We hope to better understand transitional care, or the coordination of care for individuals moving between or within settings in the health care system, from the perspective of persons with dementia and their caregivers. Your participation in the study would involve taking part in an interview, either on your own or with [your caregiver or family member / the individual that you provide care for]. The interview with me would last approximately one hour and would be held in a private setting of your choice. In appreciation of your time commitment you will receive remuneration in the form of a $10 gift card to either Chapters or Tim Hortons. Your decision to participate is completely voluntary.

I would like to assure you that this study has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. However, the final decision to participate is yours.

Are you still interested in participating?
If you are interested in hearing more about the study and participating, we can provide you with an information letter that will outline further details about the study. Would you like us to mail this to you or can I send it by e-mail?
RECORD
E-mail address:
Mailing address:

Would you be comfortable setting up a time for an interview? *List potential times/dates*
Do you have any questions?
Also inform them of the following:
- You may decline to participate in any part of the interview and may terminate the interview at any time.
- The interview will be audio-recorded to facilitate collection of information, and later transcribed for analysis.
- All information that you provide will remain confidential, will be stored in a secure location, and will be destroyed after 5 years.

If no longer interested in participating:
Thank you for your time

Appendix F

Information Letter: Caregivers

Date:
Study Name: Transitional care for persons with dementia and their caregivers
Researchers:
Paul Stolee, PhD
Associate Professor
University of Waterloo
200 University Ave W, Waterloo, ON N2L 3G1
Phone: 519-888-4567 ext 35879 **Email:** stolee@uwaterloo.ca
Jessica Ashbourne, MSc candidate
University of Waterloo
200 University Ave West, Waterloo, ON N2L 3G1
Phone: 519-888-4567 ext 35879 **Email:** jashbourne@uwaterloo.ca

Introduction:
You are being invited to participate in a research study called "Transitional care for persons with dementia and their caregivers" conducted by two researchers: Dr. Paul Stolee and Jessica Ashbourne. This study is being conducted as part of Jessica's Masters thesis project.

Your participation in this study is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research study involves. This consent letter will provide you with information about the study. It will explain the purpose of the research, your role in the research and potential benefits, risks and discomforts.

Please take the time to read the following information carefully.

Who is conducting the study?
This study is being conducted by two researchers: Dr. Paul Stolee and Jessica Ashbourne, both of whom are from the School of Public Health and Health Systems at the University of Waterloo.

What is the purpose of the study?
The purpose of this study is to learn about the movement of persons with dementia and caregivers between providers and settings in the health care system.

What will happen?
You are being invited to participate in a one hour long discussion about your experiences moving throughout the health care system along with the person that your provide care for. The interviewer will ask you to give her an overview of the services, supports and care that the person you provide care for has received since being diagnosed with dementia. Then she will ask you to discuss times when you and the person you care for have moved between these services/supports/providers. The types of questions that you will be asked include whether there were any aspects of your transitions that went well or did not go well. The conversation will take place as an individual interview or an interview with the person you provide care for if that is what you would prefer. The interview will be scheduled at your convenience. With your permission, the interview will be audio-recorded.

By providing your insights on your experiences, you will help us gain a better understanding of this research topic. Listening to your experiences will be central to the process of gaining an understanding of the movement of persons with dementia and their caregivers throughout settings and between providers in the health care system.

Where will the study take place?
The study will take place wherever you feel most comfortable. Examples of places where interviews may take place include at your local Alzheimer Society Chapter or at your home.

Will the study help you or others?
We do not know if being in the study will help you, but we hope to learn how people with dementia and their caregivers move throughout the health care system. We hope that we can make recommendations to help other people in the future.

Will the study harm you?
These are one hour conversations so we don't expect this to bother you. However, if the conversations are upsetting to you, we will stop the conversation and can make sure you have someone to talk with to get help.

What do you get for being in the study?
Whether your interview ends through self-initiated withdrawal or full completion of questions, you will receive a $10.00 gift card of your choice of Chapters or Tim Hortons for your participation in the study. The amount received is taxable. It is your responsibility to report the amount for income tax purposes

Is your participation voluntary?
Your participation in the study is completely voluntary and you may choose to withdraw from participating at any time. Your decision whether or not to participate has no effect on the care you receive or your relationship with the Alzheimer Society [or your family physician]. You can decline to participate in the study without penalty. If you agree to participate, you will be able to talk about whatever you are comfortable with. If there is a question you do not want to answer, you may say, "I don't want to answer that question."

Can you change your mind or decide not to answer a question?
You can change your mind and stop being part of the study at any time. Your decision to stop, or to refuse to answer particular questions, has no effect on your health care or any support provided through the Alzheimer Society [or your family physician] now or in the future. If you decide to leave the study, all of the data collected from you will be immediately destroyed.

What will happen to your information?
All information you give during the conversation will be held in confidence. Your information will be kept in a locked filing cabinet at the University of Waterloo, School of Public Health and Health Systems, and will be accessed only by members of the research team. You name will not appear on any of the data. Only the project team will have access to entire interviews. With your permission, anonymous quotations may be used in the following way(s):
  • in teaching and demonstration materials
  • in scholarly papers, articles and other publications, and
  • in presentations at academic, health care conferences

Confidentiality will be respected to the fullest extent possible by law.
Electronic files containing study data will be password-protected, and will be destroyed after 5 years. Audiotapes, transcriptions, questionnaires and data files will remain anonymous such that no names will be associated with the data. Each participant will be assigned an identification number, which will be used to organize the data. There are no conditions under which the confidentiality of data cannot be guaranteed.

Who can I contact if I have any questions?
If you have questions about the research or about your role in the study, please feel free to contact Dr. Paul Stolee by phone at (519) 888 4567 x 35879 or by e-mail (stolee@uwaterloo.ca) or Jessica Ashbourne by phone at (519) 888 4567 x 35879 or by email (jashbourne@uwaterloo.ca). This research has received clearance through a University of Waterloo Research Ethics Committee. If you have any comments or concerns with this study, please feel free to contact Dr. Maureen Nummelin, the Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

What will happen after the study is over?
The researchers will ask if you would like to be contacted in the future to go over the findings and give your opinions on the results. If you do not want to be contacted in the future, you may indicate this preference without penalty and without any consequences to your health care or your relationship to the Alzheimer Society.

Conclusion
We are excited about this study and are looking forward to listening to your experiences and insights on health care transitions. We sincerely hope that you will consider participating.

Appendix G

Information Letter: Person with Dementia

Date: November 2014
Study Name: Transitional care for persons with dementia and their caregivers
Researchers:
Paul Stolee, PhD
Associate Professor
University of Waterloo
200 University Ave W, Waterloo, ON N2L 3G1
Phone: 519-888-4567 ext 35879 **Email:** stolee@uwaterloo.ca
Jessica Ashbourne, MSc candidate
University of Waterloo
200 University Ave West, Waterloo, ON N2L 3G1
Phone: 519-888-4567 ext 35879 **Email:** jashbourne@uwaterloo.ca

Introduction:
You are being invited to participate in a research study called "Transitional care for persons with dementia and their caregivers" conducted by two researchers: Dr. Paul Stolee and Jessica Ashbourne. This study is being conducted as part of Jessica's Masters thesis project.

Your participation in this study is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research study involves. This consent letter will provide you with information about the study. It will explain the purpose of the research, your role in the research and potential benefits, risks and discomforts.

Please take the time to read the following information carefully.

Who is conducting the study?
This study is being conducted by two researchers: Dr. Paul Stolee and Jessica Ashbourne, both of whom are from the School of Public Health and Health Systems at the University of Waterloo.

What is the purpose of the study?
The purpose of this study is to learn about the movement of persons with dementia and caregivers between providers and settings in the health care system.

What will happen?
You are being invited to participate in a one hour long discussion about your experiences moving throughout the health care system. The interviewer will ask you to give her an overview of the services, supports and care you have received since being diagnosed with dementia. Then she will ask you to discuss times when you have moved between these services/supports/providers. The types of questions that you will be asked include whether there were any aspects of your transitions that went well or did not go well. The conversation will take place as an individual interview or an interview with your caregiver or family member, if that is what you would prefer. The interview will be scheduled at your convenience. With your permission, the interview will be audio-recorded.

By providing your insights on your experiences, you will help us gain a better understanding of this research topic. Listening to your experiences will be central to the process of gaining an understanding of the movement of persons with dementia and their caregivers throughout settings and between providers in the health care system.

Where will the study take place?
The study will take place wherever you feel most comfortable. Examples of places where interviews may take place include at your local Alzheimer Society Chapter or at your home.

Will the study help you or others?
We do not know if being in the study will help you, but we hope to learn how people with dementia and their caregivers move throughout the health care system. We hope that we can make recommendations to help other people in the future.

Will the study harm you?
These are one hour conversations so we don't expect this to bother you. However, if the conversations are upsetting to you, we will stop the conversation and can make sure you have someone to talk with to get help.

What do you get for being in the study?
Whether your interview ends through self-initiated withdrawal or full completion of questions, you will receive a $10.00 gift card of your choice of Chapters or Tim Hortons for your participation in the study. The amount received is taxable. It is your responsibility to report the amount for income tax purposes

Is your participation voluntary?
Your participation in the study is completely voluntary and you may choose to withdraw from participating at any time. Your decision whether or not to participate has no effect on the care you receive or your relationship with the Alzheimer Society. You can decline to participate in the study without penalty. If you agree to participate, you will be able to talk about whatever you are comfortable with. If there is a question you do not want to answer, you may say, "I don't want to answer that question."

Can you change your mind or decide not to answer a question?
You can change your mind and stop being part of the study at any time. Your decision to stop, or to refuse to answer particular questions, has no effect on your health care or any support provided through the Alzheimer Society now or in the future. If you decide to leave the study, all of the data collected from you will be immediately destroyed.
What will happen to your information?
All information you give during the conversation will be held in confidence. Your information will be kept in a locked filing cabinet at the University of Waterloo, School of Public Health and Health Systems, and will be accessed only by members of the research team. You name will not appear on any of the data. Only the project team will have access to entire interviews. With your permission, anonymous quotations may be used in the following way(s):
- in teaching and demonstration materials
- in scholarly papers, articles and other publications, and
- in presentations at academic, health care conferences

Confidentiality will be respected to the fullest extent possible by law.

Electronic files containing study data will be password-protected, and will be destroyed after 5 years. Audiotapes, transcriptions, questionnaires and data files will remain anonymous such that no names will be associated with the data. Each participant will be assigned an identification number, which will be used to organize the data. There are no conditions under which the confidentiality of data cannot be guaranteed.

Who can I contact if I have any questions?
If you have questions about the research or about your role in the study, please feel free to contact Dr. Paul Stolee by phone at (519) 888 4567 x 35879 or by e-mail (stolee@uwaterloo.ca) or Jessica Ashbourne by phone at (519) 888 4567 x 35879 or by email (jashbourne@uwaterloo.ca). This research has received clearance through a University of Waterloo Research Ethics Committee. If you have any comments or concerns with this study, please feel free to contact Dr. Maureen Nummelin, the Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

What will happen after the study is over?
The researchers will ask if you would like to be contacted in the future to go over the findings and give your opinions on the results. If you do not want to be contacted in the future, you may indicate this preference without penalty and without any consequences to your health care or your relationship to the Alzheimer Society.

Conclusion
We are excited about this study and are looking forward to listening to your experiences and insights on health care transitions. We sincerely hope that you will consider participating.

Appendix H
Consent Form

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

_____

I have read the information presented in the information letter about a study being conducted by Paul Stolee and Jessica Ashbourne from the School of Public Health and Health Systems at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

☐YES ☐NO

I agree to have my interview audio recorded.

☐YES ☐NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

☐YES ☐NO

Participant Name: _____ (Please print)

Participant Signature: _____

OR

*Proxy Signature: _____

Witness Name: _____ (Please print)

Witness Signature: _____

Date: _____

When this study is completed, we will write a summary of the results. Would you be interested in receiving a copy?

☐YES, please e-mail me a summary of the results. My e-mail address is:

_____

☐YES, please mail me a summary of the results. My mailing address is:

☐NO, I do not wish to receive a summary of results

*Consent by proxy: The participant (the person you care for) may be unable to give their informed consent to take part in this study. If this is so, you should note on the consent form that you have consented by proxy and that the holder of the proxy (you as carer) will act in the best interest of the participant throughout the study.

Appendix I

Background Information Form

The following information will be obtained verbally through the participant(s) (person with dementia AND/OR caregiver). The researcher will record answers on this sheet. This information will be used for sample description purposes.

<u>Person with dementia</u>

Age: _____

Sex: _____

Type of dementia diagnosis: _____

Date of diagnosis: _____

Diagnosis given by: _____

List any other chronic conditions

_____

_____

<u>Caregiver</u>

Age: _____

Sex: _____

Relationship to person with dementia: _____

Appendix J

Interview Guide Person with Dementia/Dyad

Section 1:

This question will provide an opportunity to better understand the context of the transitional care experiences described by persons with dementia and their caregivers during the interviews. The answer provided may also be used to inform probes during the discussions of transitional care experiences using questions provided in Section 2.

1. Can you please tell me about the services, support and care that you have received since you have been diagnosed with dementia? (*Give examples: specialist care, family physician, memory clinic, CCAC and other community supports*)

If more explanation is required, the table below, which has been adapted from the Alzheimer Society of Canada's "Rising Tide: The Impact of Dementia on Canadian Society," may be consulted to provide additional care setting examples (ASC, 2010).

Potential Health Care Contact Points by Stage of Disease

Disease stage	Potential Providers /Services Accessed
Diagnosis	• Family Physician • Geriatrician • Specialist services (e.g., Neurologist, Psychiatrist) • Alzheimer Society (e.g., First Link Program)
Management	• Community care services (i.e. respite care, adult day program, early stage support groups) • Community Care Access Centres (CCACs) • Home care agencies/personal support workers • Counselling services • Specialist services
Possible adverse events	• Emergency department • Hospitalization
End-of-life Care	• Long-term care • Nursing homes • Dementia-specific housing • Hospital/acute care

Section 2: OPEN-ENDED TRANSITION EXPERIENCES

Prior to asking about transition experiences I will define transitional care as the following: what is done by health care providers in order to "ensure the coordination and continuity of health care" as a person

moves within or between settings in the health care system (Coleman & Boult, 2003, pp. 556). There are
two primary interview questions and several prompts to promote discussion.

1. Can you tell me about time during which you moved from one person or setting in the health care system to another person or setting? *Give examples if necessary*
   a. In what setting did you begin your experience?
   b. What care setting did you transition to?

The following prompts may be used to promote detailed description of the experience:

- Can you walk me through what happened?
- What, if any, were the aspects of your transition from _____ to _____ that went well?
- What, if any, were the aspects of your transition from _____ to _____ that did not go well or could have been improved?
- What, if anything, could have been done to improve your experience?
- Who, if anyone, was involved in your transition from _____ to _____
  o What did the person/people do or not do that had an effect?
- Was any organization or service helpful during or after your transition? What did _____ help you with? How has it been helpful?

2. Do you think that your diagnosis of dementia influenced this experience?
   o IF YES: In what way do you think your diagnosis influenced this experience?

Section 3: STRUCTURED, FRAMEWORK-BASED QUESTIONS

These questions were developed based on the common elements of three current care transition
frameworks (Coleman, Parry, Chalmers & Min, 2006; Naylor & Van Cleave, 2010; NTOCC, 2008). They
will be used to examine previously-determined "key aspects" of transitional care from the perspective of
persons with dementia. See Table 1 for more detail.

1. Can you tell me about any instructions that you received, if any, from the care providers about how you could manage your condition(s) on your own? Were these instructions important to your experience moving between providers/settings? Why/why not?
2. Can you tell me about your participation in your health care decisions? Was this participation (or lack participation) important to your experience moving between providers/settings? Why/why not?
3. Can you tell me about any follow-up or support, if any, once you left your initial provider or care setting? Was this follow-up and/or support important to your experience moving between providers/settings? Why/why not?
4. Can you tell me about information, if any, given by those involved in your care about anything that you should watch out for that could indicate an issue or complication with your condition(s)? Was this information important to your experience moving between providers/settings? Why/why not?

5. Can you tell me about other information, if any, which you received from care providers involved in your care while moving between providers/settings? Was this information important to your experience moving between providers/settings? Why/why not?
6. Can you tell me anything about the communication that you observed or were aware of between the care providers that were involved in your care? Was this communication important to your experience moving between providers/settings? Why/why not?

Section 4: ENDING QUESTIONS

These questions are very general questions that will be asked to ensure that the participant has expressed everything that they wish to express. Participants will also have the opportunity to ask any questions that they might have for the researcher. Charmaz (2006) suggests using these types of questions to bring the interview to a more conversational, less abrupt closure.

1. Is there anything else you think I should know to understand your care transition experience better?
2. Is there anything that you would like to ask me?

Appendix K
Interview Guide Caregiver

Section 1: CONTEXTUAL INFORMATION

This question will provide an opportunity to better understand the context of the transitional care experiences described by persons with dementia and their caregivers during the interviews. The answer provided may also be used to inform probes during the discussions of transitional care experiences using questions provided in Section 2.

    2. Can you please tell me about the services, support and care that the ***person you provide care for** has received since he/she has been diagnosed with dementia? (Give examples: specialist care, family physician, memory clinic, CCAC and other community supports)

If more explanation is required, the table below, which has been adapted from the Alzheimer Society of Canada's "Rising Tide: The Impact of Dementia on Canadian Society," may be consulted to provide additional care setting examples (ASC, 2010).

Potential Health Care Contact Points by Stage of Disease

Disease stage	Potential Providers /Services Accessed
Diagnosis	- Family Physician - Geriatrician - Specialist services (e.g., Neurologist, Psychiatrist) - Alzheimer Society (e.g., First Link Program)
Management	- Community care services (i.e. respite care, adult day program, early stage support groups) - Community Care Access Centres (CCACs) - Home care agencies/personal support workers - Counselling services - Specialist services
Possible adverse events	- Emergency department - Hospitalization
End-of-life Care	- Long-term care - Nursing homes - Dementia-specific housing - Hospital/acute care

Section 2: OPEN-ENDED TRANSITION EXPERIENCES

Prior to asking about transition experiences I will define transitional care as the following: what is done by health care providers in order to "ensure the coordination and continuity of health care" as a person moves within or between settings in the health care system (Coleman & Boult, 2003, pp. 556). There are two primary interview questions and several prompts to promote discussion.

3. Can you tell me about time during which you and the ***person you provide care for** moved from one person or setting in the health care system to another person or setting? **Give examples if necessary**
    a. In what setting did you begin your experience?
    b. What care setting did you transition to?

The following prompts may be used to promote detailed description of the experience:

- Can you walk me through what happened?
- What, if any, were the aspects of the transition from _____ to _____ that went well?
- What, if any, were the aspects of the transition from _____ to _____ that did not go well or could have been improved?
- What, if anything, could have been done to improve your experience?
- Who, if anyone, was involved in the transition from _____ to _____
    o What did the person/people do or not do that had an effect?
- Was any organization or service helpful during or after the transition? What did _____ help you with? How has it been helpful?

4. Do you think that the diagnosis of dementia in the ***person you provide care for** influenced your experience?
    o IF YES: In what way do you think your diagnosis influenced this experience?

Section 3: STRUCTURED, FRAMEWORK-BASED QUESTIONS

These questions were developed based on the common elements of three current care transition frameworks (Coleman, Parry, Chalmers & Min, 2006; Naylor & Van Cleave, 2010; NTOCC, 2008). They will be used to examine previously-determined "key aspects" of transitional care from the perspective of persons with dementia. See Table 1 for more detail.

7. Can you tell me about any instructions that the ***person you provide care for** received, if any, from the care providers about how he/she could manage his/her condition(s) on their own or with your help? Were these instructions important to your experience moving between providers/settings? Why/why not?
8. Can you tell me about your participation in the health care decisions for ***the person you provide care for**? Was this participation (or lack participation) important to your experience moving between providers/settings? Why/why not?

9. Can you tell me about any follow-up or support, if any, once you and the ***person you provide care for** left your initial provider or care setting? Was this follow-up and/or support important to your experience moving between providers/settings? Why/why not?

10. Can you tell me about information, if any, given by those involved in the care of the ***person you provide care for** regarding anything that you should watch out for that could indicate an issue or complication with his/her condition(s)? Was this information important to your experience moving between providers/settings? Why/why not?

11. Can you tell me about other information, if any, which you received from care providers involved in the care of the ***person you provide care for** while moving between providers/settings? Was this information important to your experience moving between providers/settings? Why/why not?

12. Can you tell me anything about the communication that you observed or were aware of between the care providers that were involved in the care of the ***person you provide care for**? Was this communication important to your experience moving between providers/settings? Why/why not?

Section 4: ENDING QUESTIONS

These questions are very general questions that will be asked to ensure that the participant has expressed everything that they wish to express. Participants will also have the opportunity to ask any questions that they might have for the researcher. Charmaz (2006) suggests using these types of questions to bring the interview to a more conversational, less abrupt closure.

3. Is there anything else you think I should know to understand your care transition experience better?
4. Is there anything that you would like to ask me?

Appendix L
Revised Interview Guide

CONTEXT QUESTIONS

1. Can you please tell me about the services, support and care that you have received since you have been diagnosed with dementia? (*Give examples: specialist care, family physician, memory clinic, CCAC and other community supports*)
2. Can you tell me about any experiences that you've had within the health care system that have gone particularly well?
   a. What was it that made this experience so positive?
   b. Who was involved? What did they do to make the experience positive?
3. Can you tell me about any experiences that you've had with the health care system that did not go so well?
   a. What was it that made these experiences negative?
   b. What could have been done to improve your experiences?

TRANSITION QUESTIONS

4. The idea of care transitions basically means moving from provider to provider or setting to setting in the health care system.
   a. Can you tell me about what has gone well for you while moving or navigating through the health care system?
      i. What has made your transitions go smoothly?
      ii. Who was involved?
      iii. Are there any specific organizations?
   b. Can you tell me about what has not gone so well for you while moving or navigating through the health care system?
      i. What could have been improved to make your movement in the health care system easier?
5. Do you think that having dementia (or the person you care for having dementia) has influenced your health care system movement?
   a. How do you think it differs from that of those without dementia?

EXAMPLE OF A PROBING QUESTION BASED ON PREVIOUS INTERVIEWS

6. We would like to know a little be about broader community supports for people with dementia – things that are outside of the health care system (e.g., attitudes, perceptions about dementia in the community, transportation, etc)
   a. What things outside of your health care do you think influence your experience with dementia/caring for someone with dementia?
   b. What do you think can be done to make the wider community more supportive of people with dementia?

ENDING QUESTIONS

7. Is there anything else you think I should know?
8. Is there anything that you would like to ask me?

Timeline and Resources

Timeline:

Stage	2014						2015									
	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	July	Aug	Sept	Oct
Preparation of Ethics Application	�	▓														
Ethics Approval			*													
Data Collection				▓	▓	▓	▓	▓	▓	▓						
Data Analysis				▓	▓	▓	▓	▓	▓	▓	▓	▓				
Member Checking												▓	▓			
Preparation of Thesis											▓	▓	▓			
Thesis Defence														▓		
Manuscript Preparation														▓	▓	
Present Findings				**					***							****

*Ethics approval was obtained on September 2, 2014.

**Presentation of results from first iteration(s) of data collection and analysis at CAG 2014:

Landscapes of Aging; competed in the CIHR student poster competition

***Presentation of initial results at the International Conference on Integrated Care (IFIC) 2015;

won the overall poster competition

****Presentation of final results at CAG 2015

Resources:

Transcription	• Transcription were conducted by the student researcher or co-op students
Travel	• Access to a vehicle was required to move between study locations (rentals)
Other Funding	• Remuneration for participants
Other Resources	• Tape recorders • Transcription software • QSR NVivo software

Appendix N

Summary Table of Results

Table 3. Summary table of results including descriptions, sample codes and sample quotes

TRANSITION CONTEXT - broad factors that must be considered in order to fully understand a transition experience			
Multiple realities and goals: In conflict or harmony -considering who is involved in transitions and how their realties and goals might interact			
Sub-category	*Description*	*Sample Code(s)*	*Sample Quote(s)*
The dyad	Conflict arose between persons with dementia and caregiver due to communication difficulties, differences in memories, and perceived abandonment. Harmony occurred during instances of mutual understanding and respect.	Expressing importance of dyad and couple Differing perspectives between caregiver and person with dementia Caregiver struggling with person with dementia's identity	"As far as care transitions, it was great. It was just the transition for him, not being at home, and I guess trying to figure out why I would've left him at the hospital when he should be at home in his mind." **Margaret (Caregiver)**
Caregivers and the system	Conflict between the realities and goals of caregivers and the health care system often arose due to caregivers not feeling heard or being afraid to speak out; the system cannot ascertain their needs in these cases. Caregivers also often felt that they were constrained by system goals and timelines.	Caregiver not feeling heard Caregiver afraid of speaking out due to concerns about loved one's care Feeling rushed by system imposed timelines	"Trying to book these, these events, the woman that I had to book through in London, her goals were different than mine. Mine were to make Charlie happy…her goal was to have you be specific about the exact times that you would want those PSWs, and to have it a regular booking." **Beth (Caregiver)**
Persons with dementia and the system	The person with dementia often had unique views of system experiences. In some cases, caregivers were concerned that providers were not	Poor understanding of dementia in the system System mandates interfering with patient needs	"At one point he was on 20 to 22 prescription drugs per day, but you'd ask him and he'd say, 'No I don't take pills.' " **Susan (Caregiver)**

	getting the information about the individual that it needed. Being treated like people and including individuals in care decisions helped achieve a balance of realities.	Being taken seriously	"When she asked him specifically, 'do you think that you could be on your own in the home?' He said, 'Oh yes' … It was just so obvious that that was not the case… that it was almost, out of reality." **Beth (Caregiver)**
The broader community -transitions do not occur in a vacuum; they are influenced by broader support structures			
Social interactions or isolation	When persons with dementia and their caregivers had social interactions, they felt supported by others; if not, caregiver felt sole responsibility and isolation.	Expressing the importance of social interaction Maintaining a social life Having difficulty maintaining social contacts	"We've had a lot of friends pull back…even family pull back… It's a pretty lonely road at times." **Heidi (Caregiver)**
Supportive communities	Knowledgeable communities helped people manage at home by helping relieve caregiver responsibility and worry.	Public supporting dementia 'We as a community could probably do more' Perceiving lack of awareness about dementia	"It made his life easier. It made my life easier. I didn't have to be the…what do you call it? Helicopter mother? Or wife… When he was out walking I knew I had eyes on the street." **Lynne (Caregiver)**
Parallel experiences - people often compare their experiences to the experiences of others			
Seeing the future in others' experiences	People recognize that others have different experiences; if differences are related to stage of dementia/stage of the journey, then participants recognized that they might resemble their own future experiences	Seeing the future in others' experiences	"I think because we're at the early stages, the glow is still there. Like I said, as we move forward in the disease, it will get more frustrating dealing with the CCAC and bodies like that because they are stretched." **Laura (Caregiver)**
Feeling fortunate in comparison	People formed expectations for care	Recognizing that others have different	"We really haven't had any big need for the

	based on others' anecdotes; this resulted in people feeling lucky when their experiences were more positive than those about which they had heard from others.	experiences Feeling lucky	health care system, which has been fortunate… so far things have been good. But I know that there must be a lot of need for improvements by what other people are complaining about." **Emma (Caregiver)**
Helping & learning from others	People felt that their experiences could benefit others. Furthermore, hearing about others experiences helped people prepare for their own experiences.	Learning caregiver strategies Getting ideas and learning from others Persons with dementia helping others who are more advanced	"You get ideas from the other grumblers about what or how you can manage… and the things you can do… you know getting ideas from other people." **Betsy (Caregiver)**
Comfort in knowing others are going through similar experiences	Peer support for both persons with dementia and their caregivers was based on the sharing of individual experiences. People felt a sense of connectedness when they knew others had gone through similar transitions.	Expressing comfort in knowing others are going through similar experiences	**Rebecca (Caregiver):** "It was excellent, I think, because you know, as frustrating as it was, there were other people in the same situation." **Gregory (Person with dementia):** That was the best thing. Not always, but it was good to hear the others that want to get around.
TRANSITION PROCESSES -the phases of transitions that stood out to people often aligned with the dementia journey			
Pre-diagnosis and the transition into the system			
Gradual transition	Some people experienced problems long before the diagnosis. They were more prepared for transitions when they occurred. Some felt that they had to push for diagnosis causing a delay in access to services.	Experiencing problems before the diagnosis 'The signs were starting to show' 'I knew it was coming' Experiencing a slow progression into diagnosis and system	"It took… a long time to convince [the family doctor] that Andrew had memory issues." **Lauren (Caregiver)** "The negative to that was, it took our family doctor a few years before he would actually send us to a specialist." **Lynne (Caregiver)**

		Having to push for a diagnosis	
Sudden transition	Sometimes major events signified the need to address the problem of dementia. In cases like these, people were propelled into the care they needed; however, they sometimes felt unprepared for the diagnosis.	Experiencing a sudden transition into the system Crisis or event helping gain clarity about dementia Being propelled in to care needed	"I would say that was beneficial, because that helped us get right to the bottom of things." **Britney (Caregiver)** "It came as a shock when Allan was diagnosed." **Margaret (Caregiver)**
Continuous management and follow-up			
Continuous management	Many transitions occurred while individuals were managing with the diagnosis at home. They saw many providers, but did not often feel that each was a distinct transition; rather they experienced a series of related events.	'It's continuous' 'I don't think that it's ever going to be at a stand still' 'We're just sort of going along with what we're doing' Having to deal with many new providers	"Just visits to the doctors office, or the hospital, whatever comes first." **Gregory (Person with dementia)** "I mean they, things unfold and you adapt and you don't really think, 'this is a transition.' " **Betsey (Caregiver)**
Follow-up	Follow-up from providers was desired because persons with dementia and their caregivers wanted to know that someone was checking in on how they were managing.	Getting support as often as needed Having someone to call Providers checking in Desiring regular follow-up	"Alzheimer Society usually checks in and gives us a phone call every so often, and say how are you doing and do you need something, and that means a lot." **Rebecca (Caregiver)** "He took me in one of the rooms, checked my bowels, said I was fine and then I never heard another word from him." **Daniel (Person with dementia)**
Coordination and continuity			
Clear referrals to appropriate services	People felt that it was the responsibility of the health care	Not receiving clear referrals	"Everybody has their own office, and all of those offices there wasn't

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	providers to refer them to other providers and services. Failure to do so reinforced perceptions of disconnectedness.	Smooth referral to geriatrician	one person who approached Dad about… 'now that your dad has dementia, here are some of the things you can look into for helping." **Bonnie (Caregiver)**
Professional collaboration	People believed that their providers should work together to meet their needs.	Poor collaboration between providers Each provider is on their own Having multiple providers in the room 'That's another sector's issue'	"Well, a lot of them up there… they're all on their own… each one… so they got their own controls." **Fran (Caregiver)** "Everybody sort of nibbles at the sides, but there's no one concerted effort." **Bobby (Caregiver)**
Information transfer	People felt that their providers did not always transfer all relevant information, leading to repetition and safety concerns in some cases.	Perceiving poor communication between providers Repeating tests over and over	"You're constantly repeating the same thing to every person that you see" **Emma (Caregiver)** "The gerontologist told him to start taking a specific drug… somehow that never got relayed to the family doctor, and he kept prescribing it." **Leanne (Caregiver)**
Provider overview	Participants felt that there should be a provider who knows all relevant information about the care of an individual with dementia. In other words, someone should have an overview of the whole care experience.	Experiencing problems with overview Having a care hub Thinking the doctor should have any info that pertains Someone having all of person with dementia's information	"Nobody really knows what's going on when there's a pattern developing." **Beth (Caregiver)** "Having a doctor see William every 6 months… I know that someone has his journey on paper." **Maria (Caregiver)**
Provider consistency	Whenever possible, maintaining	Problems with provider consistency	"You need a little bit of continuity here with

	consistency in providers (e.g., PSWs) was seen as preferable to participants.		these poor people who don't even know who they are themselves." **Bonnie (Caregiver)** "If you have someone who's been here three times before, she's familiar with your file and she glances at her computer and she starts here and didn't have to start down here all over again." **Betsy (Caregiver)**
Adjusting to a new home and the final transition			
Emotional significance	The transition into long-term care was viewed as a difficult process and emotionally significant due to feelings of guilt and abandonment.	Waiting for LTC as a difficult transition LTC perceived as not the place for a loved one 'Him moving to a facility… it's harder on the family I swear' Caregiver experiencing a perceived loss of control Transition out of hope as a loss of hope	"It's overwhelming to be in a position where you have to face the fact that you cannot do it, and you have to turn his care over to somebody else." **Lynne (Caregiver)** "It's no easy route." **Britney (Caregiver)** "She was clinging on to every bit of hope that once her head was healed, she could go back home." **Bobby (Caregiver)**
Physical significance	Environmental disruptions were viewed as a major stressor for individuals with dementia; therefore, the move to long-term care held physical significance. Preparing the space ahead of time with familiar items helped ease the transition.	Experiencing environmental disruptions as a stressor	"He took a dive bomb as far as… understanding things, being able to… he had no idea he was in [city]… like he just dive bombed horribly and stayed that way for many, many days." **Susan (Caregiver)**
Feeling at home	Successful adjustment	Feeling at home in	"They insist and they

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|	resulted in individuals feeling at home in long-term care.	LTC	say, 'it's his home now. So he needs to be treated like he was in his home.' So it's all great that way." **Bonnie (Caregiver)**
Ambiguous loss	The beginning of caregivers' final transition occurred in some cases before the death of the loved one due to feelings of ambiguous loss, or the idea that an individual is physically there but not the same person as they used to be.	Experiencing ambiguous loss	"The person is still there, but it's not your husband anymore, and you still love them very deeply… but they are almost like a stranger." **Margaret (Caregiver)**
Transition out of caregiver role	Caregivers felt that at some point they began to transition out of their caregiver role. This was experienced at the long-term care transition or at the death of an individual with dementia.	The idea of the final transition Caregiver transitioning out of caregiver Caregiver not knowing what to do with time	"So now my transition is… the challenge for me transitioning as an individual, is how do I reorient my life… how do I go forward." **Geoffrey (Caregiver)**
INFLUENCING FACTORS -consideration of more direct contributors to transitions			
Catalysts			
Precipitating events or crises	Sometimes transitions were caused by important events that caused major changes in care needs. These major crises could occur in the lives of either caregivers or persons with dementia.	Incident accelerating decline Experiencing crises	"When he fell and hit his head, he had a hematoma and was in the hospital for over three years before he passed." **Margaret (Caregiver)** "So then it came to the point where I got a knee problem. Pain! So then I was booked for surgery. So then we decided that we'll book him for the nursing home." **Britney (Caregiver)**

Changes in patient/caregiver coping abilities	Other times, gradual changes in coping abilities built up and eventually required a transition.	Experiencing transitions in coping Dealing with new stages of dementia	"When it became obvious that it was beyond my capabilities, patience, the rest of it, physical ability, and he was going to go into long-term care, then you get extra help." **Lynne (Caregiver)** "I thought, well, I'll take him home and tomorrow I'm going to call her and tell her I can't do this anymore, I just, I've reached the end." **Heather (Caregiver)**
Buffers			
Proactivity	Patient and caregiver proactivity helped people make necessary connections in the health care system. It also helped ensure care was centred on patient and caregiver needs.	Staying on top of things Waiting for the system to come to them 'You can't just sit back and let things happen'	"If you're just going to sit and do nothing… then you're not going to get anywhere." **Matthew (Caregiver)**
Preparation	Gaining an understanding of the health care system and possible transitions helped people physically and mentally prepare for transitions, thus easing the transitions when they occurred.	Being prepared Preparing for the future Knowledge that the transition is coming easing transition	"I started to get educated and could understand what was happening. Because if you don't understand what's happening as a caregiver… ya it does make it easier if you understand what's happening." **Margaret (Caregiver)**
Facilitators			
Positive views of provider attributes and actions	Providers as people were often viewed positively. When providers were both compassionate and professional (indicated by going above and beyond for patients	Perceiving attitude of providers as positive Expressing importance of provider compassion Stressing importance	"It's that patience, that professionalism… and while I think it's a genuine compassion – that compassion may be born out of the professionalism. But it strikes me as something

	and their caregivers) people felt that they were well-supported through transitions.	of provider expertise Viewing providers as people positively	that you don't find in everyone, so clearly these people chose this profession because it suited who they are." **Geoffrey (Caregiver)**
Patient & family engagement	Engagement through effective communication and relationship-building can help people feel that their views are respected throughout care transitions.	Being included in health care decisions Person with dementia making own decision Wanting to be in control of decisions Informing the caregiver	"They were very cooperative in discussing things with us. Not saying you must do this." **Martin (Person with dementia)**
Person- and family- centred care	When asked about their loved ones' experiences navigating the health care system, caregivers often focused on their loved ones' personality and past. People was to be viewed as individuals with unique desires and needs.	Considering person with dementia as an individual Reflecting on person with dementia personality and past Responding to the needs of the individual	"[It is] important to see the person as a person instead of as the disease." **Leanne (Caregiver)** "I think that they should be able to look at that and… make it work for individual people." **Betsy (Caregiver)**
Obstacles			
System complexity and constraints	The health care system was often viewed as confusing and difficult to navigate. System constraints sometimes prevented individual needs from being addressed.	Experiencing patient and caregiver confusion Uncertainty about disease and pathways	"It can get kind of confusing." **Jessica (Caregiver)** "There's always the bottom line in health care and the needs always outweigh the funds. But I honestly feel that if they don't have a little bit more of a support system implanted... if I burn out my whole family will go under and we'll all be torn down." **Heidi (Caregiver)**
Issues with provider	Some participants believed that providers	Perceiving need for provider education	"She just, like… you know, she's in her field,

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knowledge and education	were not adequately educated about dementia or about services available to persons with dementia, people. In some cases, this delayed access to services.	Perceiving lack of training on rarer dementias Providers not knowing what is available in the community	and that's what she deals with. And she can suggest things, but she doesn't really know maybe what is really available." **Fran (Caregiver)**
Information and communication problems	Participants felt that their ability to successfully navigate the health care system was hindered by information or communication deficits.	Needing written communication Experiencing communication difficulties Searching for information Not receiving adequate explanations	"So that's what I mean by not always lying but just holding information in. And I got that feeling all the time that it was all private information and I had the bloody nerve thinking I should be entitled to stuff." **Heather (Caregiver)**
Denial and depression in persons with dementia	Psychological considerations, such as denial and/or depression, can delay access to services and transitions into the system.	Family denying dementia Denial and avoidance of dementia Person with dementia experiencing depression	"How do you move through the system with an unwilling participant?" **Betsy (Caregiver)** "She prescribed a medication which he refused to take… and continued sleeping through the afternoon and so on and so… I waited almost a year." **Heather (Caregiver)**

Appendix O

Data Reconstruction and Synthesis Diagrams

Figure 2. Photo of a theming and organization exercise undertaken during focused coding

Focused coding processes included writing all codes on note cards in order to facilitate the creation of a visual representation of the data. Approximately 500 codes were synthesized into the final model.

Figures 3 and 4. Early diagramming exercises
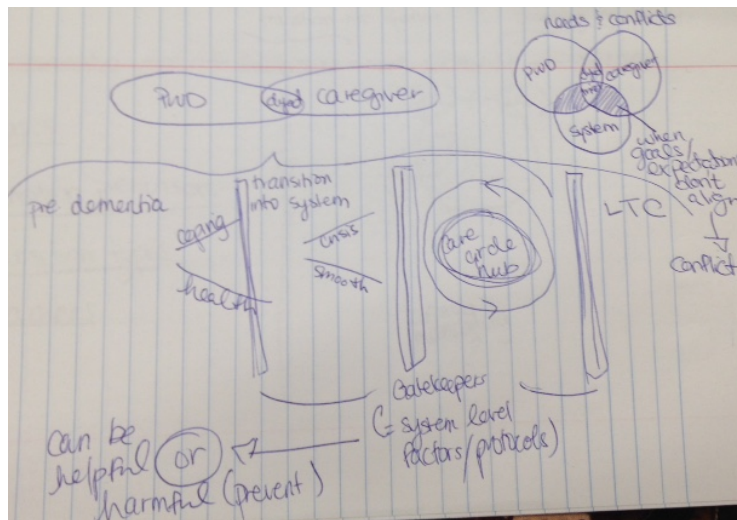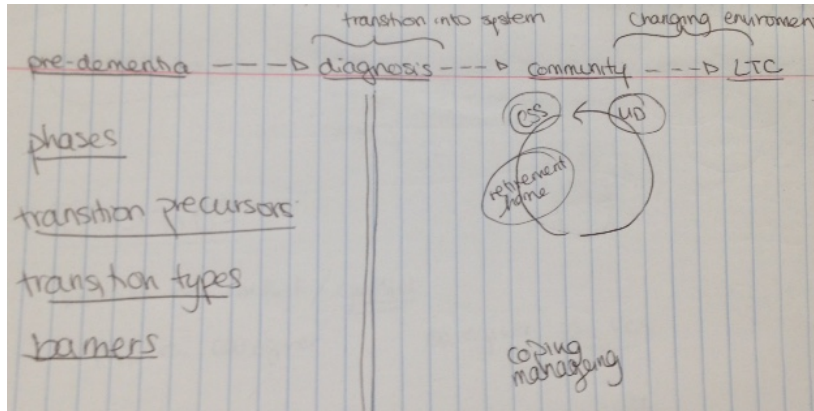
These diagrams portray early conceptions of the processes of care transitions from the perspectives of individuals with dementia and their caregivers. The researcher noted that during the time at which an individual was transitioning through many providers in the community that they were coping or managing; this idea became the process of continuous management and follow-up. Transition precursors became transition catalysts. Barriers were recognized as important but not specified. The second diagram noted the possibility that goals and expectations and needs may conflict. The phases were present again,

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but the transition into the system had been further specified as occurring due to a crisis or smoothly (gradually). Furthermore, system level constraints were outlined as a possible barrier.

Figure 5. Moving towards a final diagrammatic representation of the theoretical framework
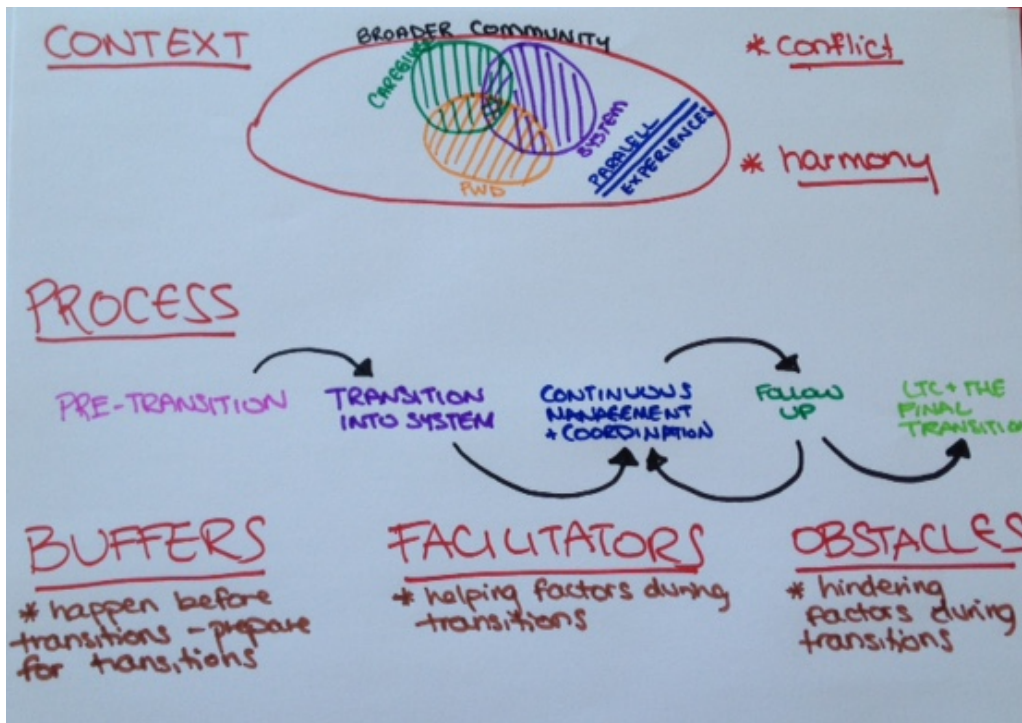
The diagram presented here is a hand-drawn version of a near-final model. The only missing elements are a) catalysts and b) continuity as a part of the connection between continuous management and follow-up.

Appendix P
Re-contact Agreement

Dr. Paul Stolee and Jessica Ashbourne, School of Public Health and Health Systems, plan to conduct a follow-up group or individual discussion of study results to ensure that findings accurately describe your experiences. With your agreement, we would like to contact you at a future point to invite you to consider taking part in one of these discussions. These discussions pertain only to a study that you have consented to participate in entitled "Transitional care for persons with dementia and their caregivers." You will not be contacted for any other future study without additional consent. Agreeing to be contacted does not obligate you to take part in the discussion. Your name and contact details will be available only to members of the research team. Please note that before any of our studies are conducted, they are reviewed and receive ethics clearance through a University of Waterloo Research Ethics Committee.

I agree to be contacted about possible participation in a future discussion of the results of the study entitled "Transitional care for persons with dementia and their caregivers" by a member of Professor Stolee's lab. I am aware that my agreement now does not obligate me to take part in this discussion, and that at any time I may request that my name and contract information be deleted.

Name: _____

Telephone Number: _____

Email address: _____

Best time to be contacted: _____

Signature: _____

Appendix Q
Member Check Guide

Opening script:

Hi it's Jessie Ashbourne calling from the University of Waterloo. I interviewed you in __(month)__ about your health care experiences. I was wondering if you have a few minutes to talk about the results of the study and perhaps provide some feedback about whether you think the results make sense to you based on your personal experiences.

If no: is there another time that works better for you?

If yes: Okay, great. I will start by giving you an overview of the process that led to the results. Then I will give you a brief overview of the results and explain in more detail section by section. I will ask for your feedback after each explanation. Does that work for you?

Overview of process:

I ended up talking to 41 people in total, 12 individuals who have dementia and 29 family members of individuals with dementia. I talked to people in 15 different cities or towns. 7 types of dementia were represented by the interviews. I transcribed each interview word for word then I assigned codes (or short units of meaning) to incidents described in the transcripts. I did not go into the analysis with any ideas for what would come out, I just let the voices of the participants speak for themselves. I organized the codes into themes and subthemes. I interviewed until everything that people were saying could fit into the themes that I had already developed. Finally, I formed a 3-part framework to describe the context, processes and influencing factors of care transitions.

Do you have any questions about the process?

Overview of results:

From the interviews, three main important considerations emerged: the context of transitions, the processes involved in transitions and the factors that could influence transitions. I will go into each of these in detail and ask you if you have questions or anything to add. **After each main theme, stop and ask for feedback/whether the theme is useful

Theme	General description	Sub-theme	Description
Transition context	The transition context section essentially indicates that transitions must be considered within a broader context: not just in relation to the direct health care system actions taken too make health care transitions go smoothly.	Multiple goals and realities	There are three main sets of views and goals that need to be considered during transitions. First there is of course the views and goals of the individual who has dementia. Next there is those of the family member or primary caregiver. Finally, there are the provider and health care system constraints and goals. When these are conflicting, issues may arise.
		Broader community	Community support for dementia is important because for many health care transitions, people are managing at home in their communities. Community and social support can help relieve stress and responsibility of caregivers. Lack of support can lead to social isolation which could prevent people from getting the help they need.
		Parallel experiences	This theme arose from an observation that people often compare their experiences to the experiences of other people who are also navigating the dementia care system. I found that people 1) prepared for the future based on others experiences, 2) formed expectations based on others experiences often causing them to feel lucky in comparison, 3) helped and learned from others and 4) found comfort in knowing that others were experiencing the same transitions
Transition processes	We found that there were three main phases of transitions through the dementia care system. These were often related to peoples' experiences with the dementia journey.	Transition into the system	The first was a transition into the care system, indicated by receiving a diagnosis. We found that these transitions could either be very gradual or sudden. When transitions were gradual, people were less shocked when the diagnosis came; however, often people felt as if they had to push for a diagnosis and their access to services was delayed. Sometimes people felt like they were waiting for a crisis. When these crises did occur, the transitions were more sudden.
		Continuous management & follow-up	The bulk of health care transitions are included under the processes of continuous management and follow up. This is the idea that when managing with

			dementia, transitions are just a continuous string of moves between health care providers or community support based on changing care needs. Follow-up with multiple providers is important to ensure that people are managing well.
		Coordination & continuity	During this process care coordination and continuity efforts helped make these transitions go smoothly. Important aspects of coordination were referrals to appropriate services, providers working together and providers giving each other necessary information. Aspects of continuity were providers having an overview of all of the care that an individual receives and provider consistency.
		Adjusting to a new home & final transition	The transition into a retirement home or into long-term care stood out as important due to the physical and emotional significance of the transition. The process is often long and complicated – it was not viewed as intuitive by very many participants. It was emotionally significant for both caregivers and persons with dementia. The physical significance of the transition was important because environmental changes were often viewed as a major stressor for individuals who have dementia.
Influencing factors	The influencing factors section consisted of more direct contributions to transitions. Four types of factors were explained by participants: catalysts, buffers, facilitators and obstacles.	Catalysts	People often talked about factors that caused or led up to their transitions. 2 main categories of catalysts came out of the interviews: first were precipitating crises or events (bigger events that caused major changes in needs) and second were changes in coping abilities (usually experienced as a more gradual transition).
		Buffers	Buffers were more intermediary steps taken between a time that one knows a transition is coming and the transition occurrence itself. The two main buffers described by participants were proactivity (i.e. taking control of one's own health care) and preparation by becoming educated about dementia and about the health care system processes.

| | | Facilitators | Facilitators of transition were the attributes and actions of the providers and the health care system that helped contribute to successful transitions. First, positive attributes of providers such as compassion and professionalism contributed to positive perceptions of transitions. Going above and beyond their duties and explicitly considering caregiver needs contributed to perceptions of compassion and professionalism. Second, patient and family engagement (or inclusion in health care decisions) helped people during transitions feel respected. Finally, person-and family-centred care contributed to positive perceptions of transitions. People have very individual needs, so rather than having strict rules and regulations, taking into account the unique needs of individuals is important. |
| | | Obstacles | The final category of influencing factors consisted of obstacles to successful transitions. The main types were system complexity and constraints (meaning that the system could be confusing and full of rules and regulations that don't meet peoples' needs), problems with provider knowledge or education, information and communication problems and finally denial and depression in the individual with dementia. |

Final questions:

Do you think we've missed anything? Is there something that was important to you that you don't believe fits in one of the themes mentioned here?

Do you have any questions for me?

Appendix R
Assent Form

By signing this assent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

_____

I have read the information presented in the information letter about a study being conducted by Paul Stolee and Jessica Ashbourne from the School of Public Health and Health Systems at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005.

☐ YES, I will be in this research study.   ☐ NO, I don't want to do this.

_____

Name of Participant with Dementia (Print)

_____   _____

Signature of Participant   Date

_____

Name of Caregiver or Legally Authorized Representative (Print)

_____   _____

Signature of Caregiver or   Date

Legally Authorized Representative

_____

Name of Person Obtaining Assent (Print)

_____   _____

Signature of Person Obtaining Assent   Date

Appendix S

List of Pseudonyms

Caregiver	Individual with dementia	Who was interviewed?
Betsy	Peter	Dyad
Alexa	Martin	Dyad
Heather	Frank	Caregiver
Alana	Lucas	Caregiver
Laura	Bill	Caregiver
Beth	Charlie	Caregiver
Susan	Steven	Caregiver
Rebecca	Gregory	Dyad
Maria	William	Dyad
Bobby	Mother unnamed	Caregiver
Fran	Daniel	Dyad
Britney	Marshall	Caregiver
Jessica	Rob	Caregiver
Emma	Edward	Caregiver
Jennifer	Rachel	Dyad
Matthew	Melissa	Dyad
Lynn	John	Caregiver
Bonnie	Kevin	Caregiver
Heidi	Geoff	Caregiver
Karen	Brad	Dyad
Monica	Lewis	Caregiver
Margaret	Allan	Caregiver
Geoffery	Amanda	Caregiver
Jim	Anne	Caregiver
Rita	Ruby	Caregiver
Anita	Rick	Dyad
Melanie	Gerrard	Dyad
Lianne	Daniel	Dyad
Lauren	Andrew	Dyad

Appendix T

Sample Description Tables

Table 4. Numbers and percentages of participants with dementia and their caregivers and dyad versus caregiver interviews

	N	%
Participants		
Persons with dementia	12	29.3
Caregivers	29	70.7
Total	41	100
Interviews		
Dyad interviews	12	41.4
Caregiver only interviews	17	58.6
Total	29	100

Table 5. Distributions of caregivers based on their relationship to persons with dementia

	N	%
Son	1	3.4
Husband	3	10.4
Daughter	4	13.8
Wife	21	72.4
Total	29	100

Table 6. Age distribution of caregivers and persons with dementia represented by the interviews (i.e., those actually interviews plus those represented by their caregivers)

	N	%
Persons with dementia		
55-64	2	6.9
65-74	6	20.7
75-84	12	41.4
85-94	4	13.8
94+	1	3.4
Passed away	4	13.8
Total	29	100
Caregivers		
35-44	1	3.4
45-54	0	0
55-64	7	24.1
65-74	15	51.7
75-84	6	20.7
Total	29	100

Table 7. Distribution of providers that gave the dementia diagnosis to individuals with dementia (self-report from persons with dementia and/or their caregivers)

	N	%
Doctor at a care home	1	3.4
Neurologist	3	10.4
Physician at a memory clinic	6	20.7
Primary care physician	8	27.6
Geriatrician	11	37.9
Total	29	100

Table 8. Distribution of persons with dementia represented in the interviews by dementia diagnosis

	N	%
Dementia with Lewy Bodies	1	3.4
Parkinson's Dementia	1	3.4
Fronto-temporal Dementia	2	6.9
Mild Cognitive Impairment	2	6.9
Mixed	3	10.4
Vascular Dementia	4	13.8
Alzheimer's Disease	8	27.6
Non-specific	8	27.6
Total	29	100

Table 9. Distribution of number of chronic conditions in the individuals with dementia represented by the interviews

Average = 2.07

	N	%
0-1	15	51.7
2-3	5	17.2
4-5	5	17.2
6+	4	13.8
Total	29	100

Table 10. Gender distribution of the persons with dementia and caregivers represented by the interviews

	N	%
Persons with dementia		
Female	6	20.7
Male	23	79.3
Total	29	100
Caregivers		
Female	25	86.2
Male	4	13.8
Total	29	100

Appendix U

Feedback Letter

October 23, 2014

Dear [Participant],

I would like to thank you for your participation in this study entitled "Transitional care for persons with dementia and their caregivers." As a reminder, the purpose of this study is to learn about the movement of persons with dementia and caregivers between providers and settings in the health care system.

The data collected during interviews will contribute to a better understanding of the experiences of persons with dementia and caregivers while moving between providers and settings in the health care system. These findings will assist in creating recommendations for improving and developing the care provided to persons with dementia and caregivers while they transition from provider to provider or setting to setting within the health care system.

Please remember that any data pertaining to you as an individual participant will be kept confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with the research community through seminars, conferences, presentations and journal articles. When the study is completed, anticipated by August of 2015, I will send you the information using the mailing address you have provided me with. Furthermore, the Alzheimer Society chapters involved in recruitment will receive a summary of the findings and the framework developed. In the meantime, if you have any questions about the study, please do not hesitate to contact me by email or telephone as noted below. As with all University of Waterloo projects involving human participant, this project was reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. Should you have any comments or concerts resulting from your participation in this study, please contact Dr. Maureen Nummelin, The Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

Sincerely,
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