

**Exploring Facilitators and Barriers of the
Neighbourhood Built Environment for People Living
with Early-Stage Dementia**

**by
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Abstract

Majority of research examining the impact of the built environment on people with dementia focuses on institutional settings, while the role of the community built environment is largely ignored. Using a mixed-methods approach this study examined the effect of the neighbourhood built environment on mobility and community participation of people with early-stage dementia. A conceptual framework was developed to represent key concepts and their interrelationships. The findings reveal that challenges to mobility and participation include: leaving the comfort zone, safety, a changing skillset, and losing their license. Environmental features that affected mobility and participation included: pedestrian-friendly areas, wayfinding support, and the availability of dementia-friendly destinations. Mobility and participation in community spaces provided: maintenance of lifestyle in a time of loss, personal freedom, and a sense of normalcy. These findings demonstrate the need for responsive planning and design of neighbourhoods to foster mobility and community participation in people with dementia.

Keywords: Dementia; built environment; neighbourhood; mobility; quality of life; social environment

To Mom and Dad,

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Definitions

Built Environment: Comprises urban design, land use, and the transportation system (Handy, Boarnet, Ewing & Killingsworth, 2002). It encompasses patterns of human activity within the physical environment (Handy, Boarnet, Ewing & Killingsworth, 2002). It is constantly changing in numerous ways, some changes are fast (like the reduction in the number of pedestrians from midday to midnight) and some are slow (like the deterioration of buildings over time) (Handy, Boarnet, Ewing & Killingsworth, 2002).

Community: Geographic areas proximate to the household of the older adult that are important sources of basic services and of opportunities for engagement (Keating & Gaudet, 2012). Using McMillan and Chavis' (1986) theory of community, this concept includes four main factors: *membership* which encompasses the feeling of belonging; *influence* which is a sense of mattering or a making a difference to a group; *integration and fulfillment of needs* which is met by the resources the individual receives; and *shared emotional connection* where people believe they share common histories, spaces, time, and experiences. In this study, these relational elements of a community will coincide with the geographical notion of community - a neighbourhood, town, or city (McMillan & Chavis, 1986).

Community Participation: Using Ndekhaa et al (2003, p. 326) as a holistic starting point for this definition, community participation can be defined as: "A social process whereby specific groups with shared needs living in a defined geographic area actively pursue identification of their needs, make decisions and establish mechanisms to meet these needs." In a more practical, day-to-day sense this study defines community participation as an opportunity for the individual to feel like a valuable member of their community and/or the experience of getting out in the community environment. This can take the form of going for a walk and smiling at people they pass on the street, contributing to the local economy by going on shopping trips, volunteering or going to work, playing sports, or taking part in a social activity. Essentially, it is an activity where they are leaving their home and taking an active role in their community – whether it be physically, socially, or both.

Dementia: A disease of the brain that is usually chronic or progressive in nature that impacts an individual's memory, thinking, orientation, judgment, comprehension, calculation, learning capacity, and language (World Health Organization & Alzheimer's Disease International, 2012). The most common form of dementia is Alzheimer's disease which contributes to approximately 60-70% of cases (World Health Organization & Alzheimer's Disease International, 2012). Other major forms of dementia include dementia with Lewy bodies, vascular dementia, and frontotemporal dementias (World Health Organization & Alzheimer's Disease International, 2012). There are three main stages of dementia: mild, moderate, and severe (World Health Organization & Alzheimer's Disease International, 2012).

Mild/Early dementia: Usually experienced during the first 1-2 years of the disease (World Health Organization & Alzheimer's Disease International, 2012). Since the symptoms of this stage are minimal they are often overlooked by others and contributed to the "normal aging" process (World Health Organization & Alzheimer's Disease International, 2012). However, a person with mild dementia will experience a gradual onset of short term memory issues, difficulty finding words, becoming lost in familiar places, losing track of time, having difficulty making decisions, and having trouble completing household tasks

(World Health Organization & Alzheimer's Disease International, 2012). It is also associated with mood or behaviour changes which can include becoming less active and motivated, increased levels of depression or anxiety, and becoming easy to anger (World Health Organization & Alzheimer's Disease International, 2012).

Mobility: Consists of moving in and around the community with the option of using various modes of transportation such as walking, cycling, public transportation, or driving (Ramachandran & D'Souza, 2016). It enables the use of services and the participation in activities outside of the home that would otherwise be unavailable to the person (Precin, Otto, Popalzai & Samuel, 2010). Mobility supports the participation of older adults in their communities and promotes active aging (Ramachandran & D'Souza, 2016).

Neighbourhood: In this study, *neighbourhoods* are distinct from *communities* because communities are considered to encompass both a geographical region and a feeling of engagement and connection (Keating & Gaudet, 2012). Conversely, neighbourhoods refer to the physical-spatial surroundings within the immediate area of a person's home (Buffel et al., 2009; Siordia & Saenz, 2013).

Physical Environment: Objective and perceived characteristics of the physical context in which individuals spend their time, including aspects of urban design (Davison & Lawson, 2006).

Quality of Life: A state of being that includes both objective and subjective measures such as health status, functional independence, overall well-being, and life satisfaction (Clarke et al., 2005).

Chapter 1.

Introduction

A growing phenomenon in the demographic change of an increasing older adult population is the rising rates of dementia, which is primarily experienced by those over the age of 65 (Alzheimer Society of Canada, 2017a). Currently, approximately one in nine people over the age of 65 have Alzheimer's Disease, the most common form of dementia, while that number rises to approximately one in three in those aged 85 and over (Alzheimer's Association, 2016). Dementia is a progressive and chronic illness that affects an individual's cognitive function (World Health Organization [WHO], 2015). This leads to deterioration in memory, thinking, behaviour, and the ability to perform everyday tasks (WHO, 2015).

In both Canadian and global contexts, the social and economic consequences associated with the rising rates of dementia are a serious public health concern in the 21st century (WHO & Alzheimer's Disease International, 2012). In Canada alone, the number of people living with dementia is expected to climb from 564,000 to 937,000 in the next 15 years (Alzheimer Society of Canada, 2016a). These rates are accompanied by an annual \$10.4 billion price tag for Canadians to care for these individuals (Alzheimer Society of Canada, 2016a). While these figures are concerning, it is important to acknowledge that the impact of the increasing rates of dementia goes far beyond economic or political consequences as there are psychosocial factors to consider when attempting to truly understand the impact of the disease.

Until recently, the lack of a national dementia strategy in Canada left both gaps and inconsistencies in the way dementia was addressed across the country (Alzheimer

Society of Canada, 2016b; Alzheimer Society of Canada, 2017b). Following a series of recommendations to develop such a strategy, the federal government passed *Bill C-233* in June 2017 as a commitment to address the overwhelming impact and cost of dementia (Alzheimer Society, 2017b). Currently there are also efforts being made to create dementia strategies in select provinces, including British Columbia (Alzheimer Society, 2017b). Federal and provincial-level strategies are essential to plan and implement best practices in dementia care. However, it is also worthwhile to understand the impact of the disease on the day-to-day lives of persons with dementia through an even more focused lens: their neighbourhoods and communities.

The integration of dementia care into the community is vital in order for Canada to adjust to the needs associated with the rising rates of this disease (Fleming et al., 2016; Knickman & Snell, 2002). It is important to keep in mind that caring for people with dementia in a community context, as opposed to an institutional one, is often cited as both a more cost-efficient strategy and as the preferred choice for many of those living with dementia (Aminzadeh & Garcia, 2010; Chappell, Dlitt, Hollander, Miller & McWilliam, 2004; Gitlin & Corcoran, 2000; van Hoof & Blom, 2010). Therefore, the development of dementia-friendly communities is an essential step in supporting people with dementia to maintain their quality of life.

1.1. Dementia-Friendly Communities

Dementia-friendly communities aim to help those living with dementia to feel safe, supported, and engaged (Alzheimer Society of British Columbia, 2015; Shih-Yin & Lewis, 2015). These communities attempt to reduce the stigma associated with the disease and recognize people living with dementia as equal contributors (Alzheimer Society of Canada,

2015; Shih-Yin & Lewis, 2015). One way to accomplish this is by providing education to professionals and members of the public who may interact with a person living with dementia (Alzheimer Society of Canada, 2015; Shih-Yin & Lewis, 2015). A community that is truly dementia-friendly can compensate for disability and allows people with dementia to remain active in their communities while maintaining control over their own lives for as long as possible (Innes, Kelly & Dincarslan, 2011; Wiersma & Denton, 2013). When consulting people living with dementia on developing dementia-friendly communities, many reports indicate that they feel both the physical and social environments are important features in promoting their quality of life (Age Friendly BC, City of New Westminster & UBCM, 2016; Feddersen & Ludtke, 2014; Fleming et al., 2016; Innovations in Dementia, 2011; Phinney, Chaudhury & O'Connor, 2007; Phinney & Purves, 2016; Smith & Croucher, 2016; Wiersma & Denton, 2013).

1.2. Expectations and Assumptions

Approaching the research in this study with a background in sociology and having completed an internship with the Alzheimer Society of British Columbia, I anticipate that the ability of the person with dementia to be mobile and to participate in their community will affect their quality of life. My background has informed me of the value of a connection to the community and of the desire of people with dementia to remain independent as long as possible. In response to this, I believe it is important to explore the role that the built environment plays in supporting their movement through their neighbourhood. My curiosity about this topic peaked after hearing the people with dementia in my life express a desire to remain as active participants in their neighbourhoods and the challenges they faced in doing so.

1.3. Focus of Study

The literature indicates that persons living with dementia desire the ability to remain active in their communities, both physically and socially, for as long as possible (Innovations in Dementia, 2011; Phinney, Chaudhury & O'Connor, 2007; Phinney & Purves, 2016; Wiersma & Denton, 2013). Research supports this idea and demonstrates that the physical and social dimensions of a community have a significant impact on the quality of life for a person living with dementia (Keating & Gaudet, 2012; Mitchell & Burton, 2010; Rahman, 2014). Further, the research suggests that the ability to effectively navigate the built environment can facilitate engagement in the community by providing a welcoming space that allows activity to happen in a way that is spontaneous and flexible (Innes, Page & Cutler, 2015; Keating & Gaudet, 2012; Phinney, Chaudhury & O'Connor, 2007). However, little is known about the specific built environmental features that support or challenge a person with dementia in remaining physically and socially active in their community. This is an important research area to develop because without an accessible and supportive built environment in community-based outdoor settings older adults — particularly those with dementia — may become effectively housebound (Sheehan, Burton & Mitchell, 2006). Ensuring the ability of persons living with dementia to effectively and confidently navigate their outdoor environments has the potential to create numerous social, psychological, and physical benefits for the individual (Mitchell & Burton, 2010; Rahman, 2014). The influence of the built environment is therefore an important feature to understand in maintaining and promoting their quality of life (Blackman et al., 2010; Keating & Gaudet, 2012; Phinney, Chaudhury & O'Connor, 2007; Rahman, 2014).

To address this underdeveloped area in the research, this study focuses primarily on the role of the neighbourhood built environment on the ability of a person living with dementia to effectively engage in their community. The primary goal is to examine the

features of the built environment that affect the individual's experience of mobility and community participation and in turn how this influences their quality of life. Using a mixed methods approach this research looks at the places persons with dementia go, how they get there, and what physical and social barriers they face in the process. The research questions are:

1. What are the challenges faced by community-dwelling persons living with dementia in mobility and participation in neighbourhood environments?
2. What are the built environmental features that facilitate and hinder mobility and participation of persons living with dementia in neighbourhood environments?
3. What do independent mobility and participation in the community mean to persons with dementia? How does this affect their quality of life?

Chapter 2.

Literature Review

The literature review for this study consists of an extensive look at the major themes and empirical findings from the existing research on the role of the neighbourhood built environment in facilitating or presenting barriers to mobility and participation for people living with dementia. While the majority of research in this area focuses on design of the built environment in *institutional care* settings, the following review specifically draws upon the research that has been done on *community* settings to identify existing theoretical knowledge and empirical findings relevant to the focus of this study.

2.1. Search Strategy

In order to identify the studies for review, electronic keyword searches of the following databases were completed: Ageline, Medline, PSYCinfo, and CINAHL. The search terms used are included in Figure 2.1.

Alzheimer's disease, dementia, mild dementia, early-stage dementia; built environment, physical environment, outdoor environment, supportive environment, social environment; dementia-friendly communities; familiarity; legibility; mobility; neighbourhood[s]; community participation;
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Figure 2.1. Search terms

This search strategy resulted in a return of 24,644 articles. The initial screening process consisted of removing duplicate articles. The secondary screening process involved examining both titles and abstracts. In order for articles to be included in this review they needed to match the following criteria: 1) written in English, 2) published in peer-reviewed journals, 3) a report or review of empirical research, 4) a specific focus on older adults, and 5) a stated focus on one or more of the topic areas for this study (dementia, the built and/or social environment, quality of life, community participation, or mobility). The next level of the screening process involved reading the abstracts more thoroughly and completing a scan of the article itself to see if it met the aforementioned criteria. Studies used in this review were also selected by examining reference lists from other sources. After this selection process was complete there were a total of 45 articles chosen to use in this review. Of these, 31 were retrieved from the database searches and 14 were retrieved from reference lists (see Appendix A for a visual representation of this process).

The remainder of this chapter will discuss the major empirical findings from the research in this area. The discussion will be framed around the following themes in the literature: dementia-friendly communities, the built environment, the social environment, and what persons with dementia value in their communities.

2.2. Dementia-Friendly Communities

There is an increasing recognition within the literature that dementia care extends beyond long-term care facilities and into the community, where the majority of people with dementia still live in their homes (Mitchell & Burton, 2006, 2010; Ohman & Nygard, 2005; Rahman, 2014). There has also been a growing recognition of the need for more guidance on how to design the neighbourhood built environment to support persons with dementia (Blackman, Schaik & Martyr, 2007; Mitchell & Burton, 2006, 2010; Rahman, 2014;

Sheehan, Burton & Mitchell, 2006; Smith & Croucher, 2016; Ward et al., 2017; Yu et al., 2015). This is an important research area to develop because it has been shown that the quality of life for people with dementia is strongly linked to their ability to independently navigate their environment and to continue participating in activities as they did before their diagnosis (Brorsson & Nygard, 2011; Innes, Page & Cutler, 2015; Mitchell & Burton, 2010; Ohman & Nygard, 2005; Phinney, Chaudhury & O'Connor, 2007; Phinney et al., 2016; Phinney & Moody, 2011; Ward et al., 2017). A well-designed built environment has the potential to support both independence and participation, along with other abilities that can promote or maintain function and quality of life (Keating & Gaudet, 2012; Smith & Croucher, 2016). In response to the identification of these needs the concept of dementia-friendly communities has recently come to the forefront of the dialogue surrounding living well with dementia.

Keating and Gaudet (2012) state that dementia-friendly communities are based on two hypotheses: first, that quality of life can be enhanced through both personal resources (such as functional status) and contextual resources (such as the neighbourhood built environment). The second hypothesis is that as the illness progresses there will actively be changes in the 'best fit' between resources and contexts. Working towards developing dementia-friendly communities can be done in two ways: a top-down approach that involves national leadership, and a bottom-up approach which is driven by grassroots initiatives (Shih-Yin, Becker & Belza, 2014). With both the conceptual and practical parameters in mind it can be argued that a well-thought out dementia-friendly community can help address the public health challenge that dementia presents to our aging society (Innes, 2013).

Broadly, the idea behind dementia-friendly communities is to enable and empower communities to work towards innovation in their neighbourhoods that will provide a high quality of life for persons with dementia (Innes, 2013). More specifically dementia-friendly

communities aim to: promote access to outdoor spaces, provide access to local leisure and recreation programs, enhance the ability of persons with dementia to independently navigate their surroundings, educate service providers and community members on how to recognize and effectively communicate with persons with dementia, implement environmental modifications that enable safe and accessible neighbourhoods, and provide diverse programs and services tailored to the needs of people with dementia (Innes, 2013; Shih-Yin & Lewis, 2015; Smith & Croucher, 2016).

Research in this area suggests that dementia-friendly communities should allow people with dementia to be equal contributors to their communities (Smith & Croucher, 2016; Wiersma & Denton, 2013). Becoming an equal contributor means that they are given the opportunity to both give and receive support (Smith & Croucher, 2016; Wiersma & Denton, 2013). A study by Wiersma and Denton (2013) examined how dementia-friendly communities enable persons with dementia to remain involved, active, and autonomous as long as possible into their disease trajectory. They concluded that social support from family, community members, and health care providers are key components of these communities (Wiersma & Denton, 2013). Involving persons with dementia directly in the research process, Smith and Croucher (2016) gathered data from this population to determine what would allow them to live better within their community. Participants identified the ability to stay connected and engaged, accommodation from service providers and community members, and attributes of the physical environment as important sources of support (Smith & Croucher, 2016).

As their disease progresses, persons with dementia often need to give up driving and are reluctant to take public transportation (Mitchell & Burton, 2010). This causes them to experience a shrinking world, both physically and socially, and limits their destinations to those within walking distance of their homes (Mitchell & Burton, 2010; Ohman & Nygard, 2005; Rahman, 2014; Ward et al., 2017). Facing these barriers ultimately limits their

independent use of community spaces (Mitchell & Burton, 2010; Ohman & Nygard, 2005; Rahman, 2014; Ward et al., 2017). Therefore, local neighbourhoods become an especially important area to examine within dementia-friendly communities. Neighbourhoods can set limits and constraints for people with dementia but also have the potential to offer significant opportunities for support, engagement, and independence (Ward et al., 2017). Creating a dementia-friendly neighbourhood grants people with dementia the opportunity to engage spontaneously and move freely in their community environment (Phinney et al., 2016).

Communities that are easy to navigate, enhance customer service, and offer diverse programs can support those experiencing physical and mental health challenges, young families, and visitors or citizens for whom English is a second language (Smith & Croucher, 2016). Therefore, it is important to note that dementia-friendly communities are inclusive for everyone and not only beneficial to persons with dementia (Mitchell & Burton, 2010; Smith & Croucher, 2016).

2.3. Dementia-Friendly Communities: The Built Environment

The extant research on the built environment influences on the experience of dementia shows that an environment that is familiar, legible, accessible, comfortable, and safe helps deal with symptoms of wandering, disorientation, agitation, and social withdrawal in dementia patients (Algase et al., 2010; Danes, 2012; Innes, Kelly & Discarsian, 2011; Mitchell & Burton, 2006, 2010). From the list of the above characteristics the focus in the literature tends to be overwhelmingly on the environmental features that facilitate wayfinding, that are legible to the person with dementia, and that are familiar (Blackman, Schaik & Martyr, 2007; Brorsson & Nygard, 2011; Brorsson, Ohman, Lundberg & Nygard, 2014; Innes, Page & Cutler, 2015; Mitchell & Burton, 2010; Mitchell,

Burton & Raman, 2004; Phinney, Chaudhury & O'Connor, 2007; Sheehan, Burton & Mitchell, 2006; Van Schaik, Martyr, Blackman & Robinson, 2008). The following section integrates the key findings from the literature that speak to each of these characteristics and will explain how they are relevant to the focus of this study.

2.3.1. Wayfinding

Wayfinding is identified in the literature as the ability of persons with dementia to confidently navigate their built environment (Mitchell & Burton, 2010; Sheehan, Burton & Mitchell, 2006). This is an important characteristic of the environment to consider because the fear of getting lost can keep these individuals from venturing outdoors to conduct their activities of daily life and be active participants in their communities (Duggan, Blackman, Martyr & Schaik, 2008; Innes, Page & Cutler, 2015; Mitchell & Burton, 2010). Therefore, a significant factor in constraining the autonomy of a person living with dementia is when they begin to feel disoriented in their environment and lose wayfinding ability (Blackman et al., 2010).

A study by Sheehan, Burton, and Mitchell (2006) that investigated outdoor wayfinding performance found that compared to older adults without dementia, people with the disease performed worse on wayfinding even in familiar areas. Meanwhile, an earlier study by Mitchell and Burton (2010) found that the risk of a person with dementia losing their way can be mitigated by a neighbourhood built environment designed to enhance their orientation and wayfinding abilities. Therefore, designing built environments with environmental cues built-in could help a person with dementia navigate their route to a predetermined destination (Blackman, Schaik & Martyr, 2007; Mitchell & Burton, 2006). For example, research has shown that when an individual does become lost wayfinding cues such as landmarks may act as items of clarification to allow the person to reorient

themselves in moments of confusion (Mitchell & Burton, 2010). On a typical journey through their neighbourhood persons with dementia have been observed using wayfinding cues that are both in close proximity and at a distance (Mitchell & Burton, 2010).

In order to facilitate wayfinding outdoors researchers Mitchell and Burton (2006) recommend that different features, shapes, colours, and landmarks be incorporated into the community to act as cues for where to go and to help maintain concentration. They also stress the importance of keeping street layouts simple as too much clutter can become confusing and may be overstimulating (Mitchell & Burton, 2006). Without these community wayfinding techniques in place individuals with dementia could become effectively housebound, limiting their independence and greatly diminishing their quality of life (Mitchell & Burton, 2006).

2.3.2. Legibility

Experiencing wayfinding challenges in the community is an indication that the neighbourhood environment is not legible enough to prevent a person with dementia from losing her/his way (Mitchell & Burton, 2010). Legibility is another recurring theme in the literature and is presented by researchers as a key feature of the built environment that encourages the independence and navigational abilities of people with dementia (Blackman, Schaik & Martyr, 2007; Mitchell & Burton, 2010; Mitchell & Burton, 2006; Van Schaik, Martyr, Blackman & Robinson, 2008). It is defined as the ability of people to read their surrounding environment (King & de Jong, 2016). Community members look for clues in their environment to inform them of where they are, what others are doing, where they want to go, and how they can get there (King & de Jong, 2016). These clues are provided by context, networks, and environmental markers (King & de Jong, 2016). Similarly to wayfinding, legibility is an important feature of the built environment to consider for

persons with dementia because it facilitates their ability to independently navigate their surroundings, thereby increasing their confidence and enhancing their quality of life (Blackman, Schaik & Martyr, 2007; Phinney, Chaudhury & O'Connor, 2007; Mitchell & Burton, 2006, 2010; Sheehan, Burton & Mitchell, 2006; Van Schaik, Martyr, Blackman & Robinson, 2008).

Mitchell and Burton (2010) found that persons with dementia do not want to ask for directions when they lose their way so they begin to rely more heavily on the legibility of their surrounding environment to reorient themselves. The literature suggests that legible environments can be of benefit to persons with dementia for numerous reasons: they are a key factor in informing the amount of perceptual stimulation that an individual receives, they promote the usability of the neighbourhood environment, they enhance engagement in health-related behaviours, and they facilitate cognitive skills such as the ability to maintain attention and practice navigation (Cassarino & Setti, 2016; Van Schaik, Martyr, Blackman & Robinson, 2008).

One key factor in creating a legible environment is the presence of signage at important decision points (Blackman, Schaik & Martyr, 2007; Mitchell & Burton, 2010; Van Schaik, Martyr, Blackman & Robinson, 2008). An example of clear signage as an environmental feature that can promote legibility is provided by Mitchell and Burton (2006) who describe this as simple, plain signs with large, dark lettering on a light background. Blackman, Schaik, and Martyr (2007) reached a similar conclusion in their study where they found that straightforward, descriptive text signs with clear lettering were best for persons with dementia. Ensuring that signage is well-placed and kept to a minimum is an essential aspect of keeping the environment legible because too many signs can result in confusion (Mitchell & Burton, 2010). Instead of an abundance of signs, Mitchell and Burton (2010) recommend that communities use other ways of providing access to environmental cues to enhance legibility. These can include: short, narrow and gently winding street

layouts which make environmental cues and decision points more visually accessible; varied architectural features and urban form; the use of different colours and contrasts in building form and style; variety in land use and street design; traditional designs where the function of buildings and places is evident; and distinct landmarks (Blackman, Schaik & Martyr, 2007; Brorsson et al., 2014; Mitchell & Burton, 2006, 2010; Van Schaik, Martyr, Blackman & Robinson, 2008). All community members can benefit from the incorporation of these features into their neighbourhoods because it creates an environment that is easy to understand, navigate, and access (Mitchell & Burton, 2010).

2.3.3. Familiarity

Another important feature of the built environment mentioned in the literature is a person's familiarity of the space. If the environmental features are familiar for the person with dementia, much like wayfinding and legibility, this aspect of the environment can facilitate their independence when navigating the outdoors (Brorsson & Nygard, 2011; Brorsson et al., 2014; Mitchell & Burton, 2010; Mitchell, Burton & Raman, 2004; Phinney, Chaudhury & O'Connor, 2007). Looking for and locating aspects of the environment that are familiar to the person with dementia is a key component in their ability to reorient themselves if they become lost (Mitchell & Burton, 2010).

Problematic situations can arise for a person with dementia if the familiarity of their environment is challenged (Brorsson & Nygard, 2011; Brorsson et al., 2014; Mitchell & Burton, 2006). A change in landmarks, the removal of identifying features, or the need to take a less familiar route to a predetermined destination may lead to some individuals with dementia losing their way (Brorsson & Nygard, 2011; Mitchell & Burton, 2010). The ability to independently find familiar landmarks and identifying features is a crucial component of

people with dementia being able to relocate their correct route without assistance (Mitchell & Burton, 2010).

Familiarity has been found to have cognitive, functional, social, and emotional benefits for persons with dementia (Mitchell & Burton, 2010; Phinney, Chaudhury & O'Connor, 2007; Son Hong & Song, 2009). The research shows that benefits of familiar surroundings for people with dementia include: a reduction in symptoms that indicate a poor objective quality of life (e.g., agitation); a decrease in wandering behaviour; enhanced feelings of joy and confidence; the natural encouragement to remain involved in their community for longer; and feeling that they are welcome participants in their neighbourhoods (Keating & Gaudet, 2012; Phinney, Chaudhury & O'Connor, 2007; Son Hong & Song, 2009; Ward et al., 2017). Further, the research suggests that familiarity with both the social and physical environment promotes involvement in activities, which in turn leads to active participation in the community (Brorsson & Nygard, 2011; Brorsson et al., 2014; Phinney, Chaudhury & O'Connor, 2007). Neighbourhoods have the capacity to encourage participation through acting as a familiar space that solicits involvement by serving as a source of cues for activities that have traditionally brought the individual joy or pleasure (Phinney, Chaudhury & O'Connor, 2007). Thus, the research demonstrates that the familiarity of one's neighbourhood both provides individuals with the confidence to find their way to their destination and solicits participation in the community over time by providing natural cues for familiar activities (Mitchell & Burton, 2006; Phinney, Chaudhury & O'Connor, 2007).

2.3.4. The Built Environment in Institutional versus Community Settings.

Much of the research on the role of the built environment in dementia care focuses on institutional care environments. As a result, a great deal of the knowledge regarding how the built environment can facilitate wayfinding, legibility, familiarity, safety, and personal autonomy for a person with dementia is based within these settings. The remainder of this section will discuss how these built environment features are presented within the institutional-based research and will draw parallels between the application of these features in institutional and community settings.

Wayfinding.

There is a strong emphasis on the importance of wayfinding techniques in institutional-based literature, particularly when applied to controlled wandering for residents with dementia (Algase et al., 2010; Danes, 2012; Gulwadi, 2013; Innes, Kelly & Discarsian, 2011; Marquardt & Schmiege, 2009; Mitchell & Burton, 2006; Son Hong & Song, 2009). A well-designed built environment has emerged through the evidence-based research as an institutional feature with great potential to support wayfinding ability (Marquardt & Schmiege, 2009). Environmental cues are cited in the research as one of the most salient wayfinding aspects for persons with dementia (Danes, 2012; Gulwadi, 2013; Marquardt & Schmiege, 2009; Nolan, Mathews, Truesdell-Tood & VanDorp, 2002). For example, helpful cues for residents when trying to locate their bedroom include their name being next to the door, landmarks being placed near their room, painting the corridors leading to their bedroom a specific colour, personalized memory boxes, and personal photographs (Danes, 2012; Gulwadi, 2013; Marquardt & Schmiege, 2009; Nolan, Mathews, Truesdell-Tood & VanDorp, 2002). The prevalence of wandering in hallways has revealed that the size and shape of corridors have a significant effect on resident orientation (Marquardt & Schmiege, 2009). The research suggests that facility designs which focus on

ensuring hallways are short and that the resident's destination is visible from any point in the corridor may serve to reduce a substantial amount of wandering (Danes, 2012; Marquardt & Schmiege, 2009; Milke, Beck, Danes & Leask, 2009).

The implications of using the environment to enhance wayfinding techniques are discussed within both institutional and community-based literature allowing parallels to be drawn between these two settings. It is apparent that the emphasis for wayfinding is on the resident's ability to locate their own room and on the design of corridors within institutional settings (Danes, 2012; Gulwadi, 2013; Marquardt & Schmiege, 2009). Comparatively, the emphasis is on the ability of persons with dementia to locate their home and/or community destinations and on street design in community-based literature (Mitchell & Burton, 2006, 2010; Mitchell, Burton & Raman, 2004). The community-based research suggests that persons with dementia tend to lose their way most frequently at road crossings and when it is difficult to see the route ahead (Mitchell & Burton, 2006). A parallel can be drawn here to research based in institutional environments where it is recommended that walking paths and corridors present simple decisions and guide individuals to their destinations by making them visible from any point to avoid confusion or disorientation (Diaz Moore, 2007; Marquardt & Schmiege, 2009).

The literature suggests that the importance of wayfinding for persons with dementia lies in the fact that the autonomy associated with independently traveling to a predetermined destination, within either an institutional or community setting, is strongly linked to an individual's quality of life (Marquardt & Schmiege, 2009; Nolan, Mathews, Truesdell-Tood & VanDorp, 2002). Challenges with orientation and wayfinding can begin in even the earliest stages of dementia which is why incorporating wayfinding techniques into the community — where most people with mild to moderate dementia live — is equally as important as incorporating them into residential facilities (Davis & Weisbeck, 2016).

Legibility.

Wayfinding and legibility are closely related concepts in the literature on the built environment of institutional settings. There is a strong emphasis on ensuring that the built environment facilitates both wayfinding and legibility in order to control wandering, which is often considered a 'problem' behaviour for residents with dementia living in long-term care (Algase et al., 2010; Danes, 2012; Gulwadi, 2013; Innes, Kelly & Discarsian, 2011; Marquardt & Schmiege, 2009; Son Hong & Song, 2009). As previously mentioned, the research indicates that the presence of useful cues is the most salient physical environmental feature to facilitate purposeful wandering in institutional settings (Davis & Weisbeck, 2016). It is important to ensure that these cues are easily understood and correctly interpreted by residents (Marquardt & Schmiege, 2009). Facilities should also ensure that features of the environment are architecturally legible so their function is evident (Marquardt & Schmiege, 2009). The research states that specific environmental features that can promote legibility in long-term care include: logical room syntax, signage, furnishing, and fixtures and fittings (Marquardt & Schmiege, 2009; Passini, Pigot, Rainville & Tetreault, 2000).

When comparing these findings to the community-based literature a common thread is the emphasis on the importance of legible environmental cues and architectural features in wayfinding (Mitchell & Burton, 2006; van Hoof & Kort, 2010). Further, signage appears as an environmental feature that researchers say can promote the legibility of the environment in both institutional and community settings (Mitchell & Burton, 2006; Passini, Pigot, Rainville & Tetreault, 2000). Mitchell and Burton (2006) recommend that within the community signage should display simple, essential information with realistic symbols and large, clear lettering. Meanwhile, interview data from Passini and colleagues (2000) suggests that a greater use of pictures on signs instead of words may be of benefit to

residents with advanced dementia. Although these researchers feel that signs may help residents when architectural and other design features are not legible enough to understand, they caution against the conclusion that picture signs are better than written ones as empirical research that specifically addresses sign design is sparse (Passini, Pigot, Rainville & Tetreault, 2000).

Familiarity.

Familiarity also emerges as an important built environmental feature within the institutional-based research. An environment that is both familiar to the individual and provides familiar cues (e.g., cues that the dining room is a place to eat) has been shown to help reinforce identity and promote the independence of persons living with dementia (Gulwadi, 2013; Son Hong & Song, 2009; Zeisel, 2007). The literature indicates that environmental features that promote familiarity in institutional settings include: biographical references; the presence of homogeneous and small groups; outdoor areas; and a noninstitutional character (i.e., the presence of home-like features) (Marquardt & Schmiege, 2009). The act of keeping familiar ties to link themselves to the past and future is key to holding on to a sense of self as the functional status of a person with dementia changes throughout the progression of their disease (Ohman & Nygard, 2005).

Comparing these findings to the community-based literature reveals the importance of familiar features in the environment that can serve as cues for involvement in activities in both settings (Gulwadi, 2013; Phinney, Chaudhury & O'Connor, 2007; Son Hong & Song, 2009; Zeisel, 2007).

Safety versus Personal Autonomy.

In addition to wayfinding, legibility, and familiarity, the interplay between safety and personal autonomy is an apparent theme within the research on both institutional and community environments. A fundamental paradox in dementia care is the need to balance

the individual's need for safety with their right to personal autonomy (Danes, 2012; Morgan, Stewart, D'Arcy & Werezak, 2004; Innes, Kelly & Discarsian, 2011). Within institutional settings the person-centered model of care strives to achieve this goal by upholding resident independence without jeopardizing their safety (Danes; 2012; Smith, Mathews & Gresham, 2009; Innes, Kelly & Discarsian, 2011). Methods for achieving this balance include locking access to kitchens and orienting the physical environment so clear sightlines can be maintained between staff and residents (Morgan, Stewart, D'Arcy & Werezak, 2004; Milke, Beck, Danes & Leask, 2009; Campo & Chaudhury, 2011). Generally, autonomy and wayfinding go hand in hand as spatial disorientation is a prime reason for institutionalization (Marquardt & Schmieg, 2009). Further, the autonomy of residents and their quality of life are strongly linked with their ability to get places independently (Marquardt & Schmieg, 2009).

Despite common concerns for the safety of people with dementia who live in the community (Brorsson et al., 2014; Duggan, Blackman, Martyr & Schaik, 2008; Marquardt & Schmieg, 2009; McDuff & Phinney, 2015) stemming from either the person themselves or their loved ones, Mitchell and Burton (2006) found that most people with dementia still went out alone on a daily basis. Although distances travelled were likely shorter and trips were less complicated, the ability to remain independent within the community was cited by participants as an important element in maintaining their sense of self and overall quality of life (Mitchell & Burton, 2006).

The research points towards the perceived importance of maintaining autonomy throughout the disease trajectory for persons with dementia (Blackman, Schaik & Martyr, 2007; Duggan, Blackman, Martyr & Schaik, 2008; Ohman & Nygard, 2005; Ward et al., 2017). Therefore, it is essential to design the built environment for persons with dementia with the independent use of these spaces in mind. When it comes to safety and personal

autonomy, the research reveals that the design of the built environment for dementia is truly a balancing act.

2.4. Dementia-Friendly Communities: The Social Environment

The built and social environments are closely related. The built environment primarily encompasses the physical features that can facilitate or hinder mobility and participation in the community (Handy, Boarnet, Ewing & Killingsworth, 2002). Meanwhile, the social environment involves concepts such as social capital, which emphasizes networks, norms, and social relationships between groups of people in society (Norstrand, Glicksman, Lubben & Kleban, 2012). The act of staying socially connected, performing activities outside of the home, and maintaining a sense of belonging are important to the overall wellbeing of a person with dementia (Brorsson & Nygard, 2011; McDuff & Phinney, 2015; Phinney, Chaudhury & O'Connor, 2007; Phinney et al., 2016; Ward et al., 2017). As such, both the physical and social environment are essential to consider when developing dementia-friendly communities.

Research in this area has found that people with dementia identify staying socially active as extremely important to their quality of life (McDuff & Phinney, 2015; Ohman & Nygard, 2005; Phinney, Chaudhury & O'Connor, 2007; Phinney et al., 2016; Phinney & Moody, 2011; Ward et al., 2017). Study participants have said that they combat loneliness and social isolation by remaining involved in a wide range of activities that enhance their social life (McDuff & Phinney, 2015; Phinney, Chaudhury & O'Connor, 2007). Community-based activities that allow them to remain socially active can include: leisure pastimes, work-related events, visiting friends or family, social recreation groups, volunteer work, running errands, exercise classes, or going for walks (McDuff & Phinney, 2015; Phinney,

Chaudhury & O'Connor, 2007; Phinney et al., 2016; Phinney & Moody, 2011; Ward et al., 2017).

A study by Phinney, Chaudhury and O'Connor (2007) found that although patterns of participation may be changing for a person with dementia (i.e., becoming more limited), the sense of continuity that accompanies being socially active allows them to feel as though their lives are fundamentally unchanged. Being active was meaningful to their participants in three ways: it provided feelings of pleasure and enjoyment, it contributed to a sense of connection and belonging, and it allowed them to retain a sense of autonomy and personal identity (Phinney, Chaudhury & O'Connor, 2007). Ohman and Nygard (2005) echo these findings in their report as they found that participant occupations supported their ordinary pattern of life and granted them the opportunity to function within a coherent context. This allowed participants to both experience and communicate autonomy and their personal identity (Ohman & Nygard, 2005). Meanwhile, Ward and colleagues (2017) found that the continuation of routine practices in the community offered a greater connection to place for persons with dementia and helped them maintain a sense of belonging to their neighbourhood and the people within it.

The opportunity to give and receive support was another common thread throughout the literature on the social environment (McDuff & Phinney, 2015; Ohman & Nygard, 2005; Phinney et al., 2016; Ward et al., 2017). People with dementia value the opportunity to enact their role as a 'friendly neighbour' in both emergency situations and during the mundane activities of everyday life (Phinney et al., 2016; Ward et al., 2017). In this sense, people with dementia can practice their everyday citizenship by reciprocating the help that they receive from others, allowing them to play a more well-rounded role in the life of their neighbourhood (Ward et al., 2017).

Dementia-friendly communities where the social and physical environment allow activity to be flexible and happen spontaneously would grant persons with dementia the

freedom of movement they need to claim their space in the community (Phinney, Chaudhury & O'Connor, 2007; Phinney et al., 2016; Ward et al., 2017). Ultimately, participating in the community becomes a subtle but powerful way of confronting the stigma surrounding dementia and encourages others to learn how to better communicate with and support those with the disease (Phinney et al., 2016).

2.5. What Persons with Dementia Value in their Communities

It is important to recognize that people with dementia are still service users and should be actively involved in shaping their care and communities (Blackman et al., 2010). The literature indicates that persons with dementia have identified the physical environment, local facilities, perceptions of accessibility and safety, support services, social networks, and local groups as community characteristics that are important to them (Brittain, Corner, Robinson & Bond, 2010; Brorsson et al., 2014; Wiersma & Denton, 2013). In addition, these individuals value being active and doing as much as they possibly can (Ohman & Nygard, 2005; Phinney, Chaudhury & O'Connor, 2007). The research reveals that the sense of continuity that comes along with continued participation in the community is of great value to individuals with dementia (Brittain et al., 2010; Ohman & Nygard, 2005; Phinney, Chaudhury & O'Connor, 2007). This idea was presented in various literature sources which indicated that persons with dementia value the ability to continue performing activities and visiting different places as they have been throughout their lives because it creates a sense of being an active and independent member of society (Brorsson et al., 2014; Ohman & Nygard, 2005).

In order to meet their needs, places open to the public must be both usable and accessible in order for persons with dementia to maintain the confidence to continue participating in the activities they enjoy (Brittain et al., 2010; Brorsson et al., 2014). A sense

of familiarity and comfort in public space was also found to be of great importance to persons with dementia in how they participate in their communities (Brorsson et al., 2014). Further, the literature indicates that making informed changes to the neighbourhood built environment is one key factor of supporting persons with dementia and their activities as the disease progresses, at least to the moderate stages (Blackman, Schaik & Martyr, 2007; Mitchell & Burton, 2010; Van Schaik, Martyr, Blackman & Robinson, 2008). Overall, research has clearly demonstrated that people with dementia value the feeling of enjoyment they get from simply being able to get out and be active members of their communities (Brittain et al., 2010; Brorsson et al., 2014; Burton & Mitchell, 2006; Ohman & Nygard, 2005; Phinney et al., 2007; Wiersma & Denton, 2013).

2.5.1. Maintaining a Sense of Continuity and Independence

The community characteristics that persons with dementia have identified as important to them are strongly linked to their ability to continue using and participating in community spaces independently. The research reveals that persons living with dementia actively seek and desire the ability to maintain a sense of continuity and independence in their use of community spaces (Blackman, Schaik & Martyr, 2007; Mitchell & Burton, 2010; Mitchell, Burton & Raman, 2004; Phinney, Chaudhury & O'Connor, 2007). However, the reality is persons with dementia are far more restricted in their independent use of the outdoor environment than older adults living without a cognitive impairment (Mitchell & Burton, 2010). A significant factor of this constraint is that because of a general reluctance to use public transportation and the need to give up driving, their choice of community destinations often needs to be within walking distance of their homes (Mitchell & Burton, 2010).

The importance of maintaining independence for a person with dementia lies in the fact that remaining involved in their communities provides these individuals with a sense of continuity in a time that they are experiencing great loss (Phinney, Chaudhury & O'Connor, 2007). Making communities accessible to persons with dementia is one way in which they can preserve their autonomy and sense of personal identity, thus helping to maintain their quality of life (Phinney, Chaudhury & O'Connor, 2007). Within the research there is a strong assertion that a well-designed neighbourhood built environment has the ability to enhance independence and accessibility for persons who are living with dementia in the community (Blackman, Schaik & Martyr, 2007; Mitchell & Burton, 2006, 2010; Phinney, Chaudhury & O'Connor, 2007; Sheehan, Burton & Mitchell, 2006).

It is important to note that there is diversity in how people experience space and accessibility in their dementia journey (Brorsson & Nygard, 2011). For this reason, individual motives and interests must also be considered when examining the features of the built environment that may influence a person's mobility and levels of participation (Brorsson & Nygard, 2011).

2.6. Gaps in the Literature

Older adults living with dementia tend to live at home until a crisis causes them to transition into institutional care (Mitchell & Burton, 2006). Despite this, the focus of research regarding the role of the physical environment in dementia care tends to be on institutional settings, while the impact of the community physical environment on persons with dementia is largely ignored (Brittain et al., 2010; Day & Calkins, 2002; Rahman, 2014). Further, much of the focus on the design of the environment for dementia in community settings focuses on the home but fails to adequately explore the community or neighbourhood environment (Rahman, 2014). This is an important area for research

because outdoor community spaces are where people can assert their independence, remain socially engaged, and continue to be physically active (Blackman, Schaik & Martyr, 2007; Phinney, Chaudhury & O'Connor, 2007).

This study addresses these gaps by evaluating how the built environment in neighbourhood settings helps or hinders the ability of persons living with dementia to continue as active, independent, and engaged members of the community. It gathers perspectives from the experts themselves – people with dementia – in understanding how the features of the neighbourhood built environment influence their mobility and their levels of participation in the community.

Chapter 3.

Conceptual Framework

This chapter will provide an overview of the conceptual framework developed in this study. It will begin by providing a theoretical background and conclude with a description of the framework, its key components, and their interrelationships.

3.1. Theoretical Background

There are several theories in the field of environmental gerontology that can help provide an organizational framework and appropriate theoretical underpinnings for this study. This chapter will present an overview of the theoretical foundation for this research. It will also explain the conceptual framework that was used to help guide the interpretation of this study's findings.

3.1.1. Ecological Theory of Aging.

The ecological model of aging developed by Lawton and Nahemow (1973) is by far the most referenced, interpreted, and applied theoretical framework within environmental gerontology (Golant, 2003). The ecological model of aging explores the relationship of the aging individual and their environment by evaluating how the degree of individual competence and the level of environmental demand (known as environmental press) influence the individual's ability to adapt and function within their environment (Lawton & Nahemow, 1973).

In order to approach the relationship between a person living with dementia and the influence of their neighbourhood built environment on their quality of life through a theoretical lens, one must take into consideration both the individual and the environment as active agents in compensating for declining abilities over the disease trajectory. As a result of changing circumstances over a person's life course the aging individual will likely need to adjust either their own ability (individual competence) or the environment itself (level of environmental press) in order to adapt (Cutchin, 2003; Lawton & Nahemow, 1973). In the context of this research, since there is no cure for dementia and it is a degenerative and progressive condition (Clark & Karlawish, 2003), the adaptation role needs to be carried out largely (and increasingly over time) by the environment.

Consider the following example to illustrate the above: research suggests that community-based environmental cues to enable a person with dementia to understand what to do in a particular context and how to find their way around is one method of maintaining their autonomy throughout the disease trajectory (Blackman et al., 2010). By including environmental cues built-in to the physical environment of the community, the level of environmental press has been reduced and can compensate for a loss in the individual's ability to confidently navigate their surroundings. Therefore, this theory is valuable in exploring the role of the built environment in a dementia-friendly communities context because it considers the interaction and variability between both the individual and their environment.

3.1.2. Theory of Insideness.

A second theory worth examining is Rowles' (1983) theory of insideness, which includes a concept that can be applied to the role of the built environment in the lives of older adults with dementia. He describes *physical insideness* as an innate body-

awareness of every detail of the environment (Rowles, 1983). This allows for older adults to continue functioning in spaces that would otherwise be beyond their level of competence (Rowles, 1983).

In the context of this study the concept of physical insideness applies to persons living with dementia when venturing out into familiar neighbourhoods in their communities. A study by Phinney, Chaudhury and O'Connor (2007) uses Rowles' (1983) theory of insideness to describe how over time older adults develop an embodied understanding of their living environment, which includes their communities. These researchers explain that being in a familiar environment solicits involvement in activities and the community at large through the ability of the individual to move through these spaces in an unreflective way (Phinney, Chaudhury & O'Connor, 2007).

Using the tenants of this theory, it can be argued that features of the built environment and a person's experience of physical insideness can coincide to create an accessible community for persons with dementia. For example, current research in this area states that the legibility of the environment is an important feature in creating dementia-friendly communities (Blackman et al., 2010; Blackman, Schaik & Martyr, 2007; Cassarino & Setti, 2016; Mitchell & Burton, 2010; Mitchell & Burton, 2006; Van Schaik, Martyr, Blackman & Robinson, 2008). Surroundings that are legible have the potential to help guide a person with dementia through an unfamiliar space or to reorient them in a moment of confusion (Blackman, Schaik & Martyr, 2007; Cassarino & Setti, 2016; Mitchell & Burton, 2010; Van Schaik, Martyr, Blackman & Robinson, 2008). While the concept of physical insideness implies that there would be an innate awareness of an environment that one is familiar with, the literature suggests that the legibility of a familiar environment can further enhance the ability of the individual to identify where they are and where they need to go (Cassarino & Setti, 2016; Mitchell & Burton, 2010; Rowles, 1983). Thus, the

built environment and the person's experience of physical insideness can work hand-in-hand to help guide a person with dementia through their community spaces.

This theory is therefore useful for the purposes of this study because it considers the cognitive-affective dimension of the individual's relationship with the environment. In addition, as discussed in the research conducted by Phinney, Chaudhury and O'Connor (2007), this theory can be used to help understand how the built environment acts as a facilitator to the participation of persons with dementia in their communities.

3.1.3. The Progressively Lowered Stress Threshold Model

The purpose of the progressively lowered stress threshold (PLST) model is to provide caregivers with a tool to track and regulate the stressors experienced by persons with dementia (Lindsey & Buckwalter, 2009; Smith, Gerdner, Hall & Buckwalter, 2004). This model posits that stress can accumulate for a person with dementia throughout the day (Smith, Gerdner, Hall & Buckwalter, 2004). Stressors can include changes in the environment, external demands that are too challenging for the person to process, and overstimulation (Lindsey & Buckwalter, 2009; Smith, Gerdner, Hall & Buckwalter, 2004). Further, it has been noted that as the disease progresses lower doses of stress triggers begin to produce stress responses such as agitation or dysfunctional behaviour (Smith, Gerdner, Hall & Buckwalter, 2004).

This model evolved from an understanding of the person-environment interaction and was influenced by Lawton's ecological model of aging (Smith, Gerdner, Hall & Buckwalter, 2004). A central tenant of the PLST model suggests that as persons with dementia experience progressive cognitive decline they need environmental conditions modified so that cues can be more easily processed (Lindsey & Buckwalter, 2009; Smith, Gerdner, Hall & Buckwalter, 2004). Modifying the environment involves supporting the

losses the person is experiencing and enhancing their safety (Lindsey & Buckwalter, 2009; Smith, Gerdner, Hall & Buckwalter, 2004). Doing so will ultimately place less stress on the individual (Lindsey & Buckwalter, 2009; Smith, Gerdner, Hall & Buckwalter, 2004).

Within the context of this study it is important to acknowledge that there is the potential for a person with dementia to experience a variety of stressors while navigating their neighbourhood environment. Learning how to manage these stressors as persons with dementia use their community spaces is one essential component in ensuring that they continue being active participants in their communities for as long as possible.

3.2. Conceptual Model

The conceptual framework for this study looks toward Lawton's (1973) ecological model of aging as a starting point for exploring the relationship between individual competence and agency, the built environment, mobility, community participation, and quality of life (Figure 3.1). The ecological model of aging is used to help examine how individual competence (the stage in the disease trajectory that the person with dementia is experiencing) is related to environmental demands (the features of the built environment).

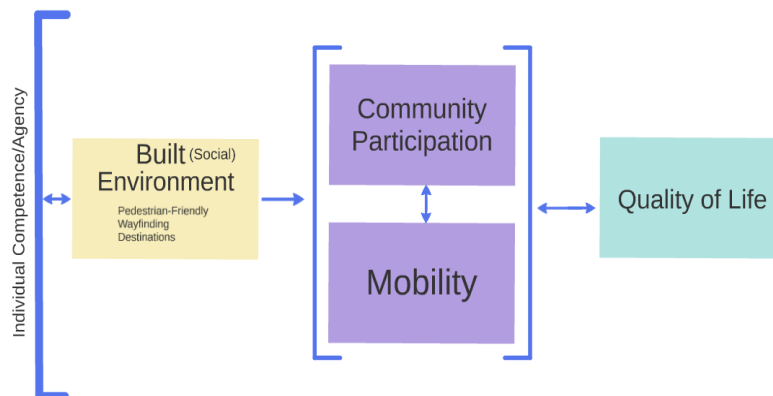


Figure 3.1. Conceptual Framework.

Moving from the left to right-hand side of the framework, this conceptual model begins with individual competence/agency. In order to demonstrate that this is an overarching factor that can influence all parts of the framework it is represented by a bracket that encompasses the entirety of the conceptual model. Individual competence is the starting point of this framework partly due to the role of agency, which is defined as a person's ability to make independent choices (Moore, 2016). Agency plays an important role in a person's experience of mobility, community participation, and quality of life as the individual is an active agent in choosing how they interact with their environment and how they interpret this interaction. The individual is crucial to consider within this framework because factors unique to each person (i.e., comorbidities, levels of support, personality, personal background, etc.) will mean that two people experiencing the same stage in their dementia journey and living in the same neighbourhood will still have two unique experiences while interacting with their community spaces.

Next, a bidirectional arrow appears between individual competence and the built environment so as not to lose the direct interaction between them (Lawton & Nahemow, 1973). This arrow represents that while the built environment may play an increasingly important role in the adaptation abilities of a person with dementia as the disease progresses, the individual is still an active agent in how they interact with and respond to the environment.

This study is based on the assumption that the level of support that the built environment provides for a person with dementia influences their experience of mobility, community participation, and quality of life. More specifically, it is hypothesized that an environment with high levels of support (characterized by a high number of facilitators as opposed to barriers) will be able to support an individual's competence (mobility) while maintaining their levels of community participation. This in turn will improve their quality of life. The aforementioned assumption is the reason that the built environment is the next

factor to appear in the framework. There is a one-sided arrow between the built environment and the remaining factors because it is thought to directly impact the outcomes of this research (mobility, community participation, and quality of life). In this section of the framework, the word “social” appears in smaller font beside the built environment because the social and built environments are closely intertwined. The results of this study point toward pedestrian-friendly features, wayfinding, and the availability of dementia-friendly destinations as built environmental features that affect the experience of persons with dementia in their community spaces (see Chapter 5). Thus, they were chosen as examples of dementia-friendly features of the built environment to be used within the framework.

Mobility and community participation appear in the same bracket in the next section of the framework because they are the primary outcomes that were addressed in this research. A double-sided arrow appears between them to represent their interacting relationship. Quality of life then appears next to the outcome bracket with a double-sided arrow to represent its role as a dependent variable in this research. In sum, the flow of the relationship represented by the conceptual framework is as follows: how the built environment affects the individual’s experience of mobility and community participation and how this influences their quality of life. The application of this framework to the findings from this study will be explored further in the discussion chapter of this document (see Chapter 6).

Chapter 4.

Methods

Recently the research involving persons with dementia has been motivated by innovative, qualitatively-driven methods and recognition of the constraints of more traditional approaches (Keady et al., 2012). This study followed that trend by including persons with dementia as active participants in the research process. This chapter will present an overview of the research methods that were used.

4.1. Research Design

The purpose of this study is to examine how features of the neighbourhood built environment influence the experiences of mobility and participation of community-dwelling persons living with dementia. In order to explore this topic, the study adopted a mixed-methods approach based on four components: first, walk-along interviews were conducted with study participants along a route of their choice. Second, the researcher took photos during the walk-along interviews of the features of the built environment that were spoken about by participants. Third, a secondary data analysis of ACT-OUT survey was conducted. Fourth, a sedentary interview was completed with each participant to capture their thoughts on what mobility and community participation mean to them.

4.2. Data Collection

4.2.1. Phase 1: Walk-along interviews.

Walk-along interviews are an innovative method of qualitative research in which the participant acts as a navigational guide and environmental expert for the area that they live (Carpiano, 2009; Garcia, Elsenberg, Frerich, Lehner & Lust, 2012). The participant takes an active role in shaping the interview and this allows the researcher to gather contextualized perspectives of the information they are being told (Garcia et al., 2012). Research indicates that there are numerous benefits to this method of data collection (Carpiano, 2009; Evans & Jones, 2011; Garcia et al., 2012; Ottoni et al., 2016; Van Cauwenberg et al., 2012). These include: rich, detailed and context specific information on how participants use their environments and why they feel a certain way about them; flexibility in the interview process as unplanned questions can arise from the environment; more variation in length and number of places mentioned; natural encouragement for the participant to focus on environmental features rather than people; the creation of a more egalitarian relationship with the researcher; and the creation of a spatial and locational discourse of place rather than a narrative which is constructed historically (Carpiano, 2009; Evans & Jones, 2011; Garcia et al., 2012; Ottoni et al., 2016; Van Cauwenberg et al., 2012). Carpiano (2009) summarizes the strength of walk-along interviews in the following quote: “by fusing the two traditional methodological techniques of field observations and qualitative interviewing, the [walk]-along simultaneously takes advantage of each method’s strengths, while employing both to compensate for each other’s limitations” (p. 265). In sum, the focus of the walk-along interview on the participant’s interaction with their environment and the depth of information gathered in comparison to sedentary interviews justified this method as a particularly useful addition

for the purposes of this study (Carpiano, 2009; Evans & Jones, 2011; Garcia et al., 2012; Ottoni et al., 2016; Van Cauwenberg et al., 2012; Van Holle et al., 2012).

While the literature suggests that there are numerous benefits to walk-along interviews as a research method, there are also limitations to consider. For instance, there are a number of conditions present in the interview setting that are out of the researcher's control (Carpiano, 2009). Weather being the main concern (Carpiano, 2009). With this in mind, the aim for this study was to conduct interviews during the summer months. This decision was based on the idea that conducting the interviews in the summer would decrease the likelihood of having to reschedule an interview due to rain, a weather condition that characterizes Metro Vancouver during the winter months. However, recruitment challenges meant that some interviews needed to be conducted in late fall when consistent rainfall had returned to the area. This proved to be a further challenge during the recruitment process. Despite their excitement at the idea of participating in research, some potential participants found the idea of walking in the rain to be discouraging enough to keep them from taking part in the study. Others stated that if it rained on the day of the scheduled interview they would prefer to reschedule for when the weather conditions were better.

An additional challenge in using this method, particularly for those with dementia, is that walking in the streets means that both the researcher and participant are more exposed to the multi-sensory stimulation of the surrounding environment (Evans & Jones, 2011; Mitchell & Burton, 2010). While this has the potential to take the interview off track, Mitchell and Burton (2010) found when using this method that in some cases it provided unplanned, useful information. In this study, it was also noted that in some cases the environmental stimuli that initially served as a distraction (e.g., the sound of noisy traffic) also acted as cues for participants and led them to delve further into an issue they may

not have otherwise. In this sense, these limitations actually served to strengthen the research by enabling the researcher to capture the reality of the participant's experience rather than just being told the highlights (Mitchell & Burton, 2006). It is important to keep in mind that participants are likely to encounter these conditions when navigating the environment on their own. One further limitation of this method is that the act of walking excludes certain kinds of interview participants and techniques (Evans & Jones, 2011). In this study, those who were not independently mobile (i.e., able to walk or propel themselves on their own) were excluded.

Before the interview process started, participants were given the option to bring a caregiver along with them. Of the eight participants, three chose to have a caregiver present for the entirety of the interview process. Only one additional participant asked for their caregiver to be nearby in case they needed help remembering specific details. Participants who decided to have a caregiver join them cited two reasons for their decision: first, greater levels of comfort when having a familiar person nearby. Second, the need for the caregiver to help them express themselves if they struggled to find the right words in conversation. Having the caregiver join the interview process was initially a concern, as it has been documented in previous research that when caregivers are present they often speak for the person with dementia (Quinn, 2017). I entered these interviews prepared to take a mediating role between the caregiver and the participant to ensure that the voice of the person with dementia was heard. However, the caregivers who participated in the interviews for this study were very sensitive to their role, recognizing that they need only interject if the person with dementia was struggling to answer a question or if they asked for help. When a caregiver did answer a question, an effort was made to confirm that this is the way that the person with dementia felt about that particular issue. This was done through asking the person with dementia directly if the caregiver had accurately captured

their thoughts on the topic at hand. The dynamic between the person with dementia, the caregiver, and myself was one imbued with respect for the role of the others in the interview process. The interviews had a conversational approach and it was considered important that everyone's voice was heard, especially the person with dementia.

This phase of the study consisted of a single walk-along interview per participant. The participant was asked to determine the walking route and the pace of the walk themselves. Allowing the participant to choose their own route was an attempt to empower them to take control during the interview process and to allow for the collection of a greater depth of information from a location that they were familiar with (Evans & Jones, 2011). One minor restriction to the walking route they chose was applied. Namely, that they choose a walking route in their local neighbourhood that they typically take within the span of a week. However, there was flexibility in the directions surrounding the reason that they take this route (i.e., it could be for leisurely purposes, to run errands, to get exercise, etc.) as the main focus was simply to explore their level of community participation in whatever form that takes. It was also requested that the participant choose a route that was within walking distance of their home. The reason behind this decision was that due to fewer responsibilities requiring older adults to go beyond their proximal spaces, particularly for individuals with dementia as their disease progresses, many of these individuals begin spending increasing amounts of time in the neighbourhoods in which they live (Mitchell & Burton, 2010).

Questions asked of participants during the walk-along touched on the following topic areas: the challenges and facilitators of their environment, improvements they feel could be made to the environment, and their mobility and participation patterns (interview guide available in Appendix B). While the primary focus of this study was on features of the built environment, flexibility was built into the interview process to ensure both the built

and social environment could be adequately explored as the two are closely related. In order for adequate information to be gathered about the built environment probes were used during the interview process to ensure this remained the primary focus. Responses were recorded using a microphone device clipped to the participant. A portable handheld microphone was used as a backup.

When beginning the research process, the aim was to spend 30-60 minutes with each participant during the walk-along portion. This was set as the ideal range because it was thought to provide a balance between being short enough that it would not be physically strenuous or tiring for participants, but also that it would allow enough time for issues to be fully addressed. Also, providing this range allowed the participant some flexibility in how far they wanted to take the interview. By the conclusion of the study the average walk-along interview length was 50 minutes. The shortest interview took 18 minutes and the longest took 2 hours and 5 minutes.

The walking route chosen was also mapped for later reference. As Evans and Jones (2011) point out, a lack of technical consideration when using the walk-along method often means that spatial location is dealt with crudely. They recommend mapping as a way to mediate this effect (Evans & Jones, 2011). In this study, this was done using a GPS tracking application on the researcher's iPhone called Nike+. This application tracks your route in real time and allows you to configure privacy settings so you are the only person with access to your GPS data (Hall & Mace, 2017). In addition, the data is transmitted securely (Hall & Mace, 2017). The researcher also used Google Maps to print out a paper copy of participant's neighbourhood and brought it to the interview as a backup to make markings on as the interview progressed (neighbourhood maps available in Figures 5-1 to 5-8).

4.2.2. Phase 2: Photo documentation.

Using photo documentation as a research method is complementary to walk-along interviews as shown in a study by Van Cauwenberg and colleagues (2012), which found that photographs taken by researchers during an interview resulted in detailed and context-specific insights into the environmental factors they were measuring. Further, using photos when conducting studies with an older adult population has been described as a great way to capture both physical and social environments (Mahmood et al., 2012; Novek & Menec, 2012). One well-known method of doing this within qualitative research is called Photovoice (Genoe & Dupuis, 2013; Mahmood et al., 2012; Novek & Menec, 2012; Wang & Burris, 1997; Wiersma, 2011). This method involves having participants in a research study take photos to depict their experience with the phenomenon under study (Mahmood et al., 2012; Novek & Menec, 2012; Wang & Burris, 1997). Participants are then asked to contextualize their photos through reflection using the photographs as prompts later, often in a group setting (Mahmood et al., 2012; Novek & Menec, 2012; Wang & Burris, 1997). The use of this method is said to give participants a voice both individually and collectively (Mahmood et al., 2012; Novek & Menec, 2012; Wiersma, 2011). When using this method specifically with older adults, researchers Novek and Menec (2012) found that this is an effective tool for eliciting older adult perceptions of their communities, giving voice to the unique concerns of older adults, and identifying strategies for change. Further, research has found that using Photovoice with persons living with dementia provides an opportunity for them to be involved in participatory research that privileges both their voices and their artistic expression (Wiersma, 2011). While the participants in this study did not take the photos themselves, the utilization of photos as a form of visual documentation still serves as a logistically feasible method to give a voice

to this population as they were the ones identifying which features of the built environment to photograph. Further justification of this alternative method of photo documentation is provided below.

In response to the challenges associated with participant-taken photos (Genoe & Dupuis, 2013; Novek & Menec, 2012; Wiersma, 2011), particularly when the users are persons with dementia (Genoe & Dupuis, 2013; Wiersma, 2011), it was decided that the researcher would take the photos in lieu of using Photovoice as a research method. The following reasons contributed to this decision: first, having the researcher take the photos simplified some of the ethical considerations that could have arisen from this process. For instance, in previous studies photo-taking raised concerns from participants regarding the inclusion of people in photos and the exterior of public spaces, suggesting that this process may elicit feelings of anxiety or fear of social consequences (Novek & Menec, 2012; Wiersma, 2011). An additional benefit of having the researcher take the photos is that instead of arranging a separate interview to discuss them with participants afterwards (Novek & Menec, 2012; Wiersma, 2011) this method allowed the researcher to gather the meaning of the photos in real time. This is particularly important when using this method with people with dementia as previous studies using Photovoice with this population found that participants would at times forget the context of the photographs (Genoe & Dupuis, 2013). Further, having the researcher take the photos allowed this form of data collection to be carried out through one source. This eased the process of data documentation by eliminating the need to rely upon participants to properly document their photos, which could have been a particular challenge with people with dementia (Genoe & Dupuis, 2013; Wiersma, 2011).

The photographs were taken on the researcher's iPhone. There was no set limit on the number of photos per interview. Rather, it was determined by the features of the

built environment that the participant indicated were important to their mobility and community participation. On average, four to five photos were taken in each interview session. The lowest number of photos taken in a single interview session was one, while the highest number was eight.

4.2.3. Phase 3: Secondary data analysis from ACT-OUT survey.

ACT-OUT is a survey tool (Appendix C) which aims to describe and understand the patterns of participation in place-based activities outside of the home for those living with mild to moderate dementia in the community (*User's Guide: ACT-OUT, 2016*). The tool was developed by researchers in Sweden in 2016. ACT-OUT is divided into three parts (*User's Guide: ACT-OUT, 2016*). Part one speaks to the places participants attend for various activities (*User's Guide: ACT-OUT, 2016*). Part two provides two sets of identical questions regarding places where the participant indicates there will be no change in their patterns of use after their diagnosis, and places where they feel there has been (or anticipate there will be) a change (*User's Guide: ACT-OUT, 2016*). Part three provides general questions about attitudes toward risk-taking, perceived life satisfaction, and potential participant concerns (*User's Guide: ACT-OUT, 2016*). The data from ACT-OUT assisted in developing an understanding of both the objective and subjective changes that a person living with dementia experiences in regard to their mobility and community participation.

The ACT-OUT surveys were used to understand where people with dementia were choosing to go in the neighbourhoods, their patterns of participation in these places, and to develop a deeper understanding of how they were getting there. The ACT-OUT surveys were read aloud to the person with dementia and the researcher was the one to record

their responses. Participants found it difficult to categorize some of their answers to the questions in ACT-OUT (e.g., rating their life satisfaction, how often they went to particular destinations, how concerned they were with falling or getting lost). As a result, the ACT-OUT survey turned into a conversation between the researcher and the participant, much like the interviews.

Data from the ACT-OUT survey was used in conjunction with the data collected in the interviews to develop an understanding of the role of the built environment in facilitating community participation. It served this purpose in the following ways: first, part one of the ACT-OUT survey collects information on the places persons living with dementia typically go (*User's Guide: ACT-OUT*, 2016). This provided context to the information that was collected during the walk-along interviews. Since the walk-along interviews did not specifically address the destination of participants, ACT-OUT developed a picture of *where* participants were choosing to go and *why/how* they participated in their communities. The information gathered in part two of the survey, which focuses on changes in patterns of use for specific destinations, was useful information for the purposes of this study as a means of contextualizing how participants feel their participation and mobility patterns have changed since their diagnosis. Part three of ACT-OUT served as a means of understanding *why* participants feel that certain features of their environment act as a facilitator or barrier to their participation. For example, participants who indicated they were concerned about getting lost were more likely to emphasize the importance of staying in their 'comfort zone'. Lastly, participant responses to ACT-OUT were used as a prompt during the sedentary interviews to capture a more in-depth picture of that person's experience of mobility and participation in their neighbourhood. Therefore, the survey data served as a useful tool in eliciting a certain level of depth to the data.

The findings chapter of this report will present the ACT-OUT data in two ways: first, data from ACT-OUT was used to support the major qualitative themes of this study. By comparing each participant's ACT-OUT data to the qualitative information that was gathered during the interviews, this study was able to capture a more in-depth picture of the experiences of mobility and participation for people with dementia in their neighbourhood environment. Second, basic statistical procedures such as frequencies and percentages were performed to obtain an overall pattern of the data from ACT-OUT. ACT-OUT was split into four categorical sections. Within each of these sections was a list of identical questions. In order to determine the frequency of answers to the questions within these sections a base number of 32 was used (8 participants x 4 answers to each question). Please refer to Appendix C for a complete list of the questions used.

4.2.4. Phase 4: Sedentary interviews.

The sedentary interview is among the most widespread and familiar approaches to collecting qualitative data in the social sciences (Brinkmann, 2014; DiCicco-Bloom & Crabtree, 2006). Qualitative interviews are considered to be a reliable method of learning about individual experiences and perspectives on a given set of issues (DiCicco-Bloom & Crabtree, 2006). While qualitative interviews can take on various structural forms (DiCicco-Bloom & Crabtree, 2006), the interviews in this study took a semi-structured approach. The aim of using a semi-structured approach was to provide structure to the interview based on the stated research interests while also allowing room for more spontaneous responses from participants (Brinkmann, 2014).

With the above considerations in mind, the final phase of this study consisted of one sedentary interview with participants. To prepare for the sedentary interviews a brief

initial analysis of the data was conducted in order to individualize the interview guides for each participant. This was done through reviewing the interview transcripts from the walk-along interviews and by analyzing the responses from the participant's ACT-OUT survey. The photographs and the neighbourhood map from the walk-along interview along with specific references to the participant's ACT-OUT responses served as prompts throughout the interview process. The rationale behind this was that the sedentary interview provided the participant with the chance to explore and contextualize the information they provided during the previous phases of the project. This interview also served as their chance to express how they thought their neighbourhood environment related to their quality of life. Similarly to the walk-along interviews, the sedentary interviews were audio-recorded on a handheld device. On average, these interviews took 15-20 minutes to complete.

The walk-along interviews and ACT-OUT surveys were completed on the same day with participants. After completing the walk-along, it was confirmed with participants whether they wanted to keep going. The sedentary interview was completed in a separate session, the timing of which varied depending on the availability of participants, with all participants having completed the sedentary interview within one week of the walk-along.

4.3. Recruitment

Engaging persons living with dementia directly in a research project is often a challenge (Nygard, 2006; Wiersma, 2011). To recruit participants a variety of resources were used in an attempt to build interest in the study. First, the researcher reached out to participants from a larger study using the ACT-OUT tool. ACT-OUT is a questionnaire that speaks to the level of participation in activities and places outside of the home for older adults (*User's Guide: ACT-OUT*, 2016). The participants for the ACT-OUT study included

older adults (55+) in the early to moderate stages of dementia who reside in the community (n=60) (*User's Guide: ACT-OUT*, 2016). This aligned well with the selection criteria for participants in this study. In order to recruit participants the researcher attended a number of the ACT-OUT interviews. Upon completion the participant was asked if they would be interested in further research. If they indicated they would be a brief informational handout (Appendix D) that outlined the focus of this proposed study, what their participation would look like, and the eligibility requirements was presented to them. Contact information was then exchanged and the researcher gave a follow-up call the same week to see if they wanted to arrange an interview for this study. At that point any further questions regarding the study were answered and a further screening was conducted to ensure that the participant was eligible. In total, three participants were recruited using this method.

Due to unanticipated recruitment challenges in the ACT-OUT study and the timeline required for the completion of this study, backup methods of recruitment were employed. Using a pre-established connection with a person living with dementia in the community the researcher was invited to present the study to their support/social group for persons living with dementia. Three participants were recruited through this method. In addition, the support group leader volunteered to share the study with another group that they ran in the area. From this, one more participant was recruited. The last participant was recruited through snowball sampling (a participant connection). The final sample size was eight participants.

Other methods of recruitment that did not result in the acquisition of any participants included presenting the study to a community group in an attempt to engage them in the research process and reaching out to various community organizations with services for persons with dementia through email and by phone.

The major challenge in recruiting persons with dementia for this study was access. This was primarily experienced in the form of safeguarding from community organizations and families throughout the recruitment process. Before being able to address the person with dementia directly the researcher often had to get approval from others first. Further, when asking permission of organizations to present the study to those they provide services to the researcher would often have to speak to multiple people in order to initiate the approval process. This was a time-consuming task that did not yield any results as many organizations failed to follow up or respond to these requests. Another challenge was the use of walk-along interviews as a research method. This was primarily due to the time of year the research was conducted. Some people decided not to participate because the weather was either too cold or too rainy. Since this is the weather trend in Metro Vancouver for that time of year (late fall), these individuals were not willing to try to schedule an interview on a nice day.

4.4. Study Participants

The study sample included eight community-dwelling people diagnosed with early stage dementia. In order for participants to be eligible for this study they needed an official diagnosis of dementia. In addition, participants must have completed an MMSE test within the last three months and received a score between 20-24 (which indicates mild dementia) (Alzheimer's Association, 2017). MMSE is a tool used by some healthcare professionals that assesses five areas of cognitive function: orientation, registration, attention and calculation, recall, and language (Kurlowicz & Wallace, 1999). In addition to meeting the above-mentioned criterion participants had to be independently mobile for the walk-along interview portion of this study. The participants needed to be able to walk or mobilize

themselves independently with or without the use of mobility device (e.g., cane) for a minimum period of 60 minutes. Finally, participants needed to be age 55 or older as this study focuses on older adults because dementia primarily affects this segment of the population (Alzheimer's Society of Canada, 2016).

In order to gain perspective on how the built environment affects the mobility patterns and community participation of persons living with dementia it seems natural to ask the experts: the people with dementia themselves (Wilkinson, 2002). A researcher cannot adequately develop an understanding of an experience through proxy reports (Wilkinson, 2002). Despite this, until recently people living with dementia have largely been left out of participatory research and have had other people speak for them (Nygard, 2006; Wiersma, 2011; Wilkinson, 2002). Continuing to work on the assumption that persons with dementia cannot participate in research is a reinforcement of a negative stereotype of incapacity (Nygard, 2006; Wilkinson, 2002). To shift the power inequalities and challenge the stigma associated with living with dementia, it is important to include the perspectives and experiences of this population within the research (Nygard, 2006; Wiersma, 2011; Wilkinson, 2002). Reflecting the need for this shift, there is now a heightened inclusion of people with dementia participating in research as the call for more participatory approaches has aligned with philosophical orientations directed towards the personhood of the individual living with dementia (Wiersma, 2011).

4.5. Research Setting

All interviews were done in the Metro Vancouver area of British Columbia, Canada. The walk-along and photo documentation phases of this study were neighbourhood walking routes determined by the study participants. Participants were asked to select an

area in their community that was meaningful to them and that they felt influenced their mobility patterns and community participation. Community was defined as a geographic area proximate to the household of the older adult that is an important source of basic services and opportunities for engagement (Keating & Gaudet, 2012). The ACT-OUT survey and sedentary interviews were conducted in the participant's home.

4.6. Data Analysis

The data obtained from the interviews and the photo documentation was sorted, analyzed, and organized using the qualitative data analysis software NVivo (version 11.3.2). In order to protect the data and the confidentiality of participants upon completion of the interviews the audio recordings and photographs were uploaded to a file on a password-protected computer the same day. Backups were stored on a portable and encrypted USB device that was kept in a locked drawer along with any hard copies of the data. Any documentation that contains identifying information of participants was kept in a separate locked drawer. Once the photographs and audio recordings were uploaded electronically, each was assigned a unique code number associated with a specific interview without providing any identifying information of the participant (i.e., names).

During the interviews, the researcher kept a small notepad on hand to jot down any pertinent information that would complement the audio recordings and photo documentation that cannot be captured in these formats, such as nonverbal cues from participants. Once the interviews were complete these notes were typed and saved as a file on a password-protected computer that was later uploaded to NVivo for analysis.

The night of or the morning following the interviews the audio recordings were transcribed using Express Scribe (version 5.82) as a means of slowing down the recordings to ease the transcription process. Following interview transcription, the interviews were coded until relevant themes emerged from the data. Coding provided an opportunity to shift from a description towards a conceptualization of the data (Charmaz, 2002). In order to get close to the data, the coding process for these interviews was done line by line (Charmaz, 2002). This process began with open coding in order to make analytic decisions and begin building a picture of the data (Charmaz, 2002; Strauss & Corbin, 1998). This was followed by focused coding that sorted, synthesized, and conceptualized the large amount of data (Charmaz, 2002; Strauss & Corbin, 1998). As the process continued and similar codes emerged, meaning began to appear through descriptive codes. The photographs were also examined in detail to complement the interview data and provide an additional set of information from which to derive meaning. Throughout this process the data was analyzed through a set of inductive steps to develop a practical and conceptual understanding of the story it is telling (Charmaz, 2002). This process was aided by the second interview with participants because, as Charmaz (2002) points out, when interviewers only rely on one interview they run the risk of missing opportunities to correct earlier errors and to construct a more dense and complex analysis of the data.

During coding, memos were created as a tool for linking the codes to the first draft of the analysis (Charmaz, 2002). Memoing is the process that translates codes into broader conceptual categories to begin establishing meaning within the data (Charmaz, 2002; Strauss & Corbin, 1998). In addition, these memos served as a useful tool in creating a data analysis trail, which contributes to establishing auditability and scientific

rigor in qualitative research (Strauss & Corbin, 1998; see further “Auditability” section below).

Data from ACT-OUT was analyzed using the descriptive analysis software SPSS 24. Frequencies, crosstabs, and percentages served as ways to present the patterns from this data. The results were used to contextualize and expand the findings from the qualitative portion of this project.

4.7. Establishing Data Reliability and Validity

Rigor and validity are important to ensure the worth, applicability, and accuracy of findings within qualitative research (Long & Johnson, 2000; Morse, Barrett, Mayan, Olson & Spiers, 2002). When compared to the hard numbers obtained from quantitative research, qualitative research is left experiencing a crisis of confidence from individuals both inside and outside the field of study (Morse et al., 2002). Efforts were taken throughout the study, rather than just at the end, to ensure reliability of the data being collected before it was too late to correct the research approach (Morse et al., 2002). The strategies identified in order to establish reliability included: triangulation and prolonged engagement, peer debriefing, member checking, and auditability (Guba & Lincoln, 1981; Lincoln & Guba, 1985; Morse et al., 2002).

4.7.1. Triangulation and prolonged engagement.

Triangulation “refers to the employment of multiple data sources, data collection methods, or investigators” (Long & Johnson, 2000, p. 35). In this study the use of

interviews, photo documentation, and the analysis of results from a larger study (ACT-OUT) meets the requirements listed above. In addition, the use of two interview sessions with each participant contributed to the factor of prolonged engagement emphasized by Guba and Lincoln (1981, 1985).

4.7.2. Peer debriefing.

Peer debriefing occurred throughout the data collection and analysis process in order to “stimulate consideration and exploration of additional perspectives and explanations at various stages” (Long & Johnson, 2000, p. 35). The researcher’s supervisory committee played a key role in ensuring the rigor of this study (Holloway & Wheeler, 1996), along with fellow graduate students.

4.7.3. Member checking.

Member checking is identified as an important method for establishing reliability within qualitative research (Lincoln & Guba, 1985; Long & Johnson, 2000; Morse et al., 2002). However, researchers have also warned against placing too much emphasis on the results of respondent validation, particularly because of issues regarding participant memory, being unconscious of the non-verbal cues that present significant findings to the researchers, or the participant denying less attractive aspects of their behaviour during the interview process (Hammersley & Atkinson, 1995; Long & Johnson, 2000; Mason, 1996; Morse et al., 2002). The point regarding the participant’s memory of the interview was a particularly relevant concern in this study because all of the participants had dementia, a progressive disease that can greatly affect a person’s memory (WHO, 2015).

In order to approach this challenge, two tasks were performed: 1) five minutes were spent with participants at the end of the interview to review its main takeaways; and 2) processes of clarification were taken throughout the interview process to ensure that the researcher understood the message the participant was trying to get across (i.e., repeating what they said back to them or explaining how their comment was interpreted and asking for clarification).

4.7.4. Auditability.

Auditability entails leaving a decision trail by presenting details of all sources of data, collection techniques, assumptions made, decisions taken, meanings interpreted, and influences on the researcher (Long & Johnson, 2000). The use of memos and field notes in this study allowed the researcher to track the data analysis process (Morse et al., 2002).

4.8. Ethics Approval

Human research ethics approval was obtained from Simon Fraser University's Office of Research Ethics before the data collection process for this study began. Major ethical considerations for this project included dealing with vulnerable persons (those with early-stage dementia) and concerns revolving around issues of capacity, particularly obtaining informed consent from participants.

4.8.1. Obtaining informed consent from persons with dementia.

Obtaining informed consent is a complicated issue for this particular study population due to the issue of cognitive capacity. However, it is important to overcome these barriers to include the perspectives of persons living with dementia in research as a means of challenging negative stereotypes of incapacity (Hubbard, Downs & Tester, 2002; Slaughter, Cole, Jennings & Reimer, 2007; Wiersma, 2011; Wilkinson, 2002). Research has shown that despite these stereotypes, people with dementia can in fact be capable of making their own decisions and choices, and of articulating their feelings and experiences (Slaughter et al., 2007; Wiersma, 2011). Further, the participants in this study were diagnosed with early-stage dementia. Therefore, they were still able to do much of what they had always done with little help (Alzheimer's Society of Canada, 2014).

To ensure that participants understood their role and wanted to participate in the study, the literature recommended obtaining consent at various points in the study process and continuously monitoring their willingness to be involved (Hubbard et al., 2002; Wiersma, 2011). In order to obtain consent at various points throughout this study a consent form (available in Appendix E) was required to be signed and dated before the data collection began. This form emphasized the voluntary nature of participation in the research, the process for withdrawal if the individual no longer wanted to participate, and explained what would be done with the data afterwards. On the day of the scheduled interview, the researcher reviewed the consent form with participants before proceeding to ensure they fully understood the nature of their participation. They were then asked to also provide their consent verbally before the interview began. Before the second interview, the participant was again asked to provide verbal consent. If the participant seemed uncomfortable or unsure about their participation at any point in the study process

they were asked if they wanted to continue before proceeding with the remainder of the interview.

Chapter 5.

Findings

This chapter will begin with descriptive profiles of the participants from this study and their neighbourhoods. The following sections will present the emergent substantive themes from the research which are: *Leaving the Comfort Zone*, *Safety*, *Changing Skills and Adaptation*, *Losing Their License*, *Pedestrian-Friendly Features*, *Wayfinding*, *Destinations*, *Maintenance in a Time of Loss*, *Freedom*, and *Sense of Normalcy*. Table 5.1 provides an overview of the themes and corresponding sub-themes from this study.

Table 5.1. Study Themes

Category	Theme	Subtheme
Challenges to Mobility and Participation	Leaving the Comfort Zone	
	Safety	
	Changing Skills and Adaptation	
	Losing Their License	
Role of Environment on Mobility and Participation	Pedestrian-Friendly Features	Sidewalks
		Ambience
		Seating Options
		Public Transportation
		Crosswalks
		Other Features
	Wayfinding	Signage and Maps
		Landmarks
		Distinct, Simple & Clear
		Consistency
		Straight Street Layouts
	Destinations	Density and Mixed-Use Development
		Proximity
Dementia-Friendly Destinations		
Other People		
Walking is More Than Transportation	Maintenance in a Time of Loss	
	Freedom	
	Sense of Normalcy	

5.1. Participant Characteristics

Eight people were interviewed in this study. The sample was evenly split between males and females totaling four participants each. The mean age of the participants was 71.8 years. The youngest participant was 59 years of age and the oldest was 93 years of age. 87.5% of the sample identified their ethnic background as Caucasian while the remaining 12.5% of participants identified as Asian-Pacific. Three quarters of participants were married and one quarter were widowed.

The majority of participants in the sample resided in their own home (75%), while others resided in the home of a family member or friend (12.5%) or in a retirement home (12.5%). One participant lived alone, six participants lived with one other person, and one participant lived with two other people. Most participants (87.5%) felt that they had a person they could rely on for support in their life, often identifying their spouse or children as their sources of support. Half of the sample indicated that they regularly use HandyDart (transportation for persons with disabilities) while the other half relied more on other modes of transportation such as rides from family or friends. All but one participant (87.5%) no longer had a valid driver's license and no longer drove a car.

All participants self-identified their health as either good or very good. 62.5% of participants felt they had a health condition that limited their activities, while 37.5% felt that they did not. Of those who felt they had a limiting health condition only 60% attributed it to dementia. The remaining participants identified a physical health condition as that which limited their activities. Three individuals in the sample received home care and the remaining five did not. There were four types of dementia represented in this study: Alzheimer's Disease (50%), Posterior Cortical Atrophy (25%), Early-Onset Alzheimer's

Disease (12.5%), and Frontotemporal dementia (12.5%). A general overview of participant characteristics appears in Table 5.2; Table 5.3 highlights individual participant profiles.

Table 5.2. Participant Characteristics

Variable	Outcome	Total (%)
Gender	Male	50
	Female	50
Age	55-59	12.5
	65-69	37.5
	70-74	25
	75-79	12.5
	90-94	12.5
Ethnicity	Caucasian	87.5
	Asian-Pacific	12.5
Residing In	Own Home	75
	Home of Relative or Friend	12.5
	Retirement Home	12.5
Number of People in Household	Lives Alone	12.5
	One Other Person	75
	Two Other People	12.5
Uses HandyDart	Yes	50
	No	50
Has a License/Drives a Car	Yes	12.5
	No	87.5
Feels Supported	Yes	87.5
	No	12.5
Self-Perceived Health Status	Very Good	50
	Good	50
Has a Limiting Health Condition	Yes	62.5
	No	37.5
Receives Home Care	Yes	37.5
	No	62.5

Table 5.3. Participant Profiles

Participant ID	Age	Length of Time in Neighbourhood	Neighbourhood Setting	Primary Reason Behind Walking Route
DFC01	93	~10 years	Suburban	Transportation
DFC02	59	1-2 years	Suburban	Getting Out
DFC03	75	~10 years	Suburban	Transportation
DFC04	72	6 months	Suburban	Practicing Independence
DFC05	66	11 years	Suburban	Socializing
DFC06	69	~ 20 years	Suburban	Socializing
DFC07	71	16 years (moved away for 4)	Suburban	Access to Services
DFC08	69	30 years	Urban	Access to Services

5.2. Community Context

Metro Vancouver is a regional district located in British Columbia, Canada. It encompasses a total of 21 municipalities, one treaty First Nation, and one electoral area (Metro Vancouver, 2017). The area spans over 2,882 square kilometres and has a population of approximately 2,463,431 (Statistics Canada, 2017). Previously known as the Greater Vancouver Regional District the area is situated north of the State of Washington, United States, east of the Strait of Georgia, west of the Fraser Valley Regional District, and is divided by the Fraser River (Statistics Canada, 2016). Seven communities within Metro Vancouver were included in this study: Vancouver, North Vancouver, Surrey, White Rock, Richmond, Delta, and Langley (Table 5.3). These municipalities were chosen as the study sites because they were the communities where participants lived.

Table 5.4. Community Profiles (Statistics Canada, 2017)

Community	Population	Residents Age 55+	Residents 55+ (%)	Km ²	Population Density/km ²
<i>Metro Vancouver</i>	<i>2,463,431</i>	<i>717,215</i>	<i>29.1</i>	<i>2882.68</i>	<i>854.6</i>
North Vancouver	115,344	35,865	31.1	335.16	344.1
Richmond	198,309	63,630	32.1	129.27	1534.1
Surrey	517,887	138,040	26.7	316.41	1636.8
White Rock	19,952	10,555	52.9	5.12	3893.1
Langley (City)	25,888	8,470	32.7	10.22	2533.6
Delta	102,238	34,380	33.6	180.20	567.4
Vancouver	631,486	176,820	28.0	114.97	5492.6

5.2.1. Neighbourhood Maps

Within each community setting participants were asked to perform a guided walk through their neighbourhood, known as a ‘walk-along interview’. It was requested that they choose a walking route that they take regularly (i.e., at least once a week). When asked to explain why they chose that particular walking route participants responded as follows:

25% took the route regularly to run errands, 25% indicated that this was their primary route to access transportation, 25% walked the route with friends or took it to meet friends, 12.5% used the walk to practice their independence, and 12.5% walked the route just to 'get out' in the community (Table 5-2).

Five participants had a specific route in mind when setting out for the walk. The remaining three participants had a specific destination in mind but spontaneously decided which direction they wanted to take as the walk went on. During these walks it was observed that there would be a change in the planned route when the participant recalled something they felt was important and required a detour to access. Although the route may have changed from their original plan, the participants were still familiar with the route they chose and took it regularly. One participant felt that it was important to walk to a destination that was visually appealing and brought them joy on their walks. The other two participants decided to detour to crosswalks in their neighbourhood that they found overwhelming and difficult to use.

Half of the participants chose a route where the roads remained completely straight. On these roads, the place the individual came from and the place they were going were clearly visible. The remaining half took a route where there were some slight curves in the road along the way but the majority of the route remained straight. None of the participants chose a route with a significant curvature in the road. Participants took an average of six turns on their walk, which includes the time that it took to walk to the destination and return home from it. Turns on the walk were defined as changes in direction along the route. The highest number of turns taken was 13 and the lowest was one. 62.5% of participants took the same route to and from their destination while the remaining 37.5% chose a slightly different route on the way back. In total, participants

travelled an average of approximately 6.25 blocks on their walk. The shortest distance was 2 blocks and the farthest was 12 blocks.

Each route was recorded and mapped during the interview process in order to track spatial location. The eight figures appearing in this section are the maps attributed to each participant. The maps are captioned with lettered entries that specify the key environmental features of the walk. In order for a lettered entry to appear on the map it needed to be emphasized by the participant during the interview. Analyzing the maps reveals important findings within the data that will be explored in more detail in the thematic sections of this chapter.

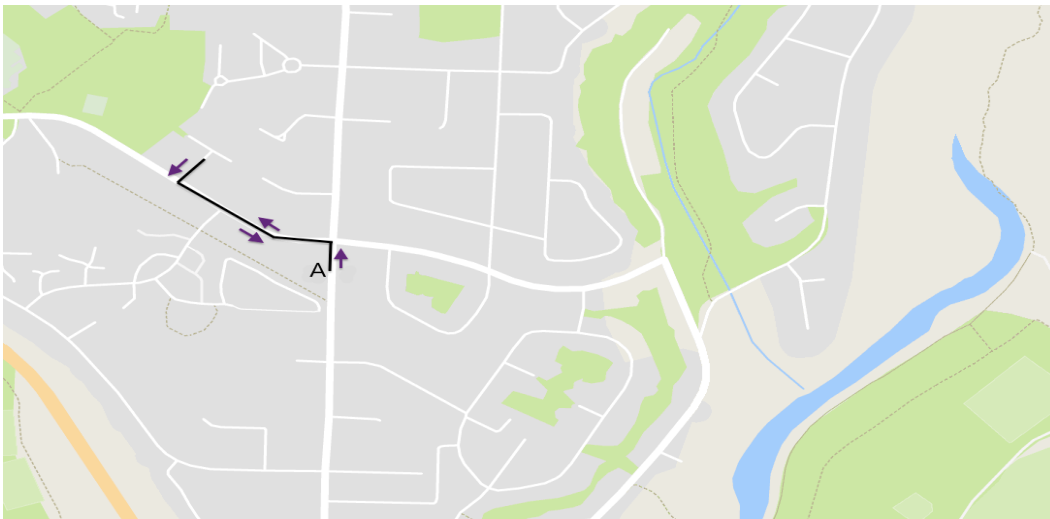


Figure 5.1. DFC01 Neighbourhood Map.

- A) A bus stop that served as DFC01's main source of transportation. This participant valued their ability to use public transit because it asserted their independence, encouraged them to exercise by walking to and from the bus stop, and saved them money.

A) A preferred destination for the participant. This particular building has an interesting art installation on an outside wall that DFC03 enjoyed going to look at on a regular basis.

B) “This is about as far as I go” – DFC03. As a result of physical health limitations, this participant was not able to walk for long before they were in too much pain to continue. They relied on the bus stop near their home to independently access community services that were outside of this walking distance.

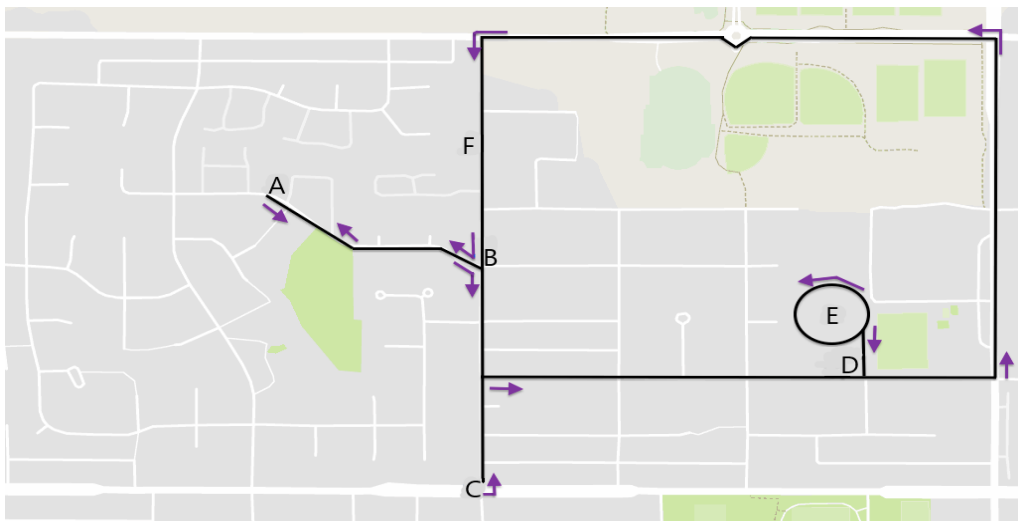


Figure 5.4. DFC04 Neighbourhood Map.

A) This participant had recently moved to the area. Their home was on the corner in their complex which meant that the two neighbouring driveways were very close to theirs. That made it difficult for this individual to distinguish between the driveways and know which one belonged them. Occasionally, this was disorienting for DFC04 and they ended up at the wrong house.

B) The mailbox at the end of the participant’s street. During the interview DFC04 said that it served as an indicator for them that they have arrived at their street.

C) A crosswalk. It was observed that DFC04 struggled with using the crosswalk. This participant (among others) expressed confusion about which button to press

to be able to safely cross in the direction they desired. DFC04 indicated the directional sounds coming from the crosswalk buttons did not help them as they were not able to make the connection between where the sound was coming from and which way that meant to go. To use the crosswalk, they typically ended up waiting for another person and then followed them if they were heading in the same direction.

D) An indoor pool that the participant planned to use for exercise once they were more settled into the neighbourhood.

E) During our walk, the participant got lost in the parking lot of a community centre. We walked around in a circle before we found our way back to the entrance. DFC04 remained calm and explained that this was the way they handled themselves whenever they got lost on their own - simply wandering until something looked familiar and allowed them to reorient themselves.

F) This street served as a landmark for the participant because it helped anchor them to their location. They felt confident and secure when they realized they were on this street because it meant they were not far from home.

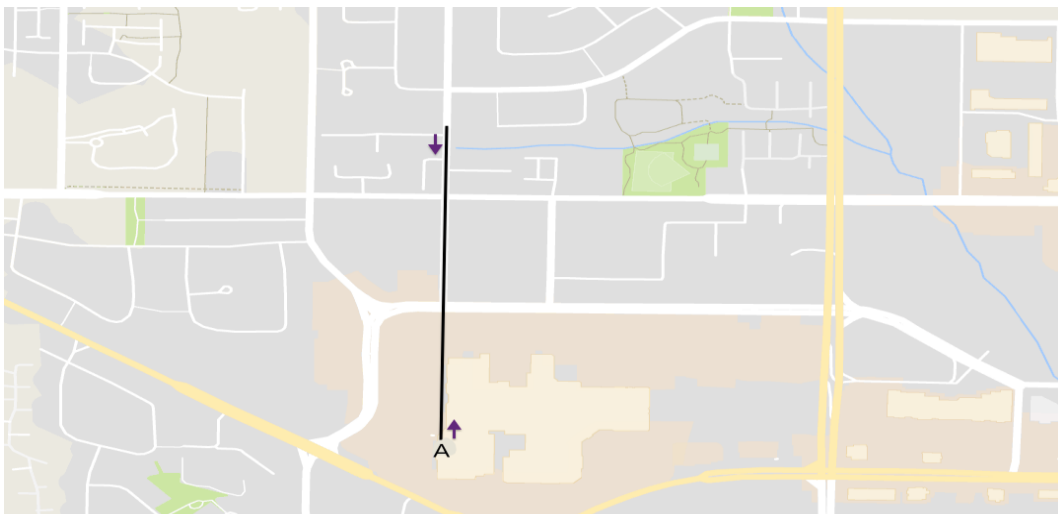


Figure 5.5. DFC05 Neighbourhood Map.

A) A common destination for the participant. A local café that served as an outing and source of socialization. They engaged in this activity either independently or with their spouse.

a. “If it’s straight I know where to go” – DFC05. This individual recounted how they recently had an incident where they got lost on a curve in the road because they were no longer able to see where they came from or where they were going. However, they were confident that when they are on a straight stretch of road that becoming lost would not be an issue. Their favourite destination and many other community services in their neighbourhood were accessible through using primarily straight roads.

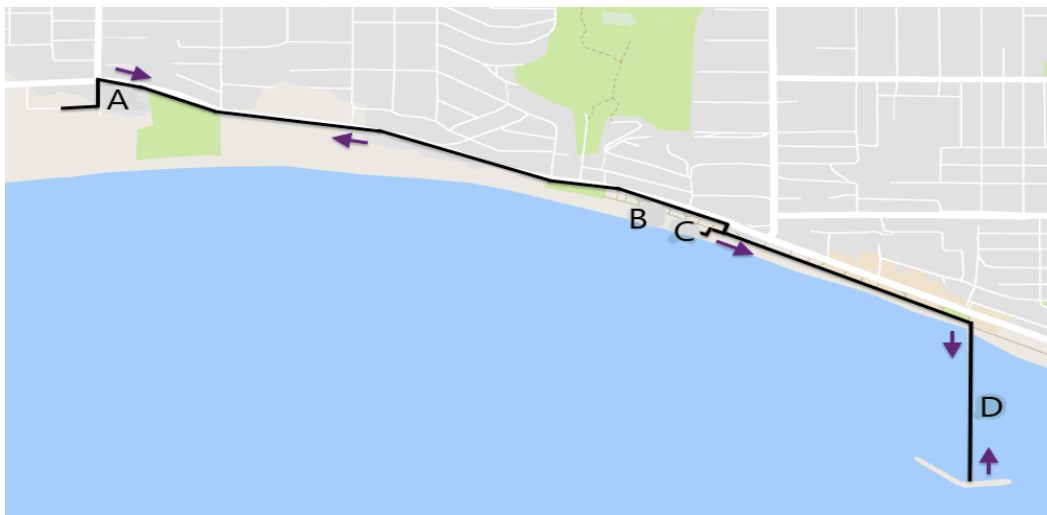


Figure 5.6. DFC06 Neighbourhood Map.

A) A forest pathway. The participant indicated this was significant to them because it brought back fond memories. They used to love hiking but they were unable to go for a hike independently anymore.

B) Railroad tracks that acted as a landmark for the participant. The tracks also helped with the participant’s orientation.

C) DFC06's favourite bench/resting place. They often sat here to listen to the ocean while on walks with friends.

D) A preferred destination for DFC06 because of the views.

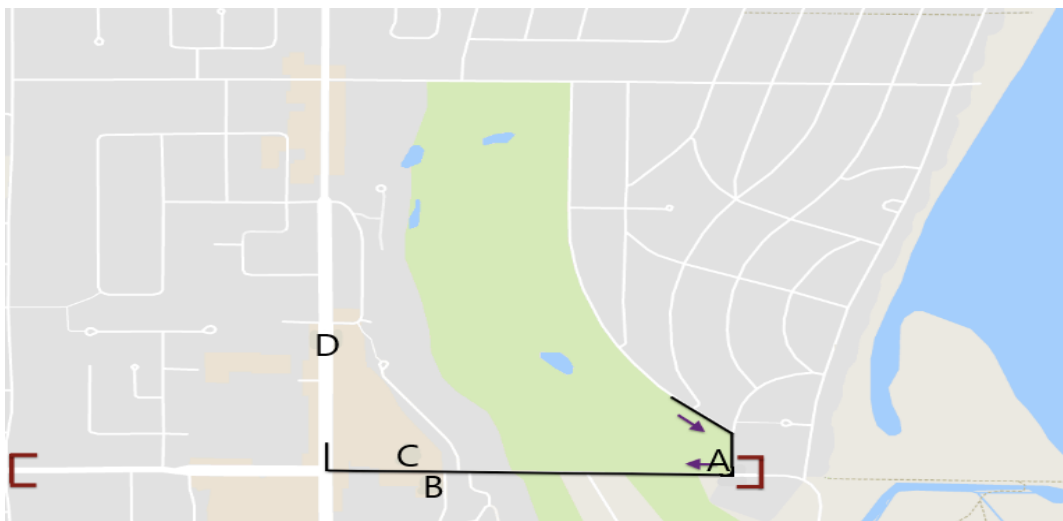


Figure 5.7. DFC07 Neighbourhood Map.

[Red brackets represent the participant's "comfort zone"]

A) A new zebra crosswalk near the participant's home. It significantly increased their feeling of safety when using this road.

B) A favourite destination for the participant. They had lived in the neighbourhood a long time and knew the people there well (staff and other customers).

C) Another favourite destination for the participant. They had lived in the neighbourhood a long time and knew the people there well (staff and other customers).

D) The mall - the most common destination for the participant. Served as both a social outing and a destination that provided access to a variety of services. It was

within walking distance of the participant's home. They primarily used walking or an electric bike as their preferred method of transportation to this location.

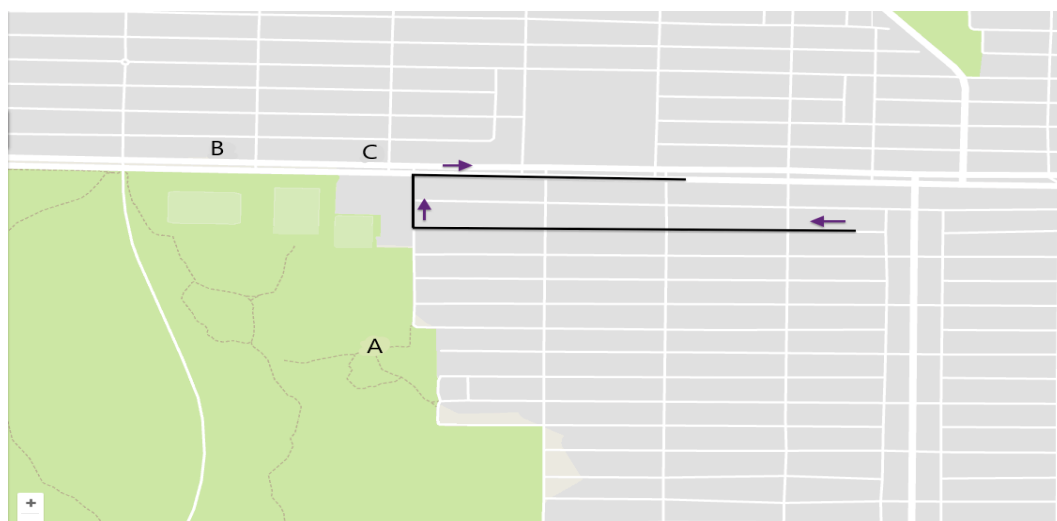


Figure 5.8. DFC08 Neighbourhood Map.

A) A park. Identified as a significant destination for DFC08 because they had always been an outdoorsy person. They valued the ability to access this park in their own neighbourhood.

B) Bike lanes that the participant used on a regular basis. Their presence allowed the participant to feel safe while using biking as a form of transportation.

C) The strip along which many of DFC08's local shops and services were located. All of their regular destinations were within walking distance of their home.

5.3. Study Findings

The remainder of this chapter presents the key themes and subthemes identified through an analysis of the data obtained in this study. The themes *Leaving the Comfort Zone*, *Safety*, *Changing Skills and Adaptation*, and *Losing Their License* are representative of the challenges that people with early-stage dementia face to their mobility and participation. The themes *Pedestrian-Friendly Features*, *Wayfinding*, *Destinations*, and *Other People* speak to the role of the environment on participant mobility and community participation. Finally, the themes of *Maintenance in a Time of Loss*, *Freedom*, and *Sense of Normalcy* are representative of what mobility and community participation mean to persons with dementia. Themes are supported by quotes from interviews, statistical frequencies from ACT-OUT surveys, and field note excerpts. The findings are representative of the relationship between the individual, the built environment, mobility, community participation, and quality of life as presented in the conceptual framework (Figure 3.1).

5.3.1. Challenges and Changes to Mobility and Participation

People with dementia generally emphasize that they value the ability to remain independent, mobile, and active in their communities as long as possible (Brittain et al., 2010; Brorsson et al., 2014; Ohman & Nygard, 2005; Phinney, Chaudhury & O'Connor, 2007). Participants in this study echoed this but suggested that as they have aged and experienced the onset of dementia they have noticed changes in their mobility and participation patterns. As new challenges arose during the progression of their illness they had to learn to adapt along the way. This section will present an overview of the most commonly reported challenges for people with dementia in being mobile and active

participants in their neighbourhoods. Challenges included: leaving the comfort zone, safety, changing skills, and losing their license.

5.3.1.1. Leaving the Comfort Zone

75% of participants had lived in their current neighbourhoods since before their diagnosis of dementia. Many of them had lived in the same home for most of their adult lives. As a result, they were very familiar with their neighbourhood spaces and felt comfortable using them independently. Their comfort zones extended to the immediate neighbourhoods of their homes to include their regularly visited destinations. This typically encompassed an area of several city blocks. One participant specifically spoke of how their comfort zone extended approximately two kilometres around their home (refer to Figure 5.7). For participants who used public transportation their comfort zone expanded to include the familiar places they could reach using the transit system.

Participants had a routine in place within these spaces that dictated where they went, when they decided to go, and how they got there. As one participant put it:

Paul: I'm pretty regular, you know. I go the same way um, I have breakfast the same.

Researcher: So you're in your routine?

Paul: Yeah.

When observed practicing this routine, it was evident that participants moved through their neighbourhood with confidence and had extensive knowledge of its environmental features. Below is a brief excerpt from an interview where the participant demonstrated a high level of knowledge about their neighbourhood as we passed through it:

Eva: So if we keep walking that way we'll go up to [street name] and then we'll turn back and over this way is a swimming pool.

Researcher: Oh nice, ok. So are there shops and stuff around here or is it mostly residential?

Eva: Um, it's mostly residential but if you, when you go to [street name] if you go to that you go into [street name] and then you've got all the shops and there's pretty much everything you could ask for.

Familiarity with their surroundings made them feel supported and at ease in their neighbourhoods. Accompanied by the feeling of comfort established through their routine, this familiarity made it easier for them to engage in their community and move through its spaces. The spouse of one participant spoke of the appreciation they had for their familiarity with their neighbourhood in the following quote:

Caregiver: Well part of the reason we live here is because, well first of all we've been here 30 years. We're familiar with the place, it's easier. We've got a bit of a village set up here. We're close to the parks, the ocean, I mean it's ideal. We're fortunate to live here and we're fortunate we got here 30 years ago.

Wayne: Yeah.

Many participants suggested that their level of comfort when using community spaces independently depended on their familiarity with the area. Feeling that they knew what to expect when they left home promoted their ability to come and go freely. A detailed understanding of their environment based on familiarity allowed them to visualize their walking routes and major destinations ahead of time. Before their diagnosis, participants became familiar with their communities by driving through them. Afterwards, they continued to enhance their familiarity with the environment by walking through these spaces and learning about the smaller, more nuanced details. If presented with a challenge in their own neighbourhood that may act as a barrier to their mobility or

participation in unfamiliar spaces (e.g., unmaintained sidewalks), participants indicated that it was their familiarity with the area that helped them overcome it. The following excerpts from three interviews speak to the feelings of comfort and confidence that participants experienced in their familiar neighbourhoods:

Here I'm just used to [the physical environment]. It's quiet here. Neighbourhood is good. (*Sue*)

Researcher: Do you think that the environment [plays] a big role in helping you get out?

Eva: Yeah in here it does. Like, the immediate area from here to the mall I'm great.

Researcher: So since you've started experiencing memory loss have you noticed a change in how you find your way around your neighbourhood?

Keith: Not my neighbourhood, no.

Caregiver: But if you went somewhere new it would be very daunting.

Even as participants noticed the symptoms of their disease having a more pronounced effect on their daily lives, they still spoke of feeling safe while independently moving through their comfort zones:

Every day I walk up this way and back down and all. It's more complicated than it was but I never feel unsafe, ever. (*Keith*)

I feel comfortable you know, going back and forth along here. (*Peter*)

Factors defining the comfort zones extended beyond features of the physical environment and included aspects of the social environment. Community members including family, friends, service providers, and neighbours contributed to the feeling of comfort for the

participants. Having a history of interaction with and/or knowledge of the people at particular locations or sensing that strangers in their area were friendly and welcoming made participants feel at ease. Below, two participants explain how both strangers and service providers contribute to establishing a feeling of comfort when they utilize community spaces:

- Researcher: So when you're out places how do you find your way?
- Sue: I normally know the way to go. If I'm in a strange place I usually don't go.
- Researcher: Oh ok, so you stick to the familiar places?
- Sue: Yeah, yeah. I go anywhere here. Here is quite safe. You don't know the way, you ask people they tell you.
- Researcher: So why do you go to that particular pharmacy?
- Peter: It was good service and uh, we had a situation where I had forgotten and had to call [location] to get a prescription and they were helpful.
- Researcher: Oh good.
- Peter: Service makes a big difference.

The social environment was a key component of the attachment participants felt to certain locations in their neighbourhood. It was what made these places memorable and enjoyable, as exemplified by one participant who said:

- Peter: It's quite a ways, but I have a friend who comes and picks me up and we go to the coffee shop.
- Researcher: Oh that's great.
- Peter: And you know, the coffee shop owner knows me by name. It makes it a good place.

Participants who had recently moved to a new area were still figuring out their comfort zones. They indicated that as their familiarity with the neighbourhood grew, the more comfortable they became moving through it. Construction, new developments, or the need to switch service providers were features perceived as disrupting a participant's familiarity with their neighbourhood:

- Researcher: Do you find that there are landmarks that you use to get around?
- Wayne: Uh, I guess.
- Researcher: Yeah? Are there any that stand out to you?
- [...]
- Caregiver: Yeah, it's not even worth pointing that out around here [because the landscape is always changing].
- Researcher: Yeah? Are there lots of new developments around here?
- Wayne: Well, houses.
- Caregiver: There are so many new and under construction around here.
- Wayne: Like that [points to house under construction].
- Researcher: How well do you know the doctor's office?
- Keith: Uh, originally very well. But now we, I have a new spade of medical, you know.

Participants also reported limiting the activities they participated in to those that they were comfortable with as their illness progressed.

5.3.1.2. Safety

Safety in the community was a prevalent concern for participants with dementia and their caregivers. Participants reported that they avoided going to strange or unfamiliar places on their own over concerns for their safety. Feeling unsafe on their own outside of their established comfort zone greatly limited their independent mobility and participation because they became confined to the borders they set for themselves. The most common safety concerns included traffic, having a fall, and getting lost. Of these, the biggest concern for participants was the traffic in their neighbourhood. The following excerpts are from interviews where participants expressed concern over the traffic in the area:

And it's bothersome to have the traffic, you know. It's uh, a lot of dangerous situations going up and down the street. (*Keith*)

Researcher: So how do you make yourself feel safe?

Sue: Just use your common sense. And watch the traffic.

Researcher: Are you careful of anything when you're out walking?

Peter: Pedestrians. And traffic, right at uh ... well it was at night and I was walking my mother-in-law, the light turned green so we walked and somebody came tearing around and I had to yell. She almost hit my mother-in-law.

Researcher: Wow, that's scary.

Peter: And then we did everything we could but we were at risk.

I've gone that way and I've gone down to [location]. Um, it's not my favourite because there's a lot more traffic a lot closer to you than if you go to the other side of [street name]. (*Eva*)

Participants defined traffic as including both cars and other pedestrians, stating that they were concerned about traffic nearly 35% of the time while they were out. Excessive traffic made the neighbourhood seem loud and busy. It was over stimulating for those who felt

they needed to actively focus their attention on the traffic, thus distracting them from other environmental factors. Further, these individuals felt that the noise and overcrowding could be frightening, overwhelming, and even anxiety provoking in some cases with 37.5% of participants feeling concerned that they could become stressed while out.

The primary safety concern stemming from heavy traffic was crossing intersections safely (Figure 5.9). The cognitive demand required when taking into account the multiple happenings at an intersection along with the threat of drivers who do not pay attention were the primary things that contributed to this concern. More than half of participants felt that they had become increasingly cautious since the onset of their disease, with 25% stating that they were uncomfortable with risk taking. When interviewing participants who opted to have a caregiver join the walk it was noted that they were noticeably more cautious than their caregivers when crossing the road. Further on this point, a few participants stated that without someone to accompany them they might be discouraged from travelling to areas with heavy traffic. Interestingly, despite these concerns participants felt that the traffic in their immediate neighbourhood was manageable. As they ventured out further into the community they became more concerned with traffic levels.



Figure 5.9. Busy Intersection. Participants expressed safety concerns at busy intersections such as the one pictured above. This intersection was viewed as being “a nightmare” by the participant. They spoke of the need to practice extreme caution while in this space. As a result, they often felt anxious and overwhelmed when crossing this street.

Traffic was also a safety concern for those who rode their bikes in the neighbourhood, particularly in the presence of buses. In order to feel safe while cycling participants used bike lanes and only biked in quiet areas. These participants indicated that they felt safer in protected and buffered bike lanes where they were clearly separated from vehicles and given more space to ride.

Another prevalent safety concern was a fear of falling, with 25% of respondents indicating that doing so concerned them and 50% stating that they had tripped or fallen recently. Participants identified curbs, curb cuts, obstructions or cracks in the sidewalk, rocks, loose sticks, uneven pathways, and sudden changes in surface level as points of



Figure 5.10. Falling Concerns. Sudden changes in surface height, such as a curb or steep sidewalk edge, were identified as points of concern for falling.

Getting lost was also a concern for participants and their caregivers, with 37.5% of participants stating that they were concerned about becoming lost and 62.5% indicating that they had become lost in the past. Caregivers said that they worried about the person with dementia wandering or getting lost if out on their own in the community. Persons with dementia most often identified getting lost on public transportation as a concern. They felt that knowing which buses to get on, where to get off, and how to transfer were the most prevalent issues. There was also apprehension about getting lost in busy places like malls or transportation centres. Having someone to check in or accompany them when they

travel to these destinations was important in ensuring their safety. Other safety concerns cited by participants included: walking at night, animals in the neighbourhood, crowded public spaces, keeping their balance when performing physical activities, and driving if they still had their license. The below are brief interview excerpts that speak to some of these concerns:

- Researcher: Do you ever go out at night?
- Sue: Nope, nope.
- Researcher: So why is that?
- Sue: Just night time I should be in. My family won't let me go. They won't let me go out all by myself. I won't go for the safety.
- Researcher: So what other ways have you seen changes in your mobility since you started experiencing your illness?
- Eva: Well I'm not as good with stairs. Um, I'm ok if I can stand and hold a railing on a side, then I can go up and down – then I can go up alright, coming down I'm slow. Like I've gone on SkyTrain with my daughter and she always makes sure to stay behind so that somebody in a hurry isn't going to bump me because even if I'm holding on tight enough I'll fall.
- Researcher: When you're driving is there anything you find more challenging than you used to?
- Wayne: Yeah, I'm looking.
- Researcher: You're more aware? Cautious?
- Wayne: Yeah I am.

Participants indicated that they valued feeling safe in their neighbourhood. A number of them suggested they were less comfortable taking risks now that they were

experiencing dementia. As a result, they will not go places if they think it might make them uncomfortable or if it could be unsafe. Participants said they felt safe when they were familiar with or 'used to' the area and the people within it, when they felt comfortable asking the people in their neighbourhood for help, when the community was quiet, and when traffic lights and crosswalks were available.

5.3.1.3. Changing Skills and Adaptation

Participants reported facing new challenges to their mobility and community participation since the onset of dementia. They spoke of slowing down physically and cognitively, contributing these changes to both their aging bodies and the symptoms of their disease. These changes presented a significant challenge to their ability to continue performing tasks that required complicated cognitive processes, like banking or driving. Participants cited the speed required to perform these tasks, overstimulation from noise and crowds that increased their anxiety, and the growing difficulty they experienced when following a conversation as factors that contributed to this. Respondents also spoke of how it was harder for them to communicate with service providers and manage their appointments because of the onset of their disease. To address this, they began to bring others to their appointments with them. They also began to rely on family or friends to help them perform difficult tasks, as mentioned in the following excerpts:

Researcher: Why does your wife go with you [to the doctor]?

Peter: Because she'd rather not sit in the car while I do it. Most times if a question comes up she's better at answering the question than I am ... [and] as far as effects [of Alzheimer's] I have problems with times and appointments.

I usually go with [him to his appointments] just so, you know, if there's answers Keith can't answer, somebody can. (*Caregiver*)

Researcher: So you used to go to the bank more in the past you'd say?

Keith: Uh, we do banking, [wife] does banking. We go together, and sometimes uh, you know, I make a gaff. Not like anything too bad, but it tells me 'why'd I do this?' you know. So I say, 'here, [wife], you do it.'

Caregiver: Of course, the big challenges are the banking. The important stuff. The day to day stuff is not a problem, it's the other stuff that's a problem, so. You know, the investments, the banking. He'll tend to do what's the easiest. And maybe walk away if he can't deal with it.

Wayne: Yes.

Participants expressed sadness at the loss of their ability to perform tasks independently, as shown in the following quotes:

Researcher: Is there anything else you'd like to add?

Diane: I don't know, I'm just kind of sad.

Researcher: Why?

Diane: Because I'm going downhill.

I wanna be able to go places where I don't have to have a babysitter ... [it's difficult to] go from [being] able to go anywhere or everywhere to having to have help all the time. (*Eva*)

Although day to day tasks were largely manageable for the participants they spoke of slowly noticing changes that affected their daily functioning. They reported being less adventurous and more selective about the tasks they chose to take on. They began to

step away from more challenging responsibilities and devoted themselves to carrying out simpler ones. They also adjusted the speed at which they performed these tasks, slowing them down to make them more manageable. Changes that affected their day to day use of neighbourhood spaces included: physical limitations that restricted the distance they could walk; increasing difficulties with balance which affected their mobility; trouble navigating through unfamiliar public spaces and following directions; increasing anxiety in busy spaces; decreased spatial awareness; and the need for enhanced focus when reading.

Participants reported that it was especially difficult to adjust to their changing skills when they were also facing the stigma surrounding dementia. They worried that as soon as others found out they had dementia the people in their life would begin to think that they are incapable of performing tasks independently. One participant spoke of a time they heard a loved one expressing this stigma:

We went there shortly after I was diagnosed and [my sister-in-law] started telling [her husband] about how [a person with dementia] was cuckoo in the head now. And I just got up and walked out of the room. (*Eva*)

As a result of this stigma they became more selective about the people they surrounded themselves with and with whom they shared their diagnosis. Ensuring they were only surrounded by those they trust was especially important to participants who were embarrassed by the symptoms of their disease. The below are interview excerpts from two participants who spoke of their view on sharing their diagnosis with others:

I only have chosen friends because yeah, it's an embarrassing disease. So the people I trust, it has to be the people I trust, or kind of uh, I've known them for a long time. (*Kathy*)

Researcher: Are you comfortable letting people know your diagnosis?

Diane: Um, not really. I don't want to be treated differently.

Participants felt that in order to address the stigma associated with dementia it is essential for people in the community to be educated about the disease and its symptoms. This way, community members can help people with dementia adjust to their changing skillset by learning communication and support techniques that promote their independence in the community for as long as possible.

Despite their changing skillsets participants proved to be innovative and adaptable by adjusting their needs, how they utilize services, and how they define their mobility and participation in order to continue as active members of their community. Most participants put a positive spin on their diagnosis by viewing it as a learning opportunity. For example, those who had previously refused to take public transit learned how to take the bus in their neighbourhood. Others reported that they had learned how to ride a bike or how to walk to a specific destination. Some people actively sought out the opportunity to learn new things, such as by attending lectures that taught them new ways to manage their memory. Although some participants were less eager to learn new things than others the majority suggested that they were willing to try to acquire new skills. However, they would sometimes face barriers in doing so. The most common example was that concerns for their safety from family or friends would keep them from learning about or continuing to use public transportation. The below quotes speak to this concern:

Researcher: So do you ever take public transit then?

Eva: I haven't because again, [my family doesn't] want me to.

Researcher: Oh ok.

Eva: They're afraid, like if I can't get around here, how am I gonna know what buses and stuff to get on?

Oh yeah, the bus. Yeah, yeah, yeah. The one thing I had to give up, you know [for safety concerns]. (*Keith*)

Researcher: Do you take the SkyTrain ever?

Wayne: Yeah, not alone.

Researcher: Is it too hard to do alone do you think?

Caregiver: Well, I think it's becoming that.

The interviews and observations from data collection revealed that there were a number of ways that participants learned to cope with their changing skills. The remainder of this section will list the key adaptations that participants made to help them stay mobile and active in their communities. First, all participants began or enhanced their use of other modes of transportation to adjust to the fact that they were no longer driving or were driving less. Second, they learned to adjust their habits slowly over time while participating in community spaces. For example, if a participant found it tiresome to walk they would keep their walks short or utilize benches along the way to take a break. They also began to spend more time in familiar spaces and chose to go places during quieter periods of the day.

Over time, making these small changes allowed them to learn how to use the built and social environments to compensate for declines in their skillset. Some participants also made significant life changes in order to adapt. For example, 37.5% of the sample decided to move in order to live in a more supportive community. A few participants did not identify the neighbourhood built environment as a barrier to them. However, it was observed that they had adjusted their behaviours and used their familiarity with the neighbourhood to adapt to the objective challenges presented by the built environment, such as a lack of well-maintained sidewalks. The below are field note excerpts in which

participants demonstrated a level of adaptation to their environment by using their familiarity with the area to their advantage:

Diane took small, deliberate steps during our walk. She was observed touching things along the way, seemingly helping her concentrate on and interpret her environment. After touching things or making note of a nearby landmark, it was observed that her posture would straighten, or she would look forward as if she was experiencing a moment of confidence about where the route would take her. This was a new area for the participant as she moved there for more support after the onset of her disease. Despite this, she seemed familiar with the challenges (or lack thereof) that the environment could present to her. As we came towards a worn sidewalk she confidently declared that the cracks that were coming up in this section were not a tripping concern for her. This was despite the conversation by the participant and her caregiver earlier that Diane's gait had changed and made her more cautious when walking.

Kathy demonstrated a keen awareness of her surroundings throughout our walk, despite the fact that she had experienced some declines in her vision since the onset of dementia. As we moved through her neighbourhood, she spoke of the things we would soon be approaching long before we arrived. She relayed this information with confidence even when questioned on it further. She knew when there were curbs or raised edges we would need to step over, how far it was until we reached the train tracks that would allow us to access her chosen destination, and when we were approaching obstacles in the middle of the sidewalk (i.e., a fire hydrant and pole that were oddly placed there). She attributed her impressive ability to navigate her neighbourhood despite the challenges she was facing to her familiarity with it after having lived in the area for most of her adult life. As we moved through these spaces, Kathy maintained an upright posture, moved quickly, and looked straight ahead with confidence.

Other adaptations included changing their behaviours or routines. For example, some participants took their daily walks indoors when it rained. Meanwhile, other participants changed the clothing they wore in order to continue participating outdoors when the weather was uncooperative. They were also more selective about the things they did, when they did them, and who they did them with. As much as they tried to maintain their activity levels from before their diagnosis participants recognized the need to scale back as necessary or to try new activities that they may have refused before. Participants also adapted their behaviour by using previously obtained knowledge to

benefit them in the present. For example, two participants said they were unconcerned about falling because their athleticism from their youth helped them learn balance and how to fall. Overall, the data reveals that the people living with dementia in this study learned how to adapt to their surroundings and to adjust their behaviour to perform daily tasks.

Another method of adaptation used by participants was incorporating technology into their lives. This helped them perform activities they could no longer conduct on their own or made them feel safe. For example, setting up automatic payments for their bills and taxes helped ease some of the anxiety or frustration participants experienced when trying to perform these tasks after the onset of dementia. 75% of participants indicated that reading had become increasingly challenging for them as their illness progressed. Audio books were a common way to adjust to this challenge. This way, they could continue using their library and participate in a recreational activity they had always enjoyed. A few participants used applications on their phones, sometimes with the help of a caregiver, to conduct daily activities or to help them remember things. Others used their phone as a safety blanket when out in the community on their own. For instance, two participants stated:

Researcher: So you'd say now you're a little bit concerned [about losing your way] because you got lost recently?

Paul: Mhm. It never happened before. I have uh, well on both [our] phones, uh, find your friend [which helps].

Researcher: So do you just, when you take your bike out do you just go to places you're familiar with?

Keith: Oh yeah. I don't, I tried that before and I, it, I never really had an episode of getting lost. Maybe a little bit at the beginning?

Caregiver: The odd time, but we're in familiar places now.

Keith: My phone.

Caregiver: But if you went somewhere new it would be daunting.

Keith: But I've got my phone.

There was comfort in the idea that if they ever got lost others could use the 'Find Your Phone' app to locate them. Or, they could give someone a call for help.

Each participant also had a support network that helped them cope with the new challenges they were facing. Family, friends, service providers, and other community members helped participants manage in unfamiliar areas or while using demanding services. For example, one participant relied on extra assistance from staff at the airport to continue taking their annual trip to visit a friend. It was important for participants to live with or close to their support network for assistance with daily activities. At times participants adapted by having other people, usually their spouse, take over the tasks that they began to find too challenging. For example, one participant spoke of passing the banking responsibilities to their spouse:

Researcher: You used to do all the banking together?

Keith: Well [wife and I] would, we'd normally go for a walk up the hill and then [wife] goes into [bank] or whatever it is. And she does it. I've stepped back from it because I don't particularly care about it.

When using services in their community, participants valued the opportunity to go to places that were designed to be accessible for people with dementia. A desire to use accessible services meant that they began to alter the services and programs that they consumed. Examples included: physical activity programs that were slower and helped with balance; library programs that were accessible to those who struggled with reading;

and support groups that allowed them to socialize with others experiencing similar challenges. Other methods of accessing accessible services included changing to locations that were closer to their home or having the services come to them.

5.3.1.4. Losing Their License

Adjusting to the need for alternative forms of transportation was a significant challenge for participants after losing their license. Driving represented independence, freedom, and mobility. Losing their license meant the loss of a role and responsibility that they had always known, along with the need to begin relying more on others. In order to practice their independence, participants had to either return to forms of transportation they used in their youth or begin learning how to use new ones. Participants indicated that they began or enhanced their use of alternative transportation options after losing their license, including: walking, rides from family or friends, public transportation, bike riding, private shuttles, and taxis. When asked to speak about their experience going to various places in their communities participants indicated that they rely on rides from friends or family nearly 44% of the time, walking over 31% of the time, multiple sources of transportation (most often a combination of walking or taking the bus and rides from friends or family) nearly 16% of the time, driving themselves just over 6% of the time, and taking the bus over 3% of the time. Regardless of the type of transportation the participant primarily chose, many felt more limited to their immediate neighbourhoods after the onset of their disease. For example, when asked if they had noticed any changes since they were diagnosed with dementia one participant responded:

Yeah, I'm a lot less adventuresome. I don't walk, you know I used to walk or bicycle far distances and uh, I haven't been ... This pace is, ten years ago this

would have been ludicrous ... And you know, the distance you can go to do something changes. You know, this is maximum distance [a few blocks from his home]. (*Participant DFC03*)

While all participants used many different transportation options to get around their community there was one that stood out amongst the rest for each person. Four participants said walking became their preferred source of transportation, while public transportation and relying on friends or family for rides had two participants each, respectively. One participant in the sample continued to drive but indicated that they had cut back significantly, were more cautious, and only drove in familiar areas.

Walking was a noteworthy method of transportation for all participants and had become a part of their daily routine. For example, when asked how often one participant went for walks they responded:

Diane: Every day.

Researcher: Oh that's great. Do you want to continue doing that?

Diane: Mhm.

Overall, participants felt that walking was good for their health, good for the community, and good for the environment. It was viewed as an affordable, healthy, and manageable way to get around:

I used to hate to walk because when you drive you always drive, you don't like to walk. But once I stopped driving I started to learn to walk and I started to learn where to go. It's better for me. Force me to do exercise, otherwise you stay home sitting. People pay the money to do exercise. I save money to walk. (*Sue*)

While there were common threads regarding how walking was viewed by participants, the practice of this activity varied depending on the person. While for some walking had always

been a source of transportation, others only began walking after losing their license. 75% of participants were comfortable walking alone while 25% refused to walk unless someone else accompanied them. A few participants liked walking for the exercise, a few liked it because of its affordability as a method of transportation, and others because they could do so independently. The reasons behind using walking as a source of transportation included: to access services, to exercise, to be active participants in their community, and to socialize. The following excerpts speak to each of these:

I have walked all the way over to [town name] on the far side where um, and I can't remember the name of it, um, it's a little village that's over there. Well I've walked to there. And there's, if you go a litter further than that you get to Walmart and BestBuy and lumberyards and all that stuff. (*Eva*)

Paul: Well when I first got diagnosed I um, couldn't drive, so I walked. I did two 36 kilometer walks different times. I did the Grouse Grind, I did um about uh, five or six half marathons.

Researcher: Oh that's great. Wow.

Paul: But I uh, I OD'd [laughs]. I'm back, getting back to walking a lot.

Researcher: Yeah? That's good. I love walking.

Paul: I do too.

Researcher: How do you get [to the mall]?

Keith: I walk. For the sake of walking.

Researcher: So you have people that take you out places as well?

Kathy: They take me for a walk. I have friends who visit me, well mostly for a walk. I have [friend] who doesn't like to walk so we only go for a short walk ... [walking for this interview] is such a treat. I love to walk.

It was also seen as a good way to familiarize themselves with their neighbourhood because its slow pace granted them the opportunity to observe and understand the nuances of the environment in a way that other forms of transportation would not allow. Participants suggested that they would ideally like to live in a neighbourhood where most destinations are walkable and the community is pedestrian-friendly. One participant felt that they lived in a neighbourhood like this:

Researcher: Yeah, based on the other places I've seen this is kind of, this is the goal for a lot of people to live in a neighbourhood like this.

Wayne: Yeah, you can [walk] over there, you can go over here and.

As an alternative to walking, participants would sometimes cycle to their destinations. The appeal of cycling was that it was faster than walking and was still an independent activity that involved exercise. Thus, bike lanes were also seen by some participants as an important feature in dementia-friendly communities.

Despite adapting to losing their license over time, participants still reported challenges to their mobility and community participation as a result of no longer driving. For example, it became difficult for some participants to arrange transportation to the community services they used. They reported feeling that they were dealing with a fragmented system where services are delivered in bits and pieces, which made it challenging to find services that addressed their complete needs in one location. Thus, they were required to regularly arrange transportation to a number of different areas in their community. Public transportation was seen by half of the participants in this study as too challenging to use on their own, consequently limiting their transportation options. Participants who experienced physical limitations that affected their ability to walk far

distances also experienced limited transportation options. Taxis were viewed as being an unaffordable option for participants if they needed to use them regularly. Safety concerns with cycling prevented many individuals from using this form of transportation to access services. Rides from family or friends were an option for all participants, but some reported frustration at the idea of having to depend on their loved ones to get to their destination. Encouraging the places in the community where people with dementia regularly go (e.g., the grocery store, the pharmacy) to offer a shuttle service that can transport individuals between their homes and their destination could help alleviate some of these challenges. An affordable, community-based driving service that could get people with dementia where they need to go is another potential solution to this problem.

Not only were there practical challenges to losing their license but there were also psychological challenges associated with this change. The need to rely on and trust others for their transportation needs was a difficult adjustment for some. It was particularly difficult if they used to do all the driving before their diagnosis or if they felt they had no control in their decision to stop driving. Two participants spoke of the upsetting experiences they had when their license was removed:

I haven't driven for over three years ... I had gone to [the doctor and had my license removed]. I mean I figure she was cruel, my daughter said she was just doing her job. But she said I don't see how you could be driving, and you're gonna have an accident, and you're gonna do this and you're gonna do that. And then I left. So about a month and a half later my family doctor calls me ... and she said this doctor had sent the forms in and that I couldn't drive ... and she said um, she had to send it in. And I said yeah I understand that. And I walked out of her office and I started to cry and I cried all the way home ... and then I had to go for a driver's test. Well I had gone to Young Drivers of Canada and had done driving with the guy and he said there's nothing wrong with your driving. But by the time I went for my license all I could hear was 'you can't drive, you shouldn't be driving' and I failed the test. And the woman says well you can come back. And I said nope, there's no way. This isn't worth it, I haven't slept in three days and it's not worth it. (Eva)

So I basically failed [the cognitive tests]. There was a senior doctor [at the hospital] and he said 'you didn't do very well on the tests'. So, um, so then when I was um, they were doing, I didn't know that someone was writing this all down. So uh, um, so um, oh yeah. Then, then um, they asked if we'd be okay to get a psychiatrist. We said whatever it takes we'll do it. And so um, what happened after that, they died me, diagnosed me for Alzheimer's ... So that Friday I lost [my license] ... it was [a hard adjustment] because I drove all the time. (*Paul*)

Participants indicated that they missed the flexibility and independence that driving provided. However, the data from this study suggests that having the right options in place; such as destinations within walking distance of their home, pedestrian and cycle-friendly features in their environment, and accessible public transportation; could make the adjustment to losing their license significantly easier. Failing to incorporate these transportation options into the community has the potential to significantly disrupt a person with dementia's life. For example, one participant from this sample had to relocate to another community after his license was removed because alternative forms of transportation were not accessible where they previously lived. This is not an ideal situation as uprooting and leaving a well-known neighbourhood is particularly challenging for people with dementia as they tend to rely heavily on their familiarity with the environment to continue independently using these spaces.

5.3.2. Role of the Environment on Mobility and Participation

Research suggests that the built and social environment have the potential to support people with dementia by making them feel safe, allowing them to remain connected to their community and to other people, and providing them an avenue through which to practice their independence (Algase et al., 2010; Innes, Kelly & Discarsian, 2011; Mitchell & Burton, 2006, 2010). This study examined how the built and social environment

facilitate or hinder mobility and community participation for this population. The built and social environment features that this study found to be facilitators or barriers for mobility and participation of people with dementia included: pedestrian-friendly neighbourhood features such as sidewalks, seating options, ambience, public transportation, and crosswalks, among others; wayfinding features such as signage and maps, landmarks, contrast, simplicity and clarity, consistency, and straight street layouts; and destinations in proximity to their homes, density and mixed-land use, dementia-friendly destinations, and support from other people.

5.3.2.1. Pedestrian-Friendly Features

I used to live in [neighbourhood]. [Neighbourhood] was inconvenient. That time I was driving but I stopped my driving. I don't want things far away.
(Sue)

Nearly all participants in this study (87.5%) no longer drove a car. This is not unusual for people with dementia as many will end up losing their license or giving up driving as the disease progresses (Alzheimer Society of British Columbia, 2018). Thus, ensuring their neighbourhoods are pedestrian-friendly is essential to maintaining their independent mobility and community participation. All participants said they felt that the built environment played an important role in supporting or inhibiting their mobility and participation in their neighbourhoods. The remainder of this section will discuss the most important pedestrian-friendly built environment features as presented by participants. They include: sidewalks, seating options, ambience, public transportation, crosswalks, washroom access, and construction, among others.

Sidewalks.

Participants felt that the sidewalks in their neighbourhoods facilitated their mobility and community participation. Interestingly, sidewalks were considered essential features to promote their feeling of safety on busy streets and at demanding intersections. However, in the quieter residential streets near the homes of participants it was found that sidewalks were not required to enhance their feeling of safety. Instead they cited the low speeds of cars in comparison to main roads, how their familiarity with the street made them feel comfortable, and the pedestrian-oriented nature of these areas as what made them feel safe. For example, one participant lived in an area where there was a road with no sidewalk that served primarily as a pedestrian pathway near their home (Figure 5.11). They noted that while the presence of cars was possible, it was rare occurrence. When there were cars the drivers were aware that the area was pedestrian oriented so they drove slowly. Another participant lived in a residential area where there were no sidewalks available until they reached the main road. This area had been designated as low speed zone. Once the participant reached the main road, there were sidewalks available and accompanied by accessible built environment features such as crosswalks that audibly counted down for the pedestrian. While the participant did not express concern over the lack of sidewalks in their residential neighbourhood, they expressed appreciation for the sidewalk as a way to protect them from traffic on the busier street. When asked if their area was pedestrian-friendly this participant responded:

Very. The sidewalks, well there aren't uh, them around here but it's the uh, low speed zone. And uh, there's sidewalks right up to the mall and there's crosswalk signs with beepers on them so. There's everything. (*Keith*)



Figure 5.11. Pedestrian-oriented Pathway. Slow-moving traffic in this area made the participant feel safe despite the lack of sidewalks.

When sidewalks were available on only one side of the road it was observed that participants chose to cross to the side equipped with the sidewalk (Figure 5.12). Below are two field note excerpts detailing this observed behaviour from participants:

As we walked up the road I asked Sue whether she was concerned about the fact that sidewalks were only available on one side of the street. She replied that she was not and that they felt comfortable walking on the road. However, as soon as we arrived at the road in question she immediately crossed over to the side with the sidewalk. A car then came zooming by moments later. She chose to cross despite the fact that staying on the side of the road without the sidewalk would have been more convenient later on.

As we moved through Eva's neighbourhood it was observed that the suburban area she lived in consisted of many streets with sidewalks on only one side, if at all. As we walked we zig-zagged across various roads to access the sidewalks.

Overall, despite sidewalks only being observed immediately outside the homes of 37.5% of participants, all participants indicated that they felt safe in their residential neighbourhoods.



Figure 5.12. Sidewalks. When sidewalks were only on one side of the street it was observed that participants would cross in order to use them even if that was less convenient.

Generally, participants felt that the sidewalks in their neighbourhoods were well maintained. However, they were seen to present a barrier to mobility if there were raised cracks that became a falling hazard:

Researcher: You don't worry about tripping or anything in those areas?

Diane: Nope. There's a crack [points to ground].

Researcher: Yeah there's a crack there, yeah.

Diane: But it's flat. It doesn't really have an edge, so it's fine.

A few participants noted that their gait had changed since experiencing the onset of dementia. As a result they began taking smaller, more deliberate steps. If their attention was diverted from the walkway for a moment and if there was a crack or obstruction on the sidewalk, their gait change would increase the probability for a fall. Therefore, proper maintenance and installation of sidewalks is essential to facilitate safe mobility and support of community participation for people with dementia.

Ambience.

Feeling that their neighbourhoods had a quiet, friendly, familiar, and safe atmosphere encouraged participants to get out more. The following interview excerpts speak to this:

Researcher: You like the quiet?

Sue: Yeah. The quiet is easy to go everywhere. I'll go back down here [points in other direction], it's close for me. Not busy like [street name].

Researcher: So do you think the fact that you have these walkways and parks nearby that help you feel safe helps you get out more?

Diane: Mhm, mhm. Yes.

Keith: The guy that runs this place, he was our neighbour.

Researcher: Oh interesting.

Keith: So it was something.

Researcher: So is this kind of like a small community and you know the people here well?

Some participants indicated that they occasionally chose to participate in their communities by travelling to a particular destination because of its visual appeal. Once they arrived, they engaged with others in appreciating the experience or used it as an opportunity for self-reflection. For example, one participant detoured their walk-along interview to attend to a building in their area that had recently installed a green wall. The wall consisted of trees, shrubs, flowers, and other plants that attracted wildlife and onlookers alike (see Figure 5.13). Throughout the interview, he persisted:

I just want to show you that wall. I think it's fantastic. (*Peter*)

This suggests that creating a neighbourhood atmosphere that connects residents with nature, is calming and quiet, and consists of unique and memorable attractions may serve to naturally encourage participation in community spaces.



Figure 5.13. Aesthetic Features. This building wall drew the participant to this location regularly.

There was a mixed response from participants regarding the lighting in their neighbourhoods, particularly at night. While some felt that the lighting was sufficient, others felt that it discouraged their community participation after dark. This was cited as a safety concern, particularly for the one participant who still drove:

- Researcher: So do you find that you just go out during the day or do you go out at night as well?
- Caregiver: We rarely go out at night.
- Wayne: We don't really do that, no.
- Researcher: Is there a particular reason for that or?
- Caregiver: We don't drive at night. It's too much. The lighting isn't good enough. It's too hard to see well now.
- Wayne: Yeah, exactly.

To address this issue, participants simply chose not to go out at night or only went out in group situations. Some participants also felt that the lighting inside community destinations (e.g., the library) was inadequate and made it difficult for them to participate in these spaces.

Seating Options.

Half of the participants in this study felt that it was important to have adequate seating options in the neighbourhood. The remaining half said they never sit down while participating in their community spaces so it was not something they noticed. Those who valued seating options cited either the need to sit because of physical limitations or the desire to sit as a form of participation in the community (i.e., people watching). Two participants were observed sitting during the walk-along interview. One of these

participants sat down a total of three times. The below is a field note observation of one of the participants sitting during their interview:

Sue noticeably slowed as we continued our walk, tired from the distance we had gone. As we approached a bus stop she chose to sit to take a break. After a few minutes there, she was ready to walk back to her house. Walking through their neighbourhood it was noted that the area was primarily residential, thus places to sit were few and far between. She needed to be aware of how far she was walking and the seating options available so as not to exhaust herself.

Participants felt that there were adequate seating options in their neighbourhoods. They most often noticed and utilized benches at bus stops (Figure 5.14). Plentiful seating options were also observed in outdoor spaces designed to encourage walking (i.e., a pier or a hiking path). One participant who was already experiencing physical limitations as they aged indicated that while walking in their neighbourhood they needed to go indoors and use the benches in the mall in order to sit down:

Researcher: Do you ever use benches when you're out walking to take a break?

Peter: I have sat down before.

Researcher: Yeah? Do you find there's enough seating options?

Peter: There, where I go to the mall, you know, has seats. There's the library where we could stop at. Uh, there could be more benches.

It was a challenge to locate places to sit in the more residential areas of participant neighbourhoods. This may become more of a challenge for these individuals as they age, particularly if they live in a primarily residential area. The below consists of a quote from one participant who spoke of the need to have more seating options available as people age. Following that is a field note excerpt from an interview with a participant who

experienced physical challenges that made it difficult for them to walk distances in their neighbourhood:

Researcher: Do you ever find that you're needing seating options when you're walking?

Keith: Uh, yeah.

Researcher: Yeah? Do you think there's enough benches and stuff?

Keith: Uh, it's pretty good. They're pretty good ... You know you need [benches] as you age.

Peter slowed down as the walk progressed, noting how his back was acting up. He mentioned that he could only walk a few blocks because anything farther than that would be too hard on his back. He held his lower back near the end of our walk and as soon as we returned to his home he immediately sat down. After sitting for a while, he was ok to get back up. It seemed if he had enough seating options available during their walk there may have been the possibility for him to travel farther after a series of short breaks. This may also help limit the pain that he experiences while out walking in his neighbourhood.



Figure 5.14. Seating options. Participants most often noticed and utilized the seating options at bus stops.

Public Transportation.

In Metro Vancouver public transportation is overseen by TransLink, which operates a number of services throughout the region. These include: buses (including express lines and small community shuttles), rapid transit (the SkyTrain), HandyDART, and the SeaBus. 37.5% of people in this study utilized these services to independently access destinations beyond their immediate neighbourhood. These participants cited the route options, affordability, mode of transportation choices (i.e., bus or train), and safety as features of the transit system that they valued. Participants chose to take transit when their destination was beyond walking distance, to avoid parking and driving in downtown Vancouver, as an alternative to driving at night, and to bypass traffic. The bus was the most common mode of public transportation used primarily because of its proximity to the homes of participants. The frequency at which the buses ran was secondary reason, particularly for those who lived near an express line. When travelling from the suburbs to downtown Vancouver, SkyTrain was the preferred choice because it was perceived as the fastest method. Below are two interview excerpts where participants speak about their typical patterns of use of the transit system. Both of these participants regularly utilized public transportation in their neighbourhoods:

Sue: When I was working I was driving and didn't know how to take a bus. I hate to take a bus with bus stop.

Researcher: Did you find it easy to learn?

Sue: Yeah. After I don't drive then I learn to take a bus. I love to take bus. It's easy and economic, saves money.

Researcher: Yes absolutely, yeah that's good. So how often do you take the bus then?

Sue: It depends. Yes, I go out then I have to take a bus. If I go downtown, I have to take a bus. If I go to Chinatown I have to take a bus. Usually I will take bus at least 3 times a week.

Researcher: Oh okay, that's quite a bit.

Sue: Yeah.

Peter: We take the train to the airport.

Researcher: Yeah, you use buses more than the train though, right?

Peter: Yeah more opportunity. If I'm going downtown I take the rush train.

Researcher: Oh ok. Yeah. Is that faster?

Peter: I haven't been downtown in probably six months or so. But I like it. Even when I was driving it was easier to take the bus/train than driving I thought.

Of the 62.5% of participants who did not use public transit, more than two thirds suggested that they would be willing to learn. These participants expressed the desire to assert their independence through using public transportation, but also expressed concern over their ability to do so as the system currently exists. While I spoke to one participant's spouse about the best way to get back to Vancouver after our interview, the participant interjected:

Keith: I couldn't have the whole transit.

Researcher: You couldn't figure this out?

Keith: I have no idea ... The big thing for me is where to hop off.

Of the eight participants, four felt that it would be too complex for them to learn to use transit on their own. One individual who was independently using public transit at the time of the study also said that it was becoming too much of a challenge for them to continue much longer. The main concerns over using public transit included safety, crowds, feeling

rushed, and fear of getting lost. The following interview excerpts speak to some of these concerns:

- Researcher: Is overcrowding an issue on transit [in this area]?
- Wayne: It's uh, sometimes.
- Caregiver: From [location name].
- Wayne: Yeah.
- Caregiver: The [bus number], you can't even get on it. Especially in the mornings.
- Researcher: Yeah, yeah, I was on that this morning and it was pretty packed.
- Wayne: Yeah.
- Caregiver: You can walk to [location] in the time it would take before a bus would get here.
- [...]
- Researcher: So pretty much if the weather's good it's worth it [to walk or ride your bike] rather than get on a crowded bus?
- Caregiver: Yeah.
- Wayne: Mhm.

Like I've gone on SkyTrain with my daughter and she always makes sure to stay behind so that somebody in a hurry isn't going to bump me. (*Eva*)

Participants also emphasized how it would be challenging to decipher and remember all the information required to use public transit. Transit users need to know which bus to get on, where to get off, what route they need to take, how to transfer, how to read the schedule, and how to plan ahead to when the next train or bus arrives (Figure 5.15). This

has the potential to be an overwhelming amount of information to process for some people with dementia.

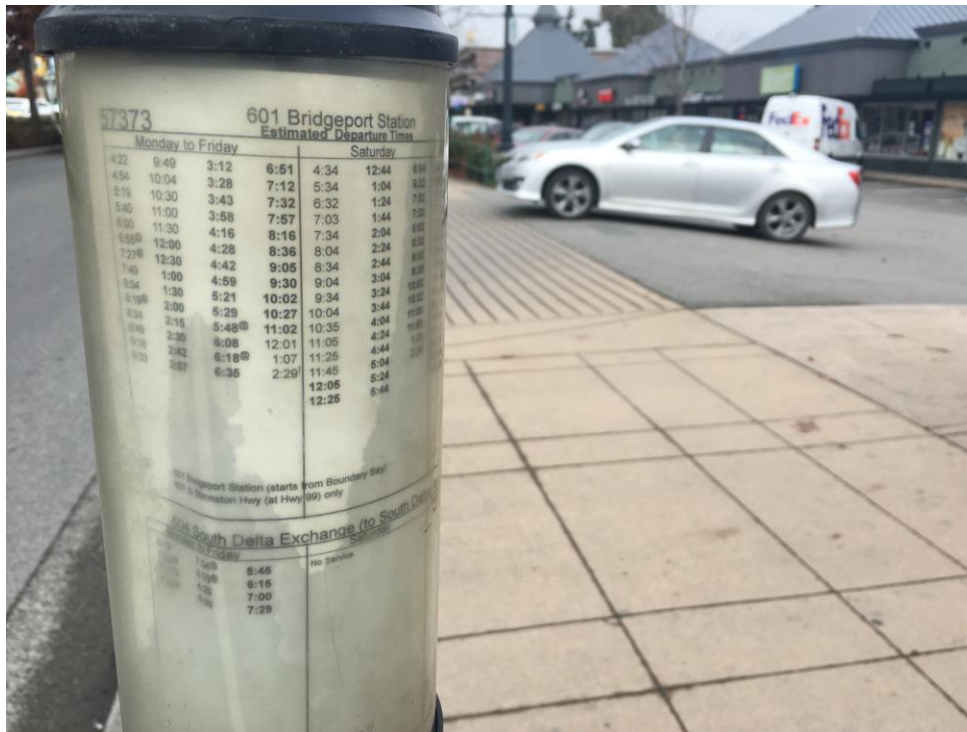


Figure 5.15. Overwhelming Information. Bus schedules like the one pictured above are difficult for some people with dementia to understand. Participants cited the small font, the amount of information presented, and their increasing difficulties with reading as contributing to their struggle to understand transportation schedules.

The data suggests that assisting transit users with dementia largely comes down to other people helping them navigate the system. When asked what would help make public transportation more accessible for them, one participant responded:

Uh, I guess you'd have to have the right people [staff, other riders]. (*Keith*)

Features that are already in place to improve accessibility, such as recorded stop announcements, may not be helpful to a person with dementia if they do not know which stop they need to get off at. One participant felt that they would need to rely on trained drivers more than anything. They suggested training bus drivers on how to communicate

with people with dementia. This would provide the driver with the skills to help the individual understand where they are going, what is the best way is for them to get there, and how to help them get on or off at the stop that they want. In this case, it would help if the person with dementia were willing to wear an identifier so the bus drivers would know they need assistance. For those who would not be willing to openly share their diagnosis, another suggestion was to incorporate special buttons on the bus that could discretely alert the driver to the fact that a rider needs support.

Other suggestions for making public transportation more accessible for this population included: more consistent timing of buses and trains; routes being serviced regularly; limiting the amount of transfers individuals need to take; having shuttles available to common community destinations like the grocery store; the addition of more routes to relieve congestion and crowding; the addition of more local trains; enhancing the frequency of buses that go to busy places; and limiting major changes to stations or having a system in place to help people with dementia adjust to the changes. One participant who uses public transit regularly spoke in detail about the changes they would like to see Translink make moving forward:

Researcher: So just a couple more routes would be helpful? And relieving congestion?

Peter: Yeah and I'd like to see more uh, local uh, trains.

Researcher: Oh yeah?

Peter: You know, light rail.

Researcher: Yeah, yeah, I love light rail.

Peter: Yeah, there's an enormous amount of usage. And there's an enormous amount of building down here.

Researcher: Yes, yeah.

Peter: And I don't think cars work anymore. It's aggravating to be stuck in traffic, you know. On Friday nights coming, going from north to south, it can be an hour, oh a couple hours or more.

There are a number of creative solutions available to make public transportation more accessible to people with dementia. It is important to ensure the person gets the support they need to utilize public transportation as a way to enhance their independent mobility and participation in the community.

Crosswalks.

Crosswalks emerged as a built environment feature that can contribute to a pedestrian-friendly neighbourhood for people with dementia. The data suggests that crosswalks have the potential to both support and present challenges to the independent mobility of this population. The design of the crosswalk was found to have a significant effect on whether it was viewed as a supportive feature of the environment. There are two aspects of crosswalk design relevant for persons with dementia: on one hand, they serve to enhance feelings of safety; but on the other, they can be seen as confusing and overwhelming.

Most participants felt safe crossing the street in their neighbourhood regardless of whether there was a crosswalk available. They cited familiarity with the street, traffic patterns, and people as factors that promoted their comfort while completing this task.

However, if a new crosswalk had recently been added to their neighbourhood, participants felt that this enhanced their safety even further:

- Researcher: And this kind of crosswalk, do you like it? Do you find it easy to use?
- Keith: Oh yeah. But I'm used to it.
- Caregiver: It wasn't long ago they put this in. It wasn't like that before.
- Keith: Yeah.
- Researcher: So before, you just had, how did you cross here? You just had to wait until?
- Caregiver: It was clear, yeah.
- Keith: I had a problem with that.

The data suggests that crosswalk features that enhance perceptions of safety for a person with dementia include: an audible beep that counts down as the individual crosses the road, easy to understand designs such as those at zebra crossings, and adequate signage to alert drivers to the pedestrian crossing (Figure 5.16). Despite feeling safe crossing the road in their neighbourhood, participants were quick to point out that they still remain alert as they do so. Particularly if they felt they had 'slowed down' with the onset of dementia:

- Researcher: Do you like crossing this street?
- Sue: I don't mind it.
- Researcher: Do you ever get worried about the cars because there's no crosswalk?
- Sue: Nope.
- Researcher: That's good. So since you retired and started having memory challenges, have you noticed that um...
- Sue: Slowed down.

- Researcher: You've slowed down?
- Sue: Yeah. Much slow down. I'm not that smart now. And also I've really had a long time and also my Alzheimer's is getting worse. I'm not that fast now.
- Researcher: Oh okay. So does that change the way that you walk in your neighbourhood?
- Sue: Uh, yeah. I have to be careful and take time. Like here [crossing the road].
- Researcher: So you're comfortable with [crossing the street in their neighbourhood]?
- Keith: Well depends what you mean by, you know. I'm comfortable around here but up there with the traffic there can be one thing, a little thing. Yeah, I'm very um, conscious.
- Caregiver: You're cautious.
- Keith: Huh? Oh right. I'm very cautious.

Participants were also observed being careful as they crossed the street during our interviews. For instance, the field notes from one interview detail the experience crossing the road with one participant and their caregiver:

Wayne was noticeably more cautious than his caregiver when crossing the road in their neighbourhood. While Wayne's caregiver boldly crossed the street in an unmarked area as a car approached, Wayne stepped forward and then back again twice, seemingly unsure of the best course of action to get to the sidewalk on the other side. The approaching car stopped to allow him to cross and the caregiver waved him forward from the other side of the road. After the confirmation from their caregiver that it was safe to cross the road, he confidently strode across.



Figure 5.16. Crosswalk Design. This crosswalk consisted of several design features that participants said made them feel safe when crossing the road, namely: flashing lights, audible beeping, a zebra design, and adequate signage.

Despite reporting feeling safe while using crosswalks, some participants found that they can be overwhelming and difficult to use. In fact, two participants detoured their walk-along interview to attend to a crosswalk that they felt presented a challenge to them. Both participants identified their ability to navigate the crosswalk independently as the primary challenge when using this built environment feature. Although they both experienced difficulties navigating a particular crosswalk in their neighbourhood, the crosswalks they experienced these challenges at were designed differently. One crosswalk was at a controlled intersection with in-roadway flashing lights activated by pedestrian-push buttons. The other was a pedestrian-priority crossing, otherwise known as a ‘scramble crossing’, where pedestrians can cross in any direction while the all-directions walk signal is on.

At the controlled intersection, the participant said that they felt confused about which direction they needed to walk in:

Eva: But there's some way that my brain just won't wrap myself around where you're supposed to go.

Researcher: Right, ok. And the sound doesn't help you?

Eva: No. Because I haven't learned what, um, what the sound means. Like I know it means to walk but I don't know where to walk.

Researcher: Right. Ok.

Eva: So usually I'm not bad walking around here but if I get down into where the library and everything is, if I get down there what I'll do is I'll push the button and then I'll wait for someone else to come and I'll follow them.

When the participant tried to demonstrate how pushing the button would allow them to cross southwards, it was observed that they were actually pressing the button that would allow them to cross eastwards. Having both directional buttons on the same pole (Figure 5.17) contributed to the confusion for the participant. They felt that it was easier for them to distinguish between the directional buttons when they were at intersections where they were placed on two separate poles and were clearly facing towards the direction that the person should be crossing.



Figure 5.17. Crosswalk Buttons. These buttons appeared on the same pole. The data reveals that this can be confusing for some people with dementia.

This participant also expressed concern over how the buttons at crosswalks are often inconsistent in their locations, appearance/design and/or the directional sound. This added to the confusion they experienced in locating and understanding how to use the buttons at each crosswalk. Although other participants did not verbally indicate that they had trouble knowing which button to press, three additional participants were observed pressing the wrong one and others looked towards their caregiver for confirmation of when it was time to cross safely.

The data suggests that keeping the location and appearance of buttons consistent, enhancing clarity, and creating a clear distinction between the buttons could contribute to

making crosswalks more accessible for people with dementia. Changes such as these would promote their independence because they would no longer need to rely on other people to demonstrate the correct way to cross.

Meanwhile, at the scramble crossing it was the design of the crosswalk itself, rather than a feature of it, which the participant found confusing. At the crosswalk there was the presence of unconventional diagonal lines meant to guide pedestrians. This particular scramble crossing also included ropes painted inside of the bold white lines meant to guide pedestrians across the road (see Figures 5-18 and 5-19). The rope design seemed like an attempt to enhance the crosswalk's visual appeal, but actually contributed to making the intersection too difficult for the person with dementia to understand.



Figure 5.18. Scramble Crossing.



Figure 5.19. Rope Design. The rope design in this scramble crossing was identified as overwhelming for the participant, making it challenging for them to navigate this crosswalk independently.

The caregiver who came along for the walk felt that this crossing was one example of the neighbourhood becoming more pedestrian-friendly. While they raved about the ingenuity and usefulness of the crosswalk on the way there, as soon as we arrived the person with dementia said that this was actually not an ideal setup for them:

- Researcher: Oh yeah this is interesting, especially with the rope design. An interesting way to do it.
- Caregiver: I thought that was kind of neat.
- Diane: I can't, I can't navigate this.
[...]
- Caregiver: So nice to look at but more confusing?

Diane: Yeah.

This suggests that keeping crosswalk design simple and traditional (e.g., zebra crossing design) may be more appropriate for persons with dementia. If the layout of the crosswalk is unfamiliar to the person, even if the design is aesthetically interesting, it was perceived as busy and overwhelming for the person with dementia. This raises the importance of familiarity in the design of micro environmental features, especially if that feature has the potential to enhance the safety and independence of a person with dementia.

While there was plenty of signage in the area that explained the new crosswalk (Figure 5.20), it did not seem to help the participant with dementia. During data collection multiple people suggested that they sometimes find verbal instructions easier to follow than signage or maps. It may have been helpful to have a person in the area that could explain how to use the crosswalk or an audio recording available to listen to with the same explanation.



Figure 5.20. Signage for Scramble Crossing.

Other Features.

Washroom access was also important for the participants who reported the desire for more well-maintained washrooms in public spaces. One participant indicated that they planned their walking routes around the washrooms available along the way. Washrooms were so important to this participant that they said they avoid certain places where public washrooms are not available. During our interview the urgency with which the participant felt the need to use the washroom while out was demonstrated when she expressed the need to use these facilities during our walk. This experience was captured in the form of field notes and interview excerpts, included below:

Diane and her caregiver spoke of the importance of public washrooms throughout our interview. It was cited as a source of great anxiety for Diane and her caregiver mentioned how she often needed to use the washroom as they explored their community. About half way through our walk, Diane mentioned that she would like to use the washroom soon. She assured us that she was okay for a little while as long as we were headed back towards home. Before she mentioned that she wanted to use the washroom, Diane walked casually and pointed out features of the environment along the way. As we continued to walk she seemed increasingly anxious. She began to walk faster and seemed more directed and focused on getting home, no longer pointing out things of interest along the way. Suddenly, the washroom situation became more urgent with the participant stating:

I'm looking forward to the washroom.

In response, we immediately headed back towards her home. Approximately two blocks from her home we approached a public washroom. Despite the proximity to home, the participant opted to use the public washroom:

Caregiver: Do you want to use this washroom?

Diane: If it's clean.

Caregiver: Do you want to use it or do you want to head home?

Diane: I guess I'll go in there.

The experience with this participant revealed that a higher number of city-owned and operated washrooms would provide a sense of ease for those that regularly require the washroom when out in the community as private businesses cannot always be relied on for washroom access. When asked if public washrooms were their first priority in dementia-friendly communities the participant mentioned above replied 'yes'. Other participants also expressed concern over the availability of washrooms, particularly if they experienced physical illnesses that required them to use the washroom on a regular basis.

Construction or other disruptions in the environment were cited as sources of confusion and inconvenience for participants because it posed a challenge to the accessibility and familiarity of their neighbourhood environment. For example, one participant lived in an area where there was often filming that disrupted regular pedestrian pathways and traffic. This caused them to unexpectedly change routes at times, which could lead to disorientation in some people with dementia who rely on staying on their predetermined route to arrive at their destination. Other participants expressed concerns about construction because of the interruptions to their daily routine, the everchanging landscape of their neighbourhoods, and the lack of communication they received about the changes being made. For instance, one participant expressed uncertainty about plans for construction in their neighbourhood:

Peter: I'm weary. I face the garden uh, is right back there and I hope they don't build a tower here.

Researcher: Oh yeah that would not be too fun. Do they have plans for this area right now?

Peter: Nobody said anything.

Researcher: Oh ok. Hopefully they let you know before anything gets started.

Peter: Well they came in and they cut this back, there was a heavy equipment came in and sawed everything down except a few trees.

Researcher: Oh yeah?

Peter: That was about a year and a half ago.

Researcher: Oh ok. Wow. And so they just kind of have left it since that point?

Peter: Well they cut it down and then, well they put the fence up.

Familiarity with the environment was also an important underlying theme. It provided confidence to the person with dementia. Because of their familiarity with their neighbourhoods, it was like second nature for them to move through these spaces intuitively and independently. Their experiences of familiarity in their neighbourhood are captured in the following quotes:

Peter: But truthfully [in this area] I have never felt lost.

Researcher: Yeah? That's good.

Peter: Yeah. I think.

Researcher: So you're just really familiar with this area then?

Peter: Pretty much. Especially when I was driving.

Eva: [When I get lost I walk around] until I find something familiar, or I ask people. I know to get in here I have to go the way that I know to go from [street name] to come to [street name] and then once I'm on [street name] I know how to go.

Researcher: Oh ok, so that's one of the, you're familiar with a couple of certain streets?

Eva: Yup.

Researcher: So since you've started experiencing [memory loss] have you noticed a change in how you find your way around your neighbourhood?

Keith: Not my neighbourhood.

Researcher: So you're pretty comfortable with the neighbourhood and everything?

Paul: Yeah I know them all.

Researcher: So how do you direct yourself [around your neighbourhood] ... ?

Kathy: Because I have a memory.

Researcher: Yeah? So it's just that spatial memory?

Kathy: Absolutely, yeah. Yeah.

Researcher: Ok. So you've lived here long enough to know you need to turn left coming up when you cross?

Kathy: Yeah.

Researcher: Uh, when you go outside how concerned are you about getting lost?

Keith: In un, unknown circumstances I'm concerned.

Researcher: Yeah? You're concerned when you're somewhere new?

Keith: Yeah, I just don't like. A couple times, you know, something, some little thing has gone haywire so.

Researcher: Yeah, so when you're in a familiar place you're unconcerned?

Keith: [That's right].

Other environmental features participants suggested would improve their mobility and community participation included: awnings on buildings that protect pedestrians from the rain; the removal of obstructions from the middle of the sidewalk (e.g., a pole and fire hydrant placed in the middle of the sidewalk were observed in one interview); installing more water fountains in public spaces; encouraging walking by designing neighbourhoods where cars park around the outside and the inside is entirely pedestrian; ensuring curb cuts merge gently onto the road as the raised bumps were a falling concern for some; installing more ramps; and having railings available on all public staircases. While participants spoke of a number of environmental features that can facilitate or hinder their mobility and participation, a few stood out as particularly important to each participant. These are presented in Table 5.5.

Table 5.5: Most Emphasized Feature of the Built Environment

Participant ID	Most Emphasized Feature of the Built Environment
DFC01	Proximity of Services
DFC02	Washroom Access
DFC03	Public Transportation
DFC04	Wayfinding
DFC05	Walkability
DFC06	Ambience
DFC07	Familiarity
DFC08	Density

5.3.2.2. Wayfinding

Wayfinding is identified in the literature as the ability of persons with dementia to confidently navigate their built environment (Mitchell & Burton, 2010; Sheehan, Burton & Mitchell, 2006). In order to facilitate wayfinding it was found that the participants in this study tended to stick to routes that were familiar to them. In familiar spaces they were less concerned about getting lost. In unknown circumstances their level of concern rose. One participant suggested that new places can be overstimulating because there is too much information to decipher at once. This is especially the case if the location is busy. Participants noted they would feel more comfortable going somewhere new if they were accompanied by someone else. Two people in the sample suggested that even in familiar spaces they are concerned about getting lost and would prefer to be accompanied by someone; otherwise they would stay at home. Participants who had been lost before were more concerned about getting lost than those who had never experienced this. Although participants expressed concern about travelling to unfamiliar places, some felt that they could possibly find their way if given enough time. They would just be slower than the average person in locating the correct route.

Although getting lost is often cited as a concern for people with dementia and their loved ones, the participants had procedures and practices in place for when they lose their way. Participants said that they try to stay calm, look for something familiar, keep walking, or ask other people to help reorient themselves. For example, one participant said:

Eva: I have a tendency to get lost.

Researcher: Oh yeah? Ok.

Eva: And my husband is waiting at home just in case I get lost.

Researcher: Ok. So when you do get lost how do you usually find your way back?

Eva: I walk around a lot until I find something that looks familiar. Or I ask people.

Later on, the above participant did get lost during the walk-along interview. Below is a short excerpt from that:

Eva: So she said you go over there and... sorry. [stops to look around]

Researcher: This looks like, I don't see...

Eva: Is there a path over there?

Researcher: I don't see one.

Eva: Ok. Let's just [walk].

[...]

Eva: So you asked me what I do when I get lost, I just keep walking.

Researcher: Yeah. Do a bit of a loop.

Eva: Yeah.

Researcher: Yeah it works.

Eva: I used to do it when I drove so this will help still.

Other participants suggested they follow similar methods when they get lost:

Well we have to get out some way, so. There's a lot of places here so you'll end up somewhere eventually. (*Keith*)

Well I went for a walk, and this was about two weeks ago. I went for a walk and I took the wrong road. If it's straight I know where to go and um, I had to, I had to ask three people where to go and how to get straight. (*Paul*)

This seems to suggest that although getting lost is concern for some people with dementia in the early stages, they usually remain confident in their ability to relocate to the correct

route on their own. This confidence helps manage the anxiety they may experience when they lose their way. While these methods reflect how participants dealt with getting lost when it happened, they also indicated that they use built environmental features to help avoid getting lost in the first place. For some people with dementia it can be difficult to follow route instructions that were given to them ahead of time. Further, it can be challenging to picture where they are on a bigger scale when out in the community. Therefore, they need things along the way that help remind them of where they are and how to get where they are going. Participants felt that there were specific built environment features (or lack thereof) that had the potential to either help or hinder their wayfinding ability in the neighbourhood. These features included: signage and maps; landmarks; distinction, simplicity and clarity; consistency; and straight street layouts. The remainder of this section will explore each of these in more detail.

Signage and Maps.

For people with dementia signage can serve as a reminder in familiar areas and a guide in unfamiliar areas. 87.5% of participants in this study felt that signage aided them as they navigated their environment. For example, two participants stated:

Caregiver: She likes to go to Starbucks and I think you've kinda got a really good handle on where that is.

Diane: Yeah.

Researcher: Do you think that would help you? Seeing more signs around?

Diane: [enthusiastically] Yeah!

Researcher: So if you were in an unfamiliar place do you think a sign would help you?

Keith: I've used signs all the time.

Even still, they had numerous suggestions for how the signage could be improved in their neighbourhoods. One participant suggested that signs pointing the way to major community destinations, like a coffee house or library, would be helpful. Improving the signage to guide people to public washrooms would also be an important change for this population. Participants felt that washrooms were often difficult to find, particularly in unfamiliar areas. Directional signage to these facilities is essential to avoid accidents and preserve the dignity of this population and others in the community. Street signs were found to be a helpful orientation tool for some while others thought that they were difficult to read. These signs were at times interpreted as unclear or contradictory by people with dementia, especially in areas where streets merge or change names part way through. To address this issue it could be useful to add a button to the pole of the street sign that a person could push to verbalize the street name.

Suggestions to improve signage included: lowering them to appear within the average person's field of vision; increasing the font size; ensuring that they consist primarily of symbols or simple words; and making them distinct (including from one another). When a person with dementia experiences disorientation, signage should serve as a tool they can use to reorient themselves. The data suggests that simple changes have the potential to make signage work better for people with dementia, such as the ones recommended by participants below:

Researcher: So do you find signs are useful for you when you're in a new area to get around or?

Peter: Well, there's something. Oh it was at Pacifica. And the signs were embedded in the door. You know, it wasn't recessed or stuck out. And you know, you had to look at

each one to know what it was for. And I couldn't remember.

Researcher: So it helps if the words are bold or stuck out?

Peter: Oh yeah. So then it doesn't blend [into the background].

You need [the sign] in the right field of vision because you can't be looking up and all over. [And making them distinct from one another] like showing a toilet and an elevator [on washroom and elevator signs]. Not just a man [or] woman. (*Caregiver*)

Compared to signs, maps were seen by people with dementia as less helpful navigational tool. Two key reasons for this were that the font was too small making it difficult to read, and the amount of information they contained was overwhelming. When asked about their experience with maps, these participants responded:

Researcher: Do you find maps are usually helpful?

Diane: Maps are too small. They need bigger words.

Researcher: Do you find [maps] helpful?

Keith: Uh no, yeah.

Caregiver: It would be hard for you to figure those out now.

Keith: I think it would be, yeah.

[...]

Researcher: Ok, so the visual aspect is harder but if somebody explains the directions out loud it's better?

Keith: Yeah.

Participants felt that as their illness progressed, maps became increasingly complicated to understand because their ability to interpret the map was impaired by dementia. Suggestions to improve maps included: simplifying them as much as possible; having individual paper maps available in areas that people with dementia regularly go; clearly indicating the neighbourhood on the map and highlighting major decision points or destinations; and removing the visual aspect of the map entirely and instead relying on verbal instructions either given by a person nearby or through a dedicated phone line.

Landmarks.

Most participants reported that they used landmarks when navigating their community. Two participants were unable to articulate what landmarks stood out to them but were confident that they used these built environment features to orient themselves in their neighbourhood:

Researcher: And do you ever use landmarks when you're going places?

Keith: Yeah.

Researcher: What kind of landmarks do you use?

Keith: I can't remember, but I know I do.

Caregiver: [Restaurant on corner] would be a landmark for you.

Keith: Yeah.

Researcher: Since you've lived in this area for so long, do you find that there are landmarks that you use to get around?

Wayne: Uh, I guess.

Researcher: Yeah? Are there any that stand out to you?

Wayne: Oh yeah.

Researcher: Can you think of any specific?

Wayne: Um, not really.

They identified landmarks as places they enjoyed, buildings or items that were interesting to look at, and unique or memorable features of the environment. Specific examples included: a store, a museum, restaurants, streets near their home, a garden wall, and a colourful mailbox (Figure 5.21). Landmarks were always meaningful to participants. They included places where they built and maintained connections with other people, locations close to their home and in their comfort zone, places where they have fond memories of shared experiences with family or friends, and locations for recreation or dining.

Landmarks served several purposes for people with dementia. Their primary use was to help the individual confirm where they were and where they were going. They were often also used as an indication that the person was close to home. These built environment features served as anchor points in the community for some participants, meaning that as soon as the person arrived at that location they always knew how to get back home. Interview excerpts from two participants commenting on the anchor points in their communities are included below:

Researcher: Are there any landmarks around here that you use? To help you know that you're getting close to a certain destination?

Diane: Well I like to walk by here [local museum]. It's near home.

See that mailbox? That's how I know where to turn to get home. (*Eva*)



Figure 5.21. Lanmark – Mailbox. An example of a landmark used by one participant. The mailbox was an indication for the participant that they had returned to their home street.

Landmarks also served as important focal points for participants with dementia to follow along their predetermined route. Pointing out the landmarks along the way reinforced their familiarity with the area and helped them provide directions to other people. For example, one participant led me around their neighbourhood by using nearby railroad tracks as a focal point:

Kathy: Um, there's a, we can sit on the uh.

Researcher: On the benches?

Kathy: Yeah but there's uh, you have to cross the railroad tracks and then there's benches. (see Figure 5.22)



Figure 5.22. Lanmark – Railway Tracks. An example of a landmark used by one participant. The railway tracks were an indication that she was approaching her favourite place to sit in their neighbourhood.

Instances where landmarks were not particularly helpful for participants included when they had just recently moved to the area. This was because they did not have enough time to become familiar or develop a meaningful connection with them. In addition, for some participants, it was difficult to rely on the landmarks in their neighbourhood because its landscape was always changing.

Distinct, Simple, and Clear

The presence of uniform undistinct homes, yards, street layouts, and other neighbourhood features can be challenging for people with dementia. Participants suggested that their disease can make it hard to distinguish between similar features of their environment. For example, a participant who lived in the suburbs spoke of how they

had a difficult time determining how to get to their friend's house even though they lived just down the street. This was due to the fact that the houses on their street all looked similar to one another and lacked identifying features:

Even to get to my friend's house is a struggle because I can't always figure out how to get home. It's hard to know what is what around here sometimes. Everything is similar. (*Eva*)

This suggests that it is important to incorporate unique features into houses in the neighbourhood to ensure they are visually easily distinguishable from one another. One participant chose to take this upon themselves by painting their door a bright colour to make their home easily identifiable from the ones around it:

Researcher: So I know we were talking about the red door on your house.

Keith: Yeah.

Researcher: So do you find that's helpful? Does that stand out to you?

Keith: I'll bet it does. At the beginning that's what I would do. The red door.

Another example of the importance of distinction involves signage. One participant pointed out that the male and female symbols used on bathroom signs are very similar to the ones used on elevator signs (Figure 5.23). Essentially, the symbols themselves are the same and they are just shown standing in a different way. This became confusing for the participant and as a result they sometimes ended up going to the elevator when they were looking for the washroom. They emphasized the importance of making these types of signs distinct from one other to avoid this confusion. Using different symbols for the two signs entirely or adding a toilet or elevator to make it clearer would be a useful change. Some emergency exit signs also use a similar symbol. Again, the participant said that this

can be confusing for them. As a result they have accidentally left a building in the past because they were trying to find the bathroom. The use of standard symbols on signage meant for different places therefore poses a challenge for people with dementia.



Figure 5.23. Distinction in Signage. The male and female symbols used on this elevator sign are similar to those used on bathroom signs. One participant spoke of the importance of making these symbols distinct in order to avoid confusion.

Ensuring that the broader layout of the neighbourhood is also distinguishable is another important finding. In this case street design was the main feature spoken about by participants. For example, one individual living in Surrey expressed concern over how some street names are only different from each other by one letter (e.g., 114 Avenue, 114A Avenue, 114B Avenue). This made it challenging at times to distinguish between them. While the participant had not experienced any significant difficulties with this system yet, they acknowledged that at times it began to feel like “too much” for them to handle. It was also suggested that decision points at intersections in a neighbourhood need to be distinct for people with dementia. Some participants felt that when streets merged into

each other or when there was a fork in the road it could be difficult to determine which way they needed to go:

Eva: And there's a way of going, uh, after we get past this cul-de-sac, there's a way of going over that way that you can go around on the sidewalks to get to the um... [street name]. But when you get there there's a street sign and the street sign says it's [another street name] but it doesn't say it's [street name]. So my husband had said try going this way and you'll get to the same place. But it doesn't tell me on [street name] that I'm on [street name] so I didn't know how to do it and I came home.

Researcher: So do the streets merge or something?

Eva: I guess so, but I can't tell.

To address this challenge adding features that distinguish one decision point from another may be beneficial. When making features distinct it is also important to ensure that they are simple and clear for a person with dementia. Landmarks, signage, street design, environmental cues, maps, and other built environment features should be simple and easy to understand.

Consistency.

Participants suggested that consistency in their environment is essential to their wayfinding ability. When familiar areas undergo changes, such as construction, it can be a difficult adjustment for the person with dementia. For example, one participant spoke of how they got lost in a remodeled parking lot that they were previously familiar with:

The last time I went they were remodeling the parking lot and he let me off and told me go that way and it took me half an hour to figure out how to get out of that level of the parking lot. (*Eva*)

The data suggests that people with dementia rely on the familiarity of their environment in order to use it independently. Disrupting this familiarity without compensating for its losses can pose a significant challenge to this population. In this particular case, other features of the environment failed the person with dementia because there were not adequate wayfinding techniques incorporated into the area to help them interpret the changes that had been made. When making changes to the environment, it may be beneficial to ensure that they are consistent with the existing environmental character so individuals can continue moving through their spaces unreflectively. Alternatively, incorporating the addition of environmental features such as signage into the area after changes are made can help mitigate this effect. The data also suggests that it is important for people with dementia to use their environment in a consistent way. For example, participants felt that it was important to take the same route to a destination every time they go:

Eva: My husband has a habit because he knows, he's been on the road enough out here so he knows where to go. So he has a habit of going one way one time and another way another time and I can't see when he's driving what the streets are and I'm forever saying 'where are we?'

Researcher: Right. So would it help if you went the same way every time you think?

Eva: Yes but I haven't convinced him of that.

This was particularly helpful if the destination was new for them. Also, consistently using the same anchor point in their neighbourhood helped participants find their way home.

Straight Street Layouts.

The data revealed that similarly to the recommended layout of hallways in institutional environments (Danes, 2012; Marquardt & Schmieg, 2009; Milke, Beck, Danes & Leask, 2009) it is best for people with dementia to walk down a straight road to allow them to see where they are going and where they came from. This was found to increase their confidence and enhance their ability to orient themselves. Straight street layouts made it easier to decide which direction to go at an intersection because both potential destinations were visible. This was especially important in areas unfamiliar for the person with dementia. In total, 37.5% of participants contributed occasions of disorientation to the lack of straight street layouts in their neighbourhood.

One participant found that cul-de-sacs posed a challenge to their wayfinding ability. The combination of curves in the road and interconnected streets was cited as confusing. Interestingly though, if they were walking through a cul-de-sac in the area directly surrounding their home they felt that wayfinding would not be a challenge for them:

Researcher: So do you find that um like when we're walking down here this is pretty straight up and down right, so when there's a curve in the road do you find it hard to picture where you're going when you can't see your destination?

Keith: Yeah it can. I've been tripped up on some of these.
[points across the street to little cul-de-sac that clearly has curves in the road design]

Researcher: Oh yeah, ok.

Keith: In there, you know. But I know I can get out of it because I've been in there enough times that, so I sort of.

Researcher: Oh ok, so you think eventually you'll see something familiar and you'll go 'oh now I know where I am' kind of thing?

Keith: Yeah.

Caregiver: It's a bit of a fog when he goes in there because it wouldn't be enough that you would clearly remember things.

The frequency at which they walked those streets allowed the individual to learn about the road patterns and walk through the space unreflectively. They referenced their familiarity with the street, saying that they know what to look for along those particular roads. For instance, if they were to come across a house with a blue door they would know they were headed in the right direction. In an unfamiliar area they believed that a grid layout would be more useful because it would present straight forward choices about which direction to go. The participant and their caregiver spoke about street design further below:

Researcher: I noticed that a lot of the streets in your neighbourhood, they're very interconnected.

Caregiver: Yes.

Researcher: They're very, so do you find that challenging at all?

Keith: I've learned it.

Caregiver: I would say that because it's not a grid.

Researcher: Yeah, because usually I'm pretty good at picturing the map of where I am but when I was wandering around your neighbourhood I was like 'I don't have a clue'.

[...]

Keith: It's hard to know to go that way. Definitely the problem is not being the, uh grid.

Researcher: Yeah, yeah. Because it can be confusing when uh all the streets just kind of run into each other like that, right.

[...]

Keith: Yeah. Well I've trained myself to know which way.

Another participant experienced trouble with curves in the road closer to home. Their street curved at their house causing the participant to share their driveway with their neighbour. This led the individual to regularly experience confusion about which house was theirs:

Eva: Like there's the driveways, ours you go in this way but then there's another one that's right here and another one that's right there. So I kind of get lost.

Researcher: Yeah because you guys are kind of on like a curve right?

Eva: Yup. Well the reason we're on a curve is we have a double driveway. And we're one of the only ones who do. And the rest of the houses in that complex have got a single garage and a single parking spot, ours has got a big single garage and two parking spots.

Having a single, straight driveway may have eliminated this concern for the participant.

5.3.2.3. Destinations

Community destinations for people with dementia included: healthcare services, places to run errands, the homes of friends or family members, places for entertainment,

places to enjoy nature, administrative offices, places to shop, and locations for self-care. Continuing to go to the places they have gone throughout their lives was found to provide a sense of familiarity and comfort to participants while also serving as a way to maintain their independence. Community destinations provided them with needed services and encouraged them to continue as active participants in their communities. This section will present an overview of the features of the built environment that encourage the use of community destinations by people with dementia. This research found that density, varied land use, and proximity were the key features in promoting the participation of these individuals in their community. The presence of other people at the destinations or to accompany them on the way there was also revealed as an important factor that influenced their decision to go to particular places.

Density and Mixed-Use Development.

Living in a higher density, mixed-use area was found to be beneficial to participants. These areas promoted their independence if they were also pedestrian-friendly. Participants indicated that one of the primary reasons they appreciated their neighbourhood was because there were many places to go and things to do. Below is a collection of interview excerpts where both participants and their caregivers expressed this appreciation:

- | | |
|-------------|---|
| Researcher: | Is this kind of residential around here and then there are shops and stuff along [street name]? Is that kind of the set up? |
| Wayne: | Yeah. |
| Caregiver: | Well it's about four blocks residential and then it's [park name]. We're really close. |

Researcher: Oh that's nice.

Wayne: Yeah.

Caregiver: We're in walking distance so we really spend a lot of time walking [...] We're really lucky living here. Our doctor's office is half a block away.

Researcher: Oh that's great.

Caregiver: Yeah, everything is nice and close.

Eva: There's so many stores around here, there's Safeway, there's two Safeway's in fact, there's two Save On's, there's Thrifty, um, there's a Market every Sunday there's a really good market. So we go usually every week.

Researcher: Oh wow, got a lot of options.

Eva: Yeah, we can stay busy around here.

Paul: Everything's close here.

Researcher: Yeah I noticed there's a lot of stuff in this area. It's a good spot to be in.

Paul: It is. We love it here.

Researcher: And how often do you go to the mall?

Keith: Oh.

Caregiver: Every other day.

Researcher: Oh yeah?

Caregiver: For some little thing. Because the drug store's up there and the grocery store, the liquor store.

Researcher: Oh so it's all in the same kind of area?

Caregiver: Yeah, mostly yeah.

[...]

Keith: Hmm, uh. There's a barber up there for instance, uh I go up and get my haircut there. All that type of thing. Yeah, and he helps because he's a guy I know from [work] so I bs with him, you know. So it's good.

They suggested that they enjoyed going to areas where they had the option to do many activities in one place, such as a plaza or a downtown street (Figure 5.24). Having several services in one location eliminated the need to figure out transportation to multiple places. Instead, they could access a number of services after making one trip. Having lots of things to do in one place meant they could also spend the day there and make an outing out of it. Density and mixed-use areas were viewed as convenient for participants. Study respondents often spoke of mixed-use areas as being a part of their comfort zone because they were familiar with the services and shops available there. If the area was within walking distance of their homes participants spoke of it being their primary destination when independently participating and being mobile in their community. They expressed appreciation for having “everything you could ask for” within walking distance, even if the immediate area surrounding their home was residential.



Figure 5.24. Density. Areas where participants could access several different services in one place were viewed as positive features of their neighbourhoods.

The data also revealed that there is a balance that needs to be struck when it comes to density in the neighbourhoods of people with dementia. An area that was too dense meant more traffic, more construction, more noise, and thus more anxiety and confusion for participants. Those who lived near very dense areas valued the options and promotion of independence that density provided but expressed the desire for more pedestrian-friendly features to help make them feel safe. For example, one participant spoke of how the lack of traffic-calming features in their neighbourhood near their local mall caused them stress at times:

- | | |
|------------|--|
| Caregiver: | The traffic gets a little daunting. Like sometimes when you're up there and it's really busy it bothers you because it's so crazy. |
| Keith: | Well it's, yeah. |
| Caregiver: | But it's not like being downtown Vancouver. |
| Keith: | Yeah you could be dead fast, and dead floor. |

Meanwhile, participants who lived in areas that were viewed as both dense and pedestrian-friendly expressed a great deal of satisfaction with their neighbourhood. In fact, the participant who lived in the densest area reported the least number of problems accessing services or utilizing community spaces and also cited a number of pedestrian-friendly features in their neighbourhood. This participant and their caregiver spoke of how the density of their neighbourhood contributed to their ability to access services and to their quality of life:

Caregiver: Oh well we're very lucky here. We don't have those kind of issues [accessing services] here.

Researcher: Yeah it seems like you guys have a good set up, yeah.

Caregiver: You know we've had people knock on our door and ask if we want to sell. But we wouldn't, at this point in our lives there's nothing better so.

Researcher: Yeah, based on the other places I've seen this is kind of, this is the goal for a lot of people to live in a neighbourhood like this.

Wayne: Yeah, you can [walk] over there, you can go over here and.

Caregiver: Yeah, you can walk anywhere here really. I'll show you, we can just walk up here.

[...]

Caregiver: You know there's some things we go to Costco for or whatever but other than that we just stop around here. We're not big fussers so we just [inaudible]. And you know one of the important things for us is the access to transportation. And staying healthy, staying mobile,

staying active. If we didn't have that, there wouldn't be much quality of life there at all.

Wayne: Yeah.

Mixed-use neighbourhoods meant that participants had a variety of shops and services nearby, including places such as: restaurants, shops, grocery stores, gas stations, healthcare services, administrative offices, educational services, entertainment options, community centres, etc. Mixed-use areas provided options for participants not only by having different types of services and destinations available, but by also providing variety within a specific service category. For example, participants valued having restaurants with a variety of cuisines available in their neighbourhood. This promoted their agency by providing them with a choice of where they wanted to eat on a particular day. Participants also appreciated a variety of land use in their neighbourhood. The downtown core of their communities provided the opportunity to socialize, run errands, access services, utilize entertainment or cultural places, or participate in other community-based activities. Meanwhile, residential areas made participants feel safe when walking and allowed them the freedom to move through their neighbourhoods at a slower pace. It was also important to participants to have places to connect to nature such as a park, which allowed time for quieter and more solitary activities (Figure 5.25). A number of participants expressed appreciation for the opportunity to be in nature while in their neighbourhoods, as demonstrated in the following interview excerpts:

Researcher: There's a bench here that we can have a seat on.

Kathy: Ok, I like the bench where we cross the [railroad tracks].

[...]

Kathy: Oh it's beautiful [here sitting by the ocean].

Peter: Uh there's a heritage trail that I lived on, down that block.

Researcher: Oh ok.

Peter: Have you ever been? It's a beautiful trail. But that has nothing to do with transportation, that's just for casual walks.

Researcher: So do you think the fact that you have these kind of safe walkways and the parks nearby, does that help you get out more?

Diane: Mhm, mhm. Yes.

Researcher: Do you think if you lived in a busier place you would walk as much?

Diane: Mmm, I don't think in a busier place I would.

Paul: Yeah we go to lots of parks.

Researcher: Ok, so what do you do when you go there?

Paul: Well um, what do we do when we're there? [...] Well we um, we enjoy watching people and uh, we like um, what's. [...] Taking pictures.



Figure 5.25. Varied Land Use. While participants valued living in dense neighbourhoods where they had a number of services available to them, they also expressed appreciation for areas in their neighbourhood where they could relax and connect with nature.

Proximity.

The proximity of neighbourhood services and destinations was very important to participants. When asked why they chose to go to a particular destination in their neighbourhood, participants responded that over 40% of the time it was because the destination was close to their home. Further, respondents felt that over 90% of the places they regularly attended in their communities were close or very close to their homes. 87.5% of participants suggested that one of the most important features of their neighbourhood was the proximity of destinations. Their familiarity with the environment and the convenience of having most of what they needed close by were the primary motivations for participants to stay in their current neighbourhood for as long as possible.

It was especially important for participants to live close to the places they went on a regular basis, such as the grocery store or the pharmacy. They also valued being near places for enjoyment or entertainment, and locations that provided healthcare or administrative services.

Participants suggested that they were willing to change their habits in order to utilize destinations that were closer to their homes. For example, participants indicated that they regularly chose to go to destinations near their homes over ones that were farther away. One participant spoke of regularly going to the library within walking distance of her home instead of the one she preferred on the other side of town. The reason behind this decision was that she could access this location independently because of its proximity to where she lived. It was not only important for participants to be close to the services in their communities, it was also important to them to have destinations to socialize within a reasonable distance from their homes. For example, one participant spoke of ceasing to attend a program that was difficult for them to access because of the distance they had to travel to get there. When a spot in a similar program opened up in their neighbourhood the participant jumped on the chance to attend. They expressed their appreciation for how the proximity of this service allowed them to participate in their community in this capacity:

Researcher: You said that you go to an adult day program right?

Keith: Yeah.

Researcher: And you've been going there for a while now?

Caregiver: Uh, just over a month.

Researcher: Oh nice, ok. So it's a pretty new thing.

Caregiver: We tried going to one downtown last year but it was just way too far to go.

Researcher: Oh yeah, wow. So is this one in [town name]?

Caregiver: Yeah, in [town name], yeah.

Keith: It's right on the hill.

Researcher: Oh ok, so everything's pretty close by then. That's good.

Keith: Everything. We won't be leaving soon ... I like [the program], I like it a lot [laughs].

Participants also spoke of the value of having service providers, such as their family doctor, close by. One participant even chose to switch their doctor to one whose office was closer to their home:

Researcher: Ok. You said you're just switching doctors?

Eva: Yup.

Researcher: And you're switching because the other one's on mat leave right?

Eva: Yeah, and also, well moreso because the new one is gonna be here and the old one is in [town name].

Participants valued having places to go in their neighbourhoods that were close enough to walk to. Being able to do so not only promoted their independent mobility and participation but was also cited as a source of exercise and enjoyment. The walkability and proximity of community services was so important to one participant that she decided to move to a neighbourhood where her destinations were closer and more accessible after she stopped driving. She stated that it was important to her to be within walking distance because she wanted to continue using these services independently without having to rely on others for transportation:

Sue: We moved here in [town name]. I used to live in [neighbourhood name]. [Neighbourhood name] was inconvenient. That time I was driving but I stopped my driving. I don't want things far away.

Researcher: Right. So you're closer to things now?

Sue: Yeah. Close to stuff.

[...]

Sue: I used to drive but now I don't drive. I have to walk. And the walk is better for me to do exercise.

Researcher: Yeah? You like the exercise?

Sue: I try to walk more and I always go out and take bus. I don't ask my son to drive me or my [spouse] to drive me.

Participants also spoke of how having things close by provided more options for how they could commute there (i.e., walking, biking, public transit, driving, etc.). Below is a collection of interview excerpts where participants demonstrate how the proximity of places to their homes allowed for flexible transportation methods:

Researcher: So pretty much if the weather's good it's worth it to [ride your bikes] rather than get on a crowded bus?

Caregiver: Yeah.

Wayne: Mhm.

Researcher: Yeah, that's a good way to do it. If you have that flexibility you might as well, right?

Wayne: Yeah.

Caregiver: But uh, we don't go downtown very much. And when we do it's the bus. But anything around here we can walk or ride bikes.

Wayne: Mhm.

I say I save money, walk. So when I want exercise I walk instead of take bus.
I don't need to take the bus there. (Sue)

Researcher: Ok, and when during the day do you go?

Eva: Anytime I feel like going down because I can walk there.

Researcher: And how do you get there? To the mall?

Keith: I can walk. For the sake of walking.

Researcher: Yeah, might as well right?

Keith: And also I bike.

Researcher: Oh interesting, yeah.

Keith: So I've got a pretty fancy bike that I ride around,
[spouse]. So it's uh, a new type of uh, motorcycle,
[spouse] help.

Caregiver: Electric bike.

Researcher: And um, you guys drive there?

Paul: Yup.

Researcher: Ok, and how long does it take you?

Paul: It's close enough that I have walked there from here.

Researcher: And do you walk there or drive there? To the salon.

Kathy: I can walk. Sometimes [caregiver] takes me for a walk
because it's so close and I like to walk.

Even though most participants in this sample lived in the suburbs they expressed feeling that the neighbourhoods they lived in were dense enough that all needed services were close by. One participant and their caregiver even compared their suburban neighbourhood to living in the city:

Caregiver: Everything's just up here. It's really close.

Keith: You're right.

Caregiver: It's almost like living in Vancouver. Everything's really close.

Keith: Oh yeah.

Dementia-Friendly Destinations.

The data from ACT-OUT creates a picture of the overall patterns of use of community destinations by persons with early-stage dementia. It provides the following information: when persons with dementia travel to destinations in their neighbourhood; who they go with and why; the changes in their patterns of use of community spaces since experiencing the symptoms of dementia; why they choose to go to particular destinations; the distance they travel to get there; what destinations remain accessible to them after the onset of their disease; and which destinations present a barrier to their independent use of community spaces. The remainder of this section will present an overview of the data from ACT-OUT and will discuss the implications of these findings.

Participants reported that they most often chose to go to community destinations in the morning (40.6% of the time). They preferred to go early because it was when they typically felt the most alert. Participants stated that throughout the day they generally

become more tired and have a harder time managing the symptoms of their disease. Despite their stated preference to go places in the mornings, participants also reported valuing the ability to be flexible in their daily routine. Incorporating a flexible routine into their week meant that participants could practice their agency through making decisions about when to go to a destination, depending on how they felt on a particular day and the schedules of others who were joining them. As a reflection of this, 31.3% of the time they indicated that they travelled to community destinations at any point during the day. Interestingly, participants indicated they only chose to go to community destinations during the evening or at night 3.1% of the time. They cited being mobile or participating in their community at night as a safety concern. Table 5.6 presents an overview of the data surrounding when participants preferred to be active in their communities.

Table 5.6. Participant’s Preferred Time of Day to Be Active in the Community

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Morning	13	40.6	40.6	40.6
Afternoon	5	15.6	15.6	56.3
During the Day	3	9.4	9.4	65.6
During the Evening/Night	1	3.1	3.1	68.8
Anytime	10	31.3	31.3	100.0
Total	32	100.0	100.0	

Respondents indicated that after their diagnosis they were accompanied by another person to community destinations 78.1% of the time. When a participant was accompanied by someone else it was for transportation to the destination or for help/care once they arrived 68% of the time. The remaining 32% of the time someone else went with them to the destination for company or to also participate in the task (see Table 5.7). Before the onset of dementia, respondents reported that they had someone accompany them to their destinations 62.5% of the time. At that point they were only accompanied for the purposes of transportation or help/care 28.5% of the time. The remaining 71.5% of the time they were accompanied before their diagnosis the purpose was either for company or for the other person to also participate in the task (see Table 5.8). These findings suggest that after the onset of dementia participants were no longer as independent in their use of community spaces. Not only were participants accompanied more often to their destinations, but they also experienced a 40% increase in their dependence on others for help or transportation to these places.

Table 5.7. Reason Participant was Accompanied to Destination – After Diagnosis

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Not Applicable	7	21.9	21.9	21.9
Transportation	7	21.9	21.9	43.8
For Help/Care	10	31.3	31.3	75.1
For Company	6	18.8	18.8	93.8
To Participate in Task	2	6.3	6.3	100.0

Total	32	100.0	100.0
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Table 5.8. Reason Participant was Accompanied to Destination – Before Diagnosis

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Not Applicable	11	34.4	34.4	34.4
Transportation	2	6.3	6.3	40.7
For Help/Care	4	12.5	12.5	53.2
For Company	8	25.0	25.0	78.1
To Participate in Task	7	21.9	21.9	100.0
Total	32	100.0	100.0	

As part of the ACT-OUT survey participants were asked to discuss places where there had been no changes in their patterns of use since their diagnosis (i.e., places they still go) and about places where there had been a change (i.e., places they no longer go or will begin to go). When asked about how long it took participants to access locations using their preferred method of travel where there had been no changes in their patterns of use, they responded that 81.3% of the time their destination was under 20 minutes from their home. Of these, half were under 10 minutes from their home (see Table 5.9). For places where there had been a change in activity participants indicated that it took them less than 20 minutes to travel there 71.9% of the time. The data reveals that there was a

10% increase in the number of places they went that were under 20 minutes from their home after the onset of their disease (see Table 5.10). Around 60% of the time respondents felt they knew the way to get to the places they still went either well or very well (see Table 5.11). Before their diagnosis participants felt that they knew the way to get to their destinations well or very well nearly 80% of the time (see Table 5.12). As their illness progressed, participants reported that their ability to find their way to a predetermined destination and their confidence in doing so was beginning to fade. This points to the importance of ensuring that the built environment helps compensate for these losses and encourages the wayfinding ability of persons with dementia.

Table 5.9. Time to Destination – After Diagnosis

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid <5 minutes	5	15.6	15.6	15.6
6-10 minutes	8	25.0	25.0	40.6
11-15 minutes	7	21.9	21.9	62.5
16-20 minutes	6	18.8	18.8	81.3
21-25 minutes	2	6.3	6.3	87.5
26-30 minutes	2	6.3	6.3	93.8
30+ minutes	1	3.1	3.1	96.9
Missing	1	3.1	3.1	100.0
Total	32	100.0	100.0	

Table 5.10. Time to Destination – Before Diagnosis

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid <5 minutes	5	15.6	15.6	15.6
6-10 minutes	4	12.5	12.5	28.1
11-15 minutes	8	25.0	25.0	53.1
16-20 minutes	6	18.8	18.8	71.9
21-25 minutes	1	3.1	3.1	75.0
26-30 minutes	4	12.5	12.5	87.5
30+ minutes	4	12.5	12.5	100.0
Total	32	100.0	100.0	

Table 5.11. Participant Knows How to Get to Destination – After Diagnosis

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Very Poorly	4	12.5	12.5	12.5
Poorly	9	28.1	28.1	40.6
Well	3	9.4	9.4	50.0
Very Well	16	50.0	50.0	100.0
Total	32	100.0	100.0	

Table 5.12. Participant Knows How to Get to Destination – Before Diagnosis

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Very Poorly	4	12.5	12.5	12.5
Poorly	3	9.4	9.4	21.9
Well	8	25.0	25.0	46.9
Very Well	17	53.1	53.1	100.0
Total	32	100.0	100.0	

Respondents stated that the reasons for going to the places they still went regularly included: proximity to their home — 40.6% of the time; people they would interact with — 18.8% of the time; familiarity — 18.8% of the time; enjoyment — 18.8% of the time; and for financial reasons – 3.1% of the time (see Table 5.13). When participants stopped going to a particular destination they said that 56.3% of time it was because they no longer used those services; 21.9% of the time it became too challenging for them to use those services; 6.3% of the time the services started to come to them; and 6.3% of the time they used technology to automate the services. 9.4% of the time they were unsure why they stopped going (see Table 5.14).

Table 5.13. Primary Reasons Participants Continued Going Places After Diagnosis

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Proximity	13	40.6	40.6	40.6
People/Staff	6	18.8	18.8	59.4
Financial	1	3.1	3.1	62.5
Familiarity	6	18.8	18.8	81.3
Enjoyment	6	18.8	18.8	100.0
Total	32	100.0	100.0	

Table 5.14. Primary Reasons Why Participants Stopped Going Places After Diagnosis

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid No Longer Uses Services	18	56.3	56.3	56.3
Too Challenging/ Someone Else Now Does It	7	21.9	21.9	78.1
Doesn't Know	3	9.4	9.4	87.5
Services Now Come to Them	2	6.3	6.3	93.8

Automated Services	2	6.3	6.3	100.0
Total	32	100.0	100.0	

ACT-OUT survey was divided into four sections that differentiated between the different types of places in the community that participants could visit. The following four paragraphs will discuss the overall data trends per category.

Overall the places in the administrative, consumer, and self-care category remained relatively accessible to people with dementia and their participation in these spaces stayed largely consistent. Places in this section included: a small grocery store, the mall, a small store, the pharmacy, a hairdresser or barbershop, the bank, and town hall. The data revealed that participants who had progressed further into their dementia (i.e., had lower MMSE scores) were more likely to stop their participation in these activities. Those who had difficulty using these services decided to either automate the service or have the service come to their home. Both methods allowed more flexibility and encouraged the participant to continue using the services even if they were no longer physically travelling to a location to do so. A number of participants spoke of two places in this section as being too challenging for them to continue using on their own. The amount of information an individual needs to memorize in order to utilize services at the pharmacy and the bank proved to be too challenging for some participants who needed another person to accompany them to these places.

The category aimed at places for medical care included: the doctor's office, the hospital, the dentist's office, therapy (including physical), and adult day care centres. The data revealed that these places were generally only used on an as-needed basis, with the

doctor and dentist being the more consistent destinations for participants. Participants indicated that they sometimes needed extra help when attending these places to be able to answer questions, process information, and remember all the details that comprised their appointments.

The social, spiritual, and cultural places section included: a friend or family member's place, restaurants, a seniors centre or social club, a building for worship, a cemetery or memorial place, and entertainment or cultural places (e.g., a movie theatre or library). These places remained largely accessible to people with dementia. Participants only used some places to attend special events, namely the cemetery and a building for worship. Embarrassment over their disease symptoms in public or social situations was cited by some participants as the reason that they no longer go to certain destinations in this category (i.e., restaurants or a social club).

The places that comprised the category for recreation and physical activities included: a garden in their backyard, a park, a forest or beach, a cottage, a neighbourhood, a sports facility, and a transportation centre. Overall, these locations also remained fairly accessible to participants. However, they did suggest that physically aging was affecting their use of some of these places (i.e., a sports facility, a forest or beach). When discussing the places included in this category participants also suggested that they were more selective with where they dedicated their energy. As a result they chose to stop doing things they did not have much of an interest in (i.e., going to the park, gardening in the backyard).

Table 5.15 presents an overview of the level of change participants experienced in their use of community spaces. No change was classified as when zero participants reported any differences in how they used the community destination, slight change was

when under 25% of participants reported a change, a moderate change was when 26-50% of participants reported a change, and a significant change was defined as 51% or more. Where there was change, it is indicated whether the change occurred in the present (i.e., they were currently experiencing different patterns in use but expected to return to old patterns in the future); in the present and future (i.e., they were currently experiencing different patterns of use and expected that to continue in the future); or if it was a future change (i.e., the patterns were currently the same as they were in the past but they expected that to change in the future).

Table 5.15. Changes in Patterns of Use for Community Destinations

Location Name	Level of Change	Period of Change
Small Grocery Store	Slight	Present and Future
Mall	Slight	Future
Small Store	Slight	Present and Future
Pharmacy	None	None
Hairdresser or Barbershop	Slight	Present and Future
Bank	Significant	Present and Future
Town Hall	Significant	Present and Future
Doctor's Office	Slight	Present and Future
Hospital	Significant	Present and Future
Dentist's Office	Slight	Present and Future
Therapy	Moderate	Present
Day Care	Significant	Future
Friend or Family Member's Place	None	None
Restaurant	Slight	Present and Future
Senior Centre or Social Club	Significant	Present
Building for Worship	Significant	Present and Future
Cemetery or Memorial Place	Significant	Present
Entertainment or Cultural Places	None	None
A Garden in the Backyard	Moderate	Present and Future
Park	Moderate	Present
Forest or Beach	None	None
Cottage	Significant	Present and Future
A Neighbourhood	None	None
Sport Facility	Significant	Present and Future
Transportation Centre	None	None

For most community destinations included in the ACT-OUT survey participants experienced little to no change in their patterns of use for these spaces. Where there was

no change in their patterns of use it was found that the activities that a person takes part in while at that location were largely passive, relaxing, comfortably social, or contemplative; meaning that people can generally participate in these spaces independently regardless of ability (i.e., a friend or family member's place, entertainment or cultural places, the forest or beach, neighbourhoods). The remaining two places where participants experienced no changes in patterns of use were places that were considered necessary for their quality of life or overall health but were too overwhelming for them to go to on their own (i.e., the pharmacy and transportation centres). Places where participants experienced a moderate to significant change in patterns of use included: the bank, town hall, the hospital, therapy, adult day centres, a seniors centre or social club, a building for worship, a cemetery or memorial place, a garden in their backyard, a park, a cottage, and a sports facility.

Three participants indicated that they experienced a change in their use of seniors centres. However, this was only thought to be a temporary change for all three of the participants. That meant that although their use of these centres had currently stopped, they hoped to go back when the programs they enjoyed started up again. The only place where participants thought there may be a significant change in their patterns of use in the future was the adult day centre. There was a significant jump between the number of people who said that they currently used these facilities (25%) and the number of people who expected to go at some point in the future (87.5%). All other places where participants indicated there was a moderate or significant change consisted of present and future changes, meaning they used to go in the past but no longer did and did not expect that to change in the future (i.e., the bank, town hall, the hospital, an office to receive therapy, a place of worship, a garden in their backyard, a cottage, and a sports facility).

For many of the places listed above, the changes occurred simply because they were destinations that participants only went to on an as needed basis (i.e., town hall, the hospital, therapy, a cemetery or memorial place), or rarely in the first place (i.e., a cottage). For other places these changes were representative of participants becoming more selective about the activities they participated in. Thus, participants no longer attended these destinations because they lost interest (i.e., a place of worship, a garden in their backyard, a sports facility, a park, a social club).

Discussions with participants revealed that the bank, the library (grouped under cultural places), and transportation centres presented the most significant accessibility challenges to people with dementia. They experienced changes to their independent use of these facilities because the skills required to participate in them (i.e., dealing with numbers, reading, and comprehending transportation schedules or navigating stations) were challenged by their symptoms. The data suggests that these destinations should be of particular interest to those working towards establishing dementia-friendly communities because they present a significant challenge to the independent use of community spaces for people with dementia.

Of the above, the bank stood out as the least accessible community destination for participants. For some, no longer being able to perform banking tasks was not only an indicator of their loss of independence in community spaces, but also represented the loss of their role as the person who manages the household finances. Participants and their caregivers reported that using and transferring money, remembering their bank codes, and handling their books were becoming increasingly challenging tasks to perform on their own:

That's how I knew I first had a problem because I would, I was doing bills for my [spouse] every month and almost every month I was sending them in wrong. I sent them in one time and told them I wanted \$24,000 for a day. And they phoned me, the gal knew me and she phoned me and she says 'I don't think you want to take this much' and I said 'what are you talking about?' ... And one of the girls used to call me 'Crazy [name]' because I made so many mistakes. And I finally when I was I diagnosed I finally went and said 'I have a reason for doing that'. (Eva)

Researcher: [Do you go to] the bank?

Paul: Um, I used to but [wife] does all the banking.

Researcher: Ok. So you don't see yourself going there again?

Paul: Well I'll go in with [wife] but uh, but...

Researcher: But you won't do any of the banking?

Paul: No, not at all.

Caregiver: You know another thing though that would be interesting is that money is something that she doesn't use as much anymore. It would be nice if there was like a card where she could go to Starbucks, well I guess there is you could buy a Starbucks card, but something...

Researcher: Like a more general one?

Caregiver: Yeah, yeah... I don't know how that would, I mean I guess they're going that direction anyways but something simpler and stuff where you don't have to remember your code.

Further, when participants were actually at the bank they reported that they found things moved too quickly for them:

Researcher: Do you go to the bank?

Keith: Um, you know I'm a little prickly on the bank. And uh, you know, I've kind of uh, I'm like an old dinosaur kind of thing, you know. Everybody else is [makes fast noises] and I'm, you know.

The ACT-OUT data suggested that there was not only a difference in their broader patterns of use at the bank, but there was also a difference in *how* they used it. Participants indicated that they began to rely on other people to perform the banking tasks. Even if they said that they still went to the bank it was largely in the role of accompanying others. Only 25% of participants reported that they still used this service independently.

5.3.2.4. Other People

Other people were a significant factor in the experience of using community destinations for persons with dementia. The support participants received from others both on their way to a predetermined destination and once they arrived appeared to be fundamental to their experience of these spaces. Their support network was a crucial component in their patterns of use of community destinations. 87.5% of participants felt that they had a strong support network. 75% of participants primarily relied on their spouse for support. Respondents also identified children, siblings, friends, and professional caregivers as essential components of their support network. Participants identified others who lived in their homes, individuals who came to their homes, and others they connected with while out in the community as part of their support network. The individuals who

comprised the closest circle of support for participants took on a number of different roles to help the person with dementia remain active in their neighbourhood. Some people provided transportation, others aided with daily tasks, and a few provided emotional support. Having a strong support network nearby was important enough to two participants that they decided to move in order to be closer to the people that comprised this network.

They said:

Researcher: So you said you moved here recently right? To this area.

Diane: To this area, yeah.

Researcher: You used to live [in town name]?

Diane: I moved to my family.

Well it was partially we moved because of my disease. And our daughter has a place out here. So she wanted us where she could be reasonably close. Plus my girlfriend lives there, her daughter lives within two or three blocks. So it sort of made more sense than us staying out there and me getting worse and worse. (*Eva*)

When receiving support from community members participants expressed gratitude for the opportunity to connect with others who were experiencing the same illness. This allowed them to create reciprocal relationships within their support network where others understood their unique set of challenges:

Kathy: [referring to friend experiencing the same kind of dementia] We're really good for each other.

Researcher: Well it must be nice to find somebody to relate to right, what you're going through.

Kathy: Yes.

Friends were a unique feature of participant support networks. Participants had mixed responses about how the disease had affected their relationship with their friends. For instance, one participant reported that they had wonderful friends who were their strongest source of support through their illness. This individual said:

You know the benefit of this disease, if there are any benefits, is that I am closer to my family, I'm close to my friends, and um, I guess that's it ... I have good friends. Yeah, yeah, no. I don't need any more friends. (*Kathy*)

Meanwhile, another participant expressed that she experienced loneliness and sadness after the onset of her disease. In reflection, she stated:

A lot of friends of mine will soon disappear. (*Diane*)

A third participant spoke of having a lifelong friend living down the street and how important it was to have a convenient opportunity to socialize during the week. They reported experiencing high levels of comfort and support from this friend and reminisced about the experiences they have shared together. This particular participant also spoke of continuing to travel to other provinces to visit friends as she had throughout her life. A fourth participant spoke of new friends that she saw on a weekly basis:

We go to [support group name] every Monday. We love it there. We're a family. (*Paul*)

These findings suggest that the existence of strong friendships in the lives of persons with dementia has the potential to be a significant source of emotional and practical support. Strong friendships provided an opportunity for escape for participants as spending time with their friends helped remove them from the reality of the condition of dementia and provide a sense of normalcy to their days. While strong friendships were shown to enhance feelings of support and joy in the lives of people with dementia, lacking this

source of support was seen as a significant loss to certain participants. These individuals felt that maintaining friendships became increasingly difficult as the disease progressed.

Two participants reported that they relied on others in order to feel comfortable travelling to the destinations in their neighbourhood. One of these participants suggested that their anxiety had grown significantly since the onset of their disease. As a result, even in an area that they were familiar with they would not be comfortable going out on their own:

Researcher:	So would you say you would never go out walking alone ever? You're usually with someone?
Diane:	Yeah, not alone. [...]
Caregiver:	Oh yeah. It would be nice if she, Diane felt comfortable enough to, well I don't know if we'd want her to wander off on her own anyways but if she had an opportunity to meet people and not have to, you know.

The other participant indicated that the symptoms of their disease required her to have someone there to support her. The remaining six participants reported that they only needed assistance from friends or family to support their journeys to community destinations once in a while. Participants reported feeling comfortable with their support network and trusting them to get them to their destinations safely. Some participants reported that over time that they began to be more selective with the people they chose to surround themselves with. These participants felt it was important to ensure that they chose people they could trust and rely on in a difficult or embarrassing situation. For instance, one participant stated:

I only have chosen friends because yeah, it is an embarrassing disease. So the people I trust, it has to be the people I trust, or kind or uh, I've known them for a long time. (*Kathy*)

Participants also spoke of receiving support from service providers and other people in their community. All participants suggested that they felt comfortable asking other community members for directions or for help. For example, three participants said:

Researcher: Were you panicking when that was happening [getting lost]?

Paul: A little bit.

Researcher: Ok, but you felt comfortable asking the people?

Paul: Oh yeah, I'm not shy.

Caregiver: Diane isn't shy and she doesn't have a problem talking to people or asking questions which is really great.

Researcher: Yeah that's good. So you're comfortable asking directions if you ever feel turned around?

Diane: Mhm.

I always ask for, if I'm by myself, like if my husband's gone to look for something else and I want something I will ask [the people in the store] for it. (*Eva*)

A number of participants said they also felt comfortable with service providers whom they have known for a while and who are aware of their diagnosis:

Researcher: So why do you go to that particular dentist?

Eva: Um, because I feel comfortable with them and they know me well enough that they cut me some slack.

Caregiver: We've been going to the same dentist for years.

Wayne: Yeah.

Caregiver: And he's a good guy, knows about his condition.

While participants were comfortable sharing their diagnosis with those they were familiar with, they preferred to keep the diagnosis private from strangers. Even still, they expressed the desire to extend their support network to include other community members. In doing so they revealed the importance of educating the public and service providers about dementia. Participants reported that they would feel more comfortable going out in their communities if others were familiar with dementia and knew how to communicate well with people living with the disease:

Researcher: So if there was more understanding and more awareness, you think it would help?

Kathy: Yeah. Would it help me [directly]? No, but everyone I meet, except strangers, I tell them I have PCA. My trusted friends, they know, yeah they know. But no one can really understand it unless you're living it right.

Further, they specified that it was important to them to experience dementia-friendly neighbourhoods without the necessity of having to openly disclose their diagnosis:

Researcher: So do you think that it would make you feel more comfortable if you knew the person was familiar with dementia and knew what it was?

Diane: Yeah of course.

Researcher: Yeah? And are you comfortable letting people know your diagnosis?

Diane: Um, not really. I don't want to be treated differently.

Participants cited their familiarity with their neighbourhood not only through features of the built environment, but also through the lens of the social environment. The way they participated in community destinations also partly depended on the people who comprised these spaces. If participants felt that the people at a particular destination were not friendly or did not provide good service it discouraged them from going to those places. Conversely, if they felt a connection to the people at a particular location they were more likely to go there. When asked why participants chose to go to certain destinations in their neighbourhood they responded that they would go to a particular place primarily because of the people that were there nearly 19% of the time.

5.3.3. Walking is More Than Transportation

The research reveals that walking takes on a multifaceted role as a source of exercise, leisure, transportation, socialization, and connection for people with dementia. Being able to do so independently has a significant impact on their quality of life. Exploring the practice of walking in a neighbourhood environment for people with dementia is an important area to study because outdoor community environments are where these individuals can assert their independence, remain socially engaged, and act as a setting where they can remain physically active (Blackman, Schaik & Martyr, 2007; Phinney, Chaudhury & O'Connor, 2007). This research reveals that walking can represent maintenance in a time of loss, freedom, and a sense of normalcy for this population.

5.3.3.1. Maintenance in a Time of Loss

Participants reported that they had experienced numerous losses since the onset of their disease. Physically and cognitively they were beginning to experience losses that

were affecting their independent functioning in neighbourhood spaces. Accompanying these losses were expressions of sadness and anxiety. Participants spoke of their sense of loss at various points throughout the interview process; longing for their old life, their friends, their independence, and their abilities. Some of the most poignant examples of this sense of loss are contained within the following quotes:

So that Friday I lost my job, I lost my car, and I lost my freedom. (*Paul*)

I'm still living with the help of friends and [caregiver]. And I still have joy in my life. But you know, it's shrunk. Like my brain. (*Kathy*)

I mean you can't go from being able to go anywhere or everywhere to having to have help all the time. Like my husband does all the cooking, he does all the cleaning, he looks after me totally. (*Eva*)

You know, I'm slipping away. I'm slipping away and I'm so aware of it. And I hate it. (*Kathy*)

Participants were now tasked with finding ways to cope with these losses along with the emotional toll the symptoms of dementia were taking on them and their loved ones.

The physical losses that participants experienced included: changes in their gait which challenged their mobility; loss of balance; and knee or back pain which limited what they could do, where they could go, and how they travelled to different destinations in their neighbourhood. For one participant their physical losses meant that she could no longer go for hikes independently. This was a difficult adjustment because hiking had always been their opportunity for quiet reflection, solitude, and the practice of their active lifestyle. For another, they could no longer participate in the 'regular' exercise classes they used to enjoy. A third participant mentioned numerous times that they missed their lifelong coping

mechanism of partaking in judo, which was a great source of stress relief. The combination of getting older and experiencing dementia meant the participant no longer felt comfortable participating in this activity. He expressed a great deal of discontent at the loss of his lifelong hobby.

Participants were also gradually noticing changes in their cognitive processing abilities throughout their disease trajectory. Losses in their ability to read, process complicated information, follow or participate in conversations, and complete familiar tasks quickly meant that there were increasing limitations in the activities they could perform independently. These losses ultimately led to increasing levels of dependence on their support network over time as demonstrated in the following quotes:

Well [caregiver]'s been here since uh, um, not that long actually. Yeah, I was more independent before. Uh how long has she been here? Maybe September? I don't know. Oh [daughter] moved out in September and that's when [caregiver] came. So it's hasn't been that long. But I've gone downhill significantly I think. I don't know. (*Kathy*)

Researcher: What about town hall or city hall? Do you ever go there?

Caregiver: Along with me.

Keith: Yeah, yeah. She's the manager and manages me.

Researcher: Do you think you have a good support system?

Paul: Yes. My wife.

Researcher: Ok.

Paul: And there's other people here too. But my wife is my rock. My driver, my lover.

Nevertheless, participants continued to get out and keep busy despite these changes. For some getting out in the community was an important method of managing the depression that accompanied their disease.

Despite their recognition of their changing skillset and concerns for their own safety, some participants expressed frustration over others being overly cautious about their independent use of neighbourhood spaces. They reported feeling a stronger sense of loss when others began to patronize or underestimate them. For example, one participant said:

Eva: She came home and I don't know what I said and she says 'it's ok'. And I'm thinking we have to have some time to talk.

Researcher: Yeah. Yeah, I guess a lot of people it's almost like they don't know what to say so that's just what they say, you know what I mean.

Eva: Well she's trying to be very protective. And she's trying to give me positive feedback and all that. But it gets to the point that by the 20th time it starts to feel like that's enough.

Researcher: Yeah, so it starts to feel a little patronizing after a certain point?

Eva: Uh-huh.

Researcher: Yeah, yeah I can definitely see how that would be frustrating.

Eva: Like I know it's coming from a good place.

Some participants even hid their struggles from their loved ones for as long as they could to maintain the impression that they were independent and able to function entirely on their own. Despite their efforts, the symptoms of their disease began to show over time and they were no longer able to hide the losses they were experiencing.

Dementia is a progressive and chronic illness that affects an individual's cognitive function (WHO, 2015). This means that over time participants will continue to experience changes and losses in their skillset. With this in mind, maintenance of their current skillset and lifestyle for as long as possible into the disease trajectory was the primary goal for participants. Continuing to participate in their communities served as an act of maintenance. They felt that their community could help them maintain their independent mobility and participation despite their losses if the environment, the people, and the services available helped support them to do so.

Some individuals felt that the losses they were experiencing were beginning to affect their social life. 75% of participants in this sample indicated that they were concerned or very concerned about becoming embarrassed by the symptoms of their disease while they were out. They expressed concern over losing friends they already had or experiencing challenges when trying to make new ones. Being able to participate in the community by going for walks, joining social groups, or visiting a friend's house were viewed by participants as imperative to maintaining their relationships throughout their disease trajectory.

Participants identified being independent, capable of making their own decisions, being aware, remaining lucid, and not becoming a burden to others as features that defined their quality of life. Of these, agency and independence were most important to participants because they made them feel in control. After taking an in-depth look at the

data it became apparent that perceived independence was closely linked to how the individual rated their quality of life. It was noted that those who cited their life satisfaction as lower were the ones that felt that they had lost a great deal of their independence with the onset of their disease. Overall, 25% of participants indicated that they were dissatisfied with their life, 25% said they were satisfied, and 50% said very satisfied. For many, walking was a noteworthy indicator of independence:

Researcher: Why do you like walking?

Diane: It's the only thing I can do. I like the exercise too.

As long as I can go walking and as long as I can do things [independently I will have a good quality of life]. (*Eva*)

Walking was viewed as being more than a way to independently practice their mobility and community participation. It also provided participants the opportunity to make numerous choices along the way, to exercise, to remain involved in the community, and to independently transport themselves from one location to another. It was an outlet for some participants who were having a difficult time adjusting to their increasing level of dependence on others. Walking was an activity that allowed participants the time to reflect on their appreciation for the things they could still do on their own. Maintaining the ability to use walking as a method to explore their neighbourhoods was very important to participants. Using other methods of transportation independently, such as riding their bike or taking public transit, also served as a way for participants to maintain their agency.

To maintain or improve their quality of life participants expressed the desire to participate in their neighbourhoods as equal community members. Keeping physically active, having the option to access the places they wanted to go independently, and

ensuring there were supportive neighbourhood destinations to go to were all factors that participants felt would help maintain their quality of life. Despite the changes that participants were experiencing, they maintained an overall positive outlook. Although having dementia meant that they felt a sense of sadness about the things they could no longer do, it also caused them to feel a greater sense of appreciation for the things that they still could do. They expressed pride in their ability to maintain their participation in certain activities. For example, one participant spoke about his ability to continue giving back to his community after the onset of his disease:

Paul: Yeah, I volunteer at the food bank every [weekday] for four hours, five or six hours and um, I just love it. We, I have um between 550 and 200 people going through and uh five hours.

Researcher: Wow. That's busy.

Paul: I'm tired when I get in.

Researcher: Yeah I bet. Are you on your feet that whole time?

Paul: Well I go for a 50 minute break.

Researcher: Ok, still though, wow ... So um, what made you start going to the food bank?

Paul: Well um, I wanted to do something. And um, I 2000 and uh, 2000 and uh, well I was diagnosed in [year] and uh, you know I wanted to do something so um there was an ad on Craigslist for a volunteer. And so, that was [month] and uh, I... I sent my resume in and never heard from them. So the first week in [month] they phoned and asked us for help so, so that's two and a half years now.

Participants reported feeling thankful for the support they received from others and the neighbourhoods in which they lived. Participating in programs that were accessible to

them allowed respondents to feel moments of joy that made them forget about their changing skillset and the other losses that they had experienced.

5.3.3.2. Freedom

Walking and other forms of active transportation, such as riding a bike or taking public transit, represented a sense of freedom for people with dementia. This sense of freedom encompassed: movement and choice; the opportunity to explore familiar places and create new memories; the practice of their agency, independence, and mobility; and the opportunity for spontaneous interaction with others. A neighbourhood built environment that supports these behaviours, and the sense of freedom that accompanies them, is essential to maintaining their quality of life.

Participants stressed that they valued the opportunity to practice their freedom of movement within their neighbourhood as often as possible. The most frequent method of doing so independently was through walking. Participating in the community by walking signified the freedom of the person with dementia to make their own choices about where they want to go, when they want to go, how they want to get there, who they want to go with, and how far they want to travel. Walking also provided more flexibility when compared to other modes of transportation such as public transit.

Engaging in active forms of transportation throughout their community allowed for spontaneous interactions with others. For example, one participant spoke of a spur-of-the-moment interaction they had with fishermen in their neighbourhood:

One day I went walking up along there and [the fishermen] went walking right up to the end of that fish boat and they showed me around. (*Diane*)

Without their freedom of movement this participant would not have had the opportunity to experience this unplanned interaction which ended up leaving a lasting impression on them. Now, every time they pass that particular spot they think of that day and value the memories it gave them. This interaction also provided them with a sense of joy, normalcy, and belonging in their community.

While participants valued the chance to have spontaneous, new experiences they also valued the freedom to do things that were familiar to them. Participants indicated that they wanted to maintain the freedom to travel to the places and participate in the activities that they have throughout their life. One participant demonstrated this by explaining how he takes annual skiing trips to Whistler during the winter. At the time of the interview he had just arrived home from doing so again, alone and independently as he had done throughout their adult life.

Some participants felt constrained in their freedom of movement as they simultaneously aged physically while experiencing cognitive decline. Three participants were not able to walk as far as they used to and one participant could no longer walk for recreational purposes. While participants valued their freedom, some also expressed the desire for more. A few participants felt they had lost the ability to come and go in their community as often as they pleased and recognized that they needed to rely more on others than they had in the past. This was a difficult adjustment for those who began to feel more confined to their homes and overly protected by their caregivers. These participants missed the ability to freely move through their community spaces without others worrying about their safety. They also longed for the days when they could freely make decisions without others telling them what to do. These individuals emphasized that they are more capable than others give them credit for and expressed frustration at how both their disease and the people around them have started to limit their freedom of choice

and movement. The experience of these frustrations is illustrated by one of the greatest challenges to the freedom of people with dementia — losing their license. Not only did this limit their independent use of community spaces, but some participants also reported feeling unheard during the process of their license being removed. Ultimately, the data reveals that concerns for the safety of people with dementia can limit their sense of freedom and flexibility in their use of neighbourhood spaces. One caregiver reflected on this loss of freedom for their loved one:

Caregiver: It would be nice if she, Diane, felt comfortable enough to, well I don't know if we'd want her to wander off on her own anyways, but if she had an opportunity to meet people and not have to, you know [rely on others]. I mean of course we're here to take her if she ever wants to see friends or anything.

Researcher: Right.

Caregiver: But yeah. In a community setting wouldn't it be nice if there was that freedom to just come and go a bit more... because I think there's times you just want to get out of the house, right?

Diane: Yeah.

This points to the importance of an environment that can support the ability of persons with dementia to use community spaces independently by keeping them safe, supporting their wayfinding abilities, and encouraging their participation.

Participants stated that they appreciated the opportunity to leave their home to engage in community-based activities. Accessible programming designed for people with dementia grants this population the opportunity to participate freely in more activities. Some participants spoke of their experience with accessible programs during their interview:

Eva: Um, we went, I went when I was in [town name] I went to a program that was called [program name].

Researcher: Oh yeah?

Eva: And it's an exercise program for people who can't do regular exercise. So we had people who were in wheelchairs, who had had strokes, who had had uh, heart attacks, who had had knee or hip surgery, who had had uh, car accidents, we had everybody in every range from uh, we had one who had MS. And it was something that, and we were lucky we had a really good instructor who could adapt everything to everybody.

Researcher: Oh ok, that's good.

Eva: And you never felt, you know, everybody got to be good friends. And have fun. So it wasn't like 'oh I've gotta go do exercise' it was 'ok I get to go see so and so', so I enjoyed doing that. It was great.

Researcher: That's great. And you said that was in [town name]?

Eva: Mhm. And there's one here that I've just found that is the same thing. So I'm going to go to that one.

Eva: There's a thing that's called something about [program name] and it's a program for people who [have trouble reading]. So you give them, you sign up with them and you give them a list of what kind of books you like. So mystery, animal, nature, all that kind of stuff. And they send you a packet of 15 books and you pick, you can either go to the main library in [town name] or you can get them sent to either of the two here. And you go pick it up and they give you this big bag of books and they're on CD's.

Researcher: Oh ok, that's an interesting program.

Eva: Well it's wonderful because it gives you something to occupy your mind.

Paul: We uh, well we go to uh, what's that called?

Researcher: Oh, [name of a program specifically for people with dementia]?

Paul: Yes. We go to [program name] every Monday. We love it there. We're a family ... They are fun.

Finding ways to “escape” the reality of their disease through participating in community programs was viewed by participants as beneficial to their overall independence and freedom. Having destinations within close proximity to their home promoted the freedom to go places, experience the things that they enjoy, and be active participants in their communities. A well-designed built environment was found to help to support this sense of freedom.

Overall, the freedom of choice to perform activities independently was very important to people with dementia. They expressed appreciation for the opportunity to safely explore both the familiar and the unfamiliar within their community spaces. Ultimately, the freedom to practice their agency and independence by continuing to act as equal contributors to their community was very important to their overall quality of life.

5.3.3.3. Sense of Normalcy

Practicing their independent mobility and community participation helped participants maintain a sense of normalcy after the onset of their disease. Feeling that things were ‘normal’ was cited as contributing to their quality of life. Participants felt a sense of normalcy in their use of community spaces when they were able to participate just as the average community member would. This meant being able to go to familiar places, socialize with others, utilize services, give back to their community, participate in exercise or leisurely activities, run errands, and engage in civic activities. More methods

of maintaining a sense of normalcy spoken about by participants included: hosting and attending social events; celebrating milestones; taking the time to nurture their relationships with friends and family; spending time in nature; attending social and physical community programming; volunteering as an act of reciprocity in their community spaces; and keeping busy by sticking to their established daily routine. The chance to independently participate in these activities on a regular basis, and to do so spontaneously at times, were essential aspects that contributed to a sense of normalcy. During one interview a participant experienced a spontaneous interaction when he ran into some friends during our walk. Another participant spoke of a spontaneous interaction they recently had at a store in their neighbourhood:

Eva: Oh yeah, I needed a haircut and I had gone for an extra long walk so I was wetter than I am now. And I was along a storefront and I saw this window that was all plants and stuff and I figured it was a plant shop so I walked in and it was a hairdresser.

Researcher: Oh yeah?

Eva: And I said, they said could they help me? And I said 'oh, you can give me a haircut, sure'. She did.

Being supported by the environment helped participants engage in these activities unreflectively without feeling limited by the symptoms of dementia.

Participants felt that maintaining a sense of normalcy contributed to their quality of life because staying socially active and engaged allowed them to forget about the challenges they were facing (Figure 5.26). It also gave them something to look forward to and allowed them to feel a sense of belonging. While participants indicated that they tried to stick with their old patterns of behaviour as much as possible, they also recognized the

need to make adaptations for their changing skillsets. Even though they may have changed the way they participated as long as they were able to hold onto a pattern of participation and mobility in the community they were still satisfied with their use of these spaces.



Figure 5.26. Sense of Normalcy. Staying socially engaged helped participants maintain a sense of normalcy. This was the location of one participant’s daily outing to socialize with family and friends.

Walking was cited as a particularly important way that participants held onto their sense of normalcy in community spaces. Walkable destinations in their neighbourhood allowed participants to engage independently in the physical and social environment just as anyone else would. Walking had become a part of participant daily routines and defined their participation in the community:

Researcher: So is it important to you to be able to get out in your community and walk around?

Keith: Oh yeah. That’s what I do.

Researcher: So being able to maintain that level of independence as long as possible is really important to you?

Eva: Yeah. Like as long as I can go walking and as long as I can do things [I will have a quality of life].

It was important for participants to stay mobile through walking because it made them feel active, capable, and independent when they may not be treated that way by others. Walking served as a way to prove to themselves and those around them that they were still able to participate independently in their community after their diagnosis. Walking was seen as a leisurely activity, a source of exercise, and a passive way to take in the world and explore their neighbourhood.

Maintaining a sense of normalcy not only applied to the maintenance of the activities they have done in the past, but also applied to the opportunity to try new things. Before their diagnosis participants were able to freely do new things and go new places. They spoke of the importance of not letting their diagnosis drastically change their lives and the things that they do. Thus, making any needed adjustments to continue exploring new places as they have throughout their lives was important to participants. While they felt the most comfortable in their familiar spaces, some participants still expressed the desire to participate in spaces outside of their immediate neighbourhood. Participants spoke of plans to travel and try new things proving that experiencing life does not end for them at diagnosis:

Researcher: So is there any place that I didn't list, that I missed, that's important to you that you go?

Peter: Uh, we covered theatre. Uh, travel.

[...]

Peter: Now [the Maritimes are] something I'd love to see ... Cape Breton is where all the fiddlers go.

Researcher: So do you usually travel to specific places or do you go like, the same kind of place over again or?

Eva: Yeah.

Researcher: [Location] usually?

Eva: Yeah, or [location]. I have a friend, the one that I was talking about she and I drove back from Ontario. Well she's moved to [location] so I go visit her once a year. Well I have, I've gone once a year for the last five years.

Researcher: Do you go to the beach?

[...]

Paul: Yeah we go to different places all the time.

Researcher: Oh good. Did you guys end up going to Whistler this week?

Wayne: I did.

Caregiver: He went alone.

This speaks to the importance of ensuring communities are dementia-friendly so people with dementia have the option to go beyond their proximal spaces and use unfamiliar areas independently. Simply, maintaining their sense of normalcy came down to being able to continue participating in community-based activities, whether the activities were routine or new and unfamiliar.

Maintaining a connection to their neighbourhood environment and the people within it was also an important factor in sustaining a sense of normalcy for people with dementia. In order to maintain a connection to other people participants felt it was

important to educate others about their illness. Knowing others in the community were educated about the disease would help them feel more comfortable and confident while practicing their independent mobility and participation. This would help by normalizing discussions surrounding the disease, combating stigma, and increasing community support for people with dementia. Maintaining a sense of connection to others in the community was vital for participants to feel involved and valued. They felt that it was important to know others and remain known to others. Encouraging normalcy for people with dementia was thought to provide a sense of belonging in that others would not have to make exceptions for them to be included in community spaces, but rather that the person with dementia could just exist in that space and enjoy it as it is. Their ability to participate independently in the community was viewed as being of utmost importance for their quality of life. Below, some participants reflect on what getting out in their community means to them:

Everything. Because you're still human. You can, like the exercise class, you're part of a community and nobody judges you. Because a lot of times you'll go somewhere and it's like the, the 'oh you can't do this, just sit over here' or 'can we do anything for you' and it's not that you're not grateful that they're wanting to help but it's, it's, I can ask. Like if I can't do something I have no problem asking for help. (*Eva*)

I like it. It gets me exercise so I'm not lazy. I am familiar, I don't ask for help. And money is not important to me, health is important to me. (*Sue*)

Well it's very important because um, like I said I love everybody and everybody knows me so it's uh, very important. (*Paul*)

Researcher: The next set of questions are more so about how these things influence your quality of life. So is it important to you to be able to get out and?

Wayne: Oh yeah.

Researcher: Yeah? So why is that important to you?

Wayne: Uh, I uh, going to, to the places.

Caregiver: That will be a hard thing for him to explain, but we've always been outdoor people. So you know, walkers, campers, hikers, we like to keep active.

Researcher: Oh yeah. So Vancouver really is the perfect place for you guys then.

Wayne: Oh yeah.

Chapter 6.

Discussion

This study sought to explore the facilitators and barriers of the neighbourhood built environment for persons in early-stage dementia. The primary goal was to examine the built environmental features that affect the individual's experience of mobility and community participation, and in turn, how this influences their quality of life. The analysis of the findings is guided by Lawton's (1973) ecological model of aging, Rowles' (1983) theory of insideness, and the progressively lowered stress threshold model (Smith, Gerdner, Hall & Buckwalter, 2004).

The findings suggest that neighbourhood built environment features that: promote alternative forms of transportation to driving, make older adults with dementia feel safe, encourage wayfinding, are pedestrian-friendly, and provide access to a variety of community destinations — enhance the quality of life for persons living with early-stage dementia. This chapter will present a review of the study findings along with a discussion on their relationship with the conceptual framework. The findings will be reviewed under subheadings reflective of the research questions for this study. This chapter will also discuss study limitations and provide suggestions for future research, implications of the findings, and general conclusions.

6.1. Review of Findings

6.1.1. Challenges to Mobility and Participation

The research suggests that leaving the comfort zone, safety, changing skills, and losing their license are the primary challenges to the mobility and community participation of persons with dementia. These findings reveal that persons with dementia must be comfortable in an area in order to navigate through and engage with it independently. Unfamiliarity, unpredictability, and sources of overstimulation in the environment are the primary sources of stress to persons with dementia when participating in public spaces. Thus, it is important to design neighbourhoods to promote feelings of safety, navigational ability, and that ease adaptation. Designing neighbourhoods in this way has the potential to provide comfort to the person with dementia as they participate in unfamiliar spaces. The existing literature on this topic echoes these findings. The importance of familiarity with the environment was a major theme in the literature with the research suggesting that familiarity promotes confidence, feeling welcome in the community, and acts as a source of natural encouragement to remain involved and participate in activities for longer (Brorsson & Nygard, 2011; Brorsson et al., 2014; Mitchell & Burton, 2010; Mitchell, Burton & Raman, 2004; Keating & Gaudet, 2012; Phinney, Chaudhury & O'Connor, 2007; Son Hong & Song, 2009; Ward et al., 2017).

The findings reveal that people with dementia learn to adapt to their surroundings and adjust their behaviour to perform daily tasks and activities. Not being able to drive any longer required participants to employ alternative methods of transportation to access their community destinations. Losing their driving license meant that their independence and the areas in which they could travel were limited. This suggests that alternative modes of transportation are essential for people with dementia to continue using public spaces

independently and to travel outside of their immediate neighbourhoods. Alternative forms of transportation that are accessible to people with dementia are thought to promote their independence and maintain their agency for as long as possible into the disease trajectory. The findings suggest that a pedestrian-oriented neighbourhood (i.e., removed from traffic, quiet, well-maintained) feels safer and promotes comfort for people with dementia.

6.1.2. Environmental Features that Influence Mobility and Participation

The findings reveal that sidewalks, seating options, ambience, public transportation, and crosswalks are the most influential pedestrian-friendly features of the built environment that effect independent mobility and participation of persons with dementia. Additionally signage and maps, landmarks, distinction, simplicity, clarity, consistency and straight street layouts are the primary features of the built environment that promote the wayfinding ability of persons with dementia in their neighbourhoods. Finally, this study demonstrates that density and mixed-use areas, proximity, dementia-friendly destinations and other people promote the involvement of persons with dementia in their neighbourhoods.

The data reveals that pedestrian-friendly features of the environment make participants feel safe (i.e., slow down traffic, give them enough space from traffic, ensure walking paths are void of tripping hazards), provide them the option to move at their own pace and take rest when needed (i.e., seating options), and make the environment visually appealing and welcoming. This study demonstrates that it is important to directly to engage persons with dementia when designing pedestrian-friendly communities meant to

support them. They have unique and valuable views on features of the neighbourhood built environment that would be difficult for someone without dementia to understand. For example, a family caregiver in this study thought a scramble design in a street crossing promoted walkability of the neighbourhood for the person with dementia. However, the person with dementia noted that the intersection design was cognitively too overwhelming for her.

The literature on this topic emphasizes the importance of wayfinding in the community for people with dementia (Blackman, Schaik & Martyr, 2007; Mitchell & Burton, 2006, 2010; Sheehan, Burton & Mitchell, 2006). Previous research has shown that appropriate features, shapes, colours, and landmarks incorporated into the neighbourhood built environment can facilitate wayfinding ability through making the environment legible (Mitchell & Burton, 2006, 2010). This study also found that distinct features and landmarks were essential to the wayfinding capability of participants. Mitchell and Burton (2006) also emphasized the importance of simple street layouts, which is supported by the findings. Much like other research on this topic, this study finds that getting lost is one of the primary concerns for people with dementia when navigating in the neighbourhood. The data reveals that having an environment that encourages their wayfinding ability in unfamiliar areas or that assists with reorientation in familiar areas is an essential feature to encourage their mobility independence in these spaces. Designing an environment that is easy to navigate supports their ability to get out in the community and to feel safe and confident when doing so. Previous research found that people with dementia generally do not want to ask for help in reorienting themselves if they become lost so they begin to rely more on the support of their surrounding environment to find their way (Mitchell & Burton, 2010). However, this research found that people with dementia do not hesitate to ask for help from other community members when they become lost.

Banks and transportation centres stand out as two community destinations that are strongly in need of changes to encourage people with dementia to independently use these services. The bank was the community destination that was most challenging for participants to continue using independently, yet most participants still expressed a desire to go there. Transportation centres also had a notable decrease in the ability of participants to use these spaces independently. Transportation centres are very important for people with dementia to maintain their mobility behaviours because most will stop driving after the onset of the disease. Thus, remaining independently mobile in their communities means that they will become increasingly reliant on other modes of transportation, such as public transit, to get around. Finding ways to reduce the feeling of being rushed and to break down the amount of information participants must process at a time is essential to helping people with dementia feel capable and at ease in these spaces. The data suggests that these two neighbourhood locations should be especially targeted for dementia-friendly community initiatives because accessing their services can be challenging, yet they are essential for the independence of this population.

Interviews with participants reveal that people with dementia enjoy going to destinations that are visually appealing, familiar, close to their home or places with fond memories. Understanding where people with dementia go, when they decide to go, why they decide to go to particular locations, and what barriers they face when independently accessing destinations in their neighbourhood provides essential information to dementia-friendly community initiatives.

6.1.3. How Independent Mobility and Participation Effect Quality of Life

The option to live at home for as long as possible into the disease trajectory is often the preferred choice of persons with dementia and is also cited as the better economic option (Aminzadeh & Garcia, 2010; Chappell, Dlitt, Hollander, Miller & McWilliam, 2004; Gitlin & Corcoran, 2000; van Hoof & Blom, 2010). Living at home means the person with dementia can continue to participate and be mobile in neighbourhood spaces that are familiar to them. This study asked participants to reflect on how being mobile and participating in their neighbourhoods influences their quality of life. The findings reveal that independent mobility and community participation represent maintenance in a time of loss, freedom, and a sense of normalcy to persons with dementia. Therefore, in order to maintain their quality of life in the community it is essential to help people with dementia maintain their independent mobility and community participation for as long as possible.

Existing literature indicates that people with dementia identify staying socially active as important to their quality of life and doing so helps them feel that their lives are fundamentally unchanged (McDuff & Phinney, 2015; Ohman and Nygard, 2005; Phinney, Chaudhury & O'Connor, 2007; Phinney et al., 2016; Phinney & Moody, 2011; Ward et al., 2017). The participants in this study echoed these findings, identifying social activities as motivators for their participation in the community. The literature also suggests that it is important to people with dementia to continue to participate in their communities much like they had before their diagnosis, and to continue engaging spontaneously in their community environments to confront the stigma surrounding dementia (Phinney, Chaudhury & O'Connor, 2007; Phinney et al., 2016; Ward et al., 2017). Participants in this study also emphasized their ability to continue participating in spaces much like they had

before their diagnosis, partly as a way to prove to others that they are still capable of performing tasks independently. The existing literature and findings from this research converge on the importance of a sense of continuity and independence in community spaces to the quality of life of persons with dementia (Blackman, Schaik & Martyr, 2007; Mitchell & Burton, 2010; Mitchell, Burton & Raman, 2004; Phinney, Chaudhury & O'Connor, 2007).

Due to challenges related to losing a major method of transportation in their neighbourhoods (i.e., driving), participants began to rely more on walking to maintain their independent mobility and community participation. An increasing reliance on walking means that they attribute their ability to walk to places as being closely linked to their quality of life. The findings reveal that walking becomes much more than just a form of transportation to participants as it is also a source of exercise, leisure, and a chance to socialize; it represents independence, autonomy, and freedom to participate in community spaces; and it helps establish a routine and provide access to preferred destinations. Walking elicits involvement in their community, gives them something to look forward to, helps them feel engaged, provides them with an opportunity to connect with others and utilize their current skillset, and makes them feel like an equal contributor to their community spaces. Designing walkable neighbourhoods is therefore a very important community feature to improve the quality of life of persons with dementia.

6.1.4. Relationship of Findings to the Conceptual Framework

Although the conceptual framework was not used to guide the data collection of this study, it was used to guide the interpretation of the findings. The conceptual framework served as a supplemental, inductive strategy to help structure and guide the interpretation

of the findings allowing for a more comprehensive understanding of the relationships explored in this study.

The theoretical underpinnings for the conceptual framework can be used to help understand the findings from this study. In addition, the findings reflect several of the relationships presented in the conceptual framework and provide support for the idea that the built environment has an effect on the independent mobility and community participation of persons with dementia. This section will begin with a discussion of the relationship between the findings and Lawton and Nahemow's (1973) ecological theory of aging, Rowles' (1983) theory of insideness, and the progressively lowered stress threshold (PLST) model (Smith, Gerdner, Hall & Buckwalter, 2004). It will then discuss how the findings reflect the conceptual framework and its implications.

Lawton and Nahemow's (1973) ecological model of aging requires that in order to approach the relationship between a person with dementia and the influence of the neighbourhood built environment on their quality of life, we need to consider both the individual and the environment as active agents in compensating for declining abilities over the disease trajectory. The findings in this study suggest that the environment serves as a means to compensate for a loss of wayfinding ability over time. People with dementia also begin to use their familiarity with the environment to compensate for declines in their skills by looking for orientation cues, avoiding places with tripping hazards, and being selective about the destinations they go to. Although individual competence is declining for the participants, they still actively work to adjust their own abilities in order to utilize the environment when it fails to support them. They do so by becoming more selective about where they go in their neighbourhood, by establishing a routine, and by asking for help when needed.

The findings from this study suggest that familiarity is one of the key features of the environment that supports the independent mobility and participation of people with dementia. This is because familiar spaces promote a feeling of comfort. Participants stated that they were “just used to [their neighbourhood]” and were observed moving through these spaces unreflectively. Similarly to the findings from a study by Phinney, Chaudhury, and O’Connor (2007) this study demonstrates that familiarity with the environment can encourage the involvement of people with dementia in familiar activities. Features of the environment that participants felt may have presented a barrier to them in other areas (e.g., not having seating options available) were not seen as a barrier to them in their own neighbourhood. This is supportive of Rowles’ (1983) theory of physical insideness which states that an innate body-awareness of the details of the environment allows older adults to continue functioning in spaces that would otherwise be beyond their level of competence.

The PLST model posits that stress can accumulate for a person throughout the day (Smith, Gerdner, Hall & Buckwalter, 2004). In this study, the findings reflect this through statements from participants that indicate that they find it easier to go out in the community in the mornings when they are the most alert. Participants felt that throughout the day they may grow increasingly stressed or tired, both physically and cognitively. The PLST model also states that as dementia progresses lower doses of stress triggers begin to produce stress responses such as dysfunctional behaviour (Smith, Gerdner, Hall & Buckwalter, 2004). Participants spoke of noticing changes in their behaviour and how they respond to situations after the onset of their illness. For example, one participant spoke of becoming extremely stressed while at a busy grocery store, something she had not experienced before. Another spoke of feeling more cautious around traffic or while at intersections. A third reported becoming too anxious to go places on their own. A number

of participants said they began to avoid busy places because they were worried about becoming stressed after their diagnosis. The PLST model also considers the environmental features that contribute to these sources of stress. The findings from this study reflect the importance of modifying the environment to support the abilities of people with dementia and to make them feel safe.

Although they were not incorporated into the conceptual framework, two additional theories apply to the findings of this research. Namely: continuity theory and selective optimization theory. Continuity theory states that older adults try to maintain the same activities, behaviours, and relationships that they have throughout their life (Atchley, 1989). This pattern of behaviour can also be seen in the participants with dementia in this study. Participants strove to maintain the same patterns of participation and mobility that they had experienced before the onset of their disease. In the case of these participants doing so helped to maintain their independence in a time that they were experiencing great loss. Further, they valued the ability to hold on to the friendships and relationships that they had before. The selective optimization and compensation theory states that in order for older adults to adapt to the aging process they need to select and optimize their abilities to compensate for their declines (Baltes & Baltes, 1990; Donnellan, 2015). The findings from this study reveal that persons with dementia undergo selection, optimization, and compensation strategies in order to continue as active members in their communities. They do so by becoming more selective with the tasks they choose to take on, deciding to step away from more challenging responsibilities and instead focusing their attention on the tasks they can still do independently.

The remainder of this section will discuss how the findings from the study reflect the relationships in the conceptual framework (Figure 3.1). Individual competence and agency is the starting point of the framework. The findings from this study reveal that

individual responses to their illness (i.e., attitude, behavioural changes) influence the way the person participates in their community. Take for example the contrasting experience of two participants who moved after the onset of their illness. One of these participants became depressed, anxious, and lost their confidence following the onset of their disease. As a result, they found it difficult to participate in community spaces without the help of others. This participant was widowed and had to rely on a support network of extended family for help, requiring her to move from their home and away from their friends. She did not have a say in the decision to move. In contrast, another participant regularly advocated to their friends and family that despite the fact that she had lost some abilities, there were also many others that remained. She took and relished in the chance to use the neighbourhood environment independently at every opportunity. This participant had a supportive spouse and actively participated in the decision to move closer to their children and friends after the onset of their disease.

Despite these two participants both having to face the challenge of a new environment they responded to it very differently. One allowed the unfamiliarity of the environment to discourage her from participating in community spaces, while the other, despite various occasions of becoming lost, continued to explore and thrive in their new neighbourhood. This is one of many examples of how individuality (e.g., comorbidities, levels of support, personality, personal background, etc.) plays a crucial role in how individuals interact with their neighbourhood spaces. The framework captures the interplay between the individual and the environment and how it affects their mobility and community participation. At the early-stage of dementia, the findings from this study reveal that individual competence and agency still play a large role in the relationship between the individual and the environment. Using the tenants of the ecological model of aging, the framework accounts for the fact that the environment will need to play an increasingly

important role in the adaptation abilities of a person with dementia as the disease progresses into the later stages.

The next section of the framework encompasses both the built and social environment. The assumption for this framework was that the level of support that the built environment provides for a person with dementia influences their experience of mobility, community participation, and quality of life. The findings from this study supported this assumption. Neighbourhoods perceived as having high levels of support (i.e., pedestrian-friendly features, features that promote wayfinding, accessible community destinations, support from other people) encouraged people with dementia to be mobile and active participants in their communities. Participants also felt comfortable using their neighbourhoods independently if they felt supported by the built and social environment. Meanwhile, neighbourhood features perceived as having a low level of support (i.e., safety hazards, busy areas, destinations consisting of challenging tasks, unsupportive people) discouraged and presented barriers to independent mobility and participation. Participants reported that if the challenges that they faced to their mobility and participation (i.e., leaving the comfort zone, safety, losing their license, and a changing skillset) were addressed through supportive built and social environment features they would be more at ease when facing these challenges. The findings reveal that where individual competence had weakened, the environment had the capacity to step in and compensate for these changes to ensure participants could still use their neighbourhoods. The findings also demonstrate that there are areas in participant neighbourhoods where the built environment could be improved even further to fuel independent mobility and participation.

Lastly, the framework suggests that a person's experience of mobility and community participation can influence their quality of life. The findings of this study demonstrate that this is indeed the case, as the ability to remain independently mobile and

to participate in their community was cited by participants as a crucial element of their quality of life. The ability to remain involved in their community through using neighbourhood spaces represented maintenance in a time of loss, freedom, and a sense of normalcy for people with dementia. Participants identified their ability to walk through neighbourhood spaces, stay connected with others in their community, and engage purposely or spontaneously in the activities they have always enjoyed as features that enhance or maintain their quality of life.

Much of the research that explores how the built and social environment influence people with dementia in the community lacks an explicit conceptual framework. This is a significant gap in the literature because conceptual frameworks can serve as a tool that: guides the approach to research, structures the findings, clarifies and focuses complex ideas and relationships thereby supporting communication across disciplines and knowledge systems, and provides a practical use for theoretical achievements (Potschin-Young et al., 2018). This framework is novel because of the relationships it explores, it is flexible, and it was designed with people with dementia in mind. The framework could also be applied to other groups of older adults in the community. Theorists within the field of environmental gerontology attempt to understand the complex relationship between a person and their sociophysical environment as they age (Wahl & Gitlin, 2007). Old age is generally considered to be a time in a person's life that is plagued by lost social roles and physical declines (Rubenstein & Parmalee, 1992). While this is certainly not true for all older adults, the declines associated with the aging process raise questions surrounding how adaptations to changing individual capacities and the accompanying environmental settings are addressed amongst this population. The vast majority of older adults indicate that they want to age in place meaning that they prefer to remain in their current home and neighbourhood as they age (Cutchin, 2003). As the findings in this study and others

show, individual capacities can decline as a person ages and as a result the environment may need to take on an increasingly compensatory role over time. This conceptual framework may serve to help guide environmental gerontologists or individuals designing age/dementia-friendly communities in understanding the relationship between the built and social environment, mobility, community participation, and quality of life amongst older adults.

6.2. Study Limitations

There are a few limitations to consider when interpreting the findings of this study. This section will discuss the study's limitations and provide suggestions for how future research can fill these gaps moving forward.

First, the choice to use walk-along interviews as a research method prevented certain groups of people from participating in the study. Namely, those who are not independently mobile. These individuals may be particularly vulnerable to social isolation and disengagement from their communities after the onset of dementia. Understanding the unique set of challenges that this group faces in maintaining their mobility and community participation is a worthwhile endeavor for future studies.

Second, all participants from this study had early-stage dementia. Thus, the findings are not reflective of the challenges faced by those further into the progression of their disease. Individuals experiencing the early stages of dementia are typically able to continue functioning much in the same way that they did before the onset of their illness (Alzheimer Society of Canada, 2017c). They often need little help at this stage (Alzheimer Society of Canada, 2017b). However, as the illness progresses they require increasing

amounts of help with daily tasks (Alzheimer Society of Canada, 2017d). Over time, this progression may create an entirely new set of challenges for the person with dementia when participating or being mobile in their community. Research states that persons with dementia tend to live at home until a crisis causes them to transition into long-term care, suggesting that many people with dementia continue to live at home at least until the moderate stages (Mitchell & Burton, 2006). Therefore, it is important for future research to address how communities can continue to support a person with dementia further into their disease trajectory.

Another limitation is that all the neighbourhoods included in this study are either in urban or suburban areas. Therefore, the findings are not reflective of the experience of those living with dementia in rural areas. This is an important avenue for future research due to the unique challenges rural communities present to mobility and participation. Alternative transportation options such as public transit and taxis are often scarce or non-existent in these areas. This has the potential to present a significant challenge to the independence of people living with dementia because many of them no longer drive. A lack of resources and services within walking distance of their homes is another potential challenge for people with dementia living in these areas. It is important that any future research that addresses this gap within a Canadian context recognizes that rural communities are not homogenous and regions across the country are vastly different from one another (Wiersma & Denton, 2013).

Lastly, the sample from this study was not reflective of the ethnocultural and socioeconomic diversity within Metro Vancouver and other Canadian regions. Research suggests that immigrant older adults for whom English is a second language are more likely to experience social isolation and depression because they face linguistic and cultural barriers when accessing services (Kim, Auh, Lee & Ahn, 2013; Jang et al., 2015).

Also, older adults of lower socioeconomic backgrounds have been shown to have lower life-space mobility than those with a higher socioeconomic status (Eronen et al., 2016). Combined with the challenges already faced by persons with dementia, members of these vulnerable population groups may face additional challenges to participating and being mobile in their communities. Having limited input from members of these groups makes the data obtained in this study less generalizable to the older adult population as a whole. Future research should attempt to include more diverse groups in their samples in order to address this issue.

6.3. Methodological Reflections

If a participant was recruited as a subsample from ACT-OUT survey the MMSE did not have to be conducted. Due to a preexisting relationship between the ACT-OUT study and the UBC Centre for Brain Health the MMSE scores for these participants were already made available to the researcher. The MMSE was conducted with the participants who were recruited using other methods. Having the MMSE as the initial interaction with the participant was challenging as they expressed their discomfort in undergoing cognitive testing. As the researcher, I also experienced discomfort in asking participants to undergo something they did not enjoy. I took steps to ensure their consent and tried to immediately turn the interview towards a conversational tone after the MMSE to shift the power dynamic from myself to the participant. I would recommend that in future studies researchers find an alternative way to confirm eligibility for participants with dementia.

Upon reflection I believe that the walk-along interview, the core method of this research, was an essential component in capturing the experience of participation and mobility in the neighbourhood for people with dementia. Using this method was useful for

the purposes of this study in the following ways: first, moving through the neighbourhood with the participant allowed the environment to serve as an interview probe. As we passed by particular things in the neighbourhood the participant would be reminded about how they interacted with these features while out. Second, walking also allowed me to experience the reality of how participants interacted with their environment. At times, I would ask about certain environmental features and the participant would respond in a way that was not accurately reflected in their behaviour when we actually arrived at that feature. For example, one participant tried to explain how they used the crosswalks in their neighbourhood. However, once we arrived at a crosswalk they exhibited behaviour that was not in line with their explanation from earlier (see Chapter 5 under subheading “Crosswalks” for more detail on this interaction). Thus, using this method allowed for a more accurate understanding of the participant experience rather than just being told their own perceptions of these interactions.

Further, using this method empowered the person with dementia to take the lead while guiding me through their neighbourhood. At first, some participants would hesitate while deciding which direction to take instead asking me which way I wanted to go. I encouraged participants to choose the direction themselves and reminded them that I was not the expert, they were. As the interview progressed they stopped asking me which way I preferred to go and began to take the lead. During the interview the participant acted as an environmental expert and constructed both a historical and personal understanding of place as we moved through their neighbourhood spaces. The nature of this interaction seemed to provide participants with a sense of control that they may not have in their day-to-day lives now that they are experiencing dementia. Participants expressed excitement at the idea of going for a walk and showed pride when directing me around their neighbourhood. In the short time I spent with them, I felt that I got to know the participant

well. I got to hear about their challenges, their triumphs, and their mundane everyday activities. I believe that the walk-along interview is a strong method to use in qualitative research particularly when exploring the environment, whether it is built or social.

6.4. Implications for Policy and Practice

Despite the limitations mentioned, this study addresses important gaps in the research on the role of the neighbourhood built environment on mobility and participation among people with early stage dementia based on their first-hand experiences in the community. The study used innovative and participatory methods of data collection to address this important topic area. The findings point toward policy implications to: develop dementia-friendly communities, inform inclusive neighbourhood design and urban regional planning policies, and support aging in place. This section will discuss these implications and what they could mean to the quality of life of people with dementia.

Policies aimed at helping persons with dementia often focus on their physical and health needs while neglecting to address their social, emotional, spiritual, or other needs (Alzheimer Society of Ontario, 2016). The importance of meeting the holistic needs of persons with dementia to create the best quality of life possible cannot be understated (Alzheimer Society of Ontario, 2016). Policies directed at creating dementia-friendly communities have the potential to address these holistic needs. They would do so by encouraging the engagement of older adults with dementia in community spaces through enhancing the support they receive from their environment and other people, improving access to services, and emphasizing their value as equal contributors to their community.

Planning and designing a neighbourhood built environment that addresses the needs and challenges of all community members requires creative vision, strategic decision-making, and a thorough implementation of infrastructure, programs and services (Toronto Public Health, 2012). All levels of government play vital roles in creating and realizing the vision for well-designed neighbourhoods. The findings from this study point toward the importance of creating walkable and transit-friendly neighbourhoods for people with dementia. It is important to consult with multiple levels of government to ensure guidelines surrounding land use planning are followed in order to create pedestrian-friendly communities (Toronto Public Health, 2012). Both provincial and federal governments have a role to play in establishing the plans, programs, policies, and funding that can support the development of pedestrian-friendly and transit-supportive neighbourhoods (Toronto Public Health, 2012).

Municipal-level governments are the ones responsible for guiding development in the community at hand. This level of government can improve the targeting and effectiveness of services, measure how agencies and partnerships are performing, prioritize built environment changes based on the needs of their residents, and create community ownership (Alzheimer Society of Ontario, 2016). The findings from this study demonstrate the importance of considering the first-hand experiences of persons with dementia and their caregivers to make effective and meaningful changes to the neighbourhood environment. Local officials should ensure that they consult with these residents to empower them to have a say in their communities. Dementia-friendly communities also emerge from the advocacy of grassroots organizations and community groups. These individuals play an important role in ensuring the voices of people with dementia and their caregivers are being heard and that the changes being made actually support and improve the quality of life of this population. Neighbourhood environmental

features need to be re-evaluated regularly and consulting persons with dementia and their caregivers throughout this process is essential to ensuring their needs are being met. The findings from this study can help guide government officials and local advocacy groups in determining which environmental features to prioritize, evaluate, and address in their neighbourhoods.

A public that is educated about dementia is an essential feature of creating dementia-friendly communities. The findings from this study speak to the importance of increasing public awareness surrounding dementia in order to combat and reduce stigma. Policies, programs, and initiatives aimed at educating members of the community who may interact with persons with dementia in either a professional or personal capacity would increase the confidence and level of comfort persons with dementia experience while out in their community.

The findings from this study demonstrate that in order to encourage their independent mobility and participation persons with dementia need to not only be supported on the way to and from their destination, but must also be supported once they arrive. To make community destinations accessible to this population the findings suggest that staff must be trained on how to effectively engage and support persons with dementia; the built environment must support them on their journey there; and the environment once they arrive should be calming, easily understood, and physically accessible. Federal, provincial, and municipal governments all play an important role in creating and implementing policies, programs, and initiatives that can support the overall health, independence, and quality of life of persons with dementia.

6.5. Conclusion

The findings of this study reveal that the quality of life of a person with dementia is linked to their experience of mobility and participation in their neighbourhood. Dementia-friendly neighbourhood built environments have the potential to help persons with dementia maintain functioning, independence, autonomy, and quality of life after the onset of the disease. The study revealed that leaving the comfort zone, safety, losing their license, and changing skills were the primary challenges facing persons with dementia in their use of community spaces. Features that were shown to facilitate or present barriers to the independent mobility and participation of persons with dementia included: pedestrian-friendly features such as sidewalks, seating options, ambience, public transportation, and crosswalks; wayfinding features such as signage and maps, landmarks, distinction, simplicity, clarity, consistency, and straight street layouts; and features that promoted the use of community destinations such as density, mixed-use areas, proximity, dementia-friendly destinations, and other people. The independent use of community spaces was found to provide maintenance in a time of loss, freedom, and a sense of normalcy to people with dementia. Moving forward, it is important to collect data from diverse groups of persons with dementia to discover how cultural barriers, community settings, and experiences at various stages throughout the disease trajectory can influence their relationship with the neighbourhood built environment. It is important to acknowledge that creating dementia-friendly communities is not only beneficial for people with dementia and their caregivers. There are economic, political, and psychosocial benefits to creating neighbourhood spaces where people with dementia have the option to participate independently as long as reasonably possible during their disease trajectory. An environment that is designed to support people with dementia can help these individuals avoid negative outcomes such as falls, disorientation, or confusion. Ultimately,

an environment that is easy to understand and navigate, that is safe, accessible, and inclusive is beneficial for everyone in the community.

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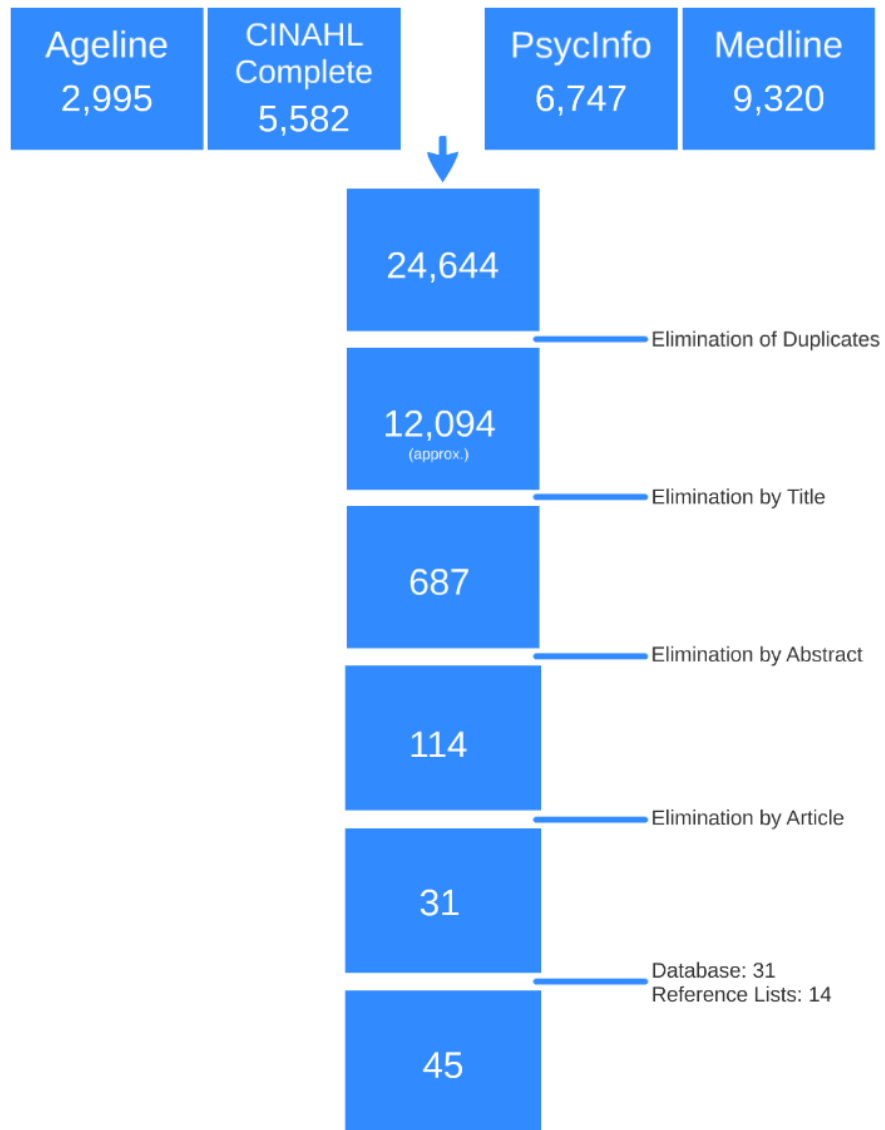
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Appendix A.

PRISMA



Appendix B.

Interview Guide

Note: *The walk-along interviews were semi-structured interviews. The below questions were only used as a general guideline. Questions may have been added or removed based on the flow and content of each individual interview.*

- 1) Why did you choose this particular walking route today?
- 2) Have you noticed a change in how you navigate your environment since experiencing memory loss? If so, how?
 - a. Do you foresee any changes as the memory loss worsens?
- 3) What do you feel are the biggest challenges presented to you by the physical environment when you are out in your community?
 - a. How do you overcome these challenges?
- 4) Are there any characteristics of the physical environment that you feel encourage you to get out more?
 - a. Are there any that discourage your participation in the community?
- 5) How could the physical environment be improved to encourage your mobility and/or participation in the community?
 - a. Do you think this would have an impact on your quality of life? If so, how?
- 6) How do you feel about public transit in your neighbourhood?
 - a. How could it be improved?
 - b. What is it doing well?
- 7) Do you walk at night?
 - a. Alone?
 - b. In the rain or bad weather?
 - c. How could the environment help support you to do so? (If applicable)
- 8) How do you feel about [specific item here] – sidewalks, crosswalks, gardens, parks, benches/seating options, neighbourhood design, roads, lighting, signage, curbcuts, washrooms, etc. – in your neighbourhood?
- 9) How do you find your way? (Landmarks? Signs? Familiarity? Other People?)
- 10) How has your mobility changed over the years?
 - a. Your community participation?
 - b. Both since losing your license? (If applicable)
- 11) How could the environment better meet your needs?
- 12) Do you take breaks when you walk? Use benches?

13) How do you make yourself feel safe?

***The interview guide for the sedentary interview was tailor-made for each participant based on the results of the walk-along interview and the ACT-OUT survey data. However, the following questions were used as general guidelines for each participant:**

Perceived importance of the role of the built environment

- 1) How important of a role do you feel the physical environment plays in your mobility and/or participation in the community? Please explain.
- 2) What else do you think contributes to increased mobility and/or participation in your community?

Perceived importance of community participation

- 1) Is participation in the community important to you? Why or why not?
- 2) Is maintaining your current level of mobility in your community important to you? Why or why not?

Perceived levels of community participation (and changes)

- 1) Can you describe a typical outing for you in your community?
 - a. Has this changed for you since experiencing memory loss? If so, how?
 - b. Have these changes had an impact on your quality of life?

Quality of life

- 1) What contributes to your quality of life?
- 2) How would you define quality of life?

Appendix C.

ACT-OUT Survey

ACT-OUT Study

Participant ID: _____

-Socio-demographic Information

Is another person present at interview to serve as support/proxy?

YES NO

I am going to ask you some basic demographic questions. Please answer each of the following with the single best answer.

Q1. Age: ___ years old

Q2. Birth date: ___/___/___
(Month / Day / Year)

Q3. Zip Code: _____

Q4. Sex: ₁ Male ₂ Female

Q5. What is your relationship status? (Check one box)

- ₁ Never married/Single
- ₂ Married
- ₃ Cohabiting
- ₄ In a relationship but not cohabiting
- ₅ Separated/Divorced
- ₆ Widowed

Q6. Which race or ethnic group do you primarily identify with? (Check all that apply)

- ₁ Black
- ₂ Mixed Race
- ₃ Hispanic
- ₄ White
- ₅ Native American
- ₆ Asian or Pacific Islander
- ₇ Middle Eastern
- ₈ Other _____

Q7. Where do you live most of the year? (Check one box)

- _1 Your home, apartment or condo
- _2 Senior citizen apartment/condo
- _3 Home of a relative/friend
- _4 Retirement home
- _5 Adult foster care
- _6 Nursing home
- _7 Other _____

Q8. How many people live with you? (Check one box)

- _0 I live alone
- _1 1 person
- _2 2 people
- _3 3 people
- _4 4 people
- _5 5 or more

Q9. How much schooling have you had? (Years of formal schooling completed)

(Check one box)

- _1 8 grades or less
- _2 Some high school
- _3 High school graduate or GED
- _4 Some college or technical school
- _5 College graduate (bachelor's degree)
- _6 Graduate degree

Q10. Which of the following best describes your current employment status? (Check one box)

- ₁ Working full-time, 35 hours or more a week
- ₂ Working part-time, less than 35 hours a week
- ₃ Unemployed or laid off and looking for work
- ₄ Unemployed and not looking for work
- ₅ Homemaker
- ₆ In school
- ₇ Retired
- ₈ Disabled, not able to work
- ₉ Something else? (Please specify): _____

Q11. Which of the categories best describes your total annual combined household income from all sources? (Check one box)

- ₀₁ Less than \$5,000
- ₀₂ \$5,000 to \$9,999
- ₀₃ \$10,000 to \$14,999
- ₀₄ \$15,000 to \$19,999
- ₀₅ \$20,000 to \$29,999
- ₀₆ \$30,000 to \$39,999
- ₀₇ \$40,000 to \$49,999
- ₀₈ \$50,000 to \$59,999
- ₀₉ \$60,000 to \$69,999
- ₁₀ \$70,000 and over

Q12. Do you use transportation for persons with medical/disability issues?

- YES NO

Q13. Do you have a valid driver's license?

- YES NO

Q14. Do you still drive a car?

- YES NO

Q15. Do you have someone who can help you if you need help?

- YES NO

Q16. Do you have home health care?

- YES NO

Q17. In general, would you say your health is:

- Excellent
 Very Good
 Good
 Fair
 Poor

Q18. In your opinion, do you have any health conditions that limit your activities?

- YES

PART 1: Clusters of places**A) Consumer, administration, and self-care places:**

Do you go to a ...		Change	Comments
A.1) Small grocery store?	Yes	No <input type="checkbox"/>	
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
A.2) Mall, supermarket, big store?	Yes	No <input type="checkbox"/>	
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
A.3) Small store?	Yes	No <input type="checkbox"/>	
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
A.4) Pharmacy?	Yes	No <input type="checkbox"/>	
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
A.5) Hairdresser, salon, or barbershop?	Yes	No <input type="checkbox"/>	
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
A.6) Bank or Post office?	Yes	No <input type="checkbox"/>	
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
A.7) Town hall or administration offices?	Yes	No <input type="checkbox"/>	
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	

PART 2: additional questions on items where there was no change

I. Questions about place and activity:

- a) What kind of activity do you do there?
- b) Why do you go to that particular place?
- c) When during the day (year) do you go there?
- d) How often do you go there?

Multiple times daily	Daily	Weekly	Monthly	Yearly	More seldom
----------------------	-------	--------	---------	--------	-------------

- e) How well do you know the place?

Very Well	Well	Poorly	Very Poorly
-----------	------	--------	-------------

- f) Picture yourself in that place. What do you have to be careful about or pay **extra** attention to? (e.g. being robbed)

.....

.....

.....

.....

II. Questions about going there and back:

- g) How do you get there?
- And back?
- h) Does somebody go with you?
- i) If yes, why does somebody go with you?
- j) How long does it take you to get there?
- And back?
- k) According to you, is it close by or far away?

Very Close	Close	Far Away	Very Far Away
------------	-------	----------	---------------

- l) How well do you know the way to get to that place?

Very well	Well	Poorly	Very Poorly
-----------	------	--------	-------------

- m) Imagine getting there. What do you have to be careful about or pay **extra** attention to? (e.g. to find the way, traffic, public transport)

.....

.....

.....

PART 2: additional questions on items where there was a change**III. Questions about place and activity:**

a) What kind of activity did OR will you do there?

b) Why don't you go OR why will you go to that particular place?

c) When during the day (year) did you go OR will you go there?

d) How often did you go OR will you go there?

Multiple times daily	Daily	Weekly	Monthly	Yearly	More seldom
----------------------	-------	--------	---------	--------	-------------

e) How familiar are you or were you with the place?

Very Familiar	Familiar	Unfamiliar	Very Unfamiliar
---------------	----------	------------	-----------------

f) Picture yourself in that place. What do you have to be careful about or pay **extra** attention to?

IV. Questions about going there and back:

g) How did you get there OR how will you get there?

 And back?

h) Did somebody go with you OR will somebody go with you?

i) If yes, why did OR will somebody go with you?

j) How long did OR will it take you to get there?

 And back?.....

k) According to you, was it/will it be close by or far away

Very Close	Close	Far Away	Very Far Away
------------	-------	----------	---------------

l) How well do you know the way to get to that place?

Very well	Well	Poorly	Very Poorly
-----------	------	--------	-------------

m) Imagine getting there. What do you have to be careful about or pay **extra** attention to?

.....
.....
.....
.....

B) Places for medical care:**Do you go to a...**

Change Comments

B.1) Doctor's office (not in a hospital)?Yes No

Did you go there in the past?

Yes No

Do you see yourself going there in the future?

Yes No

B.2) Hospital or health care center?Yes No

Did you go there in the past?

Yes No

Do you see yourself going there in the future?

Yes No

B.3) Dentist's office?Yes No

Did you go there in the past?

Yes No

Do you see yourself going there in the future?

Yes No

B.4) Therapy?Yes No

Did you go there in the past?

Yes No

Do you see yourself going there in the future?

Yes No

B.5) Day care?Yes No

Did you go there in the past?

Yes No

Do you see yourself going there in the future?

Yes No

PART 2: additional questions on items where there was no change

I. Questions about place and activity:

- a) What kind of activity do you do there?
- b) Why do you go to that particular place?
- c) When during the day (year) do you go there?
- d) How often do you go there?

Multiple times daily	Daily	Weekly	Monthly	Yearly	More seldom
----------------------	-------	--------	---------	--------	-------------

- e) How well do you know the place?

Very Well	Well	Poorly	Very Poorly
-----------	------	--------	-------------

- f) Picture yourself in that place. What do you have to be careful about or pay **extra** attention to? (e.g. being robbed)

.....

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.....

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II. Questions about going there and back:

- g) How do you get there?
- And back?
- h) Does somebody go with you?
- i) If yes, why does somebody go with you?
- j) How long does it take you to get there?
- And back?
- k) According to you, is it close-by or far away?

Very Close	Close	Far Away	Very Far Away
------------	-------	----------	---------------

- l) How well do you know the way to get to that place?

Very Well	Well	Poorly	Very Poorly
-----------	------	--------	-------------

- m) Imagine getting there. What do you have to be careful about or pay **extra** attention to? (e.g. to find the way, traffic, public transport)

.....

.....

.....

PART 2: additional questions on items where there was a change**III. Questions about place and activity:**a) What kind of activity did OR will you do there?
.....b) Why don't you go OR why will you go to that particular place?
.....
.....c) When during the day (year) did you go OR will you go there?
.....d) How often did you go OR will you go there?

Multiple times daily	Daily	Weekly	Monthly	Yearly	More seldom
-------------------------	-------	--------	---------	--------	-------------

e) How familiar are you or were you with the place?

Very Familiar	Familiar	Unfamiliar	Very Unfamiliar
---------------	----------	------------	-----------------

f) Picture yourself in that place. What do you have to be careful about or pay **extra** attention to?
.....
.....
.....**IV. Questions about going there and back:**g) How did you get there OR how will you get there?
.....

And back?

h) Did somebody go with you OR will somebody go with you?
.....i) If yes, why did OR will somebody go with you?
.....j) How long did OR will it take you to get there?
.....

And back?.....

k) According to you, is it close-by or far away?

Very Close	Close	Far Away	Very Far Away
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l) How well do you know the way to get to that place?

ACT-OUT Study

Participant ID: _____

Very well	Well	Poorly	Very Poorly
-----------	------	--------	-------------

m) Imagine getting there. What do you have to be careful about or pay **extra** attention to?

.....
.....
.....
.....

C) Social, spiritual and cultural places:

Do you go to a ...

Change Comments

C.1) Friend or family member's place?	Yes	No	<input type="checkbox"/>
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
<hr/>			
C.2) Restaurant, café or bar?	Yes	No	<input type="checkbox"/>
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
<hr/>			
C.3) Senior center or social club's premises?	Yes	No	<input type="checkbox"/>
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
<hr/>			
C.4) Building for worship? (Church, mosque, synagogue, etc.)	Yes	No	<input type="checkbox"/>
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
<hr/>			
C.5) Cemetery or memorial place?	Yes	No	<input type="checkbox"/>
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
<hr/>			
C.6) Entertainment or cultural places? (Cinema, theatre, exhibition, library, concert, cabaret, etc.)	Yes	No	<input type="checkbox"/>
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
<hr/>			

PART 2: additional questions on items where there was no change

I. Questions about place and activity:

- a) What kind of activity do you do there?
- b) Why do you go to that particular place?
- c) When during the day (year) do you go there?
- d) How often do you go there?

Multiple times daily	Daily	Weekly	Monthly	Yearly	More seldom
----------------------	-------	--------	---------	--------	-------------

- e) How well do you know the place?

Very Well	Well	Poorly	Very Poorly
-----------	------	--------	-------------

- f) Picture yourself in that place. What do you have to be careful about or pay **extra** attention to? (e.g. being robbed)

.....

.....

.....

.....

II. Questions about going there and back:

- g) How do you get there?
- And back?
- h) Does somebody go with you?
- i) If yes, why does somebody go with you?
- j) How long does it take you to get there?
- And back?
- k) According to you, is it close-by or far away?

Very Close	Close	Far Away	Very Far Away
------------	-------	----------	---------------

- l) How well do you know the way to get to that place?

Very Well	Well	Poorly	Very Poorly
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- m) Imagine getting there. What do you have to be careful about or pay **extra** attention to? (e.g. to find the way, traffic, public transport)

.....

.....

.....

PART 2: additional questions on items where there was a change

III. Questions about place and activity:

a) What kind of activity did OR will you do there?

.....

b) Why don't you go OR why will you go to that particular place?

.....
.....

c) When during the day (year) did you go OR will you go there?

.....

d) How often did you go OR will you go there?

Multiple times daily	Daily	Weekly	Monthly	Yearly	More seldom
----------------------	-------	--------	---------	--------	-------------

e) How familiar are you or were you with the place?

Very Familiar	Familiar	Unfamiliar	Very Unfamiliar
---------------	----------	------------	-----------------

f) Picture yourself in that place. What do you have to be careful about or pay **extra** attention to?

.....
.....
.....

IV. Questions about going there and back:

g) How did you get there OR how will you get there?

.....

And back?

h) Did somebody go with you OR will somebody go with you?

.....

i) If yes, why did OR will somebody go with you?

.....

j) How long did OR will it take you to get there?

.....

And back?.....

k) According to you, was it/will it be close by or far away?

Very Close	Close	Far Away	Very Far Away
------------	-------	----------	---------------

l) How well do you know the way to get to that place?

Very Well	Well	Poorly	Very Poorly
-----------	------	--------	-------------

m) Imagine getting there. What do you have to be careful about or pay **extra** attention to?

.....

.....

.....

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D) Places for recreation and physical activities:**Do you go to**

Change Comments

D.1) A garden in your backyard?	Yes	No	<input type="checkbox"/>
Did you do this in the past?	Yes	No	
Do you see yourself doing this in the future?	Yes	No	
<hr/>			
D.2) A Park, green areas, or community garden or allotment?	Yes	No	<input type="checkbox"/>
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
<hr/>			
D.3) A Forest, mountain, lake, or seaside?	Yes	No	<input type="checkbox"/>
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
<hr/>			
D.4) A Cottage, summer house, or chalet?	Yes	No	<input type="checkbox"/>
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
<hr/>			
D.5) A Neighborhood? (Walking the dog, etc.)	Yes	No	<input type="checkbox"/>
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
<hr/>			
D.6) A Sport facility? (Fitness center, swimming pool, etc...)	Yes	No	<input type="checkbox"/>
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
<hr/>			
D.7) A Transportation center? (Train station, airport, ferry terminal, bus terminal, etc.)	Yes	No	<input type="checkbox"/>
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	
<hr/>			
Is there a place that has not been listed here that is or was important to you?			
Other:	Yes	No	<input type="checkbox"/>
Did you go there in the past?	Yes	No	
Do you see yourself going there in the future?	Yes	No	

PART 2: additional questions on items where there was no change**I. Questions about place and activity:**

- a) What kind of activity do you do there?
- b) Why do you go to that particular place?
- c) When during the day (year) do you go there?
- d) How often do you go there?

Multiple times daily	Daily	Weekly	Monthly	Yearly	More seldom
-------------------------	-------	--------	---------	--------	-------------

- e) How well do you know the place?

Very Well	Well	Poorly	Very Poorly
-----------	------	--------	-------------

- f) Picture yourself in that place. What do you have to be careful about or pay **extra** attention to? (e.g. being robbed)

.....

.....

.....

.....

II. Questions about going there and back:

- g) How do you get there?
- And back?
- h) Does somebody go with you?
- i) If yes, why does somebody go with you?
- j) How long does it take you to get there?
- And back?
- k) According to you, is it close by or far away?

Very Close	Close	Far Away	Very Far Away
------------	-------	----------	---------------

- l) How well do you know the way to get to that place?

Very Well	Well	Poorly	Very Poorly
-----------	------	--------	-------------

- m) Imagine getting there. What do you have to be careful about or pay **extra** attention to? (e.g. to find the way, traffic, public transport)

.....

.....

.....

PART 2: additional questions on items where there was a change

III. Questions about place and activity:

a) What kind of activity did OR will you do there?

b) Why don't you go OR why will you go to that particular place?

c) When during the day (year) did you go OR will you go there?

d) How often did you go OR will you go there?

Multiple times daily	Daily	Weekly	Monthly	Yearly	More seldom
----------------------	-------	--------	---------	--------	-------------

e) How familiar are you or were you with the place?

Very Familiar	Familiar	Unfamiliar	Very Unfamiliar
---------------	----------	------------	-----------------

f) Picture yourself in that place. What do you have to be careful about or pay **extra** attention to?

IV. Questions about going there and back:

g) How did you get there OR how will you get there?

 And back?

h) Did somebody go with you OR will somebody go with you?

i) If yes, why did OR will somebody go with you?

j) How long did OR will it take you to get there?

 And back?.....

k) According to you, was it/will it be close by or far away?

Very Close	Close	Far Away	Very Far Away
------------	-------	----------	---------------

l) How well do you know the way to get to that place?

Very well	Well	Poorly	Very Poorly
-----------	------	--------	-------------

m) Imagine getting there. What do you have to be careful about or pay **extra** attention to?

.....
.....
.....
.....

PART 3: General questions to be asked at the end**Attitude to risk-taking:**

How comfortable are you with challenging your self?

Very comfortable	Comfortable	Uncomfortable	Very Uncomfortable
------------------	-------------	---------------	--------------------

Life satisfaction:

In all, how satisfied are you with your everyday life?

Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied
----------------	-----------	--------------	-------------------

When you go out or are outside, how concerned are you about:

- Getting lost?

Very Concerned	Concerned	Unconcerned	Very Unconcerned
----------------	-----------	-------------	------------------

- Falling?

Very Concerned	Concerned	Unconcerned	Very Unconcerned
----------------	-----------	-------------	------------------

- Being stressed when going out?

Very Concerned	Concerned	Unconcerned	Very Unconcerned
----------------	-----------	-------------	------------------

- Getting into an embarrassing situation?

Very Concerned	Concerned	Unconcerned	Very Unconcerned
----------------	-----------	-------------	------------------

Appendix D.

Informational Recruitment Handout

INVITATION TO PARTICIPATE IN RESEARCH STUDY

What is the goal of this study?

We are reaching out to members of the community to invite you to participate in our study on how the physical environment influences mobility patterns and community participation for those living with memory loss.

The researcher hopes to collect information on where people living with memory loss go, how they get there, and what physical and social issues they face in the process.

Who are we looking for?

We are recruiting older adults (aged 55+) who are living with early-stage memory loss in the Metro Vancouver area.

What would your participation look like?

This study will consist of three distinct sections. The first will consist of a walk-along interview along a route of your choice. The second will involve a survey about places you go in your community. The third will be a sit-down interview about what participating in your community means to you. Total participation is expected to take 1.5 – 3 hours.

Will I receive any compensation for my time?

As a “thank you” for your time, you will receive a \$20 gift card to Tim Hortons for the interviews and a \$40 cash incentive for the survey.

Why is this study being conducted?

This study is being conducted as part of the requirements for a graduate thesis in the Department of Gerontology at Simon Fraser University.

Would you like further information?

If you are interested in participating in the study, or would like to find out more information, please contact the principal investigator [redacted] directly:

[redacted]

Appendix E.

Informed Consent Form

Note: There are two versions of this consent form. One for participants recruited from the community and one for participants recruited from ACT-OUT. Where the consent form differs has been indicated with either [For participants recruited from the community] or [For participants recruited from ACT-OUT].



“Exploring Facilitators and Barriers of the Neighbourhood Built Environment for Persons in Early-Stage Dementia”

Who is conducting the study?

Principal Investigator: [redacted]

Faculty Supervisor: [redacted]

Why are we doing this study?

We want to learn more about how to help people who are living with memory loss continue to be active participants in their communities. We hope to do so by learning how the design of the physical environment can influence the experiences of mobility and participation for persons living with memory loss in their communities.

Your participation is voluntary

If you are interested in participating in this study, please note that your participation is completely voluntary. You have the right to refuse participation in this study. If you change your mind at any point during the research process, you may withdraw by contacting the principal investigator (redacted) to do so at any time without negative consequences.

What happens in the study?

If you say “Yes” to participating in this study, we will ask you to do the following:

- 1) Participate in one walk-along interview and one sit-down interview, each for approximately 30 minutes to 1 hour in duration.

- a. For the walk-along interview, you will choose a walking route that you are familiar with and we will ask you to discuss features of the physical environment.
 - b. For the sedentary interview, we will ask you to reflect on how your participation and mobility patterns influence your quality of life.
- 2) During the walk-along interview, the researcher will ask to take pictures of the features of the physical environment in your neighbourhood. You will not be included in these photos.
 - 3) *[For participants recruited from the community]* We will ask you to complete a survey called ACT-OUT. This questionnaire will explore how you participate in community-based activities outside of your home. This will take between 30 minutes – 1 hour to complete. Please note that ACT-OUT is an independent, additional study and that this study and ACT-OUT are linked. *[For participants recruited from ACT-OUT]* Please note that your responses to the ACT-OUT survey will also be used to capture a more in-depth picture of your mobility and participation patterns in the neighbourhood, and as a prompt during the interview process.

Total time anticipated for participation: *[For participants recruited from the community]* A minimum of 1.5 hours is expected. At maximum, your participation could take up to 3 hours. This will be spread between two interview sessions on two different days and the time it takes to complete the ACT-OUT survey. The expectation is that each interview will take between 30 minutes to 1 hour to complete. *[For participants recruited from ACT-OUT]* A minimum of 1 hour is expected. At maximum, your participation could take up to 2 hours. This will be spread between two interview sessions on two different days. The expectation is that each interview will take between 30 minutes to 1 hour to complete.

Confidentiality of photographs: We will not be asking to take photos with people in them. We will be taking pictures of the physical features of the environment on the walking route you choose for us. The photographs that are taken will be stored on a computer file only accessible by the principal investigator and all photographs will only be identified by a unique code number. Select photographs from the interviews will be used as visual references in the final report, however they will not be attributed to a specific participant or interview.

What are the potential risks of my participation?

We do not think there is anything in this study that could harm you or be bad for you. However, some of the questions we ask may upset you. If the questions bring up a sensitive topic for you, please let the researcher know.

If you would like, you may bring a friend or family member for support during the interview process. Please let the researcher know if this is the case.

What are the potential benefits of my participation?

We do not think taking part in this study will help you directly. However, in the future others may benefit from what we learn in this study. Your participation may contribute to a better

understanding of how to ensure persons living with memory loss have the opportunity to participate fully in their community environments.

Will there be any compensation for participating in this study?

As a thank you for your time you will receive a \$20 gift card to Tim Hortons.

How will my confidentiality be respected?

Your confidentiality will be respected throughout the duration, and after the completion, of this research project. Information that discloses your identity will not be released without your consent unless required by law, such as the need to report suspected or observed incidents of abuse and/or neglect. All documents will be identified only by a unique code number and kept in a locked filing cabinet. Participant names will not be included in any reports of the final study. Any names mentioned in the final report will be pseudonyms.

Once the objectives of this study have been met the physical records of the data will be kept for a period of 2 years in a locked filing cabinet. Once the 2 years are up, all copies will be destroyed. In accordance with current best practices in research, the electronic copies of the data will be kept in an online repository for future use in open access initiatives. All identifying information will be removed to ensure confidentiality.

What if I decide to withdraw my consent to participate?

You may withdraw your consent at any time during the research process without giving reasons. You may withdraw from this study by contacting the principal investigator directly (redacted). If you choose to enter the study and then decide to withdraw at a later time, all data collected about you during your participation in the study will be destroyed. Electronic copies will be permanently deleted and any physical documentation will be shredded.

What will happen with the results of the study?

The results of this study will be reported in a graduate thesis and may also be published in journal articles and books at a later date. There is the potential for the publication of anonymized data if required by a journal or other publishing body.

If you are interested in receiving the results of this study, please contact the principal investigator (redacted) and ask for a copy of the final report. An email will be sent to those who are interested in receiving this information after the study is completed.

Who can you contact if you have questions about the study?

If you have any questions regarding the study, or would like some clarification in order to fully understand the process, please contact the principal investigator [redacted] by email: [redacted]

Who can you contact if you have complaints or concerns about the study?

If you have any concerns about your rights as a research participant and/or your experiences while participating in this study, you may contact Dr. Jeffrey Toward, Director, Office of Research Ethics jtoward@sfu.ca or 778-782-6593.

Future Use of Participant Data

Since the final report will become a published document, the research data collected in the study and presented in the final report may be used for educational purposes at a future date. Any of the archived data used in publications will be anonymized.

Future Contact

Please check the appropriate box below for whether you consent to any future contact by the researcher for any follow-up purposes after the completion of this study:

Yes

No

Audio Recording

Yes, I may be audio recorded

No, I may not be audio recorded

Participant Consent and Signature Page

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you do decide to take part, you may choose to withdraw from the study at any time without giving a reason and without any negative impact.

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you consent to participate in this study.
- You do not waive any of your legal rights by participating in this study.

Participant Signature

Date (yyyy/mm/dd)

Printed Name of the Participant signing above

Consent from Authorized Third Party

The authorized third party is satisfied that the information contained in this consent form was explained to the potential participant to the extent that he/she is able to understand it, that all questions have been answered, and that the potential participant assents to participating in the research.

Authorized Third Party Signature Date (yyyy/mm/dd)

Printed Name of the Authorized Third Party signing above

Thank you for your interest in this project.

Appendix F.

Relationship of ACT-OUT to Broader Study

ACT-OUT Data	Relationship to Broader Study
Part One (Places people with dementia go)	Assisted in developing a picture of <i>where</i> participants were choosing to go when navigating their neighbourhood environments. Helped develop an understanding of <i>why/how</i> they participate in their communities.
Part Two (Changes in patterns of use)	Complimentary to sedentary interviews as participants were asked how they feel their participation and mobility patterns have changed since their diagnosis.
Part Three (Attitudes towards risk taking and life satisfaction)	Helped develop an understanding of <i>why</i> participants feel that certain features of their environment act as a facilitator or barrier to their participation. This data also spoke to the participant's quality of life.
Sample	Designed for persons with a cognitive impairment in mind.
In summary: The survey data assisted in developing an understanding of both the objective and subjective changes that a person living with dementia experiences in their mobility and community participation.	

Appendix G.

Table Summarizing Key Empirical Literature

Study	Method	Focus	Findings and Recommendations
Blackman, Schaik & Martyr (2007)	Qualitative	Disabling factors of the outdoor environment	Improving signage, buffers from traffic, appropriate seating fosters independence
Brittain et al. (2010)	Re-analysis of qualitative data	Everyday technologies in public spaces	Outside space can be both therapeutic and frightening – technologies can be used to adapt
Brorsson et al. (2014)	Qualitative	Problematic situations while using zebra crossings	Multiple layers of challenges led to problematic situations – important to consider when providing support
Brorsson & Nygard (2011)	Qualitative	Experiences of accessibility in public space for those with Alzheimer's	Problematic situations related to technology, overstimulation in crowds, and change of landmarks
Danes (2012)	Qualitative	Evolution of the Woodside Place model	Design of care facility needs to be adaptable
Duggan et al (2008)	Qualitative	Outdoor independence	Maintaining outdoor activity extends period of good quality of life
Gulwadi (2013)	Qualitative	Usefulness of memory boxes in resident rooms in long-term care	Memory boxes are beneficial in maintaining identity, assisting in orientation and wayfinding, encouraging reminiscence

Innes, Page & Cutler (2015)	Qualitative	Barriers to leisure participation	Link between age/dementia-friendly qualities and access to leisure
Keating & Gaudet (2012)	Re-examination of qualitative data	Personhood, social exclusion, and dementia-friendly environments	Enhancing the built environment for people with dementia at all stages a promising area of research to develop
Marquardt & Schmieg (2009)	Quantitative	Wayfinding in long-term care	Characteristics of the environment that enhance: legibility, familiarity, autonomy, sensory stimulation, wayfinding, and social interaction
McDuff & Phinney (2015)	Qualitative	Exploring subjective experiences of physical activity	Participants were attracted to activity, experienced impediments to activity, and made adjustments
Mitchell & Burton (2010)	Qualitative	Design features influencing mobility	Safe, familiar, distinctive, accessible, legible, comfortable
Mitchell & Burton (2006)	Qualitative	Design features influencing mobility	Safe, familiar, distinctive, accessible, legible, comfortable
Mitchell, Burton & Raman (2004)	Qualitative	Design features' impact on mobility	Space should be safe, familiar, distinctive, accessible, comfortable, legible
Ohman & Nygard (2005)	Qualitative	Meanings for engagement in self-chosen daily activities	Occupations support their patterns of activity and their identity
Phinney, Chaudhury & O'Connor (2007)	Qualitative	Meaningful activity and perceived significance	Familiarity with physical and social environment promotes involvement

Phinney et al. (2016)	Qualitative	Practicing social citizenship by walking	Walking allows people with dementia to engage and contribute to the community
Phinney & Moody (2011)	Qualitative	Impact of community-based social recreation group for people with early-stage dementia	Themes: everyone gets along well, it's more fun than anything, we're all old-timers and we know what that means, you can be yourself, you feel wanted, coming alive, like a stepping stone
Rahman (2014)	Review of mixed methods research	Overview of dementia care – including in the community	Growing evidence that outdoor spaces can enhance health and wellbeing
Sheehan, Burton & Mitchell (2006)	Qualitative	Outdoor wayfinding	Equal use of wayfinding techniques between those with and without dementia
Son Hong & Song (2009)	Quantitative	Relationship between wandering and familiar community environments	Less frequent wandering for people independent in ADLs and familiar with the environment
Smith & Croucher (2016)	Qualitative	Asking people with dementia what would make their communities dementia-friendly	Importance of being connected and engaged, accommodation from service providers and community members, raising awareness of dementia, and attributes of the physical environment
Van Schaik, Martyr, Blackman & Robinson (2008)	Qualitative	Barriers and facilitators of outdoor environments	Improve signage, create spaces free from traffic, convenient seating will encourage outdoor use

Ward et al. (2017)	Mix of qualitative and participatory approaches	How people with dementia interact with their neighbourhoods	Neighbourhood sets limits and presents opportunities
Wiersma & Denton (2013)	Qualitative	Dementia-friendly communities (DFCs) in rural Ontario	Social support a key component of DFCs