

Caring for those who once cared for us:
Dementia-friendly planning for a Winnipeg, Manitoba winter

by

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ABSTRACT

The global population is aging, and the rate of dementia is climbing. Although physical activity is thought to improve well-being, older adults often experience a decline in physical activity with age. This can be a result of physical and social barriers in their immediate environment, which can be exacerbated in winter. Through a photovoice study, interview, and a group presentation/discussion, this research aims to bring issues associated with aging-in-place with dementia into planning discussions. Findings from this research suggest snow and ice on sidewalks are significant barriers for individuals with dementia, and that intersections are distracting and confusing. Suggestions include creating opportunities for mental and physical stimulation (e.g. using color to increase distinctness), providing particular individual physical characteristics (e.g. reducing the number of curbs or painting curbs so they are more visible), improving wider urban design characteristics (e.g. maintaining a cleared sidewalk network), and increasing awareness in the community.

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1| INTRODUCTION

1.1. Introduction & Context

This research aims to explore the potential of the urban built environment to improve the cognitive health of those suffering from mild dementia. The site for this study is Winnipeg, the capital city in the province of Manitoba, known for its cold winters. Seniors face many challenges in their physical environments in all contexts. However, in colder climates like those found in many Canadian cities, extreme temperatures and weather conditions exacerbate the issues (Joseph & Skinner, 2012). In winter cities, especially those characterized by low-density development and sprawl, seniors face physical impediments to remaining involved and active in their communities, and this may result in increased isolation and decreased social participation (Garvin, Nykiforuk, Johnson, 2012).

The Canadian population is aging rapidly. In 2011, 14% of Canadians were over the age of 60, a proportion expected to nearly double by 2036 (Plouffe & Kalache, 2011). Canada is well known for having adopted the World Health Organization's *Global Age-Friendly Cities* framework, and Manitoba began its own age-friendly initiative in 2008 (Plouffe & Kalache, 2011; Veselyuk, Krauchi, Ines, Menec, 2012).

Manitoba's median age, steadily rising since the early 1970s, is now 38.4, and provincial population pyramids show that this number is expected to increase as baby boomers continue to age (Blanford, 2010; Manitoba Bureau of Statistics, 2011). Manitoba is unique in that almost two thirds of the population is concentrated in one urban centre, Winnipeg (Kagis, Menec, Blanford, 2006). Seniors (those age 65 and

over) make up 14.4% of the entire population of Manitoba, and 55% of these seniors reside in Winnipeg (Manitoba Bureau of Statistics, 2011).

Winnipeg offers a good site for this study because it is the ultimate winter city; in 2013, a number of newspapers reported that temperatures plummeted below those on Mars (CBC, 2013; Winnipeg Sun, 2013). As a slow growth, sprawling winter city, Winnipeg poses unique challenges for its senior residents, especially those suffering from dementia.

1.2. Problem Statement & Key Questions

Longer life expectancies have resulted in more people with dementia, while smaller families mean that there are fewer people to care for them in the early stages of the disease, frequently leading to early institutionalization (Sheehan, Burton, Mitchell, 2006). Since this is contrary to many aging adults' desires, and a burden on health care systems, there is an acute need for planning and urban design professionals to address this shift (Allen, Hayman, Keeling, Kerse, Palmer, Wiles, 2009; Duggan, Blackman, Martyr, Van Schaik, 2008; Timmerman, 2012). Physical barriers in the built urban environment can prevent older adults with dementia from living in their community as long as they would like.

Historically, urban design has focused on the 'average,' healthy young male, but as the population ages, this is no longer an acceptable or relevant practice (Burton & Mitchell, 2006; Blackman, Mitchell, Burton, Jenks, Parsons, Raman, Williams, 2010). A shift from this out-dated focus is evident, as a number of age-friendly and inclusive urban design movements are beginning to address the needs of

older adults with physical disabilities. However those with cognitive impairment have been largely ignored in planning and environmental design (Blackman et al., 2010).

This research attempts to better understand how individuals with dementia might continue to live active lifestyles. It looks specifically at potential interventions at a neighbourhood scale. The intended result is the production of engaging environments; urban landscapes that are both mentally and physically stimulating. Some (Burton & Mitchell, 2006; Alley Liebig, Pynoon, Banerjee, Choi, 2007) argue that this is not only beneficial for those with dementia but for the population as a whole. My research questions are:

1) What existing individual physical characteristics may have the potential to assist those experiencing dementia to make their way through the city on foot with greater ease?

A number of studies suggest that physical characteristics of the built environment act as barriers to people with dementia and prevent them from going outdoors, especially in the winter. Some of these might include broken sidewalks, lack of curb cuts, nowhere to rest, and ice and snow on sidewalks. The purpose of this question is to determine precisely what characteristics are causing individuals with dementia to avoid going outdoors so that they might be addressed in future urban design practices. Identifying barriers may help clarify urban design characteristics that make it easier for people with dementia to navigate their outdoor environment. For example, if a lack of curb cuts is identified as a barrier, then including curb cuts can

be identified as a facilitator, or if nowhere to rest is identified as a problem then installing benches periodically can be a solution.

2) What wider urban design characteristics encourage active living in people with dementia?

Much like other older adults, those with dementia prefer to age in place for as long as possible. For people with dementia their choice of destination becomes limited after diagnosis because they are no longer able to drive or take public transit, and so the physical design of their neighbourhoods become increasingly important (Burton, Mitchell, Raman, n/d). Some wider design characteristics that encourage people with dementia to continue living actively could include small blocks, buildings and facilities designed to reflect uses, and landmarks and environmental cues (Mitchell, 2012).

1.3. Significance of Study

The number of older adults is increasing across the world, and with it, the prevalence of dementia. Dementia refers to a number of disorders, chronic or progressive in nature. It is characterized by the loss of memory, judgement, and reasoning abilities, as well as changes in mood and behaviour (Alzheimers.ca; Alzheimer's Society of Canada, 2014; World Health Organization, 2012).

As age is a predominant and invariable risk factor for dementia, longer life expectancy equates to more individuals suffering from dementia (Alzheimer's Society of Canada, 2014). Only 2-10% of those with dementia are diagnosed before

the age of 65. After age 65, the prevalence increases twofold every 5 years. In 2012 there were an estimated 35.6 million people living with some form of dementia around the world; a number expected to more than triple by the year 2050 (World Health Organization, 2012). In Canada dementia is the most significant cause of disability in later life. As of 2014 there were 500,000 individuals living with Alzheimer's or dementia.

An increased aging population will continue to result in a higher prevalence of dementia. Individuals with mental disabilities have, until now, been largely ignored in planning and urban design practices, which is unacceptable. Individuals with dementia have the same right to use their communities and neighbourhoods as anyone else, and practitioners have a responsibility to plan for environments that make this possible. This research is intended to contribute to the highly relevant body of knowledge on dementia-friendly urban design and planning.

1.4. Assumptions & Limitations

The most significant assumption in this research was that a sufficient number of participants would be willing to take part in this study. Recruiting participants who suffer from dementia or Alzheimer's proved much more difficult than anticipated, therefore the sample size for the first part of this research was extremely small (1 pair of participants). Due to the small sample size and narrow scope, the findings may not be applicable in other contexts. It is also important to note that the data was gathered in the Winnipeg context, and although this major degree project suggests it might be applicable in other cities with similar climates, it may not be applicable

elsewhere.

For the first part of this research the participants were found through the Alzheimer's Society of Manitoba. Because the Alzheimer's Society does not allow direct solicitation of their members for research, interested parties were required to make initial contact if they were interested in the study. This method of recruitment results in a certain type of individuals – ones who are actively involved with the Alzheimer's Society of Manitoba and trying to participate in studies on dementia – and thus may not be representative of the wider population.

The participants for the second part of this major degree project were recruited with the help of staff at the Charleswood 55+ Active Living Centre, who emailed the recruitment poster to their members. This resulted in the attendees of the presentation and discussion being almost exclusively members of the Active Living Centre. An individual's opinions on healthy aging with dementia will vary depending on their lifestyle, and it is likely that members of the Active Living Centre share similar, active lifestyles. Because of the location of the presentation and discussion, the individuals attending were not necessarily representative of the wider population.

Another significant assumption was that once willing participants were found they would be able to participate in the study from start until finish. Dementia is unpredictable, and individuals suffering from dementia face cognitive decline at different rates. The individual with dementia who agreed to take part in a study at the start experienced decline more quickly than anticipated and was unable to complete the study. By the time we reached the photovoice and interview stages the participant with dementia was unable to contribute. Although the caregiver

participant was asked to undertake the study as if the participant with dementia was with her, it is possible that the participant with dementia might have taken different photographs, written different journal entries, or answered interview questions differently, had she been able to participate.

It was also assumed that individuals with early or mild dementia would recognize their condition and be willing to take part in research related to it. In the early stages of the disease, individuals are not necessarily aware they are experiencing cognitive decline or will not admit that they are. It is, therefore, difficult to recruit individuals with early or mild dementia for research without some level of deception. However, the participants in this study were not deceived in any way.

Finally, all of the findings are limited to the comprehension and impartialities of the participants. Every effort was made to avoid leading participants' and attendees' contributions.

1.5. Ethics

A number of ethical issues surround this study, and because it involved human participants it required review and approval by the research ethics board. The core principles outlined by the *Tri Council Policy Statement - Ethical Conduct for Research Involving Humans* are: respect for person, concern for welfare, and justice. I remained acutely aware of these principles throughout the research. Firstly, "free, informed and ongoing consent" was obtained (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social

Sciences and Humanities Research Council of Canada, 2010, p. 27). This was accomplished by making all information available to the participants from the beginning of the relationship, and it was ensured participants were aware they had the option to withdraw from the study at any time. Ongoing consent from the participant with dementia was obtained by revisiting the consent form and obtaining another signature at the outset of each separate data-gathering event.

Issues around capacity arose because of the inclusion of vulnerable participants who suffer from cognitive illnesses. People who are suffering from mild dementia may lack the capacity to fully comprehend the project and their decision to take part in it. The policy statement states, in such cases the participants must be involved to the greatest extent possible, and when they are not capable it is necessary to obtain consent from an authorized third party, most likely a relative. This was incentive to include primary caregivers in the study, as outlined in the following section. I also demonstrated how the study directly benefited the participants or others within the same community. Confidentiality and privacy were maintained by refraining from using names or any other identifying information in the study results. Since part of the collection methods includes taking photographs, this was extended to visual images as well. This is discussed further in the research methods section.

It is stated in the *Tri Council Policy Statement* that the potential benefits of the research need to outweigh the risks. To minimize the chance of personal risk, I stressed at the outset that the images to be taken were meant to capture experiences in the participants' day-to-day routine and they should not do anything or go anywhere they usually didn't. In the case of this study, the intention was that a better

understanding of the relationship between the built environment and people with mild dementia (with the help of a few people who have first hand experience) would result in more legible and accessible environments. Not only could this benefit the wider dementia community, but the entire population as well.

2| OVERVIEW

The first chapter provides a contextual foundation for the research and introduces the guiding questions. This chapter also defines the significance of the study, the assumptions and limitations of it, as well as the ethical considerations and process. Chapter three discusses the theoretical framework that guides this research. It includes the literature review with subsections about age-friendly urban design and aging in place, dementia and physical activity, wayfinding for dementia, and aging in winter cities.

Chapter four discusses the research methods that were used, including how the participants were recruited, the photovoice study, the follow-up interview, and the group presentation/discussion. It also outlines the method that was used for analysis of the data, and how the data was strengthened through triangulation and the use of verbatim quotations. Chapter five discusses the findings in four subsections, barriers to getting around, hopes and suggestions for dementia-friendly communities, overlap with other movements, and reasons for participating. This chapter also examines the implications of this research for planning practice.

Chapter six summarizes the conclusions that can be drawn from the study findings, and provides responses to the guiding research questions. It also reiterates the projects limitations, and offers recommendations for further study.

3| THEORETICAL FRAMEWORK AND LITERATURE REVIEW

3.1. Introductory theories underlying the work

The global population is aging and with it the number of age-related diseases like dementia and Alzheimer's is increasing as well. While the prevalence of these diseases increases steadily, individuals with cognitive illness or impairment, or consideration for their needs, are unusually left out of planning processes. Urban design professionals are beginning to address the needs of an aging population by including those with physical disabilities in design processes. However, failing to include older adults with cognitive illness is resulting in environments that do not allow for people with early or mild dementia to remain active in their communities and navigate their environments, which is contributing to early institutionalization.

The theories that create the foundation for this research include aging-in-place, active aging, and universal design, each of which are further discussed in this chapter. This chapter first discusses the progress that has been made in the field of age-friendly planning and how it has contributed to older adults' desire to age in place. It then discusses the role that active living can play in the health of older adults and its potential to safeguard individuals from further cognitive decline. Next, this chapter outlines the benefits of wayfinding strategies specifically designed for people suffering from early or mild dementia, as well as the additional impacts extreme weather can play for an aging individual.

3.2. Age-Friendly Urban Design & Aging in Place

As the largest age cohorts move up the population “pyramid,” the choices that older adults make about where to live is becoming more relevant (Bookman, 2008). While older adults are a diverse group, an overwhelmingly large proportion prefer to *age in place*, or at least remain in their communities, while staying active, engaged, and connected (Alley et al., 2007; Bookman, 2008; Ball, 2012). Burton et al. (2011), note that as people age, the amount of time they spend in their homes and communities increases. Therefore, physical characteristics of these environments greatly influence older adults’ ability to age in place. Changes that occur in the physical environment affect all who reside within it, however individuals who rely on their immediate physical environment for support and assistance are affected to a greater degree (Buffel, Phillipson, Scharf, 2012).

The foundation of growth and development pattern in the Western World were laid immediately following the Second World War. In response to large numbers of young families and their needs, development consisted of increasingly dispersed single-family homes, or suburban “sprawl.” Today, older adults are finding these environments difficult places to age for a number of reasons. Many are unable to relocate to more suitable housing types within their communities, and become socially and physically isolated when they are no longer able to drive. Since the overwhelming majority of older adults prefer to age in place, this is a significant issue that is becoming increasingly relevant (O’Hehir, 2014).

Older adults become more vulnerable to various barriers that affect their quality of life due to reduced mobility and loss of independence (Burton et al., 2011).

There has been a revival in the belief that the built environment affects health; this theory is not new. Although it has a long history, the relationship between environment and health has largely been omitted in macro or neighbourhood scale design (Burton et al., 2011; Menec, Means, Keating, Parkhurst, Eales, 2011).

Alley et al. (2007) define *aging in place* as “individuals growing old in their own homes, with an emphasis on using environmental modification to compensate for limitations and disabilities” (p.4). Furthermore, Burton and Mitchell (2006) argue that being in contact with, and deriving pleasure from outdoor environments is essential to older people’s quality of life. Blackman et al. (2010) further reason that maintaining outdoor activity is linked to social, physical, and psychological benefits for older adults.

However, making physical changes that reflect a changing demographic often requires changing policies, and changing policies takes time. Most existing policies are based on out-dated notions of what being old is. Baby boomers are living longer, healthier, more active lives and changing what it means to age. While most policy remains unchanged, some changes are occurring that aim to support older people living in their own community as long as possible as it is more economically and socially beneficial (O’Hehir, 2014).

The concept of *age-friendly environments* is rooted in urban development movements from the 1990s and 2000s. O’Hehir (2014) argues that the idea of age-friendliness in the built environment can be traced back to the ‘healthy cities,’ ‘livable cities,’ and ‘lifetime neighbourhoods’ movements, together with the themes of accessibility, sustainability and universal design. Each of these movements and

themes share an underlying recognition of the impact that both physical and social infrastructure can have on the lives of older people (O’Hehir, 2014).

In 2007 the World Health Organization used the momentum that the age-friendly movement was gaining to launch their active aging project, and released *Global Age-Friendly Cities: A Guide* in 2007. The guide includes age-friendly checklists for eight key focus areas: outdoor spaces and buildings, transportation, housing, social participation, respect and social inclusion, civic participation and employment, communication and information, and community support and health services.

Aspects of these eight focus areas overlap and interact with one another to create age-friendly cities and communities. The WHO (2014) describes age-friendly cities and communities as: recognizing capacities and resources among older people; anticipating and responding to age related needs and preferences; respecting older adults choices and decisions in terms of lifestyle; protection the most vulnerable older adults; and promoting the inclusion and promotion of older people (2014).

To create the guide, the WHO used a bottom-up participatory approach that involved people in the community identifying and examining elements that positively or negatively contribute to making a city or community age-friendly (O’Hehir, 2014). *Global Age-Friendly Cities: A Guide* is not meant to be rigid formula for success but rather soft guide that can be adjusted to suit the unique needs of each community. While there are no clearly laid out or universally accepted methods for creating an age-friendly community, the WHO (2014) stresses that in order to make age-friendly cities and communities happen it is of utmost importance

to listen to and involve older people in planning processes, as they did in creating the guide.

Since the global network of age-friendly cities and communities was launched in 2010, 26 countries have become formal partners. Canada has taken this partnership seriously, with 8 of its 10 provinces having already implemented age-friendly initiatives. Canada has recognized age-friendly cities as a part of its federal public health agenda, and developed its own guide recognizing the challenges older adults face in rural and remote communities as well. The Province of Manitoba has actively implemented a number of age-friendly initiatives, and the University of Manitoba is home to the Centre on Aging.

3.3. Dementia & Physical Activity

According to Adams-Fryatt (2010, p.187) “physical activity is one of our most basic functions,” and while it has been proven that a physically active lifestyle is conducive to aging well, Michael, Green and Farquhar (2006) report that physical activity levels generally decrease with age. Although the benefits of physical activity are well known, older adults are the least physically active of any age cohort, and 70% (Brawley, Rajeski, King, 2003, p.173) do not meet suggested amounts of physical activity (Brownson, 2000; Adams-Fryatt, 2010). This is likely, at least partially, due to older adults experiencing more barriers to physical activity than any other age cohort, because of increasing disability and pain (Buman, Yasova, Giacobbi, 2010). This is significant because physical activity has immense health benefits for older adults.

Adams-Fryatt (2010) argues that physical activity can delay biological aging by 10 – 12 years, slowing and even reversing loss of strength, endurance, and flexibility, which are often thought to be a “normal” part of aging. Although exercise recommendations for older adults have been made available to the public, researchers stress that they do not have to be met in order for health improvements to be realized (Adams-Fryatt, 2010). Exercise does not need to be arduous and uncomfortable in order to see results (Brawley et al., 2003). Results can be achieved by simply living an active lifestyle. Even for older adults who have lived largely inactive lives, taking part in low intensity physical activity can decrease the risk of cardiovascular disease (Mazzeo & Tanaka, 2001). For example, everyday walking has incredible health benefits, and is already widely accepted by the population, and by older adults especially (Brownson, Housemann, Brown, Jackson-Thompson, King, Malone, Sallis, 2000). For this reason the provision of walking trails is an attractive option for increasing active living in older adults, even for those seniors who are largely sedentary (Shasberger, Hussa, Polgar, McMonagle, Burke, Gegaris, 2009; Brownson et al., 2000).

Adams-Fryatt (2010) suggests that physical activity plays a critical role in successful aging, as it contributes to disease management and prevention. But physical health is only one element of health; keeping the mind active in order to maintain mental health is equally important (Belza, Walwick, Shiu-Thornton, Schwartz, Taylor, LoGerfo, 2004). For older adults remaining active is associated with increased functional capacity, and in turn associated with a lower risk of cognitive illness (Mazzeo & Tanaka, 2001; Larson, Wang, Bowen, McCormick,

Teri, Crane, Kukull, 2006). Larson et al. (2006) argue that regular physical activity has the potential to delay the onset of Alzheimer's and dementia. Laurin et al. (2001) go so far as to suggest that physical activity may even help prevent the onset of cognitive illness entirely. This is incredibly relevant considering that Alzheimer's and dementia are for many, the most feared potential consequences of aging (Adams-Fryatt, 2010; Larson et al., 2006).

However, enticing people to become more physically active, no matter the benefits, can be difficult. Older adults face particular barriers to physical activity, many of which are associated with disability and pain, such as a fear of further injury (Adams-Fryatt, 2010; Buman, Yasova, Giacobbi, 2010). Some other barriers include weather, quality of sidewalks, and lack of places to rest (Brawley et al., 2003). To counteract this resistance or lack of enthusiasm, being active can be assimilated into regular routines (Adams-Fryatt, 2010).

Kerr et al. (2012) argue that the built environment plays a critical role in both promoting and impeding active living in older adults. Brawley et al. (2003) suggest that people are more inclined to take part in activities that are moderate in intensity, inexpensive, simple, convenient, and have some sort of social component. The urban built environment has the potential to meet each of these requisites by facilitating physical activity through active living and active transportation.

3.4. Wayfinding for Dementia

In the early stages, people who are suffering from dementia are often confronted with spatial disorientation, and an inability to find their way through both unfamiliar and

familiar environments (Marquardt, 2011; Rainville, Passini, Marchand, 2001). Marquardt (2011, p.76) argues, “[a] decline in orientation limits a persons ability to perform daily activities independently therefore it is a prime reason for institutionalization.” This is critical, because most people suffering from dementia live at home, and wish to stay there (Day, Calkins, 2002). Subsequently, when people who have dementia move to unfamiliar neighbourhoods, there can be negative ramifications (Sheehan, Burton, Mitchell, 2006).

Until recently, the environment was not seen as a significant factor in the treatment of dementia. This is beginning to change, however (Calkins, 2011). The idea that the built environment has remarkable effects on people who suffer from cognitive illness is gaining momentum (Day, Calkins, 2002; Calkins, 2011). As dementia and person-environment relationships are better understood, the therapeutic possibilities of supportive environments are illuminated. People who have dementia struggle to create mental images of places they literally can not see, which means they are not able to depend on what Tolman (1948) refers to as *cognitive maps*. Cognitive or mental maps are mental pictures of the environment, and are considered critical for orientation. When someone is suffering from dementia their cognitive maps are fragmented, hence they experience increasing disorientation, and subsequently, difficulties with wayfinding (Marquart, 2011).

Lynch (1960) further reinforces the importance of mental maps, arguing that they provide emotional security, and help individuals avoid disorientation. Lynch (1960) suggests there are five components of an individual’s mental map: paths, which are channels that people move along and, for many, the most important

element; edges, which are linear elements that are not used as pathways, but are considered boundaries or seams between two areas; districts, which are “medium to large sections of the city” (Lynch, 1960, p.47) and have some identifiable commonality within them; nodes, which are points, junctions, or simply concentrations, and are identified as important because of some form of physical significance; and landmarks, which are not entered into, but are most often a physical point of reference. These elements are inextricably connected, and consistently overlap. Landmarks dot districts, which are permeated with paths, defined by edges, and supported by nodes. Lynch (1960, p.90) asserts that people are persistently trying to organize these elements in order create mental maps that make sense of their environments.

Rainville et al. (2001) suggest that spatial problem-solving is imperative to social orientation, but without the ability to use cognitive mapping, people with dementia are not fully capable of this type of problem-solving. Supportive wayfinding interventions, like personalized and unique signage, can help people with dementia navigate an environment, and find their destination (Calkins, 2011). Marquardt (2011) argues that even those with severe dementia are capable of identifying certain destinations if their environment has supportive wayfinding features.

The literature suggests that wayfinding strategies for dementia have been researched extensively for care homes and other interior environments. The design of these spaces is informed by familiarity, legibility, distinctness, accessibility, comfort, and safety. They are also designed with the intent of appeasing symptoms like

agitation and aggression – common side-effects of dementia (Marquardt, 2011).

Although literature on outdoor wayfinding is not as thorough, it is equally important, because the ability to utilize outdoor environments has the potential to increase quality of life (Sheehan et al, 2006). The concepts that inform interior dementia-friendly design may also apply to outdoor environments, and translate to things like small street blocks, direct and connected routes, good visual access, and distinctive urban form and environmental cues (Marquardt, 2011).

3.5. Aging in Winter Cities

There is a large gap in the literature about aging in winter cities or cold climates, and the role of weather conditions in older adults physical activity levels (Tucker, Gilliland, 2007; Li, Hsu, Fernie, 2012). Although perhaps out-dated, several papers written for a report published by National Advisory Council on Aging in 1989 provided some lasting advice. The report included valuable information about what older adults desire in the winter, such as ice removal, wind protection, and opportunities to connect with other people (Matthews, 1989). Maintaining social connections during the winter is difficult but crucial. Not only is it important to older adults, but those who are socially withdrawn may also become depressed (Presinger, 1989).

Presinger (1989) argues that mental health is greatly influenced by mood, and mood is determined by three environmental sources: physical changes, like light and temperature; an undesired reduction in physical activity; and the level of sense of

control over personal environment. Each of these affects perceptions and behaviours in Canadian urban environments, and are exacerbated during winter months.

Accepting the importance of outdoor environments for mental health means exploring different ways of encouraging going outside (Duggan et al., 2008). In *Recreation and fitness in winter: Winters aren't what they used to be – but they could be more enjoyable!* Pepper (1989) acknowledges that winter becomes less fun as we grow older, but emphasizes that this does not have to be the case. Although winter conditions present additional challenges to aging adults, if designed and maintained properly, winter environments have the potential to offer exciting activities for them. Pepper (1989) identifies a number of activities for a range of older adults, from the mildly active to the very active. Some of these include: people watching, bird watching, walking a dog, sleigh rides, skating, ice-fishing, snowshoeing, playing outdoors with grandchildren, and curling. While it is likely that most of these activities take place outside of one's community, it is important to have the opportunity to maintain a physically active lifestyle within the community. This helps to ensure that the ability to take part in more physically demanding activities is maintained.

Garvin et al. (2012) stress that age-supportive environments are critical, and can help prevent injury and chronic disease. Their study provided a number of older adults in Edmonton, Alberta with cameras, and asked them to document their stories about summer and winter issues in their community. The study found that winter issues dominated the focus group's discussions, even in the summer. Such findings suggest that severe weather plays a vital role in the lives of older adults all year

round. Li et al. (2012) suggest that poor weather is a deterrent to physical activity, and that daily activity levels decrease as rain and snow increase and temperatures fall. Tucker and Gilliland (2007) also state that weather conditions can encourage or discourage physical activity. They suggest that physical activity decreases in the winter months because activities become both physically and financially inconvenient and inaccessible.

While temperature alone is shown to have little impact on how often older adults go outside, snow and ice generally keeps them inside (Li, et al., 2012). This is likely because of the risk of falling. Wennberg, Stahl, and Hyden (2009) state that older adults make a significant number of their journeys on foot. However, the streets, roads, and sidewalks that they usually use can become treacherous in the winter (Li, et al., 2012). Environments that are accessible in the summer can quickly become inaccessible in the winter. Snow and ice can cover walking surfaces and hide curbs (Wennberg, et al., 2009).

These barriers become even more challenging for individuals with reduced mobility because of potential vision problems or obstructed visibility, and difficult surface conditions like slipperiness and unevenness. Individuals with cognitive decline face additional challenges because of reduced visual and tactile guidance. For example signage and other wayfinding items can become covered in snow, making it more difficult for people to orient themselves (Wennberg, et al., 2009).

In 1989, Matthews wrote: “Winter harshness either reinforces or tears apart behavioural and special relationships” (p. 1). This is still relevant today. Winter

environments often tear these relationships apart, and with this research I hope to explore the potential of rebuilding and maintaining them.

3.6. Conclusions

As the global population ages, it is predicted that the prevalence of dementia and Alzheimer's will also increase (Adams-Fryatt, 2010; Sheehan et al., 2006).

Consequently, designing for people with dementia will become more and more relevant (Marquardt, 2011). Existing initiatives are beginning to address the unique issues that older people face in their environments due to physical disability, but environmental design for cognitive illness is still largely neglected (Blackman et al., 2010). This is unacceptable. Research shows that older people, especially those with dementia, are more susceptible to, and dependent on their outside environments. However, they cannot always read them (Marquardt, 2011). Appropriate wayfinding strategies can help with outdoor navigation, and contribute to remaining active and independent longer (Day & Calkin, 2002).

Research also shows that people suffering from dementia can be protected from further cognitive decline by remaining active in their daily lives, and that they are more likely to do so if low-intensity physical activity is incorporated into their daily routines. Society has a responsibility to ensure that people who suffer from dementia are supported in their outdoor environments, and able to use them to remain active and socially engaged.

The literature also suggests that older adults are greatly influenced by climate, which is especially important in Canada due to long, cold winters. Older adults can

end up being socially isolated and inactive for long periods of time if their environments are not supportive. Older adults who suffer from dementia and live in cold climates are faced with additional challenges. Through this research I hope to shed light on specific barriers and facilitators of physical activity for older adults with dementia in a winter climate so that future urban design and planning practices can be more inclusive of their needs.

4| RESEARCH METHODS & ANALYSIS

4.1. Participant Recruitment

This research study has two data collection components. The first component was a photovoice and follow-up interview, and the second component was a group presentation and discussion.

I initially intended to conduct the photovoice with pairs of participants – a person with early or mild dementia and their primary caregiver. I had hoped to recruit three pairs — a person with mild dementia and their primary caregiver — for a total of six participants. Participant recruitment for the photovoice proved to be the most difficult and unpredictable aspect of this major degree project in a number of ways. I had initially intended to recruit with the help of the Alzheimer’s society and my advisors, or by contacting seniors’ homes directly. I was looking specifically for a people who have dementia, who were still living in their communities and were physically able to move around on their own mostly, and who were also living with their primary caregiver.

Including primary caregivers had numerous advantages in this study. Incorporating a role for the primary caregiver from the outset helped to ensure that the individual with dementia remained safe and comfortable, and also allowed for the primary caregiver to take over when the individual with dementia was no longer able to contribute. It also provided the opportunity for the primary caregiver to offer their own valuable insights.

Once ethics had been submitted and approved, I emailed a number of contacts at the Alzheimer’s Society of Manitoba, and a number of home care providers

including: Comforts of Home Care, VIP Home Care, and Compassionate Care. This communication included information about the purpose of the study, what would be expected of the participants, my timeline, and how and why a photovoice works. The only response came from the program director at the Alzheimer's Society of Manitoba. The program director was able to put a call for participants on the Alzheimer's Society of Manitoba website with a link to the project backgrounder at the beginning of December 2014. A project backgrounder was also included in the Alzheimer's Society eNewsletter at the beginning of January 2015 (see *Research project seeks participants* at <http://www.alzheimer.mb.ca/january-2015-enewsletter/#research>). This resulted in one response from an individual who had seen the call for participants online in early January.

In an attempt to reach more potential participants, I contacted additional key individuals in February 2015. These included a clinical nurse specialist in research and Geriatrics at the Health Science Centre as well as the medical director at the Geriatric Day Hospital. The medical director of the Geriatric Day Hospital offered to put up posters calling for participants, and pass around the project backgrounder at his place of work. This failed to result in any additional interested participants.

After waiting more than two months for responses, and consulting with my advisory committee, I decided to move forward with the one pair that had already shown interest. This pair included a woman (caregiver participant) and her mother (participant with dementia). As this would result in less data, it was decided that the preliminary research would be presented at a semi-public presentation with the intent of gathering additional data from the ensuing discussion.

Throughout this entire process, I continually communicated with the one interested pair of participants to ensure they were kept up to date on the progress of recruitment. During this time the participant with dementia was well enough to walk regularly, and so the participant caregiver made mental notes about the barriers they were facing on their walks in their neighbourhood.

After deciding to move forward with one pair, I met with the caregiver participant. We discussed the quickly deteriorating condition of the participant with dementia and their inability to take part in the photovoice process because of it. We decided to have the participant caregiver conduct the photovoice as if the participant with dementia was with her. We held the information session immediately following the decision to move forward with one pair. At the session I provided the caregiver participant with an information package that included an explanation of what to do both for the photographs and for the journal entries (see appendix II).

We also discussed the consent form and issues of privacy. In a photovoice project in Flint, Michigan, Wang and Redwood (2001) used three different consent forms to ensure people's privacy was respected throughout the study. The first was used to obtain consent to take part in the study. A second was given to participants to take with them to ask for consent from people who ended up in their pictures, and a third was again given to participants to provide consent that the researchers could publish their photographs for their research.

For this study, I merged the first and third consent forms so that all the information regarding participation in the project and allowing it to be published was included in one form that both the participant caregiver and participant with

dementia signed. The consent form for the participant with dementia also ensured ongoing consent by requiring a signature at the outset of each data collection event. I also provided an additional consent form for the participant to give to other people if they ended up in their photographs, letting them know what the research is and how the images will be used. As anticipated, the photographs taken for this study did not include other people and so the additional consent forms were not used.

Recruitment for the presentation/discussion was more successful. Members of the Active Living Centre were invited to attend the presentation with the help of the program manager, who forwarded the recruitment poster to them. The program manager also kept me updated on the number of individuals registered for the presentation/discussion as the date came closer. I also forwarded the recruitment poster to individuals from the Alzheimer's Society of Manitoba, Mensheds Manitoba, the Geriatric Day Hospital, Good Neighbours Active Living Centre, and various Extendicare facilities, however members from these organizations did not attend. There was no consent form for the presentation/discussion, as consent was obtained verbally. This is discussed further in the *Group presentation and discussion* section.

4.2. Photovoice Study

Photovoice is a qualitative and participatory research method (Novel, Morris-Oswald, Menec, 2011). It was established in the 1990s by Wang and Burris, and is informed by a number of theoretical bodies of thought. Paulo Freire (1970) suggests that the visual image is a powerful tool to get people to begin thinking critically

about their community. However, feminist theory (see for example Smith, 1987) informed the idea behind putting the camera, or data collection tool, into the hands of participants, with the intention of giving a voice to people who do not always have one (Wang & Redwood-Jones, 2001). Finally, the development of photovoice was, in part, influenced by documentary photography, described as illuminating social conscious through visual images (Wang & Burris, 1997; Wang & Redwood-Jones, 2001).

Photovoice has three primary goals: to give people the chance to record and reflect on the strengths and weaknesses in their community, to promote critical dialogue and knowledge, and finally to reach policy makers (Wang & Burris, 1997). Yankeelov et al. (2013) argue findings from a photovoice study are likely to produce more culturally appropriate responses and solutions for policy problems because the findings are more relevant to the local context they were discovered in. I wanted to illuminate the barriers and obstacles that people with dementia face in their day-to-day routines and capturing these issues through photography had the potential to engage this specific community in a deeper way than simply talking about the issues.

Photovoice is a data collection method that involves giving study participants a camera and asking them to document issues in their communities through photography, and is usually followed by a focus group. It is the data collection method that was used for the primary data collection in this study. Although I initially intended to include three pairs of participants, only one pair showed interest in this study, and in the interest of time, I chose to move forward with one pair instead of three. The pair of participants was asked to document issues in their

community through photography together, however due to her quickly deteriorating condition, the participant with dementia was unable to take part. Thus the photovoice was done by the caregiver participant as though the participant with dementia (her mother) was with her.

After conducting an information session I offered to give the participant a digital camera, however she preferred to use her own. I also gave her a digital journal to make image-related notes about the context of the images. I then gave the participant two weeks to document the issues related to the built environment through 15 photographs and corresponding journal entries.

4.3. Follow-up Interview

Grey (2009, p. 371) suggests it is important to conduct interviews when there is a need to probe and in this case there was. It was important that I understood exactly what the intended subject was when the participant took the photographs, and so after collecting the photographs and journals from the participant I conducted a short interview with her and her mother. Although the participant with dementia was unable to contribute, she was able to sit with us while conducting the interview.

The post-photovoice interview was approximately one hour long. It was intended that the interview strive for a more accurate representation of the data because it enabled me to interact directly with the individual with dementia, and for the primary caregiver to interpret for them if they were unable to communicate how they felt about certain characteristics in the built environment. In the case of this research, the participant with dementia had deteriorated to the point they could not

contribute during the interview. It was therefore necessary for the participant caregiver to interpret entirely for the participant with dementia.

The interview took place at the nursing home where the participant with dementia had recently been admitted. Initially the participant caregiver had booked a private room, however the facility needed the space for something else, and so the interview was conducted in a public visiting space. At the outset, the participants and I were the only ones in the room. However, eventually the distractions became more significant; a resident came around asking if we wanted to be part of a bowling team; a family came to visit their loved one, speaking and laughing loudly; and a cat wandered about. This was an interesting and suitable tribute to the fact that this research was being done with individuals who suffer from dementia, and the distractions they face on a daily basis.

The interview was semi-structured as defined by Berg (2001). It was set up in sections. First, introductions were made, as it was the first time I met the participant with dementia. Following the introductions, the initial part of the interview involved going through each individual photograph and its corresponding journal entry, in order to clarify the subject and meaning of them. I then asked the participant caregiver overarching questions that involved analysis of both the process and the images as a group. Afterwards, the participant caregiver offered a tour of the facility.

The interview questions and discussions were largely based around the content of the photographs. Questions that were asked included:

- 1) Which picture best shows something in the environment that helps you get around on foot outdoors?

- 2) Which picture is your favourite and why?
- 3) Which photo best highlights something that stops you from getting around outdoors on foot?
- 4) Which photograph was the most difficult to take and why?
- 5) Is there anything you feel you couldn't capture in a photograph? Please explain.
- 6) What physical characteristics would make it easier for you to get around outdoors on foot?
- 7) What is the most important thing in each photo?

4.4. Group presentation & discussion

In photovoice studies, researchers usually coordinate a final focus group with all the participants. The focus group is an important step because it can contribute to the empowerment of participants, and foster a co-learning environment for everyone involved (Yankeelov, Faul, D'Ambrosio, Collins, Gordon, 2013). In this study a focus group with the participants was not conducted because it would have likely caused considerable stress for those with dementia, and because there were only two participants. Instead, I conducted a semi-public presentation at the Charleswood 55+ Active Living Centre, with the intent of gathering additional data from the ensuing discussion.

Charleswood is an old residential neighbourhood, situated at the south western edge of Winnipeg, and is bordered by the Assiniboine River, Assiniboine Forest, and the Perimeter Highway. Although the area is somewhat removed from

the rest of the city, and not easily accessible through active transportation, it has a high proportion of seniors already living in it. The presentation and discussion were advertised as a Lunch 'n Learn, which meant individuals attending were encouraged to bring a bagged lunch. It was held on a Wednesday morning in April 2015 at 11:00 am, and lasted approximately 1 hour. There were 21 attendees at the start of the presentation, who were all members of the Active Living Centre. All of the attendees stayed throughout the entire presentation and ensuing discussion. The large majority of the attendees were women, and only two or three were men. There were no individuals with visible physical limitations, however there was one individual with hearing loss. All of the attendees spoke from the perspective of living with or caring for someone with dementia, and not necessarily from the perspective of suffering from dementia themselves.

The presentation was separated into three main sections. For the initial 20 minutes, I presented the preliminary research, process, and findings. Following this, the participant who took part in the photovoice presented her experience and thoughts on the research and findings for approximately 5 minutes. Finally, in a semi-structured discussion following the presentation, and for the remaining 35 minutes, attendees were asked to share their own experiences, opinions, and thoughts on the topic, and the research process and findings. The physical layout of the presentation/discussion involved myself standing in front of the attendees. The photovoice participant stood to one side of me, and the attendees sat around three tables in a large U shape in front of us (see figure 1). I believe this layout allowed the

attendees to both address the questions I was asking them, as well as to talk to one another and build off of each other's responses.

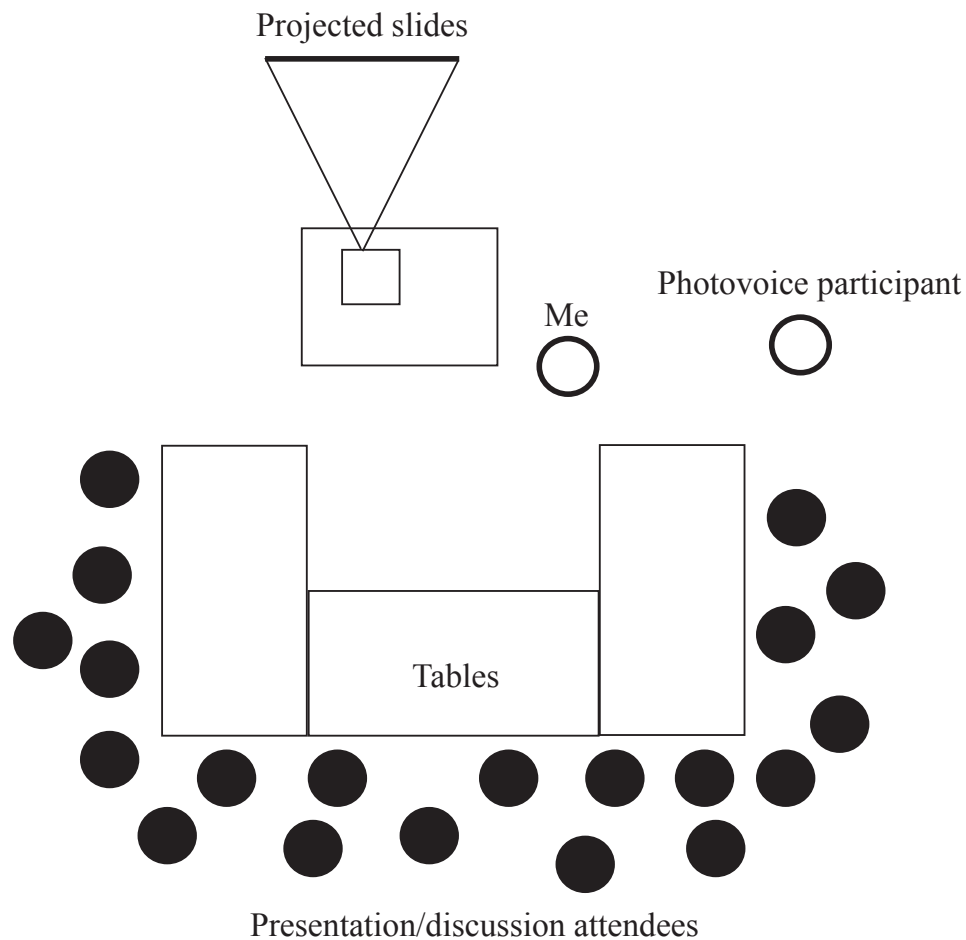


Figure 1 Top view of the layout of the presentation/discussion.

In order to ensure the entire presentation/discussion were recorded, three recording devices were used: the Mac laptop that was used to project the presentation; a Sony Linear PCM Recorder on a chair in front of the attendees; and a second Sony Linear PCM Recorder that was walked to different areas of the room depending on who was speaking. This is discussed further in *the Lecompte's framework for qualitative data analysis* section.

The questions for the discussion focused on acquiring additional data in the form of feedback from presentation attendees. This information was critical in understanding present interactions between people with cognitive illness and their outdoor environments, and informing future urban design and planning that takes into account their needs. Some of the questions that were asked to foster additional discussion included:

- 1) How does the information presented here resonate with your own experiences?
- 2) Is there anything you would like to add?
- 3) In your opinion, what is the biggest barrier in the urban built environment for someone with dementia?
- 4) What changes in the built environment might help someone living with dementia to continue taking part in everyday activities in the community?

4.5. Analysis & Applications

Auerbach et al. (2003) describe qualitative research as the practice of interpreting texts and interviews in order explain certain events, situations, experiences, and circumstances. Dey (1993) states text is not the only or most effective way to communicate an idea and suggests sounds, pictures, videos, music, and poetry can also help a researcher further understand meaning. Compared to measuring numbers, evaluating meaning can appear fallible, which makes qualitative data analysis difficult and complicated (Dey, 1993; Dierckx de Casterlé, Gastmans, Bryon, Denier,

2012). In this section I will demonstrate the framework I used for analyzing the data and how I maintained credibility, validity, plausibility and authenticity through triangulation, verbatim quotations and member checking.

4.5.1. Lecompte's framework for qualitative data analysis

Lecompte (2010) provides a helpful framework for analyzing qualitative data that includes five simplified steps. Step one is *tidying up*, and she means this quite literally. Often, she observes, researchers underestimate the importance of arranging their data in a legible way, so this was my first step. She also recommends reviewing research questions to compare them to all data collected. This is a really important step so as not to lose sight of the research goals. This step also allowed me to make initial evaluations about the data. I compared the preliminary findings to the initial research questions and included them in the presentation/discussion data collection.

Step two is finding items, or units of analysis. This involves sifting through the data to identify what can be related back to the research questions. During this stage I looked at the frequency with which items were mentioned, whether or not they were omitted entirely, or specifically pointed out by study participants. Step three involves organizing the items found in step two into groups. This included identifying both *parent codes* and *sub codes*. After transcribing my interview and group discussion I pulled out statements and grouped them in an excel spreadsheet under specific themes (parent codes - for example, barriers to getting around outdoors on foot for someone with dementia). Two of the themes were derived through deductive means and relate directly back to my

research questions, and two were derived through inductive means and came out of the data I collected. Then I broke down each theme again (sub codes - for example, individual physical characteristics that are barriers)

After the various codes are identified, step four deals with identifying patterns. Lacompte (2010) draws parallels between the process of collecting data and finding items with “taking them apart,” and identifying patterns with “reassembling them.” Solutions to problems are revealed through the establishment of similarities, co-occurrences, sequences, and corroborations. This also aligns with Dey’s (1993, p31) interpretation of analysis as “breaking down data into bits and then ‘beating’ the bits back together.” This allows the researcher to pull the body of data apart, distilling it down into its basic elements, in order put it together again in a more cohesive way (Day, 1993). Finally, Lecompte’s step five encompasses linking the patterns described in step four, in order to construct an account of whatever is being studied. Steps one, two, and three involved take the data apart and distilling it to its fundamental components, and steps four and five involved reconstructing the data in a more cohesive way (Lacompte, 2010).

Table 1. Data analysis steps in Lecompte's method and the steps taken in this research project.

	Step 1	Step 2	Step 3	Step 4	Step 5
Lecompte	Tidy up	Find initial items	Stable set of items	Identify patters	Link patterns
This research project	• Transcription • Colour coding • Labeled folders	• Used research question to guide • Added items based on data collected	• Include existing barriers, desires of the participants, and overlap with other movements	• Identification of common themes • Grouping the items in meaningful ways	• Use common themes to reassemble the information • Draw conclusions

The data collected through the photovoice included images and complementary journal entries. The interview and presentation/discussion were recorded, and I transcribed them the day after that data was collected. The interview was recorded on a MacBook Pro and the presentation/discussion was recorded with a Sony Linear PCM Recorder. In order to *tidy up* the data, both were then transcribed with Express Scribe Transcription Software, version 5.7. The transcriptions were stored in clearly labeled folders with all other material from that specific data collection event, and copies were made and colour-coded for the next steps of the data analysis. This was done so the data source could be easily identified, and included in the results section.

I read through the transcriptions numerous times. During each read through, emerging ideas and themes, and individual items (based on frequency) were noted. I identified items using both deductive and inductive means. Statements made by participants in both the journal entries, and transcribed interview and presentation/discussion were categorized in a tabular spreadsheet format, and grouped together based on commonalities. Deductive items, which were derived from the literature and influenced the initial research questions, included: barriers to going outdoors for people with dementia, and ideas for creating urban environments that are inclusive of the needs of individuals with dementia. Inductive items, derived from the data collected from the study participants included: overlap with other inclusive design movements, and perspectives on why the research topic is important. These are discussed in greater detail in chapter 4.

4.5.2. Triangulation

To increase validity and credibility in this research, triangulation was used. The concept of *triangulation* originated in the disciplines of land surveying and navigation, and initially implied that a single point had been examined from three distinct sources (Bauwens, 2010; Decrop, 1999). The method was first introduced by Campbell and Fiske (1979), and then continuously refined by various authors (see Webb et al., 1966 and Jick, 1979). After adoption into the social sciences, triangulation was initially used to exhibit how quantitative and qualitative data could be used to complement one other. Eventually it became common to use triangulation in qualitative research alone, in order to strengthen and justify qualitative research approaches (Decrop, 1999).

In social science research triangulation can be described as viewing the same phenomena from multiple (two or more) sources of data. It involves gathering information from varying perspectives in order to “corroborate, elaborate, or illuminate the research problem” (Decrop, 1999, p158). Although triangulation in social science research was first intended to lend validity to the data, it has matured into a practice that is used to secure a more thorough understanding of the phenomena being studied (Flick, Kardoff, Steinke, 2004).

Denzin (1978) distinguishes between four types of triangulation: data triangulation, method triangulation, investigator triangulation, and theoretical triangulation. For this research, I used both data triangulation and method triangulation. Data triangulation is the inclusion of different data sources for one study, or to address one research problem (Decrop, 1999). In this study the different

written data sources were the journal entries written by the participant caregiver, and the transcriptions from both the follow-up interview and the discussion/presentation. In addition to written data sources, visual data sources – like photographs and videos, are being used in qualitative research much more frequently (Flick et al., 2004). In this study, the written data sources – journal entries and transcriptions– were also triangulated with the photographs from the photovoice.

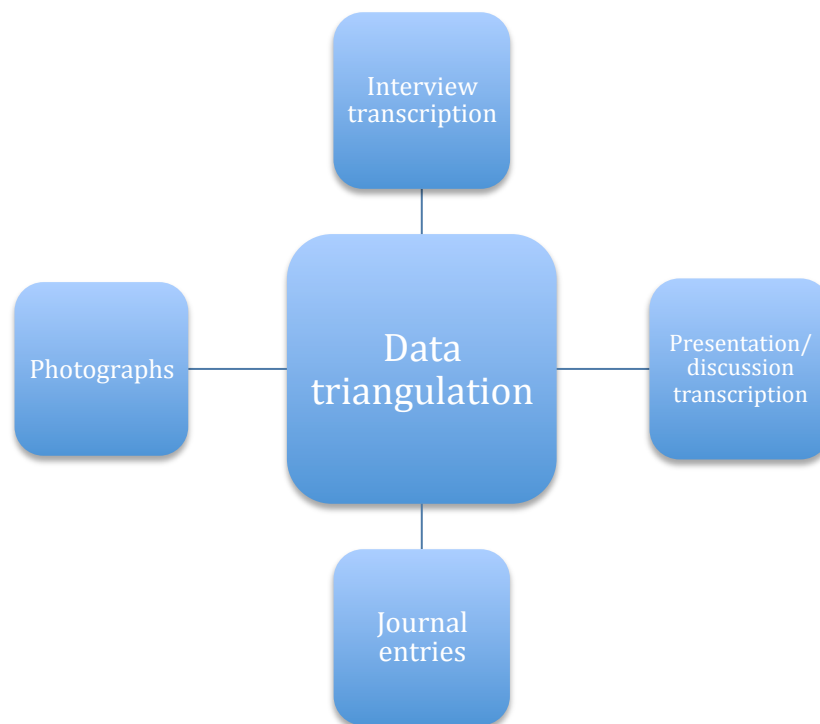


Figure 2. Data sources used for data triangulation.

Method triangulation is the combination of different methods of collecting data, and is used in recognition that every method has unique flaws and partialities. If these methods are used alone, they can result in biases. However, the use of multiple methods can offset those biases and help to produce more credible and reliable information (Decrop, 1999). Using different methods allows the researcher to capture

different aspects of the issue being researched (Flick et al., 2004). The methods triangulated for this research were the photovoice – which produced the photographs and journal entries – the follow up interview, the presentation/discussion, and the literature review – which lent rigor to the process, and helped to frame the findings.

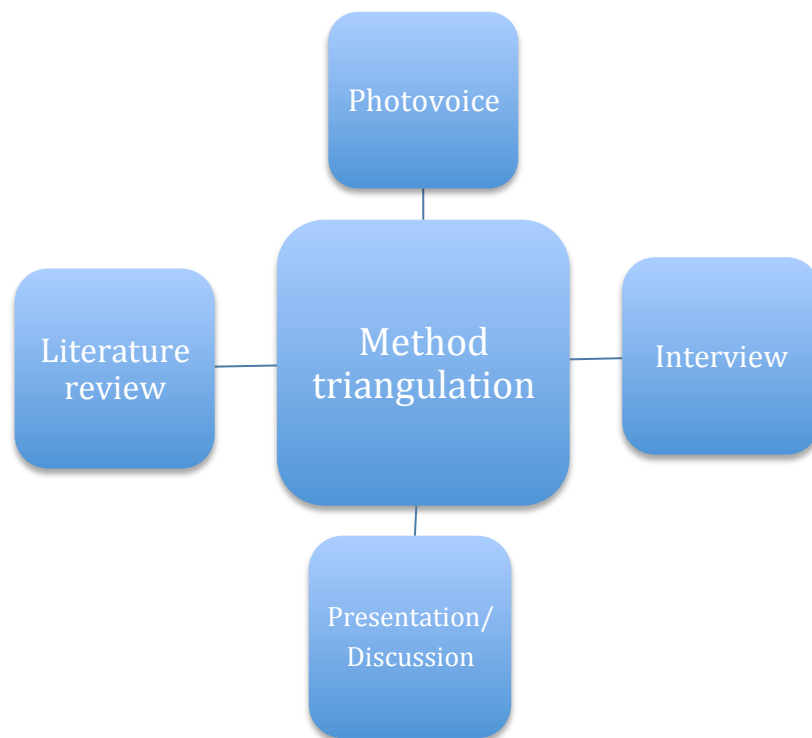


Figure 3. Methods used for method triangulation.

4.5.3. Verbatim quotations & member checking

To further increase plausibility, credibility and validity, I used verbatim quotations from the journal entries, and interview and presentation/discussion transcripts (Cohen, Crabtree, 2006). Corden and Sainsbury (2006) identify various reasons for using verbatim quotations, many of which support their use in this study. Verbatim quotations can be used as evidence and explanation. When using them, readers are shown some of the original data, and can thus draw their own conclusions about the

accuracy and fairness of the analysis. Verbatim quotations can also be used to help explain a phenomenon and clarify participant's particular – and sometimes complicated – views (Corden, Sainsbury, 2006).

Verbatim quotations are also used in qualitative research to deepen understanding of a phenomenon, and to provide study participants with a voice. Often the spoken or written words of a participant offer a much deeper and greater understanding of a phenomenon they are experiencing, than a researcher's words ever could. The use of verbatim quotations also provides the opportunity for a participant to share their own opinions about something that directly affects them, and demonstrates the value of participants input (Corden, Sainsbury, 2006).

Additionally, verbatim quotations are used to increase readability of a research report. Spoken or written words from the participant can offer “color, vividness, and sometimes humour” amongst what can become long-winded and unending text (Corden, Sainsburg, 2006, p14).

In this research study I used verbatim quotations: as evidence and explanation of the impacts the built environment and winter weather can have on individuals with dementia; to deepen understanding of the difficulties people with dementia face when trying to get around outdoors in the winter; to empower participants and give a voice to a group of individuals who have largely been left out of urban design and planning processes; and to enliven the text.

Corden and Sainsbury (2006) also stress the importance of presenting any transcribed material with as little editing as possible in order to preserve accuracy. The verbatim quotations from the transcriptions included in this research study have

been edited in only a few ways. The pauses and repetitions common in spoken language have been removed to enhance readability, and names and other identifying information have been replaced with a general term in square brackets. The only other changes involved adding a word when something was implied but not said by the person speaking. This was only done when necessary to ensure the quotation is legible and coherent to someone reading it. Anytime a word was added, it was indicated by square brackets. The quotations from the journal entries were not edited.

Corden and Sainsbury (2006) and Cohen and Crabtree (2006) also emphasize the need for clearly distinguishing between verbatim quotations and the researchers narrative. This research study follows the most commonly used – and most easily and quickly recognizable by readers – “house style” of including quotations. All quotations are indented and shown in italicized font (Corden and Sainsbury, 2006, p20).

Cope (2014) also suggests using member checking to increase authenticity and trustworthiness of the data. Member checking involves communicating the analyzed data and themes derived by the researcher back to the study participants. The participants then have the opportunity to validate that the data has been accurately interpreted. After transcribing the interview I sent the edited transcription to the participant to strike or add anything. The presentation/discussion also offered a unique opportunity to member check. The presentation slides were a summary of the emerging themes, and were sent to the photovoice participant before being presented, and the participant was asked to review the conclusions and provide feedback.

5| RESULTS

5.1. Findings

In order to begin to understand how individuals with dementia interact with their outdoor environments and how urban design practices can better incorporate their needs, this section integrates the findings from the photovoice, the interview, and the presentation/discussion. In so doing the findings help to give insight into various perspectives on the topic, and the issues brought about through the research questions. The following section discusses: barriers for individuals with dementia getting around outdoor on foot; hopes and suggestions for dementia-friendly communities; how the dementia-friendly communities concept overlaps with other movements that advocate for inclusivity in urban design; and why this research is important to people and how this can help improve future research attempts.

5.1.1. Barriers to getting around

As anticipated, barriers to getting around outdoors in the winter for individuals with dementia were abundant. These barriers made up the bulk of the data from the photovoice and follow-up interview. The themes about barriers can be clustered into concerns about winter, individual physical characteristics, wider urban design characteristics, negative experiences, and the progression of the disease.

Winter

The data collected through the interview, presentation/discussion, and especially the photovoice supported the fact that winter increases risk for someone with dementia.

The participant from the photovoice said:

The most important thing is that snow, winter adds risk. In the summertime you can trip over a crack but in the wintertime your challenge is much greater, and your risk is much greater of injury.

This opinion was reinforced a number of times throughout the interview and in the journal entries. The participant wrote about the difficulties that winter presents before even getting outside. In regards to photograph two the participant wrote:

There are times when you wake up to find the overnight snow is so high you cannot easily get out of the house. Complications can be overwhelming to persons with Alzheimer's.

Figure 4. Photograph #2 – Getting out the door.



The participant reaffirmed the stress winter can have on an individual with dementia before going outside, in the interview again:

[The participant with dementia] would get up in the morning and she'd look out and say, well we won't be going out today because [the snow] would be so piled up... So it's already a deterrent before you even go any further.

The concern about winter, as a deterrent in general, was reiterated at the presentation/discussion by a number of participants. They discussed the importance of clearing snow so there are places to walk. One participant called the roads where she was forced to walk in the wintertime “treacherous.” Another participant talked about snow lumps getting in her way of walking, and wore cleats because of them. A number of participants touched on the heightened fear of falling when going out in the winter, not only for individuals with dementia but for all older adults. One said:

If it's snowing, if it's slippery, if it's icy...we all don't go out...we avoid it because we don't want that fall.

Other participants spoke about the cold specifically. One participant voiced concerns about a loved one with dementia going outdoors alone in the winter, because they would not know to come in from the cold. She said:

They can't be there by themselves because when it's thirty below they wouldn't know whether to come in after five minutes, so there should be somebody there....

Snow and ice were brought up repeatedly in the photographs, journal entries and interview. In the journal entries the participant wrote about ice in photograph's two, three, five, and eleven. However, upon comparing this with the interview transcript, ice was referred to much more often. While discussing photograph five the photovoice participant said:

Ice was the biggest problem...trudging through snow was one thing but ice...seems to be the biggest barrier, and it was always unseen ice.

Figure 5. Photograph #5 – Winter melting.



Later in the interview, she reiterated:

...it came up in a number [of photographs] that there was ice...ice seems to be the biggest barrier.

Then later, when asked what the biggest barrier to getting around outdoors for individuals with dementia would be, she reaffirmed that it was ice, especially unseen ice. During the interview the participant talked about ice when discussing photographs two, three, four,



Figure 6. Photograph #4 – The bumpy path.

five, six, seven, ten, and eleven.

Snow was written about in eight of the journal entries – two, four, six, seven, eleven, and twelve. The photovoice participant described snow piles and deep snow in the journal entries for photographs two, seven, and ten. In the journal entry for photograph two, the participant talked specifically about high snow making it difficult to even leave the house. In photograph seven, she talked about piled snow creating visual barriers both for pedestrians and cars. She wrote:

When the city piles snow in back lanes or near intersections it creates a limited visual view of cars and for drivers to see pedestrians.

Figure 7. Photograph #7 – Can they see me?



In regards to photograph ten, the participant talked about snow piles blocking

pedestrian routes in times of heavy snowfall. In the interview transcript, however, snow was mentioned when discussing photographs two, three, five, six, seven, ten, and twelve.

Table 2. Mention of ice and snow in the journal entries.

Photograph	1	2	3	4	5	6	7	8	9	10	11	12	13
Ice		✓	✓		✓						✓		
Snow		✓		✓		✓	✓			✓	✓	✓	

Table 3. Mention of ice or snow when talking about individual photographs in the interview transcript.

Photograph	1	2	3	4	5	6	7	8	9	10	11	12	13
Ice		✓	✓	✓	✓	✓	✓			✓	✓		
Snow		✓	✓		✓	✓	✓			✓		✓	

This exercise reinforced the significance of the follow-up interview. As can be seen when comparing table two and table three the reasons behind taking some of the photographs were not obvious or explicitly stated in the journal entries alone. Conducting the follow-up interviews illuminated that the participant was actually referring to both snow and ice as barriers for individuals with dementia in photographs two, three, four, five, six, seven, ten and eleven. Snow and ice were discussed considerably less during the presentation/discussion. In total ice and snow were mentioned only six times throughout the transcript for the presentation/discussion, most of which took place after being prompted with a question about winter.

The participant in the photovoice and follow-up interview also discussed some temporary barriers that are dependent on precipitation and weather. One

participant talked about the drainage areas from buildings. She said:

Eaves and drainage areas from public and private buildings can be dangerous. It is difficult to remove the ice. As winter warms the ice factor becomes a major issue on the roads and around homes.

Another participant talked about deep snow and how it can be difficult for someone with dementia to walk through.

Individual physical characteristics

Participants also discussed individual physical barriers in the built environment. A barrier that came up numerous times was the curb. Many participants discussed a loved ones inability to step up or down as their condition deteriorated. One participant commented on the abundance of curbs in the built environment. She said:

I never noticed how many there were and how little space there actually was that had no curb for her to go through.

Participants also talked about the difficulty of navigating stairs, both when leaving the home and in public spaces. The individual that took part in the photovoice and interview discussed the merits of visiting The Forks, but also stressed the constant fear of the set of stairs. She talked about the risk of not knowing what the surface of each step might be like. In the interview she said:

We could go to the Forks...the thing that was always a risk was this set of stairs...every step is a new experience of ice, or level or uneven surface.

She reiterated this is the journal entry for photograph eleven by saying:

Navigating steps requires focus and for someone with Alzheimer's every step can contain a number of risks such as snow, ice, and uneven surfaces.

Figure 8. Photograph #11 – Enjoying winter activities.



Steps or stairs were only mentioned in the journal entries for photographs two and eleven, however stairs can be seen in four different photographs – two, three, five, and eleven. While only one of these images showed a public set of stairs (photograph eleven), the remaining three included residential entryway stairs, suggesting entries into or out of an individual's home, can be a significant barrier.

Figure 9. Photograph #3 – Slippery or not slippery?



Table 4. Mention of stairs or steps in the journal entries and photographs.

Steps or stairs	1	2	3	4	5	6	7	8	9	10	11	12	13
Journal entries		✓									✓		
Photographs		✓	✓		✓						✓		

A participant at the presentation/discussion further supported the idea that steps and curbs are barriers for individuals with dementia. She stated that her loved one also had trouble with curbs, and going up and down any number of steps.

Wider urban design characteristics

Some wider urban design characteristics were also seen as barriers. The participant

in the photovoice and interview talked extensively about traffic, busy intersections, and the confusion associated with multiple lanes of cars. Intersections, cars, lanes, and traffic were mentioned in five of the journal entries – for photographs one, seven, eight, nine, and thirteen. This nearly aligned with the number of photographs that included roads or lanes, with two exceptions.

Table 5. Traffic related content in the journal entries and photographs

Traffic related content	1	2	3	4	5	6	7	8	9	10	11	12	13
Journal entries	✓						✓	✓	✓				✓
Photographs							✓	✓	✓	✓			✓

In photograph one, the participant did not photograph any roadway, but talked about the individual being distracted at intersections because of her bulky winter wear. She wrote:

Even the winter clothing you have to wear can be a serious distraction when walking outdoors. Her hat is warm but it can shift and correcting it can distract her at an intersection... .

Figure 10. [Participant with dementia] bundled up for winter weather.



Photograph ten included a back lane, and while the journal entry did not refer to traffic, it did refer to drivers and their ability or inability to see pedestrians.

Crossing the street can be a challenge for someone with dementia and this was brought up numerous times in the photovoice, interview, and presentation/discussion. The photovoice participant talked about crossing the street at busy intersections. Although there are walk signals and lights to help guide the pedestrians, distractions also abound. In the journal entry for photograph thirteen, which depicted a busy four-way traffic-signalized intersection, she wrote:

Many cars are turning and a lot is happening. The light may say go but persons turning right on a red require caution. Major intersections require the ability to focus on multiple things. This was a challenge.

Figure 11. Photograph #13 – Where do I look!



In the interview the participant elaborated, talking about her mother's inability to concentrate on more than one feature in a busy intersection. She stressed that even though her mother could understand that the walk signal meant she could go, she would not be able to also process the turning cars.

This barrier was further discussed in the presentation/discussion, when a participant spoke in great detail about crossing the street with her mother. She said:

When we were crossing the street we only made it halfway across and then there's dividers, so I wanted her to stand on the dividers and wait where we had to, and she got very, very upset because, she said, you can't stop there. And I could just see her anxiety increasing because we were now in the middle of the

road; traffic going both ways, and her anxiety was escalating. She didn't feel that that was safe, and I never realized that that was a barrier to her mentally, and then we could go again I had a hard time actually getting her to go because she was scared.

In this particular case, the amount of time allocated to cross the street was not enough for the participant and her mother to make it to the other side of the intersection and so they would get stranded in the middle boulevard. This caused great stress for the individual with dementia. Even though she did not want to stop in between the two directions of traffic, she had difficulty moving to the other side once the traffic had once again stopped.

In the journal entries the participant also wrote about the difficulties of navigating uncontrolled intersections, especially those with traffic going in three directions. Wide roads and corners, as seen in photograph eight, make it easier for cars to speed through the space. They also make it harder for pedestrians, especially someone with dementia, to cross the street safely.

Figure 12. Photograph #8 – Uncontrolled intersection.



Participants also discussed their frustration with long blocks, and limited designated crossings. In the summer, walking the extra distance to the nearest crossing might not be a problem. However, in the winter, when temperatures drop pedestrians might choose to cross mid-block regardless of whether or not there is a designated crossing. In the journal entry for photograph nine, the participant wrote:

When your destination is in the middle of long [blocks] a decision could be made to cross rather than dealing with the cold while you walk around to find a safe way to cross.

During the interview she further explained:

Sometimes instead of going to the intersection we'd try and go between the parked cars and then we only had one thing, just the traffic in front of us...and the easiest route rather than going around would be...come across this way and then we'd trudge through this way between the parked cars, which isn't the

Figure 13. Photograph #9 – Parked cars.



Figure 14. Photograph #6 – Avoiding the slippery and the uneven



safest thing. But in forty below weather, going out of the way... You tend to want to take the shortest route and then you're looking at risk.

In this quotation the participant alludes to taking extra risk when walking around outdoors in the winter. She notes that it becomes too cold to walk the entire length of the block to get to the next safe crossing.

Another major barrier that was talked about was blocked walkways. One of the participants commented on the lack of sidewalks in her neighborhood. While during the summer months walking on the streets is an option, in the winter with snow piles and ice, it becomes more difficult and dangerous. During the interview, the participant reiterated this by stating that having sidewalks puts her and her mother in a safer environment when walking. Participants also discussed sidewalks becoming unusable in the winter. In the journal entry for photograph ten the participant wrote:

During repeated days of snow these hills can become higher. Until the weather breaks the pathways for pedestrians can be barred until the city can clear them.

Figure 15. Photograph #10 – Climbing the hills.



The participant also talked about ice and snow being plowed off the streets and piled on the boulevards. Sometimes these pile-ups would prevent them from accessing the sidewalks, and they would be forced to walk down a back lane instead. Once on the back lane they were again confronted with traffic. Snow piles blocking walkways is a reoccurring issue during the winter months. This was supported in the participant's statement during the interview:

Snow mounded up as high as the fence...It's getting past the mounds of snow and the ploughing because every time they ploughed we had to move it somewhere.

During the presentation/discussion a number of participants alluded to the need for variety in the built environment. One participant spoke of her parents

moving into an assisted living facility, and as their conditions worsened they began getting lost because everything looks the same. She said:

My stepmom cannot find the door to her building because all of them are the same, because she doesn't recognize her building when she gets out of the car I have to take her to the door.

Although these comments were made about an assisted living facility, they can be applied in the community and to the urban built environment. The issue that this participant's parents were facing stemmed from sameness in their environment, which can be confusing for anyone, especially someone who is suffering from dementia. The same participant also said:

As the dementia is increasing she's now starting to get lost within the building because all the hallways are the same, and all the doors are the same.

Characteristics of the urban built environment that all look the same could have a similar effect on someone, and could further contribute to them getting lost while trying to get around outdoors.

Negative experiences

Another significant barrier for individuals with dementia that was brought up at the presentation/discussion was the detrimental effect of a bad experience in the urban environment, and the ripple effect it can have. One participant talked about her parents getting lost in the Ikea parking lot. She said:

My father drove [the Ikea parking lot] once, didn't know where to go, never went back, so he was still in the early stages so he could still do it but that experience of it being so complicated...now they stopped doing it. So now they're no longer having that social stimulation because the parking lot was not user friendly.

Although this is not an urban or walkable environment, the story brought up an

important point. Unreadable and confusing environments add stress and can have a lasting impact, and this participant's parents never returned because of it. This stresses the importance of creating dementia-friendly communities *before* individuals decide to avoid places in their communities because of experiences like these.

Another participant described her mother's struggle with transportation. She said:

So it's all the progression. And she was taking the bus all over the city, she didn't have a license, but then that got to much for her and then she did the handi-transit, which was good. She could still go to the doctor by herself, stuff like that. And then getting a little more forgetful, and then one day she was late so I guess the guy balled her out, because I guess he had a schedule to keep and after that she would never take the handi-transit anymore. She said, he said I can't take it anymore. I said, I don't think he would have said, that but that's the way she took it.

This story illuminated the importance of increasing awareness, especially for individuals in public service positions. This participant's mother refused to use handi-transit again after this confrontation. A loss of independence like this can result in isolation, loneliness and potentially, further cognitive decline.

Progression of the disease

A concern that was consistently raised throughout the photovoice, interview, and presentation/discussion was the progressive nature of dementia. At the presentation/discussion, the participant from the photovoice spoke about her experience taking part in this research study. She said:

We have someone from the younger generation that's going to make things better for me...so I jumped on this and it's been a great experience. The only barrier that [the researcher] and I had was progressive Alzheimer's.

She also discussed some of the challenges she had taking the photographs during the photovoice. When asked what, if any, barriers she felt she could not capture through

taking photographs, she talked about her inability to capture her mother's perception.

She also discussed concern with the variability of the disease. She said:

You can't capture their thinking today because tomorrow it could be different. So you can't capture that in a picture, so that made it difficult for me because it was like...but that's just her, maybe someone else would be different.

Other participants were concerned about individuals with dementia and their ability to navigate their immediate outdoor environment on their own. Most participants felt nervous about a loved one with dementia being out alone. One participant said:

Most of the [people with dementia] would have to have supervision...I would have to go with my mother, first of all she's to afraid to go alone...you could test your parent out and ask them to make them do some thinking...I don't think I'd want my mother going out on her own.

During the presentation/discussion the photovoice participant reiterated this by stating:

In most cases I think unsupervised becomes difficult...things progress and everybody progresses differently. I could never leave my mom on her own.

These statements suggest that even if urban environments were more dementia-friendly, caregivers would still have concerns about leaving their loved ones with dementia to navigate their community on their own.

5.1.2. Hopes and suggestions for dementia-friendly communities

While barriers dominated the photovoice and parts of the follow-up interview, the presentation/discussion brought up a number of suggestions for increasing dementia-friendliness, and hopes that people had for their future communities. These included opportunities for mental and physical stimulation, individual physical characteristics, wider urban design characteristics, and a greater awareness and increased sense of

community.

Opportunities for mental and physical stimulation

In the photovoice participant talked repeatedly about the importance of including obstacles that offer optional activity in the urban built environment. Such installations could allow the opportunity for both mental and physical stimulation. Although the participant did not write about it in any of the journal entries, when asked during the interview what her favorite image was and why she responded:

The Forks, number eleven, because there is so many things to do there...the ice skating pathway, they have the walking pathway. So there's a little more attention to getting around, getting exercise. It was a nice place to go, you could stop for coffee, up could do a million things...it's another safe environment...and different stimulation, different things that stimulate you mentally, physically.

In this statement the participant is alluding to the benefits of an informal gathering space and the mental and physical stimulation it provides. When at The Forks the participant and her mother had the option of light physical activity, for example, using the walking path or getting coffee. But they also had the option of not doing any of that. When prompted, the participant spoke about what she felt mentally stimulated her mother in this space. She said:

...there's statues, there's lots of people, children, activities going on that keep you thinking. They have mimes...or children skating. There's lots of shopping, tasting, all your senses can be explored in that environment.

The participant is suggesting that mental stimulation can be something as simple as watching other people in a space. She also touches briefly about the possibility of experiencing different tastes at The Forks, suggesting that a variety of opportunities

are important in informal gathering spaces.

However, these kinds of spaces can not exist everywhere and so the participant talked about optional physical challenges, and how she felt they could be incorporated along walkways and in parks. When talking about what she was hoping to find in her environment she said:

If there was a sidewalk pathway, if it had challenges along the way, like little step up bridge with railings. You know it's safe but it gets you up, gets you down...gives you something as you're moving along that stimulates you thinking and keeps your balance, practicing your balance.

Maintaining balance in older age is very important to being able to age in place, and so an environment that presents the opportunity to practice balance as a part of a person's daily routine can be beneficial to not only individuals with dementia but for other older adults as well. The participant also talked about simple changes like small inclines and declines along a path. She said:

A walkway that's kept clear and along the walkway, it's a little incline, decline, couple steps up, couple steps down, where you can go around it or have the choice to challenge it.

The participant stressed the importance of having the option to go around these small challenges because they can easily and quickly become stressful for someone with dementia.

The participant also discussed the possibility of specific installations, much like playground equipment, but specifically designed for individuals with dementia. She discussed a pole and ball, saying:

...something where you have a pole with a ball, and just hitting the ball so it gives you, it swings around. There's all kinds of toys and things out there in other countries that stimulate physical activity and mental activity.

She also talked about a ball and pipe, saying:

Drop the ball down a pipe, a PVC pipe that they use for plumbing, you can get a tennis ball size. You can drop the balls down, but that in an enclosed environment that belongs to a nursing home. You take the balls out there, they throw the balls down, when it hits the...180 at the end it pops out.

Although the participant is suggesting this installation for a nursing home environment, there is the possibility of some transferability into the urban built environment.

Individual physical characteristics

Almost all the participants, both from the photovoice and follow-up interview, and the presentation/discussion agreed that accessible pathways were a necessary component in a dementia-friendly community. Most participants visualized a cleared, and well-maintained pathway in a park environment. One participant said:

A pathway around the outside of [the park] and possibly things along the way, things that would challenge us along the way but something that was maintained.

A few of the participants at the presentation/discussion talked about the benefits of a circular path in a park that is protected with a fence. This would provide individuals with dementia that are using the space with some protection.

At the presentation/discussion participants shared their frustration about snow and ice on sidewalks and the barriers they can cause. One said:

Things that we hear...heard all winter, plough the damn sidewalks.

Another suggested:

Unless we wait for climate change the only other option is to keep [the sidewalks] ploughed.

In the interview, when asked what would make it easier for someone with dementia to get around, the participant said:

There are some, which are railings, salt – you know the ice salt, especially in front of buildings and that type of thing, when they really use the ice salt and keep that space clear. So places like the library, places people go all the time. So that would make it easier to get around.

Some spaces that are otherwise frequently visited might be avoided in the winter because of pavement conditions. Ice removal or salt can lower the risk of a fall, and increase the feeling of safety in the winter months. Referring to photograph eleven, the participant also discussed the importance of railings and walls. They can help individuals with dementia steady and balance themselves when navigating steps and slippery surfaces.

One participant referred back to the trouble individuals with dementia can have with curbs, and suggested larger areas they could walk without any curbs. Other participants talked about painting the curbs so individuals with dementia could quickly see them. One participant said:

The curbs painted...would help in the snow and ice because once they cleared it we'd see a blue curb or something other than grey and white, so we'd tell where it was if they were painted. Any bumps in the concrete would be nice to be painted

One participant suggested strategic placement of painted surfaces, for example at road crossings. She talked specifically about

Figure 16. Walkway rumble strips at an intersection in North Kildonan.



walkway rumble strips and seeing them in the United States. At the road the sidewalk is painted yellow and it also has small bumps. Walkway rumble strips do already exist in some Winnipeg neighbourhoods. Figure 15 shows them at an intersection in North Kildonan.

Another participant suggested many of the changes that would make a community dementia-friendly were simple, quick fixes. She stated:

[It's] simple things, like increase the length of the light that allows pedestrians to cross.

This would help individuals with dementia avoid the stress of having to stop and wait in the median boulevard of the road.

Another participant suggested a place where individuals with dementia could go to warm up in the winter when they are out. She said:

I think the City could put warming huts as they do for the general populace on the river that spend tons of money scraping the river and putting those warming huts, but they won't do it for a special park.

This participant expressed a desire for the City to take a leading role in implementing small, well-maintained huts in some local parks.

Wider urban design characteristics

The most common wider urban design characteristic that was brought up throughout the photovoice, interview, and presentation/discussion were usable sidewalk networks and paths. The participant from the photovoice said:

A lot of the rural areas – and some of the newer areas too - with the bays, don't have sidewalks. So I mean, we had the benefit of that, and I recognized that the environment I was in, because it's an old environment, had sidewalks.

Participants discussed not only sidewalks along streets but also pathways

through parks, and the importance of parks in general. When asked if there was anything she felt she couldn't capture in a photograph, the photovoice participant said:

It would have been nice to find one safe park with clear paths.

She stressed that while parks may not always be accessible in the winter because of deep snow and ice, they always provide a space that is safe from traffic. The participant expressed a desire to see walking paths in parks ploughed on a regular basis. Referring to a park near her mother's nursing home, she stated:

They go down to the park some days but not in the winter because what's the use of sitting on a frozen park bench in the winter? But in the winter that could have been utilized if they pathways were clear and the challenges were there, and it's a sunny day...it's facing south.

During the presentation/discussion one participant elaborated on this by saying:

I know you can't have all parks accessible all winter, if within each region you could do a pilot project where you chose a park here and there that people will have to drive to just to get it started to see how it would work and to make it so that a) it's cleared and b) there's a safety perimeter around it. You know, maybe some that are already more conducive to that that already have some of the safety, some fencing or something so that maybe start with one and then see how it goes.

This participant suggested an incremental approach to making the city's parks more accessible and usable for a wider range of individuals, including those with dementia.

The photovoice participant reiterated this by suggesting a park near her home could serve more than one audience. When discussing photograph twelve she said:

Now this park has nothing in it except a children's playground. But it's huge. Now if it had a walkway, a ploughed sidewalk that were all the way around, that kept you in a safe environment...we would have been better off.

Figure 17. Photograph #12 – Un-used park.



Another participant suggested if a community had a park that was fenced off, an individual with dementia would only be required to remember how to get the park to be able to use it. She said:

If you had a park that was protected and you could work in that park or ride your bike around that park, and get your exercise without leaving it, you could just have to remember to get from your house to the park.

Recognizing that large-scale changes like these can be slow and expensive, one participant suggested privatization of some parks. She said:

...if it could make money too. You think about the parks being probably – not that I go – but pretty empty in the winter right? I mean, if you had a facility that was maintained, even if you had to buy a membership to go and use the loops, and the challenges section... .

While many different opinions were shared about what a dementia-friendly park

might encompass, participants overwhelmingly agreed that accessible parks are vitally important.

A number of participants at the presentation/discussion talked about the use of murals and colours. One participant spoke specifically about street signs and how they might better help individuals with dementia orient themselves. She said:

What about changing the color of street name signs? They're all white with black frames. Maybe making them more visible so we can find them...and larger. And put them on the corner right. The same corner, rather than changing them all the time so you don't know which corner, especially when it's winter, like you say, everything is white.

This statement suggests both variety and sameness on different levels. Important objects in the built environment, like wayfinding signage, should be interesting and unique, but should also be easily locatable.

Another participant at the presentation/discussion talked about the use of murals and color to differentiate the different residential areas in a nursing home. She said:

My mother's last address was a personal care home and it addressed that very nicely, in that it was kind of a spoke around a centre and every hallway was a different flower address, like my mother lived in Lilac Lane and there was a Daisy Path and there was paintings on the entrance doors, and it was very colorful and it wasn't demeaning in anyway, like they needed those cues. It wasn't just which hallway is it, they all had a different mural and they were all themed, and they also had an outdoor component where they could go out a couple of doors, but the whole area was fenced and so they could wander at will with the cats and lots of wildlife. So the environment, like what I think we can learn from, even though you say we're not in a personal care home yet, but they're doing those things to keep people safe, but not to lose those special touches, and for them to have cues. Oh, there's the lilac door, I know I'm on my way home.

Although this participant was talking specifically about a nursing home, there might be some aspects that can be applied to the urban built environment. The participant

stressed the importance of differentiating certain areas from others so that residents could more easily understand where they were. In the nursing home these cues were paintings on the walls, and unique names for different areas, both of which are possible to mimic in the urban built environment. Another participant began to touch on this. Talking about her mother, she said:

When we're driving, and as we're going over the perimeter, she'll say that's where I live because she recognizes that group of coloring...it was a colorful building so in the winter you did notice it had green on it so that's why I think she could recognize it. So in the car she knew, that's where I live!

This participant's mother could remember and identify her building from a distance because it was distinct from its surroundings.

Another participant talked about the possibility of putting signage up on certain properties. She compared this to the Block Parent signs that exist for children. However, other participants were hesitant about this working. One said:

Signage could help if we could instill in them that block parents sign is a place to go if you get lost, but you don't know if they're going to retain that.

The Block Parent Program of Canada states that the Block Parent sign signifies a safe place for children, teens, and seniors if they are experiencing difficulty or feel threatened (Blockparent.ca, 2011). However, individuals with dementia may not have the capacity to recognize or remember the specific sign.

Greater awareness and increased sense of community

Another important hope that was expressed in the discussion that followed the presentation was the desire for the general public to gain a deeper understanding of dementia and the needs that those suffering from dementia have. Many participants

thought this alone would help individuals with dementia stay independent longer, and might also relieve some of the pressure on caregivers. One participant suggested:

Perhaps general education can help that person with dementia. I don't live in a new community, I live here, but the fact is a lot of the communities are trying to make enclosed, with many many structures, many many businesses, and options in it. So I think if getting those structures [to be] more friendly toward people that have dementia plus really educating people on that particular street because everything has to start at home, and it's good to start at the street and then it has to expand.

This is a very important step in increasing dementia-friendliness. If community residents and business owners are better educated and more empathetic to the needs of individuals with dementia, it might result in reduced fear of going out. Individuals with dementia might feel less worried about losing their way if they know their community members will help if needed.

Another participant suggested implementing signage that signifies a place for someone with dementia to go if they need help. She said:

The Block Parent thing, right? Where people put in the windows, safe places for kids, could have signage that was somehow more specific....

This would involve greater education for the specific households or businesses that choose to display this type of sign. It would also likely require that the individuals or businesses that choose to be a 'Block Parent' for individuals with dementia look out for them in the community as they might not always be able to recognize the sign that signifies a safe place for getting help. For example, if a homeowner were to notice an elderly individual who looks lost out their window, it might be necessary to go out and assist that individual rather than waiting for them to come inside and ask for help.

As with many things, change often starts with education, and the participants

in this research study agreed. Creating dementia-friendly communities is no exception.

5.1.3. Overlap with other movements

As outlined by both the participants in the interview and in the presentation/discussion, there is the possibility of overlap between dementia-friendly and other movements that advocate for inclusivity in design.

Design for individuals with physical disabilities

Participants talked specifically about individuals with physical disabilities, and how addressing their needs in the built environment might also help to increase dementia friendliness. One participant at the presentation/discussion said:

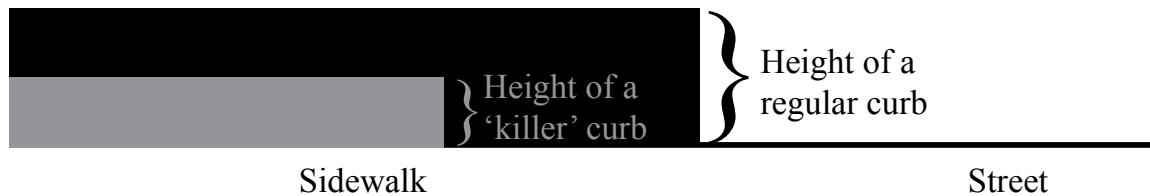
I wonder if we can pick up anything and shortcut the process at all from all of the physical disability [initiatives]...can we kind of piggy back on what the Manitoban's with Disabilities [Society for Manitobans with Disabilities] has done to make buildings accessible and streets...so we don't have to reinvent all of the wheels? Because a lot of them are kind of the same things.

Other participants suggested that physical interventions that are used to help individuals with vision loss could also help individuals with dementia. One participant talked specifically about yellow walkway rumble strips that demarcate where sidewalks meet streets. A number of participants talked about a loved ones' struggles with curbs after diagnosis. One participant at the presentation/discussion said of a parent:

I'm noticing now as she's deteriorating is she's forgetting to lift her feet. So every time we came to a curb she didn't quite know what to do. So she'd stop and then finally remember that she had to lift up her foot. So that was a serious barrier.

Participants then linked this issue to a blind person's difficulty with the 'killer curb' as a trip hazard. The killer curb refers to a curb that has a height in between a regular curb and no curb at all.

Figure 18. Difference between a regular curb and a 'killer' curb.



Another participant observed the potential benefits for individuals in wheelchairs. An accessible park with a well-maintained pathway and small, optional challenges was brought up a number of times. It was suggested that the pathway could have small hills which individuals in wheelchairs could easily navigate, offering the opportunity to use a different muscle group than usual to push themselves up and down the small hills.

Design for individuals with mental disabilities

Participants also spoke to the benefits of dementia-friendly interventions for other mental disabilities by suggesting that those with dementia wear some form of identification. This could help to increase awareness in the community, and might make it more possible for community members to offer assistance. One participant related this suggestion to an autistic individual carrying a card or a plaque. He proposed that other community members can more easily offer assistance if they are aware of the condition or disability that the struggling individual is dealing with.

Another participant related this to his experience growing up near the Canadian

National Institute for the Blind. He said:

We were instructed by our parents and other families that...everything had to be put away, nothing left on the sidewalk [because blind individuals would be walking around the neighbourhood]. We were also instructed if we saw somebody having a little bit of an issue, we were told to go and offer assistance. You don't know everybody in your community...when you talk about the blind, of course if they're out walking around they'll most likely have a white cane. Now is there a way of identifying [individuals with] Alzheimer's or dementia?

Participants passionately affirmed that of any sort of identification for individuals suffering from Alzheimer's or dementia remain respectful, for example, a tasteful pin on a lapel.

Pedestrian-friendly and age-friendly cities

Other participant's linked aspects of the dementia-friendly movement to the pedestrian-friendly, and age-friendly movements. One individual pointed out parallels between this research and the work that Age-Friendly Manitoba is doing. Another observed that Winnipeg is not pedestrian-friendly, which likely results in problems for individuals with dementia trying to navigate their communities on foot. The participant who took part in the photovoice and interview talked about moving to an older, more walkable neighbourhood when her mother was diagnosed with Alzheimer's. She said:

One of the reasons I moved her and me [here] was because there is so much more in the area than the newer – no sidewalk, walk ten miles to the nearest store type walking. I wanted a walking environment.

This statement alludes to the idea that many people already understand the benefits of pedestrian-friendly environments and how they may assist individuals suffering from dementia in moving around their communities.

Child-friendly cities

In 1996, UNICEF launched the Child Friendly Cities Initiative, with the intention of making cities livable places for all and putting children first. A major component of this initiative is fulfilling the rights of children to meet friends and to play (UNICEF, 2009). A number of the suggestions made by participants in regards to mentally and physically stimulating interventions in the environment could also double as places for children to play. For example, one participant talked about the children's playground at the Winnipeg Airport. She said:

Winnipeg Airport has a children's stimulation centre...it has beads you can roll, it's a giant version of that, and the kids can move the beads along. Well that on the pathway so that they can take all the yellow beads, put them at the end...you can make your own challenge with that. But everything is polled in, stationary, it can't be moved, but as you're walking along the path...you've got a mental challenge.

Another participant talked about the challenge of getting children to go outside at all. She suggested that some of the interventions that might make the environment better for someone with dementia, might also make it more appealing for children.

The complaint is that children spend too much time in front of the T.V., too much time not getting out. While taking a child and saying come on let's go for a walk in the park, when they're used to being stimulated...isn't going to happen unless there is something there that challenges them. I've seen this type of thing done for Alzheimer's or dementia but it also seems to attract a broader range.

These statements support the concept that including mentally and physically stimulating interventions in the built environment is not only beneficial for people with dementia, but also for people with other mental disabilities, older adults in general, and children as well.

5.1.4. Reasons for participating

Another important subject that was discussed during the interview and presentation/discussion was the underlying reasons that participants decided to take part in this research study. This is important to include because of the difficulties I had recruiting participants, and might help future researchers if they are attempting to recruit a similar group of people.

The participant that took part in the photovoice and interview related it back to her family history. Alzheimer's runs in her family. All of the elderly relatives on her mother's side, without fail, have been diagnosed with dementia. She said:

[My mother] is from a long line of people – [Alzheimer's] hasn't missed a person in her family – I'm next by the way. So it's very important for me to see a better future and when I [saw the researcher's] ...article in the Alzheimer's website I thought I have this kind of passion or vision for the future...I thought what a wonderful idea, we have someone from the younger generation that's going to maybe make things better for me.

The feeling was reiterated during the presentation/discussion when I asked the participants what made them decide to attend. A few participants came because of concern for their own future. One participant said:

Like [participant from photovoice], hoping for a better future for ourselves.

Some of the other participants said they came because of a loved one, most often an extended family member, with dementia. A couple of the participants' interests had grown because they had lost a close family member to dementia. These participants were also surprised there was not greater interest from the public in taking part in a study on this topic. Speaking for herself and the participant sitting next to her, one participant said:

I'm kind of surprised and disappointed you didn't get more people interested.

Both of us have lost our mothers to dementia, so we're on deck, so we're interested in our future....

Another participant recognized the inevitable increase in the prevalence of dementia because of demographic changes. She said:

I wish you all the best...because it's a really big problem and it's going to get a lot worse with all the baby boomers.

5.2. Implications for Planning Practice

These findings are important to planning practice in a few key ways. The data showed repeatedly that snow and ice were significant barriers, and that it was imperative that sidewalks be kept clear of them. Planners in colder climates need to ensure that neighbourhoods are designed for quick removal of snow and ice from walking spaces. The data also showed that the barriers created by snow and ice change regularly and frequently because they depend on the amount of precipitation and the temperature. This suggests that planners and policy makers need to remain flexible and able to respond to changing barriers quickly and efficiently.

This data also showed that intersections are confusing, stressful, and dangerous places for individuals with dementia. It suggests there is a need for a change in the way intersections are designed. They should be designed with more attention paid to the hierarchy of movement through them, especially the movement of pedestrians. There is also a need for route options through the built environment that are free of curbs.

Finally, a finding that affects planning practice is the need for both variation and sameness in the environment. Important wayfinding items like statues, signs and buildings, should be distinct from their surroundings. However, items that appear

repeatedly in the environment should have a commonality to make them quickly recognizable. For example, all street signs should be located in the same place, or all places that offer a public restroom should have the same colour sign, or all pharmacies should include a door made from a certain, distinguishable material. Participants talked specifically about using colours to denote different areas. Planners could suggest the use of different and distinct materials to specify important areas or buildings, and routes.

6| CONCLUSIONS & RECOMMENDATIONS FOR FURTHER STUDY

6.1. Discussion

An aging population means an increase in the prevalence of dementia. While older adults, especially those suffering from dementia, are greatly affected by their environment, those who live in colder climates face additional and changing barriers to living actively and aging in place. This study investigated some of the barriers and facilitators to active living in Winnipeg, Manitoba during the winter, through a photovoice, follow-up interview, and group presentation/discussion.

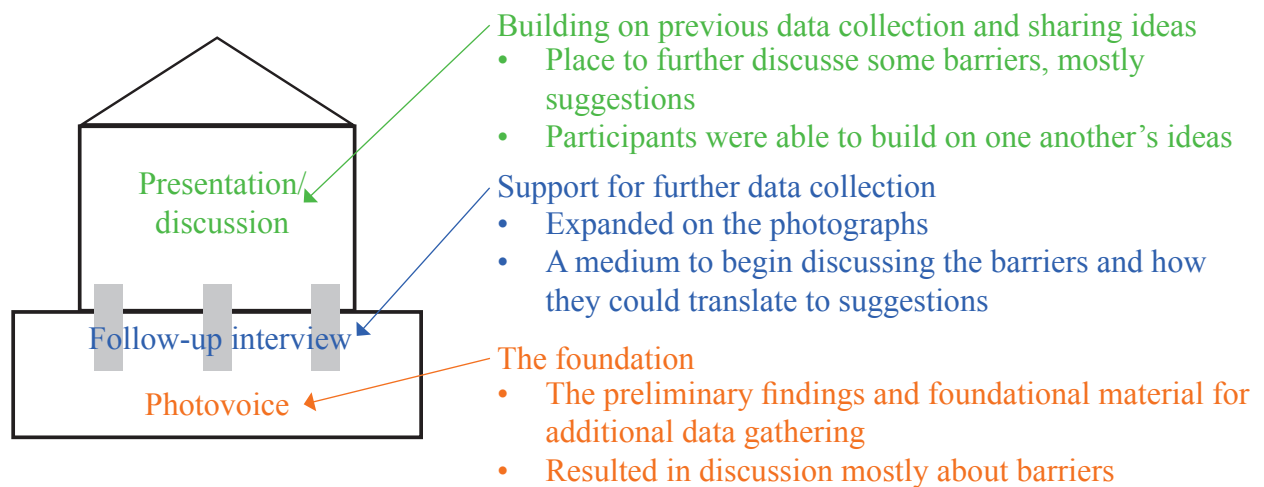
The photovoice participant, from the beginning, had a clear understanding of the importance of maintaining an active lifestyle into old age. However, she voiced concerns early on, as she felt the barriers for individuals with dementia might be the same as barriers for all older adults. The participants from the presentation/discussion immediately understood the importance of being active and getting around outdoors, but they found it difficult to discuss the urban built environment and its affects on a person with dementia directly. Often they spoke of their experiences with a loved one in a nursing home or assisted-living facility, and discussed the ways in which it might be applicable in the built environment at a neighbourhood scale.

The study design worked well for this research area. Conducting the photovoice and interview first meant the preliminary data gathered from them could be used as the foundation for the group presentation/discussion. The photovoice and journal entries involved photographing and writing mostly about barriers to getting around outdoors on foot for someone with dementia. The follow-up interview

provided an opportunity for the photovoice participant to elaborate on the photographs and journal entries, and begin discussing some ideas for increasing dementia-friendliness.

This preliminary data was then used to give the presentation/discussion participants a quick overview of what the research was about, and to help them understand the topic and what was being requested of them. The group presentation/discussion offered a safe platform for participants to talk about their ideas. It was also a stepping stone to help the participants further discuss some barriers for people with dementia trying to get around on foot, and suggestions for what a dementia-friendly community could look like.

Figure 19. How the research design allowed each data collection event to become a platform for the following one.



Although a focus group was not possible for this particular study, the group presentation/discussion resulted in outcomes similar to what might have been expected from a focus group. Participants' contributions were taken seriously, and used as a springboard by other participants.

Participants discussed barriers to getting around outdoors on foot for someone with dementia and offered suggestions for how to increase dementia-friendliness through interventions in the built environment at a neighbourhood scale. Some of the barriers that were discussed include:

- Dementia progresses at a different rate for each individual, and can change from day to day. It is unpredictable and thus difficult to plan for.
- Participants expressed fear of leaving their loved ones with dementia to navigate their community on their own regardless of how it is designed.
- Winter in general, especially snow and ice, add risk each time an individual with dementia leaves their home. Ice, especially unseen ice, was identified as the biggest barrier in the photovoice and follow-up interview.
- Cold temperatures, as individuals with dementia aren't necessarily able to determine they should go inside at certain points to avoid frostbite.
- Building drainage areas were identified as especially hazardous because of ice build up.
- Unmaintained sidewalks and walkways, both along streets and in parks. Parks were highly valued by the participants, but often became unusable in the winter. Deep snow and cold, icy benches were identified as significant deterrents.
- Lack of sidewalks or safe walking spaces for pedestrians.
- Curbs, especially killer curbs, become barriers as individuals with dementia deteriorate and forget they need to step up. For the same reason stairs also become difficult to navigate, as each new step is seen as a new challenge.

- Traffic causes stress for individuals with dementia and makes it more difficult for them to concentrate on other things in the environment. This is especially true at busy intersections where they have difficulty also processing cars turning right, even though there may be cues like walk signals.
- Parked cars and piled snow can make it difficult for pedestrians and drivers to see one another.
- Long blocks with few designated street crossings. In the winter, colder weather might force individuals to cross where there is no designated crossing, requiring them to interact with traffic, and adding risk to their journey.
- Walking signals at large intersections are often too short for an elderly individual with dementia to make it across safely.
- Blocked sidewalks or snow ploughed onto the sidewalks was also identified as a deterrent. Participants talked about having to walk along the road in traffic, which can become stressful and dangerous.
- Sameness in the environment was also recognized as a barrier, especially in the winter when the environment can become blanketed in white.
- A significant bad experience where an individual with dementia felt threatened, confused, or was made to feel small can have a ripple effect. It can result in the individual deciding not to take part in a certain activity, potentially resulting in increased isolation and a lower quality of life.

The data collection process revealed that some barriers, especially those related to winter, were not fixed in the environment – ice and snow build up, for example.

The photovoice participant also included some photographs from previous years to compare to the ones she took for this study.

Figure 20. Photograph #7a taken for the photovoice in winter 2015, and photograph #7b taken in the winter of the previous year, respectively.



Figure 21. Photograph #10a taken for the photovoice in winter 2015, and photograph #10b taken in the winter of the previous year, respectively.



This suggested that the barriers related to winter are changing from year to year depending on the amount of precipitation and the temperatures, as well as how often, and how well snow and ice is cleared from areas used for walking.

Many of the barriers discussed were brought to light during the preliminary data collection – during the photovoice and follow-up interview. This provided a foundation for both the photovoice participant and the presentation/discussion participants to talk about suggestions for increasing dementia-friendliness.

Suggestions that were discussed include:

- Optional, small physical challenges in the built environment that could provide mental and physical stimulation for an individual with dementia.
- Informal spaces can create opportunities for other mental stimulation through things like statues, people watching, watching children playing, shopping, and tasting.
- Clear, well-maintained paths and circular paths in parks. A usable sidewalk network clear of snow and ice.
- Railings can assist individuals with dementia to steady themselves, especially on stairs.
- Ice salt can make important areas that are otherwise avoided in the winter, like in front of public buildings, more accessible.
- Adding colour and distinctness in the environment helps individuals with dementia orient themselves. However it is important to ensure that important wayfinding signage remains easily locatable and recognizable.
- Painting curbs can make them more visible, and implementing walkway rumble strips can help older individuals navigating the transition between sidewalk and road.

- Longer walk signals at intersections ensures individuals with dementia aren't caught waiting between two lanes of busy traffic.
- Warming huts can provide a quick place for older adults to warm up in parks.
- Signage indicating a safe place for individuals with dementia to get help with trained individuals can ease stress related to getting lost.
- Large areas without any curbs or stairs can reduce the risk of tripping and falling.
- Parks that remain accessible in the winter can have installations that can be used by different groups of people. An incremental approach can be taken in making parks more dementia-friendly. Some participants suggested creating pilot parks in certain areas of the city first and then applying them in other locations. Others suggested implementing membership fees for dementia-friendly parks to help pay for facilities, and someone to look out for individuals with dementia who are using it.
- Increasing awareness and training the community to recognize the signs of dementia and help if necessary. This can help ease individuals concerns with leaving their loved ones with dementia to navigate their community on their own.

Through the data collection process, it could be interpreted that safe spaces for walking that remain clear of snow and ice, and separated from traffic, are imperative for individuals with dementia. Many participants found it difficult to envision a community in which their loved ones could walk around without

supervision at the start. Eventually the participants stepped out of their comfort zones and, as evidenced above, provided some valuable suggestions for increasing dementia-friendliness at a neighbourhood scale.

Participants also talked about the ways in which a dementia-friendly movement could potentially overlap with other movements concerned with inclusivity in urban design and planning. Overlap with other movements was substantiated by the following findings:

- Working together with the Society for Manitobans with Disabilities so that the work done for dementia-friendly is not repetitive.
- Interventions used to help people with vision loss could also help individuals with dementia, for example, walkway rumble strips.
- Changes in the built environment that create additional physical stimulation for individuals with dementia can also create spaces that are accessible for individuals in wheelchairs. Small inclines and declines allow both groups to work different muscles than they normally would.
- Individuals with dementia could carry or wear something that signifies their condition. Participants compared this to people with autism carrying a card or a blind individual using a white cane. Someone with dementia could wear a respectful pin on his or her lapel, for example.
- According to the literature and the data collected in this study much of what would make a community age-friendly would also make it dementia-friendly, especially increasing pedestrian-friendliness.

- Specific dementia-friendly interventions can also make environments more mentally and physical stimulating for children.

The data showed that there is potential for overlap between dementia-friendly and the principles of universal design for both physical disability and other mental disability, and the age-friendly and child-friendly cities movements.

Another notable theme that arose from the data was the reasons participants had for taking part in this study. The participants in this study identified the following reasons:

- They had recently lost a loved one because of dementia, and since then their interest in the topic has grown.
- They were currently caring for a family member with dementia or someone in their extended family was suffering from dementia.
- Many participants voiced concern for their own futures in which they felt dementia was probable.
- In recognition of a changing demographic and the difficulties that will come along with it, thus making research like this especially important to them.

This is an important aspect because I had difficulty recruiting participants for this research. A better understanding of why the participants chose to take part could help future researchers who intend to recruit participant for similar research.

The findings from this study support the literature in a number of ways. The literature stated that winter plays a significant role in the lives of older adults and can create additional barriers for individuals with dementia. This is further evidenced by the participants' focus on snow and ice throughout the data collection

process. The literature also showed that active living is crucial to aging in place. Most participants already acknowledged this at the start of the data collection process. Their support of this concept was substantiated by extensive discussion about techniques for getting individuals with dementia out more. Many also noted a loved one's condition deteriorating once they stopped going out and walking regularly. The literature also suggested that signage can still assist individuals who suffer from dementia with wayfinding and orienting themselves. While some participants weren't convinced, others agreed signage would be beneficial for and understood by their loved ones.

In the following sections I will discuss the original research questions that guided this research study, and offer some suggestions for future research.

6.2. Response to Research Questions

In chapter one, I identified two research questions. While the data from this study is inconclusive, I can attempt to answer them with the help of the literature, and the data collected from the photovoice, follow-up interview, and group presentation/discussion. The research questions were revisited regularly throughout this research. Lecompte's method (Lecompte, 2010) for analyzing qualitative data involved reflection of the initial research questions throughout the process. I also used the research questions to help identify some of the items for the data coding. The research questions were also referred to during preparation for the group presentation/ discussion, and thus helped guide the ensuing conversation.

1) What existing individual physical characteristics may have the potential to assist those experiencing dementia to make their way through the city on foot with greater ease?

The purpose of this question was to determine the particular characteristics that are causing individuals with dementia to avoid going outdoors so that they might be addressed in future urban design practices. According to the literature, these might be things like damaged sidewalks, lack of curb cuts, lack of places to rest and snow and ice on sidewalks. The data I collected supported this. Participants overwhelmingly agreed that snow and ice caused problems in many different ways. Ice on sidewalks, specifically where building drainage was located, and on stairs was seen as particularly hazardous. Participants also identified snow piles on sidewalks, and deep snow on pathways in parks as barriers. Numerous participants also identified curbs as barriers. In their experience, individuals with dementia forget to lift their foot as their condition deteriorates.

Suggestions for individual design characteristics that could have the potential to assist those suffering from dementia to get around outdoors on foot with greater ease that arose from this research were quite simple. Participants discussed the importance of prompt and regular snow and ice removal. They also suggested implementing railings and using ice salt.

Participants talked about using colour strategically to help individuals with dementia better understand their environments. They suggested painted curbs so people can see clearly where they need to step up if they are able to. They also talked about placing walkway rumble strips where sidewalks meet streets. Another

participant expressed a desire to see warming huts in parks so that individuals with dementia would have a place to warm up when they are out. The participant from the preliminary data collection talked frequently about incorporating opportunities for mental and physical stimulation in the built environment, for example, small inclines and declines along a path. However, she also stressed the importance of these challenges being optional as to not increase stress for an individual with dementia.

2) What wider urban design characteristics encourage active living in people with dementia?

The purpose of this research question was to determine some of the neighbourhood characteristics that allow or encourage a person with dementia to continue going out and walking around their community. According to Mitchell (2012), some of these wider design characteristics could include small blocks, buildings and facilities designed to reflect uses, landmarks, and environmental cues.

By first identifying the wider barriers that were discussed, facilitators for getting around outdoors on foot for someone with dementia became more evident. Some of the wider urban design barriers that were identified include traffic, busy intersections, and multiple lanes and directions of cars. Participants from each of the data collection processes talked about the difficulty of crossing the street for someone with dementia, as they are unable to concentrate on multiple things at once. Participants also discussed the short duration of walk signals at intersections, and many found they were not able to get to the other side of the street safely

before the lights turned again. This often caused additional stress for an individual with dementia.

Participants also identified uncontrolled intersections as barriers, as a person with dementia would have difficulty processing everything in order to determine a safe time to cross. They also expressed frustration with long blocks and a lack of designated crossings within them. Some talked about crossing the street where it is not necessarily safe especially when the weather got colder. Some participants also talked about the barrier that sameness in the environment can be. When there is nothing distinct in the built environment it becomes difficult for anyone to orient themselves, especially for those with dementia. Blocked sidewalks were also mentioned numerous times.

The most significant wider urban design characteristic that was understood as necessary for dementia-friendliness was a usable, accessible sidewalk network. It was stressed that sidewalks should be kept clear of ploughed and piled up snow and ice. It was also noted that pathways in parks are especially important because they are safe from traffic, and should also be kept clear. Some participant's suggested parks can also include equipment designed specifically for individuals with dementia. They recognized that this might take time and money so some participants suggested an incremental approach to creating these parks. Another participant suggested charging a membership fee for people to use them. They noted the money could go to a facility within the park and to hiring people who could be there to help if necessary.

Participants made some valuable contributions about signage. They talked about using something similar to Block Parent signage but specifically for individuals with dementia. Some felt this might be difficult because their loved one would not necessarily remember what the sign meant. Others felt their loved ones could remember and that such signage would be helpful. Other participants discussed street signs. They felt street signs could be more colourful and distinct, but should always be located in the same place. This suggests that wayfinding should be interesting, unique, and distinct, but that it should also be easily locatable and recognizable. Participants also talked about the use of murals and colors to identify certain areas in nursing homes. This has some transferability to the urban built environment, where murals and colors could be used to demarcate certain buildings, streets, or neighbourhoods. Participants also expressed a desire for walk signals at intersections to be longer.

6.3. Project Limitations

Before discussing suggested areas for future study it is necessary to revisit the limitations of this research study. It is important to note that there were no participants who were suffering from dementia. All participants were caregivers or had extended family member with dementia, and although they provided valuable insights, the data may have been different if individuals with dementia could have been included.

It is also important to be aware of the small sample size. Only one participant took part in the photovoice and follow-up interview, however the participant's

contributions were further substantiated as they aligned with much of the existing literature. The presentation/discussion had approximately 20 participants. However, it took place in a part of the city that is not walkable or easily accessible by public transit, which influenced the individuals that were able to attend. Furthermore, the discussion/presentation participants were mostly women, and mostly Caucasian. This group of participants did not reflect a mix of sexes or of ethnicities.

Upon reflection on the research methods, the preliminary data collection could have begun earlier. Initially, I felt it was necessary that each pair of participants conduct the photovoice portion of the data collection at the same time. Even if more pairs had shown interest they could have completed the photovoice at different times, and it would not have had a significant impact on the quality of the data. Determining when the photovoice was conducted should have been primarily dependent on accommodating the participant with dementia.

The presentation/discussion could have also been more structured to direct the conversation away from interior environments. Although, some of the insights about interior environments were directly related to the outdoor environment, some participants had trouble discussing the urban built environment.

6.4. Areas for Further Study

Remaining aware of the aforementioned limitations, I suggest four areas of further research. Recruitment for this research project was difficult and unpredictable. It resulted in many ethics amendments and additional time spent waiting. Future research should focus on best practices for doing research with people who are

suffering from early or mild dementia. This research could attempt to determine how and where to best recruit them so they can be better represented in the future. It should also determine whether a certain level of deceit is necessary and ethical when recruiting individuals with mild or early dementia.

The second suggestion for further research is determining how to increase awareness and educational opportunities about dementia for the public. Many participants touched on the importance of increasing awareness of dementia in the community, so that community members can help an individual if they suspect they have dementia and require assistance. One participant also discussed her hearing loss. She stated she had been mistakenly diagnosed with dementia because she was not able to hear what was being said to her. Increasing awareness about the disease could potentially help to avoid situations like these. Increased awareness through education could also help to reduce stigma about mental illness. Further research could help ascertain whether or not this would result in individuals with mild or early dementia admitting to their condition in the early stages. It could also help determine if increased awareness would result in individuals with dementia feeling more comfortable asking community members for assistance if needed.

This research could also include an educational component that talks about the therapeutic possibilities of environmental interventions for individuals suffering from dementia. Many of the participants found it difficult to speak directly about the urban built environment, but could easily talk about interventions in interior environments. Greater education and awareness about the potential of the built environment to help individuals age in place and age actively has the potential to

lead to greater acceptance, and perhaps increased support.

A third, and critical area of further study is determining a middle ground between complete dementia-friendly neighbourhoods where individuals with dementia are able to get around without supervision – such as Hogeweyk Village, in Weesp, Netherlands or Georgian Bay Retirement Home in Penetanguishene, Ontario – and the neighbourhoods that exist today. Future research can help illuminate specific interventions that increase comfort for individuals with dementia. Many participants expressed fear of leaving their loved ones with dementia to navigate the environment on their own, and so it is unlikely that it would happen even if neighbourhoods were quickly retrofitted to become dementia-friendly. Alternatively, some participants spoke of their loved ones having a negative experience as a result of becoming confused or being made to feel incapable, and then stopped taking part in that specific activity. This suggests that increasing dementia-friendliness in the built environment should begin as soon as possible, in order to avoid the negative experiences that result in an individual with dementia removing themselves from social situations and interactions.

A participant at the presentation effectively summed this idea up by saying:

I also happened to see the Netherlands village [Hogeweyk Village], which I thought was amazing. And while that's like a really nice high goal, I wondered if you have between where we are, with empty winter parks, to where that village is, are there incremental steps and goals that you can see us being able to reach? You know, we're not going to be Netherlands for a while but what can we do, do you have some things in mind?

Future research should look at what can be done in the meantime. It should look in more detail at the similarities between dementia-friendly environments, universal design, and the age-friendly and child-friendly cities movements. Future research

can determine where there is overlap between these movements and how they can build on each other.

Finally, further research should look at what cities across the world are doing to increase dementia-friendliness in their neighbourhoods. The dementia-friendly movement has gained momentum since the outset of this major degree project, and many cities are already making strides. Towards the latter half of this research project I attempted to add a section about current research, however the breadth of information was overwhelming. At this point I decided to refrain from looking at current developments in the field in order to finish my thesis. Although outside the scope of this project, the rise of the dementia-friendly movement is highly relevant to this research topic.

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8| APPENDICES

I. Photovoice photographs & journal entries



Photograph # 1

Photograph title: Elaine bundled up for winter weather.

I took this photograph because...Part of the challenge for outdoor walking is to dress warm enough. For persons with Alzheimer's the slightest distraction can affect their concentration while walking.

What does this photograph say about getting around outdoors on foot?

Even the winter clothing you have to wear can be a serious distraction when walking outdoors. Her hat is warm but it can shift and correcting it can distract her at an intersection or on uneven ground. If she puts her hood up her vision is restricted. We had a time when the wind was very cold and once she pulled her hood up she became less aware of her surroundings.



Photograph # 2

Photograph title: Getting out the door

I took this photograph because...Getting out the door can be a challenge with snow and ice.

What does this photograph say about getting around outdoors on foot?

Snow and ice on the steps can be a challenge and a deterrent when considering a walk outdoors. There are times when you wake up to find the overnight snow is so high you cannot easily get out of the house. Complications are overwhelming to persons with Alzheimer's. I remember my mom telling me one morning we can't go out the door is blocked.



Photograph # 3

Photograph title: Slippery or not slippery?

I took this photograph because... Keeping up with shoveling is a challenge but even more risky is when the warm Winnipeg sun turns your walkway into ice.

What does this photograph say about getting around outdoors on foot?

It is difficult enough for a quick thinking person to catch themselves from a fall when there is unexpected ice. A person with Alzheimer's focused on the path may have trouble determining ice and safety may be misjudged. It requires quick adjustment to stabilize yourself if you begin to slip and fall. This also can be a challenge.



Photograph # 4

Photograph title: The bumpy path

I took this photograph because... The challenge with packed snow is determining at a glance if it is safe

What does this photograph say about getting around outdoors on foot?

Packed snow creates uneven surfaces and visually hidden challenges. To look at this it appears safe. There is actually an incline on the right that is difficult to see.



Photograph # 5

Photograph title: Winter melting

I took this photograph because...Areas where there is drainage from buildings creates challenges.

What does this photograph say about getting around outdoors on foot?

Eaves and drainage areas from public and private buildings can be dangerous. It is difficult to remove the ice. As winter warms the ice factor becomes a major issue on the roads and around homes.



Photograph # 6

Photograph title: Avoiding the slippery and the uneven

I took this photograph because... Avoiding areas where you may feel insecure you could plunge into a deep snow area

What does this photograph say about getting around outdoors on foot?

Decisions sometimes have to be made and trudging through deep snow may be the only course however not always easy.



Photograph # 7a and #7b

Photograph title: Can they see me?

I took this photograph because... This picture is minor as some years the piling of shovelled snow can create visual barriers.

What does this photograph say about getting around outdoors on foot?

When the city piles snow in back lanes or near intersections it creates a limited visual view of cars and for drivers to see pedestrians. Note picture 7A from the winter of 2013-2014 where the same shot is much higher.



Photograph # 8

Photograph title: Uncontrolled intersection

I took this photograph because... Managing to focus on cars from three different directions is difficult.

What does this photograph say about getting around outdoors on foot?

Navigating through intersections with traffic from three directions is a challenge. Add the parked cars which limit view and you have possible risk.



Photograph # 9

Photograph title: Parked cars

I took this photograph because... Getting to the bus stop or the door of the school between parked cars can be risky.

What does this photograph say about getting around outdoors on foot?

When your destination is in the middle of the long intersections a decision could be made to cross rather than dealing with the cold while you walk around to find a safe way to cross



Photograph #10a and #10b

Photograph title: Climbing the hills

I took this photograph because...Piling snow when the city plows can create mountains to climb.

What does this photograph say about getting around outdoors on foot?

During repeated days of snow these hills can become higher. Until the weather breaks the pathways for pedestrians can be barred until the city can clear them. Roadways are a priority. Note the picture from the winter of 2013-2014 where the snow plowed in the back lanes had to be stored in driveway space so you could exit safely.



Photograph # 11

Photograph title: Enjoying winter activities

I took this photograph because...Attending events at the forks and other public areas during winter can be challenging.

What does this photograph say about getting around outdoors on foot?

Activities in the outdoor areas are hampered by winter weather. Winds, blowing snow and slippery steps can create limitations. Navigating steps requires focus and for someone with Alzheimer's every step can contain a number of risks such as snow, ice and uneven surfaces.



Photograph # 12

Photograph title: Un-used park

I took this photograph because...It is a wonderful thing that we have a few parks walking distance from our home. It is unfortunate that they are really unused in the winter.

What does this photograph say about getting around outdoors on foot?

The snow is deep and it would be difficult to make my way to the bench. This park is a safe environment. It is really too bad there was not a cleared walking circle filled with physical challenges. I could get my exercise in a safe area.



Photograph # 13

Photograph title: Where do I look!

I took this photograph because...Crossing to the library with all the turning cars can be confusing

What does this photograph say about getting around outdoors on foot?

Although this is a controlled intersection there is always room for caution. Many cars are turning and a lot is happening. The light may say go but persons turning right on red require caution. Major intersections require the ability to focus on multiple things. This was a challenge.

II. Instructions for information package

What to do?

Taking photos and using journals

In the box below you will find the questions I would like you to focus on when you are taking photos for this study. You might want to take some time before you begin to make a list of some of the things you want to capture so you know what pictures you want to take before even starting.

Taking photos

For this study you are being asked to take a total of 15 photos with the provided cameras.

I am asking you to take photos that show barriers and/or facilitators for individuals with dementia or Alzheimer's getting around outdoors on foot in the winter in Winnipeg.

This can include anything you view as helping or hindering those with dementia or Alzheimer's in the outdoor environment. The photos can be taken at any time of day, and you can take any number in a day. It is acceptable to take the photos from a window in your home or from a car as long as they still speak to moving around outdoors on foot.

Facilitators might include: smooth sidewalks, curb cuts, benches, shaded areas, recognizable/unique landmarks, easily identifiable paths

Barriers might include: ice, snow, cracked/broken sidewalks, nowhere to rest, dead ends, streets that all look the same

.....
I will collect your camera and the corresponding journals I have provided you with in two weeks time.

Using journals

You are also being asked to keep a journal entry for each photo on the sheets I have provided. Each photo must be given a title, and you will be asked to explain in detail why you took the photograph and what it says about getting around outdoors on foot for someone with dementia or Alzheimer's. This is to ensure that I understand the focus of each of your photographs.

III. Interview schedule

OPENING

1. Establish Rapport

Good morning [interviewee 1]. It is nice to see you again. [Interviewee 2] it is nice to finally meet you.

I hope you are both doing well and enjoying the wonderful weather we've had!

I wanted to, first of all thank you both for taking part in this study. Your lived experiences are invaluable and a necessary part of this kind of research.

2. Explain purpose & confirm ongoing consent

I'd like to just take a second here and make sure that you, [interviewee 2], are ok with taking part in this interview and with me audiotaping it. The point of this interview is to help me better understand the photographs you took and the journal entries you guys wrote.

The photos and journal entries were meant to gather information from experienced individuals regarding getting around outdoors for people with dementia or Alzheimer's in Winnipeg, MB in the hopes that it can eventually inform future community design that better supports people with dementia or Alzheimer's.

3. Assure anonymity

After we've finished I will be transcribing the interview and using data from it for my major degree project. However all names and any other identifying information will be left out of it. And remember that you have every right to refuse participation at any point, or to refuse to answer any questions if you don't feel comfortable. Do you still want to participate?

Can I just get your initials here where I've changed the date to today's date, March 13, 2015? Is there anything I can get you guys before we get started?

Transition... First we will go through all 13 photographs and briefly discuss each one, and then I have 8 questions for you guys. If you'd like we can take a break in between, just let me know.

4. Interview

TOPIC A: Discussion of individual photographs

The Principal Investigator and participants will go through each photograph and journal entry to ensure mutual understanding of the content of the photographs.

TOPIC B: Identification of most important content

- 1) Which picture best shows something in the environment that helps you get around on foot outdoors?
- 2) Which picture is your favourite and why?

- 3) Which photo best highlights something that stops you from getting around outdoors on foot?
- 4) Which photograph was the most difficult to take and why?
- 5) Is there anything you feel you couldn't capture in a photograph? Please explain.
- 6) What physical characteristics would make it easier for you to get around outdoors on foot?
- 7) In your opinion what physical characteristics would a dementia friendly community have?
- 8) What is the most important thing in each photo?

CLOSING

1. Maintain Rapport

Thank you so much for taking the time to meet with me today and help me to better understand the relationship between people who have dementia and the built environment.

2. Action

I should have all the information I need from you now. I will transcribe this interview and send it to you. You can then strike anything you don't agree with and add anything you like. I plan to have the presentation material ready to send to you by the first week in April, at which point you can look it over and make sure I am representing this process and your participation accurately. Thanks again.

IV. Consent form for photovoice participant with dementia



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Faculty of Architecture Statement of Informed Consent

Research Project Study: *'Caring for those who once cared for us: Dementia friendly planning for a Winnipeg, Manitoba winter'*

Principal Investigator: Lea Rempel, Graduate Student, Master of City Planning,
Faculty of Architecture, University of Manitoba

Advisory Committee: **Supervisor** - Rae Bridgman, Professor, Department of City Planning, Faculty of Architecture, University of Manitoba
Internal Advisor - Richard Milgrom, Associate Dean and Associate Professor, Department of City Planning, Faculty of Architecture, University of Manitoba
External Advisor - Verena Menec, Professor, Department of Community Health Sciences, College of Medicine, University of Manitoba

Introduction

You are invited to take part in a research study. This consent form, a copy of which you can keep for your records, is intended to ensure you have consented willingly and with all necessary information. It should explain what is involved in the research and what is expected of you as a participant.

Please take time to read, understand, and review the consent form and information about the research. If you would like more information please feel free to ask me (the Principal Investigator).

Purpose of the study

The proposed research explores the potential of the built environment to improve the cognitive health of those suffering from dementia. This research aims to illuminate some of the barriers and facilitators to active living that older adults' with dementia

experience when getting around outdoors during the winter in Winnipeg, Manitoba. Information for this study will be gathered through a photovoice study. Photovoice is a data collection method that involves giving study participants a camera and asking them to document issues in their communities through photography. One pair of participants (a community dwelling person with mild/early dementia and their primary caregiver) will be given a digital camera and a journal, and asked to document barriers and facilitators you might experience getting around outdoors through photography and correlating journal entries. The pair of participants will then be asked to participate in one post-photovoice semi-structured interview to further discuss the contents of their photographs.

This research project is my Major Degree Project, a requirement of the two-year Master of City Planning program at the University of Manitoba.

Study procedures

If you participate in this study you will be asked to attend an information session where I will ensure you are familiar with the camera, and provide helpful tips for using the camera (like where to place your fingers on the camera and point it away from the sun whenever possible). An explanation of what is expected for the corresponding journal entries will also be provided at the information session. The information session will be approximately 45 minutes to one hour long. Once you feel comfortable using the camera you and your primary caregiver will each be given a digital camera and a journal, and asked to document barriers and facilitators to getting around outdoors on foot through 15 photographs (and journal entries) to be taken in the two weeks following the information session. You will also be asked to keep a journal that further explains each photograph (for example, why you took the photograph, what it means to you, what you were trying to capture in the photograph, what you couldn't capture in the photograph, etc.). After two weeks, I will collect your individual camera and journal entries and the photographs will be uploaded to my computer.

You and your partner will then be asked to participate together in one semi-structured interview with the Principal Investigator. You will be asked to talk about your experiences during the study, and further explain the content of the photographs and journal entries. Finally the principal investigator will share the study processes and findings at a public presentation. You will have the choice to take part in the presentation or to remain anonymous. In total, this research project will take up approximately 4 hours of your time.

Participant risks, benefits, costs

There is no evident, direct risk in taking photographs; I do ask that you take every precaution while taking photographs outdoors and do not partake in anything out of the ordinary to get a particular photograph. Indirect risks may arise while taking photographs outdoors during the winter. It is acceptable to get help from your partner or to take photographs of the outdoors from inside if you feel unable to go out.

There is no risk to you in taking part in the interview. It can take place wherever is most comfortable for you, and will only include you, your partner and the Principal Investigator.

There are no direct benefits of taking part in the study, however participation does provide you with a platform to share your valuable insights, that may help future researchers better understand the relationship between people with dementia and their outdoor environments.

Audiotaping & confidentiality

With your permission, the interviews will be audio recorded and transcribed at a later time to ensure accuracy. The transcriptions and journal entries will contain no identifying information, and names and other personal information will be omitted from the final Major Degree Project document. Photographs will only be included if they are accompanied by a signed consent form for people appearing in photographs. Transcriptions, photographs, and journal entries will be kept in a secure place during the study, and destroyed (by myself) at the end of the study. All material for the final, public presentation will be approved by both you and your partner before being shared, and if preferred any identifying information will be omitted.

Feedback & debriefing

Once the interview is done, I will provide you with an interview transcript giving you the opportunity to verify the information and strike anything you feel uncomfortable with. I will provide individual feedback to you within two months of the interview through phone, email, or in person to ensure the information I have compiled from the photovoice and interviews is accurate. I will also provide you with a copy of the presentation material to ensure it is accurate, and that you are comfortable with the information being shared. Once the Major Degree Project has been completed I will provide you with a digital copy.

Dissemination of results

Study results will be shared at a final presentation that will be approved by the participants beforehand. Study results will be disseminated through my Master of City Planning Major Degree Project, a hard copy held at the Architecture/Fine Arts library at the University of Manitoba, a digital copy online through University of Manitoba's M Space, and my oral defense.

Voluntary participation/Withdrawal from study

Your decision to take part in this study is entirely voluntary. Initial consent will be obtained from interested participants at the end of the information session. Ongoing consent will be confirmed when the Principal Investigator collects the cameras and journal entries from you, and again before the interview is conducted. You are able to refuse participation or to withdraw from the research study at any time. If you decide to participate you have the right to refuse to answer any question or to refuse participation in any activity, at any time.

Contact information

Student researcher

Lea Rempel, Graduate Student, Department of City Planning, Faculty of Architecture, University of Manitoba

Phone: 204-xxx-xxxx

Email: -----@myumanitoba.ca

Research supervisor

Rae Bridgman, Professor, Department of City Planning, Faculty of Architecture, University of Manitoba

Phone: 204-xxx-xxxx

Email: -----@cc.umanitoba.ca

Statement of consent

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Joint-Faculty Research Ethics Board (JFREB) If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator (HEC) at 474-7122 or by email at Margaret.Bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

I have read this consent form. I have had the opportunity to discuss this research study with the student researcher. I have had my questions answered by her in language that I understand. I understand that I will be given a copy of this consent form after signing it. I understand that my participation is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that the information I provide will be incorporated in a presentation and report by the Principal Investigator. I also understand that all information will be treated as confidential, stored in a private and secure place, and destroyed two years after the end of the project by the student researcher.

Consent for audiotaping the interviews

- ☐ I consent to having the interview audiotaped and transcribed
☐ I do not consent to having the interview audiotaped and transcribed

Preference for final presentation

- ☐ I consent to being a part of the final presentation
☐ I do not consent to being a part of the final presentation and prefer that all identifying information about me be omitted

Initial Consent – after the information session

Participant #1 printed name

Signature of Participant #1

Date

Authorized third party printed name (Primary Caregiver)

Authorized third party (Primary Caregiver)

Date

Name of Principal Investigator

Date

Signature of Principal Investigator

Date

Ongoing consent – when cameras and journal entries are collected

Your signature on this form indicates that you understand to your satisfaction the information regarding participation in the research project and agree to continue participating as a subject, as per the statement of consent above.

Participant #1's signature

Date

Authorized third party's signature Date

Principal Investigators signature Date

Ongoing consent – At the start of the interviews

Your signature on this form indicates that you understand to your satisfaction the information regarding participation in the research project and agree to continue participating as a subject, as per the statement of consent above.

Consent for audiotaping the interviews

- ☐ I consent to having the interview audiotaped and transcribed
- ☐ I do not consent to having the interview audiotaped and transcribed

Participant #1's signature Date

Authorized third party's signature Date

Principal Investigators signature Date

V. Consent form for photovoice participant caregiver



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External Advisor - Verena Menec, Professor, Department of Community Health Sciences, College of Medicine, University of Manitoba

Introduction

You are invited to take part in a research study. This consent form, a copy of which you can keep for your records, is intended to ensure you have consented willingly and with all necessary information. It should explain what is involved in the research and what is expected of you as a participant.

Please take time to read, understand, and review the consent form and information about the research. If you would like more information please feel free to ask me (the Principal Investigator).

Purpose of the study

The proposed research explores the potential of the built environment to improve the cognitive health of those suffering from dementia. This research aims to illuminate

some of the barriers and facilitators to active living that older adults' with dementia experience when getting around outdoors during the winter in Winnipeg, Manitoba. Information for this study will be gathered through a photovoice study. Photovoice is a data collection method that involves giving study participants a camera and asking them to document issues in their communities through photography. One pair of participants (a community dwelling person with mild/early dementia and their primary caregiver) will be given a digital camera and a journal, and asked to document barriers and facilitators you might experience getting around outdoors through photography and correlating journal entries. The pair of participants will then be asked to participate in one post-photovoice semi-structured interview to further discuss the contents of their photographs.

This research project is my Major Degree Project, a requirement of the two-year Master of City Planning program at the University of Manitoba.

Study procedures

If you participate in this study you will be asked to attend an information session where I will ensure you are familiar with the camera, and provide helpful tips for using the camera (like where to place your fingers on the camera and point it away from the sun whenever possible). An explanation of what is expected for the corresponding journal entries will also be provided at the information session. The information session will be approximately 45 minutes to one hour long. Once you feel comfortable using the camera you and your partner (person with early/mild dementia) will each be given a digital camera and a journal, and asked to document barriers and facilitators that people with early or mild dementia might face when getting around outdoors on foot. You will be asked to show this through 15 photographs (and journal entries) to be taken in the two weeks following the information session. You will also be asked to keep a journal that further explains each photograph (for example, why you took the photograph, what it means to you, what you were trying to capture in the photograph, what you couldn't capture in the photograph, etc.). After two weeks, I will collect your individual camera and journal entries and the photographs will be uploaded to my computer.

You and your partner will then be asked to participate together in one semi-structured interview with the Principal Investigator. You will be asked to talk about your experiences during the study, and further explain the content of the photographs and journal entries. Finally the principal investigator will share the study processes and findings at a public presentation. You will have the choice to take part in the presentation or to remain anonymous. In total, this research project will take up approximately 4 hours of your time.

Participant risks, benefits, costs

There is no evident, direct risk in taking photographs; I do ask that you take every precaution while taking photographs outdoors and do not partake in anything out of the ordinary to get a particular photograph. Indirect risks may arise while taking

photographs outdoors during the winter. It is acceptable to get help from your partner or to take photographs of the outdoors from inside if you feel unable to go out.

There is no risk to you in taking part in the interview. It can take place wherever is most comfortable for you, and will only include you, your partner and the Principal Investigator.

There are no direct benefits of taking part in the study, however participation does provide you with a platform to share your valuable insights, that may help future researchers better understand the relationship between people with dementia and their outdoor environments.

Audiotaping & confidentiality

With your permission, the interviews will be audio recorded and transcribed at a later time to ensure accuracy. The transcriptions and journal entries will contain no identifying information, and names and other personal information will be omitted from the final Major Degree Project document. Photographs will only be included if they are accompanied by a signed consent form for people appearing in photographs. Transcriptions, photographs, and journal entries will be kept in a secure place during the study, and destroyed (by myself) at the end of the study. All material for the final, public presentation will be approved by both you and your partner before being shared, and if preferred any identifying information will be omitted.

Feedback & debriefing

Once the interview is done, I will provide you with an interview transcript giving you the opportunity to verify the information and strike anything you feel uncomfortable with. I will provide individual feedback to you within two months of the interview through phone, email, or in person to ensure the information I have compiled from the photovoice and interviews is accurate. I will also provide you with a copy of the presentation material to ensure it is accurate, and that you are comfortable with the information being shared. Once the Major Degree Project has been completed I will provide you with a digital copy.

Dissemination of results

Study results will be shared at a final presentation that will be approved by the participants beforehand. Study results will be disseminated through my Master of City Planning Major Degree Project, a hard copy held at the Architecture/Fine Arts library at the University of Manitoba, a digital copy online through University of Manitoba's M Space, and my oral defense.

Voluntary participation/Withdrawal from study

Your decision to take part in this study is entirely voluntary. Initial consent will be obtained from interested participants at the end of the information session. Ongoing consent will be confirmed when the Principal Investigator collects the cameras and journal entries from you, and again before the interview is conducted. You are able to refuse participation or to withdraw from the research study at any time. If you

decide to participate you have the right to refuse to answer any question or to refuse participation in any activity, at any time.

Contact information

Student researcher

Lea Rempel, Graduate Student, Department of City Planning, Faculty of Architecture, University of Manitoba

Phone: 204-xxx-xxxx

Email: -----@myumanitoba.ca

Research supervisor

Rae Bridgman, Professor, Department of City Planning, Faculty of Architecture, University of Manitoba

Phone: 204-xxx-xxx

Email: -----@cc.umanitoba.ca

Statement of consent

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Joint-Faculty Research Ethics Board (JFREB) If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator (HEC) at 474-7122 or by email at Margaret.Bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

I have read this consent form. I have had the opportunity to discuss this research study with the student researcher. I have had my questions answered by her in language that I understand. I understand that I will be given a copy of this consent form after signing it. I understand that my participation is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that the information I provide will be incorporated in a presentation and report by the Principal Investigator. I also understand that all information will be treated as confidential, stored in a private and secure place, and destroyed two years after the end of the project by the student researcher.

Consent for audiotaping the interviews

- ☐ I consent to having the interview audiotaped and transcribed
- ☐ I do not consent to having the interview audiotaped and transcribed

Preference for final presentation

- ☐ I consent to being a part of the final presentation
- ☐ I do not consent to being a part of the final presentation and prefer that all identifying information about me be omitted

Participant #2 (primary caregiver) printed name

Signature of Participant #2 (primary caregiver)

Date

VI. Consent form for people appearing in photovoice photographs



UNIVERSITY
OF MANITOBA

City Planning
201 Russell Building
84 Curry Place
Winnipeg, Manitoba
R3T 2N2
Tel: (204) 474-9458
Fax: (204) 474-7532

Consent for people appearing in photographs

I, _____ (printed name of person appearing in photo),
give my permission for _____ (printed name of photographer)
to include me in a photograph for the research project **“Caring for those who once
cared for us: Dementia friendly planning for a Winnipeg, Manitoba winter.”** I
understand that every effort will be made to ensure I remain unidentifiable in the
photographs (i.e. my back is turned to the photographer, I am too far away to be
clearly identified, etc.) but that complete anonymity cannot be guaranteed.

I understand that the research is being conducted as a part of a Major Degree Project
(MDP) for the Department of City Planning at the University of Manitoba, and that I
may direct any questions to the Principal Investigator, Lea Rempel at telephone
number: 204-xxx-xxxx or email address: -----@myumanitoba.ca. I also
understand that this photograph may be seen by other people (through a hard copy of
the final MDP held at the Architecture/Fine Arts library at the University of
Manitoba, a digital copy online, or the Principal Investigator’s oral defense), but that
my name will never be identified. I understand that confidentiality cannot be
guaranteed due to the nature of this photography project.

Signature of Person Photographed

Date

Signature of Photographer

Date

VII. Presentation/discussion schedule

OPENING

1. Establish Rapport

Good morning everyone. Thank you so much for coming out today. I really appreciate it.

The name of this presentation and the name of my major degree project is ‘Caring for those who once cared for us: Dementia friendly planning for a Winnipeg, Manitoba winter.’ I'm just going to go over a few important things right away.

2. Explain purpose, assure anonymity & confirm consent

My name is Lea Rempel and I am the lead researcher. I am a student at the University of Manitoba and am undertaking this project as a requirement of the two-year Master of City Planning program. My research project is called ***‘Caring for those who once cared for us: Dementia friendly planning for a Winnipeg, Manitoba winter’***. My research aims to explore the potential of the built environment to improve the cognitive health of those suffering from dementia and to define some of the things that make it easier or harder for someone with dementia to get around outdoors during the winter in Winnipeg, Manitoba.

Today I will be presenting the findings from the first stages of my research that included a photovoice study with both a person with dementia and their primary caregiver. Photovoice is a data collection method that involves giving study participants a camera and asking them to document issues in their communities through photography. Afterwards I will be asking you to discuss what I have presented, as well as your own thoughts and experience on the topic. Together the presentation and discussion will take approximately 1 hour.

Today’s entire discussion will be taped and transcribed but the transcripts won’t contain any identifying information (e.g. no names). The data collected from the discussion will be used in my final degree project. Because there will be a number people taking part in the discussion, I cannot completely guarantee confidentiality. However, I ask that participants do not share the details of the group discussions outside of the group setting.

The results of the study will be made public only through my Master of City Planning Major Degree Project, a hard copy held at the Architecture/Fine Arts library at the University of Manitoba, a digital copy online through University of Manitoba’s M Space, and my oral defense.

Your decision to take part in this discussion is entirely voluntary. Your remaining here after this has been read and I have answered any questions implies you understand that the data gathered from today’s discussion might be used in my major degree project. However, all identifying information will be left out. You are able to

leave the presentation or withdraw from the discussion at any time. If you decide to stay you have the right to refuse to answer any question at any time.

Are there any questions about your participation or how information from this presentation and discussion might be used?

3. Researcher Presentation

[5 minutes mingling, getting coffee and/or donuts]

5 minutes presenting the background & literature

5 minutes presenting the photovoice and interview

5 minutes presenting the findings

Transition... So now I'm going to invite [participant] to just say a few words about what it was like to be a participant, how she felt about the process, and what she hopes to see come of it.

4. Participant presentation

5 minutes [participant] presenting

Transition... Now that we've had a chance to go over the preliminary findings I'm going to put a few guiding questions up on the screen. At this point I invite anyone to ask any questions or to share their own thoughts and/or experiences on the topic.

5. Group discussion

Guiding questions for group discussion

- a. How does the information presented here resonate with your own experiences?
- b. Is there anything you would like to add?
- c. In your opinion, what is the biggest barrier in the urban built environment for someone with dementia?
- d. What changes in the built environment might help someone living with dementia to continue taking part in everyday activities in the community?

CLOSING

6. Maintain rapport

Thank you so much coming today and giving me your thoughts. It's always really important to have lived or learned knowledge from the people who are actually living with dementia or caring for someone with dementia. It helps to make sure that the research we do is credible and valid.

7. Action

Now I will transcribe this presentation and discussion, and pull out pieces of it to use in my major degree project. I will stick around here for a couple minutes and anyone who would like to speak to me is more than welcome to. Also, if anyone is interested

in receiving a copy of my major degree project can leave their email address with me.

VIII. Recruitment poster for presentation/discussion



When:

**11am - 12pm
April 15, 2015**

What:

**A discussion on dementia
friendly communities and
winter**

Where:

**CHARLESWOOD ACTIVE
LIVING CENTRE**

My name is Lea Rempel and I am a graduate student in the Department of City Planning at the University of Manitoba. I am conducting research on the barriers and facilitators that people with dementia face when getting around outdoors in the winter in Winnipeg.

- Do you or does someone you love have dementia?
- Do you possess valuable knowledge about what it's like to get around outdoors in the winter?

**We will be discussing
the preliminary findings
from my research on
dementia friendly urban
design, winter, and
active living, and I would
love to include your
feedback in my research!**

We will be talking about...

- The aging population and increasing prevalence of dementia
- The connection between urban design, mental health, and winter
- My own research with people who are affected by dementia in Winnipeg
- Your thoughts on getting around outdoors for someone with dementia

**If you are interested in any of these, or know someone who might be
please come to the presentation and share your thoughts.**

ALL are welcome!

If you would like any additional information, please contact Lea Rempel:
phone [REDACTED], **or email** [REDACTED]

IX. Verbal consent for presentation/discussion participants

For anyone attending the presentation and discussion that cannot read extended text due to language barriers or difficulty in reading I will read this verbal script to seek consent.

My research project is called ***‘Caring for those who once cared for us: Dementia friendly planning for a Winnipeg, Manitoba winter’***. My name is Lea Rempel and I am the lead researcher. I am a student at the University of Manitoba and am undertaking this project as a requirement of the two-year Master of City Planning program.

My research aims to explore the potential of the built environment to improve the cognitive health of those suffering from dementia and to define some of the things that make it easier or harder for someone with dementia to get around outdoors during the winter in Winnipeg, Manitoba.

Today I will be presenting the findings from the first stages of my research that included a photovoice study with both a person with dementia and their primary caregiver. Photovoice is a data collection method that involves giving study participants a camera and asking them to document issues in their communities through photography. Afterwards I will be asking you to discuss what I have presented, as well as your own thoughts and experience on the topic. Together the, presentation and discussion will take approximately 1 hour.

Because there will be a number attendees that take part in the discussion, I cannot completely guarantee confidentiality. However, I ask that participants do not share the details of the group discussions outside of the group setting.

Today’s entire discussion will be taped and transcribed but the transcripts won’t contain any identifying information (e.g. no names). The data collected from the discussion will be used in my final degree project.

The results of the study will be made public only through my Master of City Planning Major Degree Project, a hard copy held at the Architecture/Fine Arts library at the University of Manitoba, a digital copy online through University of Manitoba’s M Space, and my oral defense.

Your decision to take part in this discussion is entirely voluntary. Your remaining here after this has been read and I have answered any questions implies you understand that the data gathered from today’s discussion might be used in my major degree project. However, all identifying information will be left out. You are able to

leave the presentation or withdraw from the discussion at any time. If you decide to stay you have the right to refuse to answer any question at any time.

X. Ethics approval and amendments



Research Ethics and Compliance

Office of the Vice-President (Research and International)

Human Ethics
208-194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Phone +204-474-7122
Fax +204-269-7173

APPROVAL CERTIFICATE

November 24, 2014

TO: Lea Rempel (Advisor R. Bridgman)
Principal Investigator

FROM: Susan Frohlick, Chair [REDACTED]
Joint-Faculty Research Ethics Board (JFREB)

Re: Protocol #J2014:156
"Caring for those who once cared for us: Dementia friendly planning for a
Winnipeg, Manitoba winter"

Please be advised that your above-referenced protocol has received human ethics approval by the **Joint-Faculty Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement (2). **This approval is valid for one year only.**

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- If you have funds pending human ethics approval, please mail/e-mail/fax (261-0325) a copy of this Approval (Identifying the related UM Project Number) to the Research Grants Officer in ORS in order to initiate fund setup. (How to find your UM Project Number: <http://umanitoba.ca/research/ors/mrt-faq.html#pr0>)
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Quality Management Office may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/orec/ethics/human_ethics_REB_forms_guidelines.html) **in order to be in compliance with Tri-Council Guidelines.**

umanitoba.ca/research

AMENDMENT APPROVAL

February 2, 2015

TO: **Lea Rempel**
Principal Investigator

FROM: **Susan Frohlick, Chair**
Joint-Faculty Research Ethics Board (JFREB)

Re: **Protocol #J2014:156**
**"Caring for those who once cared for us: Dementia friendly
planning for a Winnipeg, Manitoba winter"**

This will acknowledge your request dated January 29, 2014, requesting amendment to your above-noted protocol.

Approval is given for this amendment. Any further changes to the protocol must be reported to the Human Ethics Secretariat in advance of implementation.



**Research Ethics
and Compliance**
Office of the Vice-President (Research and International)

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Canada R3T 2N2
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AMENDMENT APPROVAL

March 2, 2015

TO: Lea Rempel
Principal Investigator

FROM: Susan Frohlick, Chair
Joint-Faculty Research Ethics Board (JFREB)

Re: Protocol #J2014:156
"Caring for those who once cared for us: Dementia friendly
planning for a Winnipeg, Manitoba winter"

This will acknowledge your request dated February 20, 2014, requesting amendment to your above-noted protocol.

Approval is given for this amendment. Any further changes to the protocol must be reported to the Human Ethics Secretariat in advance of implementation.



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and Compliance**
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AMENDMENT APPROVAL

March 11, 2015

TO: **Lea Rempel**
Principal Investigator

FROM: **Susan Frohlick, Chair**
Joint-Faculty Research Ethics Board (JF REB)

Re: **Protocol #J2014:156**
**"Caring for those who once cared for us: Dementia friendly
planning for a Winnipeg, Manitoba winter"**

This will acknowledge your Amendment Request dated March 4, 2015 requesting amendment to your above-noted protocol.

Approval is given for this amendment. Any further changes to the protocol must be reported to the Human Ethics Secretariat in advance of implementation.