Planning Dementia-Inclusive Suburban Neighbourhoods

by

Samantha Biglieri

A thesis
presented to the University of Waterloo
in fulfillment of the
thesis requirement for the degree of
Doctorate of Philosophy
in
Planning

Waterloo, Ontario, Canada, 2019

Author's Declaration

This thesis consists of material all of which I authored or co-authored: see Statement of Contributions included in the thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners. I understand that my thesis may be made electronically available to the public.

Statement of Contributions

Exceptions to sole authorship:

Chapter 3: Everyday built environments of care: Examining the socio-spatial relationalities of suburban neighbourhoods for people living with dementia

Chapter 4: Fostering mobility for PLWD in suburban neighbourhoods through land use, urban design and wayfinding

Samantha Biglieri was the sole author for Chapters 1, 2, and 6 which were written under the supervision of Dr. Jennifer Dean. This thesis consists in part of three manuscripts written for publication. I hereby declare that I, Samantha Biglieri was sole author of Chapter 5. Further, I declare that as the lead author on Chapters 3 and 4, I was responsible for the research conceptualization and design, methodology, data collection, analysis, and drafting/editing of manuscripts. Exceptions to sole authorship of material are as follows: Dr. Jennifer Dean, as the primary supervisor, provided supervisory directions in terms of data collection, feedback on draft manuscripts and editorial assistance for Chapters 3 and 4.

Abstract

Globally, the population is ageing at a rapid rate, and with that comes the prevalence of dementia. Dementia is an umbrella term to describe a progressive set of symptoms impacting cognition that will affect 115.4 million people worldwide in 2050. In Canada, an estimated two-thirds of the 402,000 people living with dementia (PLWD) live in community, as opposed to congregate living settings (Alzheimer's Society of Canada, 2010). PLWD are likely to experience a 'shrinking world' effect (Duggan, Blackman, Martyr, & Van Schaik, 2008; Shoval et al., 2011), making it essential to investigate supportive features in public space near their homes. These features can enable the positive outcomes associated with continued access to one's neighbourhood, such as maintaining daily activities, improved physical and mental health, independence, and a sense of dignity (Burton & Mitchell, 2006; O'Connor et al., 2007).

Most older Canadians have expressed the desire to age-in-place, and PLWD deserve to access this option and their neighbourhood, just like any other citizen (Fainstein, 2010; Swaffer, 2014). However, there is a paucity of research on the impact of the built environment on PLWD, with the majority of studies being based in Europe, and no research on North American suburban neighbourhoods. Existing studies are critiqued for a lack of attention to the relational experiences of place, and lack of focus on planning processes. Despite this lack of evidence, policies continue to be put forward, such as 'age-friendly cities' and the newer 'dementia-friendly cities'. In response, this dissertation explored how PLWD experience their local suburban neighbourhoods and what planning practitioners can do to support them. The research then focused on three broad objectives: 1) to investigate everyday outdoor practices of PLWD and how they are shaped by their socio-spatial relationships; 2) to identify barriers and supports to PLWD's mobility; and, 3) to investigate the accessibility of the planning process for PLWD.

Using a socio-spatial relational approach, and applying a critical disability lens to Fainstein's (2010) 'Just City' to form a framework for conducting planning research with PLWD, a mixed-methods case study was employed. Participants included seven (7) PLWD from suburban areas in Waterloo Region who were engaged using several methods: introductory and multiple go-along interviews, GPS tracking, travel diaries, experience sampling methods, as well as a field experiment using participant observation and a post-experience interview. The findings are described in three separate manuscripts focusing on each of the objectives. The first manuscript highlights the socio-spatial relational complexities associated with outdoor practices as a PLWD. It was found that PLWD care for themselves in place over time (including the past, present and future); that they care for close others and build interdependencies in place; and encounter with un/familiar others in public spaces is a form of support. This also speaks to the importance of understanding PLWD as complex individuals, disrupting their consistent portrayal in media and academia as dependent (Swaffer, 2014). The second manuscript focuses on what planning practitioners can do to support PLWD, by identifying recommendations to support mobility through land-use, urban design, and wayfinding, as informed by socio-spatial understandings. Finally, the third manuscript found that the open house, a public engagement tool, could be made accessible to PLWD with a few modifications, and considers the implications for using this to make further claims to citizenship for PLWD. This dissertation makes several theoretical, methodological, and substantive contributions to planning scholarship and practice.

Overall, this research provides planning practitioners in suburban areas with empirical evidence conducted in a context similar to their own. This could serve as a starting point upon which to begin incorporating dementia-inclusive recommendations in terms of land-use and design, as well as how to alter the planning process itself. Ultimately, the goal must be to change how planning professionals view PWLD, and to work collaboratively with PLWD to build more accessible, inclusive neighbourhoods.

Acknowledgements

A PhD is, without a doubt, a daunting, often lonely endeavor. However, I firmly believe that it takes a village to finish it, and I am so incredibly lucky to say I have felt supported by a community that spans disciplines and national borders. At the University of Waterloo, I want to thank: the School of Planning (my colleagues - the faculty, staff, and students who have made me feel like I belong, pushed me to be a better planner), the Faculty of Applied Health Sciences (who welcomed me with open arms to their Aging, Health and Wellbeing classes, and connected me to the Symposium on Aging Research, the Network on Aging Research, and multiple interdisciplinary teaching opportunities), and the Department of Athletics and Recreation (for mentoring me and giving me the opportunity to get people excited about fitness as a spin instructor). I want to thank my friends for getting me through this – from ACSP (for our supportive messages and reunions), from the Global Suburbanisms trip in Italy in 2018 (you all opened my eyes to so many new potentialities in planning), the GoHelp Lab, and from the School of Planning. I would not have gotten through this without your support, and I cannot tell you how much you mean to me! Back in Toronto, thank you to team at The Biglieri Group – for working with my schedule, and for keeping me connected to practice. To the Toronto Council on Aging, for supporting me in my development as a Board member and Vice-President, and teaching me so much. Thank you to my mentors from Ryerson's School of Urban and Regional Planning – you have believed in me since the beginning, and have challenged me to be a better researcher, teacher, mentor and planner. I want to thank Dr. Aspa Rigopoulou-Melcher – my conference mom, and mentor, as well as my future Post-Doc supervisor and mentor, Dr. Roger Keil, for being so supportive. Finally, I want to thank Dr. Maxx Hartt and Nick Revington, for being my collaborators, mentors, and friends, as well as Nabila Prayitno, Margaret Ellis-Young and Roxanne Springer for always believing in me.

I want to extend a special thank you to the members of my committee – Dr. Sherry Dupuis, Dr. John Lewis, Dr. Sean Doherty – and my external examiner Dr. Richard Milgrom – for your insights, constructive critiques and help throughout this journey. I also want to thank my supervisor, Dr. Jennifer Dean, for always pushing me to do more, be better – but also being a confidant and advisor in every sense of the word.

Finally, I want to thank my family and friends, for putting up with me, and supporting me no matter what. To my friends back home in Toronto for being so understanding when I had to spend more weekends in Waterloo and supporting me from afar. To mom and dad for being my official supporters at conferences, and to my sister for always being there when I needed to talk. I want to thank my dad for having us name the land-uses as we passed them as kids, and for inspiring me to become a planner in the first place. To my partner, for getting me through frustrating times, being an expert at Excel, and for reading my work no matter what. I would not be here without you all. Thank you.

Dedication

I dedicate this PhD to my family, friends, and colleagues, as I truly believe it took a village. I also want to dedicate this to the participants that I had the privilege to work with. You are all absolutely wonderful people, and I am incredibly lucky that I got to do this research with you. Finally, I want to dedicate this to my grandparents – my Nonni, Nonno, Nanny, Poppa, and Gran. I am so lucky to have grown up with you, learned from you and been the recipient of your love. Thank you for reminding me on the dark days why I was doing this research in the first place.

Table of Contents

List of Figures

List of Tables

Chapter 1: Introduction

Globally, the greatest demographic changes are a rapidly urbanizing and aging population. With these changes has come the recognition that where we live impacts our health and wellbeing, and this impact is often experienced more acutely by marginalized populations. Beginning with the 'Healthy City' movement in the 1980s, and over the past few decades, there has been an understanding of the role that planners can play in researching and building healthy, accessible, and inclusive communities through their practice. In researching this topic, there has also been a recognition of the importance of relational approaches to planning. This dissertation builds on a legacy of planning research into inclusive, just, healthy cities as well as several other disciplines to understand one understudied population in public space – people living with dementia (PLWD). Since I am a planner - in practice and as a scholar - this thesis seeks not only to understand how people living with dementia experience their suburban neighbourhoods, but also what can be done to improve their experiences and interactions.

The World Health Organization [WHO] (2012) calls dementia "the leading cause of dependency and disability among older persons in both high-income countries and Low to Middle Income countries" (p. 8). It is estimated that globally, 47 million people currently live with dementia and this number will rise to 115.4 million by 2050, with 7.7 million new cases per year (WHO, 2012). Canadian estimates show that up to two thirds of PLWD live at home (as opposed to congregate living) (Alzheimer's Society of Canada, 2010). This sizeable percentage of PLWD who live in neighbourhoods and communities is an area for targeted action by urban planners and policy makers who can make a difference by identifying and eliminating barriers, and by facilitating opportunities for PLWD. PLWD are citizens of the places they live in, and they have the right to have their disabilities accommodated within those places, in the built environment and in the political processes that shape those built environments (Shakespeare, Zeilig, & Mittler, 2019). This citizenship perspective is tightly related to the growing advocacy movement of PLWD, and challenges hegemonic misconceptions of dementia as a tragedy requiring prescribed disengagement (Swaffer, 2014).

Dementia is an umbrella term used to describe progressive symptoms that affect cognition like impaired memory, confusion navigating space, inability to focus, reduced visual perception, and difficulty with communication, behaviour, reasoning, and judgement. Approximately 60-80% of all PLWD have Alzheimer's disease, and there are no known treatments to reverse the symptoms (WHO, 2017). Accordingly, many of the efforts to date have focused on supporting the wellbeing and quality of life for PLWD, including work on the role of built environments in this process. This is due to evidence suggesting behaviours and performance of the neuropathology of dementia is influenced by personal histories, social interactions/contexts, their immediate environment and the broader socio-cultural context (Kitwood, 1990, 1997; O'Connor et al., 2007). For PLWD, being supported by their neighbourhood in terms of access has many benefits: more social interaction, sense of worth, dignity and improved physical/mental health. However, they are more likely to experience a 'shrinking world' effect (Mitchell & Burton, 2006; Shoval et al., 2011). With approximately two dozen studies on PLWD and public outdoor spaces, existing research has been primarily based in Europe, with no research in the suburban North American context, where a majority of people are choosing to age-in-place. Most of the research on the subject falls into one of two characterizations: (1) examining social characteristics (like social ties and connection to place) in a geographically defined place; and (2) by focusing exclusively on the built environment features, with little meaningful inquiry into socio-spatial relationalities. Further, existing research has not been operationalized into ways of thinking about how to plan for/with PLWD in different contexts, nor does it examine how to include them within the process of planning as citizens of their city. Recommendations have nearly always focused on the call for more research or stagnant built environment recommendations. This is often characteristic of traditional planning scholarship, and contrary to Graham and Healy's (1999) call on planners to examine geometries of power and take a socio-spatial relational approach to studying place.

Recently, Manthorpe and Iliffe (2018) have asserted that "the impact of people with dementia on cityscapes is not well understood" (p.8). The existing research focusing on built environment outcomes has mostly been concentrated in the past decade and a half, and the variety of disciplines engaged in this work is vast[1]. While using a multitude of theoretical frameworks, methodologies, scales and perspectives to understand the experiences of people and place can be considered a strength (Corburn, 2009), it can also be considered fragmented, non-systematic, and lacking an important consideration of the processes that shape the built environment. Further, in the wider world of urban policy there has been the rise of several policies to break down barriers and foster inclusion for PLWD, such as 'age-friendly' and 'dementia-friendly' city policies in addition to universal

---

[1] Including (in alphabetical order): anthropology, architecture, computer science, engineering, epidemiology, geography, interior design, medicine, nursing, neuroscience, occupational therapy, policy, psychology, public health, recreation and leisure, social gerontology, social work, speech pathology, technology studies and urban planning.

design. That being said, these policies are inadequate for addressing the needs of PLWD, and remain under-evaluated. Fundamentally, these approaches do not see PLWD as citizens with the right to be accommodated in space. Given the demographic imperative and realities of where PLWD live, the lack of research in suburban areas and under-evaluated practical policies – this thesis is timely and relevant. But before discussing the questions and objectives of this work, it is important to situate myself in terms of ontology and epistemology, as well as situate this thesis in planning theory. My relational ontology means that I understand the world as a series of relations between the socio-spatial, institutions, societal structures, human and more-than human entities through time and scale (Tornaghi, 2015). My social constructivist epistemology (way of understanding knowledge) recognizes that individuals have multiple social realities influenced by the contexts in which they live (Guba & Lincoln, 1989; Hershberg, 2014). These multiple realities can be understood through a co-construction of meaning between the participants and the researcher (Franke, Sims-Gould, Chaudhury, Winters, & Mckay, 2019; Mills, Bonner, & Francis, 2006).

In terms of addressing this issue from a planning theory standpoint, I subscribe to the 'Just City', which states that planners and policy-makers, can within the system of capitalism, create incremental change by shifting policy evaluation from that of economic analyses to those of justice (Fainstein, 2010, 2014). Fainstein (2014) acknowledges that cities do not have the same reach as federal governments (which can enact more transformative change), however, local level policies such as housing, transport, recreation – "can differentially affect people's quality of life" (p. 14). While she does not specify policies, Fainstein does establish what she calls "bases of judgement". The three themes for her "bases of judgement" are democracy, diversity and equity, based on case study analysis and a detailed theoretical inquiry into what justice is. While Fainstein's (2010) bases of judgement for these three categories would likely benefit PLWD (such as ensuring affordable housing and access to good transit), the only mention that might affect PLWD directly is in reference to the need for "widely accessible public space" and that "public authorities should assist groups who have historically suffered from discrimination in achieving access to opportunity in housing, education and employment," (p. 174), however disabled people are not mentioned as one of these groups.

While it can be said that there is room for disability in Fainstein's (2010) list of ascriptive characteristics, it is notably absent. Establishing these "bases of judgement" as a policy evaluation tool for planners is a tangible instrument that could be used in their daily work. However, in order for PLWD to be served by these "bases of judgement", their experiences have to be accurately reflected and explicitly stated. As Fainstein (2014) says, how we respond to the "relatively disadvantaged has been the result of local political pressures and the ways in which problems are framed" (p. 14). In order for PLWD to have their voices heard and needs met, their experiences have to be framed explicitly. However, to be able to establish a "base of judgement" for understanding what justice in access for PLWD looks like, research must be undertaken from a relational ontology to learn about what enables or disables PLWD in accessing their communities. This relational ontology will be explored later in this chapter, and more in depth in Chapter 2. Planning outcomes are only part of the puzzle – the success of using justice as a criterion also relies on a mobilized electorate, access to the planning process, and supportive decision-makers (Throgmorton, 2008 as cited in Fainstein, 2010, p. 181) as well as supportive planners themselves. Therefore, I recognize the other systems and relational understandings of power, professional practice, the development industry, as well as the role of citizenship and broader socio-cultural discourses, such as the stigmatization of PLWD. The 'Just City' is limited in that it does not directly address injustice as related to disabled people, like individuals living with dementia. To fill this theoretical gap and substantive/policy gaps, in the next part of this chapter I draw on insights from critical disability scholarship (CDS) to propose a way forward for research with PLWD in the built environment.

1.1 Research Questions + Objectives

To address the gaps in the substantive, policy and theoretical realms, I created research questions that balance inquiry into theoretical interpretations of space and place with practical guidance for practitioners (Lapintie, 2007; Schon, 1983 as cited in Farthing, 2016; Schiefelbusch, 2010 as cited in Lloyd & Stirling, 2014, p. 16-17). The planning field does not just undertake research for the advancement of knowledge, but also, critically, to "inform, evaluate and even help to transform practical activity" (Silva, Healy, Harris, & Van den Broeck, 2015, p. xxxv). Thus, the overall research questions for this thesis are:

Overall Research Question(s)

1. How do PLWD experience their local neighbourhoods?
2. How can planners support PLWD in their local neighbourhoods?

Further to these questions, I seek to answer three objectives, which form the intent of each manuscript (Chapters 3-5)

Research Objective(s)

1. To understand how PLWD experience their suburban neighbourhoods, and how these everyday practices shape/are shaped by their past, present, and future(s), as well as their personal relationships (Chapter 3).
2. To identify how and what PLWD identify as socio-spatial barriers and supports to mobility in their familiar suburban neighbourhoods (Chapter 4).
3. To identify how and what PLWD identify as barriers and facilitators to accessing the planning process (Chapter 5).

1.2 Literature Overview

The literature overview for this thesis first covers the existing substantive literature on PLWD and the built environment, as well as the policy context. Next, insights from critical disability studies are used to critique the planning theory of the 'Just City', and together with relational approaches to place, form a framework for conducting planning research with PLWD.

1.2.1 Existing Literature on the Built Environment for PLWD

The majority of the existing literature on the outdoor built environment for PLWD relates to changing the design of built environment features or studying its impacts on one's sense of self and health and wellbeing. This section outlines the insights from planning literature as well as other disciplines.

1.2.1.1 Planning Literature

In their realist review of the literature on the relationship between the built environment (BE) and PLWD, Keady et al. (2012) discovered that there were only 14 articles on the topic, and I identified only one author who was a planning scholar (Lynne Mitchell), who co-authored 7 articles and one book (comprising of two separate research studies and literature reviews).[2] It should be noted that in that review, Keady et al. (2012) did not include any articles which had a biomedical focus, looking at symptoms and behaviour of PLWD, as these studies "fail to acknowledge the role that the environment may play in promoting independence for people with dementia beyond the home," (p.160). This thesis takes the same approach. Upon re-review in 2018, I (Biglieri, 2018) found five

---

[2] These pieces include: literature reviews (Blackman et al., 2003; Mitchell et al., 2003), the first mixed methods research study (Mitchell, Burton & Raman, 2004; Mitchell & Burton (2006); Mitchell, 2007; Mitchell & Burton, 2010) and second research study specifically on legibility/wayfinding (Sheehan, Burton & Mitchell, 2006), all as cited in Keady et al. (2012).

additional articles to add, with no planning scholars listed as authors (Brorsson, Öhman, Cutchin, & Nygård, 2013; Brorsson, Öhman, Lundberg, & Nygård, 2014; Passini, Rainville, Marchand, & Joanette, 1998; Rainville, Passini, & Marchand,2001; Shoval et al., 2011). More recently, after a search of articles which cite the original Burton and Mitchell (2006) research study on the relationship between the built environment (BE) and PLWD, I discovered that there are no articles written by planning scholars, but rather three Master's theses in urban planning (Lacey-Avon, 2016; Rempel, 2015; Su, 2013) and six from other disciplines (Bartlett & Brannelly, 2019; Clarke et al., 2012, Clarke, Ailshire, House, Morenoff, King, Melendez, & Langa, 2015; Gaber, Nygård, Brorsson, Kottorp, & Malinowsky, 2019; Fleming, Bennett, Preece, & Phillipson, 2016; Lloyd & Stirling, 2015; Odzakovic, Hellstrom, Ward, & Kullberg, 2018; Ward et al., 2018). While the studies listed above can give future research direction in terms of building an evidence base for what may enable or disable PLWD in their neighbourhoods, they do not adequately address questions regarding larger processes which shape our built environment. None of these studies have investigated how PLWD access formalized planning processes which shape cities, nor have they adequately addressed how and why stigmatization of dementia is spatially reflected in the built environment. Critically, these studies do not examine the processes, actors and power structures that created those environments.

1.2.1.2 Other Disciplines

Urban planning scholars do not have the monopoly on research involving the built environment. When it comes to researching space and PLWD, the variety of backgrounds in terms of scholarship is vast. Some scholars used virtual reality as part of a study protocol that also involved an outdoor walking activity (Blackman, Van Schaik, & Martyr, 2007; Van Shaik, Martyr, Blackman, & Robinson, 2008). These authors tried to add features to the BE in virtual reality to test the impact of alterations to the built environment. Blackman et al. (2007) concluded that clearer textual signs were effective in improving performance, and while adding landmarks did not necessarily achieve the same results, it did not mean they should not be sought after. Occupational therapy researchers used transactionalism and critical incident technique (CIT) (Brorsson, Öhman, Lundberg, & Nygård, 2011; Brorsson et al., 2013, 2014), which takes into account the idea that the relationship between the person, the physical environment and the social as constantly changing over time. CIT allows for the development of principles to develop responses/strategies to negative incidents. Environmental designers and cognitive neuroscientists conducted a wayfinding experiment in which they recorded the decisions of people with and without dementia in a hospital, finding that PLWD had a more difficult time navigating, but that landmarks, clear signage and visual access made the process easier for them (Passini et al., 1998; Rainville et al., 2001). These experiments took place in a controlled, unfamiliar place, meaning that their findings are not directly applicable to the neighbourhood scale, nor tell us about how PLWD navigate in familiar places. (Findings from Gärling, Böök, and Lindberg (2013) indicate that these two cognitive processes are related, but different). One architect's study aimed to use the current evidence about the dementia-friendliness of buildings and work with planners and architects to develop an objective checklist designers could use (Fleming et al., 2016). The primary function was to create a tool for designers, and consultation with PLWD was limited to two individuals. In addition, the study assumed that a trip started and ended at a car park, neglecting the impact of neighbourhood design, streetscapes, public spaces or public transport.

Other studies looked at the metaphorical idea of the 'shrinking world', both physically and socially through interviews with PLWD and their care partners (Duggan et al., 2008). GPS studies like Shoval et al. (2011) found that this metaphorical world is supported by empirical evidence, with PLWD travelling on average 400m from their homes and those without dementia travelling 1.5km. Empirical findings from Clarke et al. (2012, 2015) postulates the idea of the neighbourhood as cognitive reserve, suggesting that neighbourhoods with certain features were associated with less cognitive decline, such as proximity to community centres and public transport, implying that being enabled to continue activities by virtue of the area one lives in could be considered a protective factor. Scholars from health and social gerontology examined everyday technologies (from smartphones to the built environment) that help support PLWD in outdoor spaces in continuing activities through examining the lived experience and meanings (Brittain, Corner, Robinson, & Bond, 2010; Duggan et al., 2008) as well as delving deeply into socio-spatial meaning making – life spaces – for PLWD (Lloyd & Stirling, 2014). Duggan et al. (2008) found that BEs can be a source of identity and inclusion (p. 282), and Lloyd and Stirling (2014) found four themes of particular salience in regards to life spaces and mobility for PLWD: access to public space, social distance and proximity, changing meanings of space and objects, and imaginative co-presence. In detailed interviews with PLWD, Brittain et al. (2010) found that built environments have the potential to be both therapeutic and frightening:

> It could be argued that they [PLWD] are more aware of their sense of place, in that they may feel at 'risk' of becoming disorientated. Physical and social landscapes in this sense are therapeutic in that they reassure and are used as an explicit way of getting home or providing a sense of security. The use of everyday technologies (or technologies of place) in public spaces

> such as signs, familiar bus routes and shops can all be used as a way of mapping out where it is a person wants to go. (p. 282).

While Brittain et al. (2010) discussed citizenship for PLWD and the social model of disability, they argued that the built environments should be studied as an everyday technology. Unfortunately, studying the built environment as a 'technology of place' does not address the political and power structures that influence how cities are constructed – those of the planning process and practice, the development industry, and politics. The evidence presented here demonstrates that one's community does play a role in living well with dementia and that there are certain land use patterns, design features, locations of resources that are enabling/disabling for a PLWD. That being said, the extent to which these features play a role is unclear, as Keating and Gaudet (2012) note that there is still insufficient evidence to demonstrate that "augmenting the contexts of persons with Alzheimer's disease will lead to a better quality of life" (p. 456).

In addition to the assertions by many authors that there is an insufficient amount of evidence about what an enabling neighbourhood might look like, or to its efficacy in enhancing quality of life, there are a few other critiques to highlight. First, there is a need to highlight the geographic context of these studies and their relevance to a North American context. Nearly all of these studies have taken place in either the United Kingdom (Burton & Mitchell, 2006; Blackman et al. 2003, Duggan et al., 2008), Sweden (Brorsson et al., 2011, 2013, 2014) or Australia (Lloyd & Stirling, 2015). While Australia could be considered more like Canada or the United States of America in terms of suburban development, and Sweden has a more winter focused climate akin to Canada and parts of the USA, the fact remains that neither are a North American context. Two studies that took place in British Columbia provided important insight into the importance of the maintenance of activities for PLWD in public space (Phinney, Chaudhury, & O'Connor, 2007) and the success of a walking program for PLWD in the neighbourhood as a form of expressing social citizenship (Phinney, Kelson, Baumbusch, O'Connor, & Purves, 2016), however these studies do not capture the full picture in terms of the role of the built environment in the lives of PLWD.

1.2.2 Policy + Practice Context

In terms of the planning profession, there have been policies written in the UK in the form of guiding documents, but the policies are often based on the singular study completed by Burton and Mitchell (2006) in the UK (Royal Town Planning Institute [RTPI], 2017). In Canada, Przydatek (2012) interviewed planners on whether they were aware of or could incorporate the principles of 'dementia-friendly’ design (i.e. familiarity, legibility, distinctiveness, accessibility, comfort and safety - based off of the Burton and Mitchell (2006) study) into their daily work. While many indicated that they would be open to doing so, it was not something that was on their radar. Based on my informal conversations with professional planners in Ontario, while it is acknowledged as potentially important, many admitted they would not know where to start (Biglieri, 2015). In response, I demonstrated that each of Burton and Mitchell’s (2006) 17 design recommendations could be validated by at least one other peer reviewed study and represented good planning principles, and that it was also possible to implement these recommendations within a greenfield subdivision near Toronto from a policy and financial feasibility perspective (Biglieri, 2018). The nature of the uptake of a dementia-specific approach to planning so far in the profession has been based on the Burton & Mitchell (2006) study, which focused on providing a checklist of built environment features. There have been other policy attempts to in/directly influence the lives of PLWD, including ‘age-friendly cities’, ‘dementia-friendly cities’ and universal design.

The Age-Friendly City (AFC) model was created by the World Health Organization (WHO) in 2007, after conducting extensive focus groups in 33 higher and lower to middle income countries around the world. This model was created in response to a recognition that one’s local neighbourhood played a large role in affecting older adults’ independence, sense of dignity and overall quality of life (Hodge, 2008; Plouffe & Kalache, 2010; Thomas & Blanchard, 2009). The model defined eight domains for consideration and action, with a corresponding checklist of essential features of AFCs. The WHO encouraged municipalities to use this model as a guide, conduct local age-friendly audits, involve older adults in the consultation process, and develop a local action plan. However, even this model and the checklist have no mention of dementia (Plouffe & Kalache, 2010). It is also worth noting that the WHO places information on dementia under their Department of Mental Health, whereas ‘Age-Friendly Cities’ are classified under the Department of Ageing and Life Course. Further, the AFC model has been critiqued as homogenizing one of the most diverse demographic groups, being apolitical, ignoring structural issues of ageism, inequality, and global financial forces, being too prescriptive in regards to what is supposed to be a localized policy response, and lacking empirical study (Lui, Everingham, Warburton, Cuthill, & Bartlett, 2009; Philipson, 2011; Williams-Roberts, Jeffery, Johnson, & Muhajarine, 2015). Buffel and Philipson (2012) argue that we should shift from the AFC idealistic model to asking “What are the actual opportunities and constraints in maintaining quality of life as people age?” which can actually address the complex nature of cities and their interrelated physical, commercial, political, and social aspects

(p. 601). Not only are there only two evaluations of AFC initiatives since 2007 (Williams-Roberts et al., 2015), but PLWD are often excluded from the discourse on AFCs.

Dementia-friendly city (DFC) policies are a recent phenomenon, which go beyond the typical recommendations of 'age-friendly' cities, but is still largely apolitical. DFC policies encourage changes in physical environments, reducing stigma through education, emphasizing social networks and citizen participation, training service staff on how to interact, and adapting public transport without context-specific recommendations on how to improve the built environment for PLWD. If they discuss built form, they tend to cite the principles and recommendations from Burton and Mitchell's (2006) study. There is, however, one policy that places importance on 'dementia-friendly' built form recommendations – the Lifetime Neighbourhoods[3] national level policy document from the UK that incorporates 'dementia-friendly' built form recommendations, and a similar guiding document from the RTPI (2017) and directs the reader to papers published by Mitchell and Burton (Bevan & Croucher, 2011; RTPI, 2017). In terms of evaluation of this approach, not only is there is no consensus as to what constitutes a 'dementia-friendly city', as of 2015, there were no studies evaluating their efficacy (Williams-Roberts et al., 2015).

From a national level, Lin and Lewis (2015) summarize dementia-friendly, dementia-capable and dementia positive approaches as part of their recommendations to the US government. Ireland, Scotland and Malta were the only countries to discuss physical environments, but in the context of hospitals and care homes only. Lin and Lewis (2015) concluded that "people may agree PLWDs deserve to live a meaningful life, but without positive beliefs, they may not believe PLWDs can actually live a meaningful life" (p. 242). Lin and Lewis' (2015) recommendations to the (US) government, as part of a national dementia policy, concluded that the US should expand research on PLWD from health/social care to urban planning, then expand 'dementia capable' to a dementia positive framework that goes beyond supporting PLWD to truly seeing them as equal contributors and citizens, leading to changing attitudes about PLWD (p. 242).

In summary, current dementia-friendly or dementia-specific approaches to policy focus on social environments and neglect the potential impact of built environment features of the neighbourhood on the health and wellbeing of PLWD (unless the discussion is limited to the findings from the Burton and Mitchell, 2006 study), but perhaps most importantly, treat PLWD as consumers

---

[3] The Lifetime Neighbourhood concept is considered a way to look holistically at the neighbourhood, with six key components of resident empowerment, access, service and amenities, built and natural environments, social networks/well-being and housing (Bevan & Croucher, 2011, p. 8).

who need to be helped as opposed to encouraging them to demand rights. Dementia activists have cautioned against DFC policies as tokenistic inclusion of PLWD in the development of these policies (Swaffer, 2014). They also note it is a paternalistic way of supporting PLWD, which often emphasizes segregation of PWLD from the rest of society – through memory cafes and dementia village living areas (Rahman & Swaffer, 2018; Shakespeare et al.,2019). Dementia Alliance International (DAI) has officially condemned the practice of 'dementia-friendly', stating "From the perspective of people living with a diagnosis of dementia, it is less about being friendly, and so much more than awareness of what dementia is. It is about access to our communities, as citizens, in the same way any other person with a disability is supported to live. It is so much more than professionals and interested others (without dementia) working together to make OUR community more inclusive and accessible" (DAI, 2018).

Universal Design (UD) is a list of key principles that support a design approach that is equitable, does not disadvantage any group of users and involves many types of users from the beginning. The principles – simple and intuitive use, equitable use, perceptible information, tolerance for error, flexibility in use, low physical effort and size/space for approach and use – have been applied to design related areas such as the provision of services, consumer products and the BE (Imrie and Hall, 2001). In UD there is no such thing as 'normal' and 'different than normal', rather "there is only one population with varying characteristics," (Carr, Weir, Azar, & Azar, 2013, p. 4) that are constantly changing (Imrie & Hall, 2001, p. 15). UD seeks to integrate accommodation into design from the beginning, and views accessible or 'additive design' as demeaning, drawing attention to a person with disability, and perpetuating stigma and social exclusion (Imrie & Hall, 2001, p.14). UD characterizes users as consumers (Hamraie, 2013; Imrie & Hall, 2001, p.17), and sees impairment as something to be 'overcome' through design instead of seeing it as part of someone's identity (Imrie & Hall, 2001, p. 17). Seeing users as consumers also frames the designer as the ultimate expert in the relationship with the user (Imrie & Hall, 2001). Fundamentally, UD assumes that a technical or design solution will create tangible change on its own (without the development of a social or political program for change). UD is apolitical in that "there is little or no recognition of the interrelationships between the social, technical, political and economic processes underpinning building and design" (Imrie & Hall, 2001, p. 16). UD assumes that an 'objective environment' exists, even as authors have noted there is no such thing as an 'objective' built environment without social interpretation (Wahl & Gitlin, 2007; Wahl & Oswald, 2010). UD also assumes that the resultant BE from using the UD principles will be objectively universal, able to be 'checked off' by a list. Hamraie

(2013), took a different approach by discussing the potential of UD as a tool for social justice in disability studies, however to do that it would have to be reoriented as a political tool that re-examines how society thinks about a range of ability, as opposed to using UD to define the 'normate'.

Regardless of these important theoretical issues, on the practical side, Carr et al. (2013) notes there are several drawbacks to UD in terms of implementation, primarily in the observation that "…we are currently at a time when norms and codes of practice take precedence over theory for guiding decisions and actions" (Carr et al., 2013, p.6).[4] This points to a need for planning scholarship to enquire as to why this is the case, through the process of planning itself, the complex relationships in the development process and the education of practitioners. In addition to this profound statement, Carr et al. (2013) cites three other challenges:

- Little to no education of professionals;
- Most professionals are able bodied, and it is difficult for them to anticipate disabled users needs, and there is limited opportunity to ask these users; and
- There is a discrepancy between the ideals of academics when it comes to implementing UD, and how much it costs in the real world. Architects ultimately serve clients, and if it is not in the building code, there is no reason to 'waste money' on other accessible features. (p.5-6).

Planners face similar challenges in that they are often limited to developing and advising on land use and urban design policies. That being said, planners can recommend putting principles into planning policies, such as visioning statements or guiding principles that encourage aspects of universal design for example, in addition to specific code-based policy (Biglieri, 2018). However, as this section has shown, the resultant form-based policies and technical solutions from UD are not enough to create tangible change. There has to be a change in how planning practitioners think about users (in response to one of Carr et al.'s (2013) main challenges), an examination of the planning process itself as well as attitudes and values towards disabled people. Another important difference is that planners have a greater opportunity to engage with the public than architects, since all planning policies and requests for amendments must go through some form of public consultation process, and that is a great prospect for citizen participation and engagement.

---

[4] Carr et al. (2013)'s critiques are mainly in reference to architects, who are an allied profession of planning. Thus, these critiques have the potential to apply to planners as well, however further study would be required to determine the extent.

1.3 Theoretical Gap

Planning is an applied discipline with its own robust theoretical debates and discussions in terms of the planning process, planning outcomes and perceptions of its practitioners (and the rest of the city-building community). I subscribe to the idea that one must be able to create a just process, just outcomes, as well as train city-builders to think about people who are different from themselves. This perspective responds to the current limitations of planning theory, which in my opinion neglects important insights from critical disability studies.

Planning practice, conceived of as "the processes, institutions and discourses that generate physical plans and interventions that shape cities" (Corburn, 2009, p.4-5) is an essential part of urban governance. Everyday, planners, both private and public, shape the content and direction of these city-building processes, which involves making subjective judgements about what to release to the public, what is acceptable evidence for policies or for changes to them, as well as how to conduct public engagement and who to invite (Forester, 1999; Friedman, 1987). Ultimately, the power of the planner is to advise and influence decision-makers, who make decisions about policy implementation. The decisions that planners make can have "significant influence over the content and outcomes of planning processes," (Corburn, 2009, p.4) and while working in the complex world that is urban governance (many contexts, actors, arenas, issues and politics), planners can make decisions that empower some and disempower others (Forester, 1999).[5]

In geography and planning, Gleeson (2013) discusses how research topics *de jour* in those disciplines focus on modalities like the creative class, the global economy, and knowledge society, noting that there is a serious lack of research interest in "enduring questions of injustice, disembodiment and the abuse of power," (p.70). Some scholars believe that it is the neoliberalization of the academy that has weakened "faith in the project of human emancipation" (Gleeson, 2013, p. 70). Gleeson's (2013) hope is that research in disability geography will not only identify spaces that are disabling, but also give a depth of insight into a rich realm of wisdom about human flourishing – reconceiving space as having the potential to both enable and disable (p. 71). In addition to my subscribing to an understanding of disability as relational, both socially constructed and embodied, it

---

[5] This is especially true in the Ontario context; wherein public planners are bureaucrats advising politicians about how to vote in regards to policy. Private planners face a similar situation, although in addition to convincing public planners that their evidence for change is sound, they must also advise their client, often a member of the development industry, whom they represent. The presence of a client is a key factor, as convincing developers to address the needs of the marginalized beyond legislative requirements is often, an uphill battle (Imrie & Hall, 2001).

is fundamentally about justice, about what Lefebvre (1996) called the right to urban life, the right of inhabitants to (re)produce, and transform the city by living in it (p. 158). Fainstein notes after the publication of her book *The Just City*: “The ultimate intent of my book is to specify policies that would benefit relatively disadvantaged social groups, as defined by income or marginality” (Fainstein, 2014, p. 14). However, as stated previously, these policy prescriptions are not sufficient to answer the questions posed for this thesis, as they do not explicitly speak to the experiences of disabled people. That is why I turn to insights from critical disability studies (CDS)[6].

Dementia is a cognitive impairment, and therefore can be conceived of as a disability, however PLWD and individuals with a cognitive impairment are not featured prominently in disability studies (Bartlett & O’Connor, 2010, p.126; Blackman et al., 2003, p.361). There is a strong desire in the activist movement for PLWD to be considered as people with a disability, and some scholars have argued in favor of this orientation as well. This desire has culminated in activists living with dementia (part of Dementia Alliance International) to demand, along with Alzheimer’s Disease International (ADI), access to the human rights associated with the United Nations Conventions on the Rights of Persons with Disabilities (CRPD), and this was unanimously granted in 2016 (Shakespeare et al., 2019). ADI’s main policy initiative is for national governments to recognize dementia as a disability so that PLWD will be recognized as citizens with rights to be accommodated, be involved in research and policy making directly (instead of interviewing care partners or medical professionals only) (Lin & Lewis, 2015; Shakespeare et al., 2019). Activists like Swaffer (2014) see the utility of conceiving dementia as a disability in that there are many ideas to point to, such as problematizing the conceptualization of dementia as only a tragedy (and the negative stigma and demeaning language that comes with that (Mitchell, Dupuis, & Kontos, 2013)), questioning how research on PLWD is often done with care partners and healthcare providers (instead of PLWD themselves) (Dupuis, Gillies, et al., 2012), and rejecting the idea of ‘prescribed disengagement™’[7] (Dupuis, Whyte, et al., 2012; Swaffer, 2014, 2015).

Conceptualizing dementia as a disability allows this work to turn to the interdisciplinary field of CDS[8] to understand a variety of relational and power issues, and to situate them in a greater socio-

---

[6] This includes research done in the disability geography realm.

[7] A term coined by Swaffer (2014, 2015) to refer to the tendency of doctors when giving a diagnosis of dementia to encourage patients to ‘get their lives in order’ and begin retreating from their lives.

[8] The distinction between CDS and Disability Studies is contested, however, Meekosha & Shuttleworth (2009) see the change in nomenclature as an evolution in the field, moving on from the social model of disability to more contextualized understandings of the relationship between impairment and disability. “Using the term ‘CDS’ is a move away from the preoccupation with binary understandings — social v medical model, British v

cultural-political-spatial-temporal context. It is acknowledged that disability is not based on some absolute norm, rather a "deviation from some ambiguous social norm," in which society has taken the continuum of the human experience and turned it into an 'other' (Dear, Wilton, Gaber, & Takahashi, 1997, p. 458). Thus, disability can be understood as a socially constructed phenomenon that is also inherently reflected in how our cities are built (Dear et al., 1997, p. 455). As Hamarie (2013) notes:

> …the design of buildings [and public spaces] is not a value-neutral and passive act; rather the design of the built environment actively conditions and shapes the assumptions that the designers, architects, and planners of these value-laden contexts hold with respect to who will (and should) inhabit the world. In short, built environments serve as litmus tests of broader social exclusions. (p. 2)

I take this approach – which understands the built environment and society as posing barriers - disabling - by virtue of the processes, professionals, and publics that construct them, as opposed to placing fault on the individual (Dear et al., 1997, p. 457). I also recognize the other side of the coin as vital – the lived experience of impairment, and embodiment. Disability and impairment must be studied in tandem as in everyday life it is difficult to separate the two (Hall & Wilton, 2017) and one must remain "ever vigilant of political, ontological and theoretical complexity" (Goodley, 2011, p.157). Three main insights from CDS add to the Just City model, expanding understanding of how to determine in/justice in city policies and practices.

1.3.1 Stigma, Boundary Setting + Spatiality

Disability is a socially constructed phenomenon, not based on an absolute quality, but rather a "deviation from some ambiguous social norm" (Dear et al., 1997, p. erred to as 'boundary setting', the continuum of the human experience has been taken and turned into a binary of abled/disabled (., 1997). This artificial boundary setting is related to what many have referred to as hierarchies of acceptance, which manifest spatially within our society. Disabilities deemed less acceptable are more

---

American disability studies, disability v impairment,"(Meekosha & Shuttleworth, 2009, p.50). Hosking (2008) argues that the social model of disability should still be included within CDS, since his proposal for Critical Disability Theory is one which "disability is a social construct, not the inevitable result of impairment. Disability is a complex inter-relationship between impairment, an individual's response to that impairment and the physical, institutional and attitudinal (together, the 'social') environment. The social disadvantage experienced by disabled people is the result of the failure of the social environment to respond adequately to the diversity presented by disability," (p.1). This thesis understands Disability Studies and CDS to be parts of the same field, one that recognizes the social construction of disability, as well as the contextualized understanding of lived experience and the influence of embodiment, while also being reflexive and politicized (Goodley et al., 2019) .

likely to be negatively stigmatized, and as Swaffer (2014) notes for PLWD, this often turns into discrimination, which can manifest as negative health effects or, as Corburn (2009) calls it in terms of neighbourhood health, a pathogen (p.98). Discrimination has been called a public health risk (Link & Phelen, 2006), and discrimination that PLWD experience has been demonstrated to negatively affect their health, as it "compounds the neurological related problems a person already has and reduces opportunities for self-expression and growth" (Woods, 2001 as cited in Barlett & O'Connor, 2007, p.108). The stigma attached to dementia is powerful, and it is produced and re-produced by scholars, media, policy makers and advocacy groups (Mitchell et al., 2013). Some examples include: the continued use of medicalized models and framing PLWD as a burden in policy making (Nedlund & Nordh, 2013, p.21); continuation of the tragedy discourse and referring to PLWD as sufferers, incapable of growth beyond the diagnosis (Mitchell et al., 2013; Swaffer, 2014); tokenistic involvement in research by PLWD, not being included at all or having stigma prevent PLWD from participating (Dupuis et al., 2012; Swaffer, 2014); and prescribed disengagement™ from specialists and other medical professionals (Swaffer, 2014). PLWD may not access the outdoors for fear of stigma/discrimination, of being labelled a wanderer (Blackman et al., 2003), demonstrating a spatial component to this attitude.

1.3.2 Moving Away from the Medical Model

The disabled rights movement in the 1960s and 70s in the United Kingdom and US was in direct protest of the medical model of disability, which believed that disability was a result of impairment (Thomas, 2004a). The movement also challenged the discourse of disability as a personal tragedy. Activists like Finkelstein and Oliver reformulated disability to mean "the social disadvantages and exclusions that people with impairment faced in all areas of life," (Finkelstein. 2004, p.13). Oliver (2013) coined the term 'the social model of disability', which understood that for disabled people, "we were not disabled by our impairments but by the disabling barriers we faced in society" (p.1024). I take the view that society creates socialized barriers for PLWD (what is referred to as disability), in the form of negative stigma attached to it and the prescribed disengagement™ by medical professionals (Swaffer, 2015), both of which are reflected in who we build cities for. I also take the view that it is nearly impossible to separate these socialized impacts from embodied experiences of living with impairment (like dementia) (Goodley, Lawthom, Liddiard, & Runswick-Cole, 2019; Hall & Wilton, 2017; Hughes & Paterson, 1997; Thomas, 2004b). Thomas (2004b) recalls that Finkelstein's original conceptualization called for a socio-relational understanding of disability – that impairment can cause restrictions of activity and pain, but it is disablism (on par with sexism, racism, homophobia) that layers on top to create social oppression. This understanding integrates personal and embodied experiences of disability with broader socio-cultural, political and built environment ways in which people are disabled. “We can say, ‘Yes, of course impairment causes some restrictions of activity—but these are not what is of interest in studying and combating disability’. Disability is a form of social oppression on a par with other forms of oppression in our society associated with gender, race, class, and sexuality” (Thomas, 2004b, p. 581). Studying disability in this way is to “scrutinize inequality”, but also can be considered an opportunity to disrupt the false able/disabled binary, and change practice to create more inclusive communities (Goodley et al., 2019). Thus, this research looks at both impairment and disability in tandem, and is sensitive to the caution from Oliver (2013) that an embodied approach might encourage a medicalized, individual version of disability to reappear.

1.3.3 Space as a Result of Normative Conceptions of the Body

Since Lefebvre wrote the *Production of Space* and revealed everyday geography as a place of power and struggle, and that the powerful dominate the production of space, often to the disadvantage of the disempowered – there has been an understanding of space as socially produced (as cited in Gleeson, 2013, p.72). Understanding space as socialized means that access/inaccess to space is a result of the values and conceptions of the planners and designers who created that space (Hamraie, 2013). These societal structures of ‘who belongs’ are evident in the way we design and plan our cities and communities and are therefore spatially manifested. We have designed these places based on what Garland-Thompson (1996) calls the ‘normate’ which “represents the unmarked privilege of majority embodiments—white, male, cisgender, heterosexual, able-bodied, and middle-class bodies—that appear neutral when their social location is in fact highly specific,” (as cited in Hamraie, 2013, p. 8). In his study of architects’ perceptions of the body, Imrie (2003) found that the architects saw the body as “pre-social, fixed and beyond culture… characterized by a corporeality that revolves around a singular sex, while generally failing to acknowledge ethnic, gender or physical differences,” in addition to stating that “the human body is usually absent in architects' conceptual schemata, and is rarely an explicit term of reference in their education or in the broader design process” (p. 63). The result of these attitudes, and thus, decisions made on a local scale, are that the disabled body is denied a presence in our cities and communities (Imrie, 2010, as cited in Hamraie, 2013, p.8).

1.3.4 Moving Forward

Based on these theoretical critiques, planning for/with PLWD should draw on the lessons from the Just City and CDS to expose injustice, as well as try to learn from the critiques of AFCs (by having PLWD actively participate in city building, focusing on socio-political structures), DFCs (including the BE in the analysis, seeing PLWD as relational citizens) and UD (addressing user needs, but also elevating the user to a co-producer of knowledge). A key part of the development of this approach is recognizing that PLWD are treated differently from older adults, and in research on the hierarchy of acceptability for disabled people is telling. In the late 1990s, Dear et al. (1997) reviewed studies on the 'acceptability' of disabilities from the late 1960s to 1990s, identifying eight factors that influence which types of disabilities are most acceptable to the general public. Older adults were viewed much more favorably than those perceived to be 'not in control' or 'losing themselves'. Those with intellectual disabilities or mental health issues were among the least accepted of all disabilities, with curable conditions like asthma or other inevitable issues like older age seen as more acceptable in the hierarchy. Although dementia is not explicitly mentioned, it can be hypothesized that it would be included in the least acceptable categories, and this is reflected in the persistent language used to describe PLWD as sufferers "doomed, gutted, ravaged, taken over by a beast, and … the living dead", perpetuating the tragedy discourse (Mitchell et al., 2013, p. 2; Swaffer, 2014).

This kind of a discussion begs questions about disabled identity – do PLWD desire the label of disabled, would they consider it part of their identity, and how much does this matter to them? As stated previously, many activists living with dementia have fought hard to have dementia considered a disability (Shakespeare et al., 2019). However, there are PLWD who are reluctant to adopt this label or are silent (Whitman, 2015). This is not an uncommon position for disabled people more generally, particularly for older adults, and individuals with mental health conditions (Shakespeare et al., 2019). Finkelstein and Stuart (1996) note, "the vast majority of disabled people are non-politicized. Marinated in a disabling culture and identify themselves with repressive individualist models of disability" (as paraphrased by Goodley, 2011, p. 30). It should be noted that throughout this thesis work, I spent time convincing some participants that they had the right to the city, and the right to comment on city-building. This revealed the impact of broader socio-cultural conceptions of dementia as well.

Flowing from my critique of the Just City based on insights from CDS, it is important to ask: "Who belongs in neighbourhoods?" To understand how/if PLWD 'belong' in the neighbourhood, it is integral to understand how PLWD have been/are conceptualized within the literature and socio-cultural-political structures. Up until the 1990s, dementia was conceptualized primarily through a biomedical lens, in which people were seen as 'sufferers' of a deadly disease.[9] Kitwood (1990; 1997) moved the discussion from a medical model to one that focused on the unique individual person, what has come to be known as the 'personhood approach'. This humanistic approach focuses on the individual as inherently worthy of respect, and as Bartlett & O'Connor (2007) note, "has done much to challenge the stigma and discrimination associated with dementia," and is arguably the most influential shift in the past decade (p.108). Primarily the personhood approach has accomplished two things:

- Shifted away from the assumption that people with dementia are 'already considered gone', 'sufferers' and do not have anything worthwhile to say to acknowledging that PLWD can provide insight into their lived experiences.
- Offered hope that change can occur, by changing one's environment or situation to be more supportive, stimulating and comfortable. O'Connor et al. (2007) demonstrated that the neuropathology of dementia is influenced by one's environment, personal relationships, personal histories and how one is perceived within their own social context.

However, while personhood has achieved great strides, there is still widespread stigma and a misunderstanding by many about PLWD (Mitchell et al., 2013). Personhood lacks a political dimension, and is flawed in three ways: (1) it is individualized, and therefore makes it difficult to research macro-level issues related to the impact of social structures, and a broader socio-cultural-political context; (2) personhood is seen as something you "confer" on PLWD, relying on a cognitively intact person to give the PLWD their 'personhood', which does not recognize a PLWD as being a social actor; and (3) it is an apolitical concept (Bartlett & O'Connor, 2007, p. 109).

In response to the critiques of personhood, and inspired by the disability rights movement, Bartlett and O'Connor (2007) proposed the idea of thinking of PLWD through the lens of citizenship, which could fill the void created by the critiques, inherently involving a discussion of the political, and power (or lack thereof). The conceptualization of PLWD as citizens moves the research agenda from asking what people need to having them set the research agenda and priorities themselves (Dupuis et al., 2012; Genoe & Dupuis, 2013). Citizenship can be seen as practice, a way in which people relate to their communities, like the desire to make the built environment accessible as a 'quest for citizenship' (Barnes, 1997 as cited in Bartlett & O'Connor, 2007, p. 112). Citizenship can also be

---

[9] Many authors (Bartlett & O'Connor, 2007, 2010; Nedlund & Nordh, 2013; Mitchell et al. 2013; Swaffer, 2014) would argue that the biomedical approach to PLWD is alive and well in academia, policy discourses and advocacy organizations. However since the 1990s, there have been pushes in these realms to change this discussion from personhood to a citizenship approach.

thought of in the democratic, policy-making sense, as having the right to have "vote and voice" in state-led decision making (Sonnicksen, 2016). According to Brannelly (2016), citizenship for PLWD is currently challenged in three ways: through the relationship between the PLWD and the state, citizenship as practice, and citizenship as identity and belonging.

With these three challenges in mind, there have recently been calls to see citizenship as relational for PLWD (Keyes, Clarke, & Gibb, 2019; Kontos, Miller, & Kontos, 2017; Shakespeare et al., 2019). This relational citizenship perspective combines a human rights approach, with a centralizing understanding of agency as expressed through embodied selfhood of PLWD (like bodily actions in relation to others) and a focus on interdependence (Kontos, Grigorovich, Kontos, & Miller, 2016; Kontos et al., 2017). This relational citizenship model has been applied to long-term care settings (Kontos et al., 2016, 2017) and the everyday decision making with care-partners in the community (Keyes et al., 2019). Relational citizenship for PLWD would recognize the messy nature of embodied experiences of impairment with disablism, and would be able to take a nuanced approach, while still being rights-based and contextual (Shakespeare et al., 2019). In my opinion, planning scholarship and practitioners can move this relational citizenship idea forward, through examining citizenship for PLWD as practice and as inclusion (through access and connection in the neighbourhood), as well as their relationship with the state in terms of city building (through access to the planning process).

1.4 A Relational Framework for Dementia-Specific Planning Scholarship + Practice

In light of these outlined substantive, methodological, practical, and theoretical gaps, and guided by a relational ontology and social constructivist epistemology, I designed a framework for dementia-specific approach in planning scholarship and practice, which is then supported by three empirical manuscript(s) addressing two out of three of the categories ('building an evidence base' and 'reclaiming the planning process'). The framework and empirical research are informed by the demonstrated importance of the neighbourhood in the lives of PLWD, with inspiration from my CDS critique of the 'Just City' theory and relational citizenship for PLWD in the community.

Yiftachel (1998) argued planning scholars spend too much time theorizing about communication, and not enough time examining how spatial policies and processes create injustice and serve the needs of the privileged. This framework aims to examine how spatial policies, scholarship and practice are discriminatory towards PLWD, and this examination of the 'dark side' is influenced by planning scholars like Flyvbjerg (1998) and Richardson (1996) who emphasize the importance of examining power relations. This is in opposition to one of the most dominant theories in planning –communicative rationality, the notion that with the right conditions, Habermas' apolitical 'Ideal Speech Situation' can take place and all voices can be heard in the planning process (Flyvbjerg & Richardson, 2002). This view sees the planner as an apolitical facilitator, creating the platform for equal debate and consensus, presenting rational, apolitical professional opinions to serve the public interest. Only focusing on a just planning process, Fainstein (2010) argues "is an insufficient guide to producing justice in actual policy making," as it has to be combined with just outcomes (p. 14). Specifically, this framework rejects the role of the planner as only a facilitator and aims to expose injustice in terms of how PLWD are excluded from space, planning scholarship, the process of planning, and the profession's perceptions in a meaningful way. I offer a framework for analysis for understanding the impact of the neighbourhood on PLWD, the realm in which professional planners have influence. This is in response to Shakespere's (2006) call for many different levels of analysis, but also creation of actions at different levels.

Inspired by Graham and Healy's (1999) idea of multi-layered power geometries, the framework identifies three overlapping areas at the community scale, which should be the focus of planning scholarship and practice moving forward in the quest to create dementia-inclusive public spaces. This framework was also inspired by Bartlett and O'Connor's (2010) "Multidimensional Approach to Intervention" for PLWD, in the hopes of steering practice to becoming social justice oriented (p.90). Their four dimensions of focus include: the individual (subjective experience), interpersonal relationships, community, and sociopolitical structures (p. 91). The purpose of these levels is to provide a starting off point for an action, and then having practitioners move "iteratively between and among the different levels" (p.78). For planning scholarship, the natural scale of change is the community. Under this dimension, Bartlett and O'Connor (2010) outline three bridging tasks, problem-solving activities, primary targets for change and the primary roles of the practitioner (p. 91). See **Table 1.1**:

Table 1.1: Dimension of Focus - Community (From Bartlett & O'Connor, 2010)

Bridging Tasks	Problem Solving Activities	Primary Target for Change	Primary Roles of Practitioner
Examine how an individual with dementia is being supported/constrained by: • ***The physical environment*** • ***Opportunities for meaningful involvement*** • ***Community practices and policies*** Examine how community practices are organized by broader societal discourses.	Foster and support involvement of PLWD in decision-making capacities and leadership roles; Reveal oppressive policies and practices and their impact	Environment; Organizational policies and practices	Advocate; Community development; Social change agent

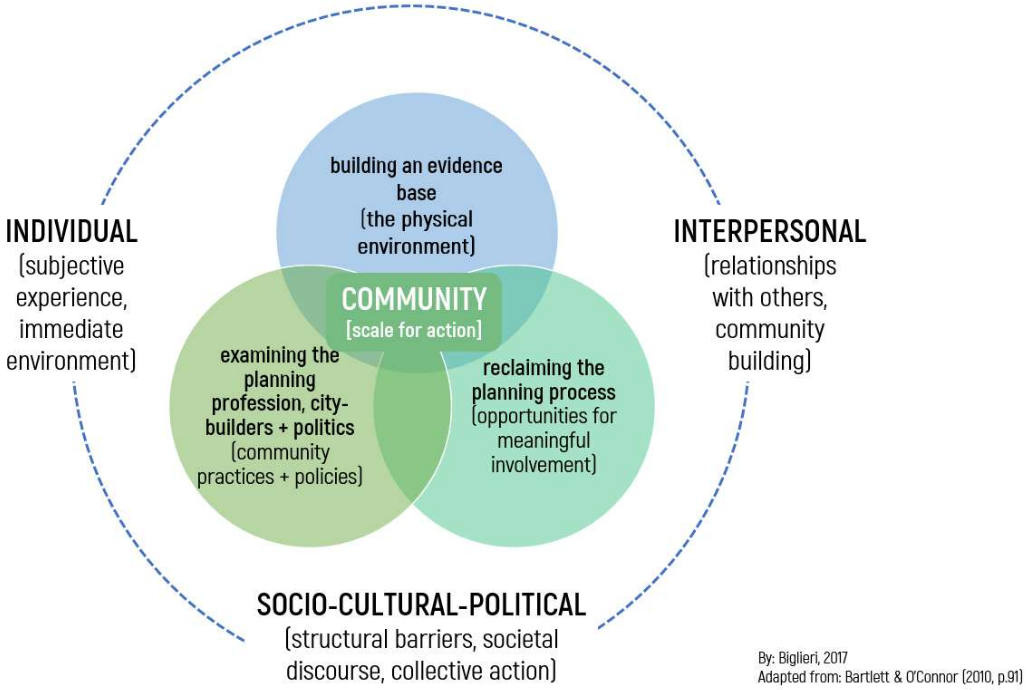
The framework starts with the three bridging tasks (indicated in bold italics in Table 1.1, also referred to as *power geometries* here) and expands upon them to explore what a dementia-specific social justice-oriented approach to planning scholarship and practice could look like. These *power geometries* are as follows, and are indicated visually in **Figure 1.1**:

Building an Evidence Base: This involves garnering a better understanding of socio-spatial relational experiences in one's neighbourhood for PLWD. The evidence produced by this research would help build context-specific principles and preliminary recommendations for professional planners from which to build off of. It would also help to expose how PLWD are being excluded in public spaces.

Reclaiming the Planning Process: This involves research into how to engage PLWD in the city building process in a meaningful and accessible way.

Examining the Planning Profession, Development Industry and Politics: This involves studying the impact of planning and development industry professionals' values on planning for/with PLWD. The rationale for looking at the development industry is in response to research done by Imrie & Hall (2001) and a recognition that it is private investors who are often the primary drivers behind urban change.

Figure 1.1: Relational Framework for Dementia-Specific Planning Scholarship + Practice



By: Biglieri, 2017
Adapted from: Bartlett & O'Connor (2010, p.91)

This relational conceptual approach allows scholars to truly examine all parts of what Machiavelli (in Flyvbjerg, 1998) called *la verità effetuale.* Flyvbjerg (1998) argues, along with scholars like Machiavelli and Nietzsche, that there is a danger in only ever theorizing about normative ideals. One has to learn *la verità effetuale*, moving from “what should be done” to “what is actually done”. Flyvbjerg (1998) notes, “In this way we obtain a better grasp – less idealistic, more grounded – of what modernity and modern democracy are and what kind of strategies and tactics may help change them for the better,” (p. 3). Each of the community level *power geometries* interact in an iterative way with each other, and as is indicated by the diagram, constantly being influenced by individual, interpersonal and socio-cultural-political factors.

1.4.1 Building an Evidence Base

The influence of place, neighbourhood and context are recognized as some of the most important determinants of human wellbeing (Corburn, 2009, p.13). It is the environment (home and community) that is the “primary factor that creates opportunities and constraints for the individual,” (Rowe & Kahn, as cited in Carr et al., 2013, p.2). It is also the neighbourhood which Yiftachel (1998) has argued is one of the ways in which planners exert social control, through aspects like land use policy and neighbourhood design, which could manifest as potential barriers or facilitators for PLWD. Imrie and Hall (2001) found that many in the development industry regard accessibility as an issue of common sense, such as the use of ramps for persons using a wheelchair. This issue is that based on current literature from Section 1.2, there is less of a consensus on what wellbeing in one's neighbourhood means for PLWD. To use a metaphor from Dementia Alliance International member Peter Mittler, this means building *cognitive ramps* for PLWD (Graham, 2017). In her work on how to make UD more social justice-oriented, Hamraie (2013) argues that building an evidence base would have scholars and practitioners:

> continue to develop strategies for participatory design, shifting from value-explicit design for disability to design with and by misfitting bodies more generally. These subtle differences in framing could shift both the role and work of designers, as well as render UD as a more capacious and social justice-oriented material-discursive practice. (p. 23)

The idea of designing with and by PLWD is the most important factor in building an evidence base, one in which all other ideas of how to accomplish building that base have to stem from. The continuum of disability studies research consists of knowledge/theory development (non-participatory, researcher led) to shared knowledge (participatory research, researcher invites participants in) and action research/emancipatory approaches (co-researchers) (Goodley, 2011, p.24). Further to the method used, the way one frames inquiries is significant – "assess(ing) the social conditions of disablism or measur(ing) the impacts of impairment," which lead to different but complimentary approaches to studying disablism (Goodley, 2011 p.25). Building an evidence base will require both in order to understand disablism for PLWD, as Goodley (2011) quotes Barnes (1995, p. 8) in saying that issues like physical access are easy to measure, whereas prejudice is not (p. 24).

Building an evidence base is necessary to determine if changes in one's neighbourhood or certain aspects of existing neighbourhoods make a difference in terms of quality of life, which is currently unclear (Keating & Gaudet, 2012). In addition, Burton and Mitchell (2006) argue that planners have a responsibility to "make use of evidence from research," (p.3). The purpose of investigating the impact of the built environment on PLWD in a relational way is to determine if some neighbourhoods are better than others at enabling PLWD to do activities as they have always done (Phinney et al., 2007), remain connected to their community through the maintenance of relationships (Carr et al., 2013), and maintain one's own sense of wellbeing. As individuals, we are embedded within networks of social relations, living our lives through them everyday – and no one, including PLWD "can be understood separately from the relationships of the individual with others"

(Emirbayer, 1997, as cited in Blackman et al., 2003, p.361). This is congruent with evidence that engagement in activities and maintenance of relationships can play compensatory role in the maintenance of quality of life and wellbeing of older adults following an adverse event (Carr et al., 2003, p.3) and this is likely to be the case for PLWD as well. How communities are built has an influence on these social relations, indicating a spatial component. As Worth (2013) notes, "Although it is helpful to understand disability as a social relationship—the dynamics of the space where that relationship is negotiated is vitally important," (p. 119). For example, continuance of activities is partially dependant on one's mobility, which can be constrained by the neighbourhood they live in (Webber, Porter & Menec, 2010). Duggan et al. (2008) demonstrated a conceptual shrinking social and physical world for PLWD and Shoval et al. (2011) demonstrated it empirically. There is evidence that suggests behaviours and performance of the neuropathology of dementia is also influenced by personal histories, social interactions and social contexts, and there is a need to understand how these function (O'Connor et al., 2007). All of these influences can be linked to the BE and community level of action, in which planners can have an impact.

The focus on changing the physical configuration of the environment rather than the individual is seen as favourable "as it increases an individual's functional abilities with the least amount of effort required from the individual," (Carr et al., 2013, p.2). In terms of building this evidence base, ideally planning scholarship should look at all facets of neighbourhood that influence lived experience, including for example: the quality and meaning of public spaces (like streets, parks, open spaces, shops, services); quality, accessibility, and meaning of housing and public transportation (Risser, Lexell, Bell, Iwarsson, & Ståhl, 2015); the impact of land use patterns, legibility, and meaning-making on mobility (Brittain et al., 2010; Cassarino & Setti, 2016); and the impact of the neighbourhood on wellbeing in a relational way (Corburn et al., 2009). The call for more context dependant and problem-oriented research that is relational has been echoed by other scholars (Andrews, Evans, & Wiles, 2013; Corburn, 2009; Cummins, Curtis, Diez-Roux, & Macintyre, 2007). This is a call for researchers to emphasize "relationships between places, people and meaning-making on one hand and the political institutions and processes that shape these relationships on the other," (Cummins et al., 2007, as cited in Corburn, 2009, p. 15).

It is also important to acknowledge that the roots of building an 'evidence base' comes from anthropometry, which has its roots in the eugenics movement (Hamraie, 2013). In addition, there is considerable critique of scholars like Golledge who focused on empirical studies of disabled people, instead of focusing on political issues (Park, Radford & Vickers, 1998, p.225). In contrast, some authors have argued that the act of building an evidence base with disabled people/PLWD is political in that it ensures the voices of PLWD are included and heard in city building and makes it easier for planners and designers to implement on the ground (Imrie & Hall, 2001; Lloyd & Stirling, 2015). While I take the latter position, I also acknowledge that for social justice practice to be realized, planning scholarship must also include research into the planning process and the profession itself. After all, altering the built environment to better suit the needs of PLWD living in the community is not a linear process, nor is it a simple matter of changing certain features. There are many layers of relational interactions between people, place, time and power that call for interdisciplinary actions at all scales.

1.4.2 Planning Process as Citizenship

Yiftachel (1998) argued that planning manifested itself as social control, and one of the ways in which this is accomplished is procedurally, through controlling access to communicative infrastructure and decision-making processes. PLWD are not specifically sought by planners to be part of the planning process, which Yiftachel (1998) might argue could result in contributing to their "marginalization and repression" (p. 402). This is most likely largely due to perpetuated societal ideas about PLWD as being presumed incapable, since there has often been the assumption that once diagnosed with dementia, a person "should no longer participate in decision making at governmental level," (Bartlett & O'Connor, 2010, p. 44; Dupuis et al., 2012). This presumption is influenced by things like using the Mini Mental State Examination (MMSE) score to test PLWD to determine their 'level' of capacity – a measure which is deficit focused, and standardized, which tends to ignore a great deal of information that can be learned from talking and taking a holistic approach (Bartlett & O'Connor, 2010, p. 66-67). As PLWD activist Swaffer (2014) has said, "We want to access services and to participate in the community the way everyone has a right to expect, and to have our disabilities respected with acceptance, support and enablement," (p. 714).

An integral part of this respect is to examine the relation between PLWD and the state, because PLWD often have to fight for their rights (Brannelly, 2016). It is also a particularly important area of action for planning scholarship and practice, as it is concerned with policy processes. This relationship with the state can be thought of as democratic citizenship for PLWD, voting for elected representatives and having the right to comment on policy that affects you as a citizen (Sonnicksen, 2016). Sonnicksen (2016) discusses three principles to examine in this instance: congruence (match between being affected by policy and having the right to comment on it); responsiveness (ability of a government to respond to comments); and representation (government providing meaningful opportunities to comment on policy). For the most part, PLWD have only been asked to participate in democratic citizenship when it is about policy that affects their own care (Bartlett & O'Connor, 2010). Planning scholarship and practice however, is uniquely positioned to further ideas of democratic citizenship beyond commenting on one's own care (Bartlett & O'Connor, 2010) and into the realm of politically contributing to city-building.

1.4.3 Examining the Planning Profession

Another way that planning can be considered a form of social control is culturally, through the dominance of a single culture/experience (Yiftachel, 1998). While Yiftachel (1998) was mostly referring to the dominance of socio-economic status (SES), or in some countries, along ethnic lines, this idea can be extended to disabled people, and PLWD. Hamraie (2013) discussed how the values of what planners, designers, architects, the development industry, consider a 'normate body' in our society – able bodied, middle-aged, middle to high socio-economic status, white, male, heteronormative – is spatially manifested in our cities, essentially that this dominant culture of what is 'normal' and accommodated. The attitudes and values of these groups, specifically the development industry and architecture, has been examined by Imrie and Hall (2001) as well as planners (Lewis, 2011) in regards to their perceptions of disabled people, however they are more in relation to mobility and sensory disabilities, rather than cognitive disabilities. This is the third part of the puzzle – examining the planning profession, as well as its counterpart – the development industry – in terms of their attitudes towards PLWD, and eventually, research how to change those attitudes. Convincing professionals to move beyond legislation and codes is one of the major barriers to creating inclusive built environments according to Imrie and Hall (2001, p.127). This tendency for design professionals and planners to plan for people who are like themselves (Carr et al., 2013) has to be changed.

According to Corburn (2009), one of the biggest challenges to healthy city planning is established norms of practice that dictate ways of addressing social issues that are deemed acceptable over time. Ways of understanding the world are difficult to change, the institutional environment within which planners practice encourage the status quo. Gunder (2010) argues that planning is based on what might be called "experientially based intuition", in which we begin to understand successful planning as repeating prior successful actions and avoiding unsuccessful ones leaving no room for experimentation or new ideas (p.205). Changing institutional attitudes is a slow process, as Sandercock (2003) notes, it is bureaucracies, politicians, and the planners that serve them that are notorious for being risk-averse. Changing attitudes could include examining the formal education of planners in school, creating a mandatory accessibility component to the competencies of the profession or offering coursework through professional associations as continuous professional learning. In an examination of the effect of accessibility training on urban planning students, Lewis (2011) found that while students are more likely to have humanistic attitudes, they come from a society with stereotypical views of people with disabilities, and that existence of accessibility standards and legislation is not enough - the focus should be on changing the attitudes and values of planning students and practitioners. Finally, in the spirit of Imrie and Hall (2001), there should be an examination of the actors in the development process in regards to planning for/with PLWD, since changing the attitudes of the planning profession alone will not be enough.

1.4.4 Summary

PLWD are marginalized due to broad socio-cultural-political factors, such as stigma, perceived ‘competence’, a research agenda that is often exclusionary, and persistent advocacy which focuses on the ‘dementia as tragedy’ discourse. When it comes to planning scholarship and practice – the built environment can exclude PLWD by preventing them from continuing to participate in activities and social relations, the planning process can exclude PLWD from (re)making their city as a citizen, and the attitudes and values of planners can perpetuate these issues. Layered on top of these issues are the importance of the individual experience and interpersonal relationships that PLWD have, and their impact on a PLWD’s wellbeing as well as the broader socio-cultural-political discourses about dementia. A dementia-specific approach to planning scholarship and practice is necessary, and the tripartite interactional framework is a good starting point. Through the scholarly process of engaging PLWD in an examination of their neighbourhood that privileges their experiences is an opportunity to develop tools for future engagement projects for practitioners, contribute to the creation of an evidence base, and challenge current theoretical understandings. These projects, like the use of storytelling, might then spin off into research about how to educate the planning profession, ideally forming Lefebvre’s (1996) ideal iterative feedback loop between all three areas that is sensitive to influences from individual experience, interpersonal relationships and socio-political factors (Bartlett & O’Connor, 2010). Research with PLWD can not only improve their experiences in public outdoor spaces by identifying barriers/facilitators, but by researching their everyday practices, we can gain a depth of insight into a rich realm of human wisdom about human flourishing (Gleeson, 2013).

1.5 Thesis Outline

The outline for this thesis is as follows: Chapter 1 has outlined the existing research on the impact of the built environment on PLWD, the substantive, practical, methodological, and theoretical gaps in the literature, and described a relational framework for research on this topic. Chapter 2 outlines the ontology, epistemology, methodology, methods, and research process that was undertaken for the overall thesis. Chapters 3-5 encompass three manuscripts, with each answering one of the research objectives and responding to a different part of the proposed framework. Chapter 3 is an exploration of the lived experiences in the neighbourhood for PLWD using a relational ethic of care approach. This paper was used to understand that landscape of experience, contributing to the literature by highlighting the complex outdoor lives of PLWD in suburban neighbourhoods that spans timescales, human/more than human encounters, and interdependencies. Chapter 4 focuses in on one aspect of outdoor life –mobility – and identifies built environment features that can be improved/retained in order to better facilitate the mobility of PLWD in suburban neighbourhoods. Chapter 4 concludes with recommendations for land use, urban design and wayfinding, as informed by socio-spatial relational and embodied understandings. Chapter 5 investigates the accessibility of a planning process tool, the open house, for PLWD, and the implications for conceptualizing democratic citizenship. Chapter 6 concludes the thesis, outlining the substantive, methodological, theoretical, and practical contributions, as well as future research directions.

Chapter 2: Research Design and Methods

Informed by a relational ontology, and social constructivist epistemology, this thesis used a case study methodology (specifically a multiple-case embedded design) to address the aforementioned research questions and objectives (Section 1.1). The phenomenon under study is how familiar neighbourhoods influence the lived experiences of PLWD, and the context is suburban neighbourhoods. The case study context was the Regional Municipality of Waterloo, Canada, with seven (7) people living with dementia (PLWD) comprising individual cases. A variety of methods were used with each participant (case). Based on the three objectives as laid out previously, the data generated was analyzed in diverse ways, according to individual objectives. Rigour was ensured through a variety of means, including overall research design, timeline of methods process, analysis of generated data and positionality (see Section 2.4). This research protocol was approved by the Office of Research Ethics at the University of Waterloo.

2.1 Ontology + Epistemology

Ontology is the way in which one understands reality and epistemology is the techniques by which one studies the world (Berbary & Boles, 2014). Put another way, ontology is "being able to articulate clear assumptions about how people and other forces are likely to behave" and epistemology is "carefully positioning a research inquiry in assumptions about how knowledge is produced and validated," (epistemology) (Silva, Healy, Harris, & Van den Broeck, 2015, p. xxxv). As our understanding of the world is always partial, it is integral to make clear one's assumptions about the world (Silva et al., 2015, p. xxxiii). A relational ontology guides this thesis – which seeks to "understand our world in terms of the connections that bind us together," (Lawson, 2008, p.4). A relational ontology understands reality as a series of relations between the socio-spatial, institutions, societal structures, human and more-than human entities through time and scale (Tornaghi, 2015).

Lefebvre (1996) once said that planners cannot create social relations, although "under certain favorable conditions they help trends to be formulated (to take shape). Only social life (praxis) in its global capacity possesses such powers – or does not possess them," (p.151). As a way forward, Lefebvre (1996) offers the idea of an incessant feedback loop between planners and the public to introduce rigor into the process and a call to study interventions on the ground (p.151). Relational theory posits that people make places and places make people, there are multiple and varying experiences of spaces and places that are temporal, spatial and operate at a variety of scales, from the individual body to the planetary level and rejects the idea of space as a container, upon which social, economic and political activities take place – instead everything is related, with relationships between these forces forming reality. A relational ontology sees space as dynamic, constantly evolving, with deeply contextual factors mediated through power, with multiple layers of understanding (Cummins et al., 2007). Relational geography had a profound impact on planning scholars, Graham and Healy (1999) who use the ideas of relationality as a way to conceptualize four ways forward for better planning theory and practice:

1. Planning must consider *relations and processes* instead of *objects and forms.* Ex. Generalizations about desirable urban forms (like compact form to stop sprawl) must be replaced by "polyvalent, pluralistic and culturally-sensitive appreciation between social processes and urban form," (p.642).
2. Planning must stress multiple meanings of space and time, and these layers are multivariant and must be examined.
3. Planning as multiple layers of relational assets and resources which generate a power geometry. The layering is not neutral or value free.
4. Need to acknowledge that these layers are shaped by relational processes by the power of agency through communication and interpretation (p. 642-643).

The preference of relational ontology over other models lies in its ability to understand lived experiences in a way that engages with contextual and dynamic factors, like space, time, people and socio-cultural-political structures, as well as provide a coherent way to relate several perspectives and players. In addition, a relational view of place can help counter policies that believe health and wellbeing is a result of physical determinism, in which the built environment and places are merely a result of what is constructed and designed (e.g. Smart Growth, New Urbanism) (Corburn, 2009, p.93). A relational view of place is one which looks beyond forms to the social, economic, political and meaning-making processes that combine to make a space a place (Cummins et, al, 2007). In other words, "a space becomes a place as meanings are assigned through social relations, and these social meaning, in turn, act to reshape places," (Corburn, 2009, p.92). Understanding the meaning of places for PLWD in their neighbourhoods is essential for investigating wellbeing – as a sense of place can foster feelings of inclusion whereas lack of place could mean feelings of isolation and depression (Jackson, 1984 as cited in Corburn, 2009). A relational ontology can help understanding lived experiences in space, questioning the power dynamics in bigger processes like the development industry, and examining professional planning values. I argue a relational ontology and the concept of interactional power geometries at a multitude of scales, from the individual to the socio-cultural-political, is a vital component of social justice practice for PLWD in the realm of planning scholarship.

I also subscribe to a social constructivist epistemology, denying the existence of an objective reality (Guba & Lincoln, 1989), acknowledging that "people live in multiple social realities" (Farthing, 2016, p. 20) influenced by context (Mills et al., 2006). Social constructivists posit that "reality can only be known through multiple mental constructions that are based on experience and socialization but are also local and specific in nature," (Guba & Lincoln, 2005, as paraphrased in Hershberg, 2014). Social constructivism asserts that people have consciousness and can reflect on their own realities (Farthing, 2016). Thus, this thesis is interested in exploring interpretations and meanings as socially constructed (Farthing, 2016). This allows me to investigate the lived worlds of participants by understanding their interpretations of the world (Sparks & Smith, 2004 as cited in Franke, Sims-Gould, Chaudhury, Winters, & Mckay, 2019). Social constructivism also rejects the idea of the objective observer, believing rather that the participants and the researcher are involved in a co-construction of meaning, influenced by positionality and values (Franke et al., 2019; Mills et al., 2006). (That is part of the reason why this methods chapter spends a considerable time on positionality). Social constructivism also draws on critical theories, and has the potential to expose social injustice and reduce oppression, increase compassion and cultural sensitivity as well as having emancipatory aims (Charmaz, 2016; Hershberg, 2014).

Table 2.1: Building Blocks of Research

Building Block	Definition	How it is used in the thesis
Ontology	What is out there to know? (how things are)	Relational ontology of the socio-spatial. Want to understand the relations between the socio-spatial, institutions, human and more-than-human, through time.
Epistemology	What and how can we know it? (how 'we' know what 'we' know)	Social constructivist. There is no objective reality, rather multiple constructed realities in context. A social constructivist epistemology allows me as a researcher to critically examine the institutional and societal values that planners and designers had when they built the suburban neighbourhoods in this study. It also allows me to place the power in the participant's hands to understand their sensorial, embodied experiences of their neighbourhood, and co-create knowledge for how to improve/retain certain parts of their neighbourhoods.
Theory	Ideas with which to think about content, methodology and 'analysis'	Just City theory with critiques from critical disability studies (see Chapter 1)

Methodology	How can we go about acquiring that knowledge?	Case study of everyday lived experiences (of PLWD) in place (familiar suburban neighbourhoods)
Methods + Data Generation	Which precise procedures can we use to acquire that knowledge?	Traditional and go-along interviews, GPS tracking, travel diaries, Experience Sampling Methods, participant observation, focus groups
Analysis	Procedure for seeing the data	Chapter 3: Constructivist grounded theory approach Chapter 4: Image-based Thematic Analysis Chapter 5: Framework Analysis
Representation	How data is represented to an audience	Chapter 3: Traditional Chapter 4: Evidence-based practice Chapter 5: Evidence-based practice

2.2 Research in Planning – Case Study Methodology

> *"The advantage of the case study is that it can "close in" on real-life situations and test views directly in relation to phenomena as they unfold in practice," (Flyvbjerg, 2006, p.235)*

Case study methodology is a research design committed to examining the complexity of real life situations (Simpson, 2009 as cited in Thomas, 2011) with diverse methods (Thomas, 2011). Instead of examining a few variables in a large dataset, case study researchers study the complex relations and interactions between many factors in a few cases, trading extensiveness for intensiveness (Thomas, 2011). This approach places the cases (participants) centre stage, instead of the variables (Ragin, 1992, as cited in Thomas, 2011). Case studies are a commonly used tool in planning research, as they seek a deep understanding of a particular context and cases, and then often provide recommendations about that phenomenon. Planners recognize the importance of context in their professional judgement and often operate based on detailed previous case experience (Flyvbjerg, 2006; Gunder, 2010). A case study can do what large scale systematic studies cannot – it describes in detail, the phenomenon and the factors that influenced observations – with the purpose of depth. Large systematic reviews for instance, do not, rather they serve the purpose of breadth. Both are required in the development of social science (Flyvbjerg, 2006), however for urban planners, the more information provided by a case study, the more it allows them to better consider its findings for their community context. In terms of generalizing the findings from case studies to other contexts, planners can use 'analytic generalization', a logic which is in opposition to the sample-to-population logic (Bromley, 1986, p. 290-291; Burawoy, 1991, p. 271-287; Donmoyer, 1990; Gomm et al., 2000; Mitchell, 1983; Small, 2009 as cited in Yin, 2013). The idea of 'analytic generalization' in a case study methodology means to extract more abstract ideas from the findings that can apply to other contexts, and is improved further still when the case study and findings are explicitly linked to existing research literature/theories, and involve more than one case (Yin, 2013, p. 325-326). Further, diverse mixed methods used in case study methodology contribute to methodological triangulation, setting the stage for a "close-up, in-depth study of a specific case in its real-world context" which is the "strongest empirical foundation for these generalizations" (p. 327).

Case study methodology has been used in a number of instances by planning scholars, for example: by Fainstein (2010) in the conceptual development of the 'Just City' and its three bases for judgement, Flyvberg's (1998) study on urban politics and planning in Denmark, examining the experiences of a city centre by people with learning disabilities (McClimens, Partridge, & Sexton, 2014) and activity space research with people with visual impairments (Wong, 2018). Case studies have also been used by a number of researchers working on quality of life for PLWD (Cedervall, Åberg, Cristina, & Berg, 2010; O'Connor, Phinney, & Hulko, 2009; Ward et al., 2018). Case studies are used "because [they] generate knowledge that is setting specific and problem focused," (Schiedt & Windley, 2006, p.114). Flyvbjerg (1998) demonstrated that case study research can be a powerful tool in examining what Niccolò Machiavelli called *la verità effetuale*, or 'understanding the truth of a situation'. The call for more context dependant and problem-oriented research that is relational has been echoed by other scholars (Andrews et al., 2013; Cummins et al., 2007; Corburn, 2009). This is a call for researchers to emphasize "relationships between places, people and meaning-making on one hand and the political institutions and processes that shape these relationships on the other," (Cummins et al., 2007, as cited in Corburn, 2009, p. 15), which fits well with the relational ontology and social constructivist epistemology being used in this research.

2.3 Defining the Case Study

I selected a case study methodology because: the focus of the research was to answer 'how' and 'why' questions; the behaviour of participants could not be manipulated (as the objectives are seeking information about familiar neighbourhoods and everyday experiences); the thesis wanted to cover contextual conditions and relations (based on existing literature that cites their importance); and the boundary between the phenomena (everyday life for PLWD in public spaces) and the context (suburban neighbourhoods) is unclear (Yin, 2009). Further, Yin (2009) calls on the researcher to know the purpose of the descriptive effort. The purpose of this descriptive effort for this thesis is to understand how PLWD experience their familiar suburban neighbourhoods, and what planners can do to support them – asking why certain built environment features constrain/enable their mobility and how they experience the accessibility of the process that shapes those built environments. Yin (2009) also calls on researchers to create a list of topics that will make the case study a full description of the phenomena. To be a complete description, I begin with a socio-spatial relational picture of how PLWD live in suburban neighbourhoods (Chapter 3). Then, I investigate the mobility of PLWD through go-along interviews and through non-intrusive pattern monitoring (GPS, travel diary) to contribute to the evidence base of data on best practices for planning outcomes for PLWD (Chapter 4). The final manuscript addresses the process that shapes the built environment – the planning process itself – by investigating how accessible the process is to a PLWD (Chapter 5). See **Figure 2.1-2.2** below for a visual depiction summarizing the case study methodology design of this thesis, and for each individual objective/chapter.

Figure 2.1: Overall Case Study Methodology

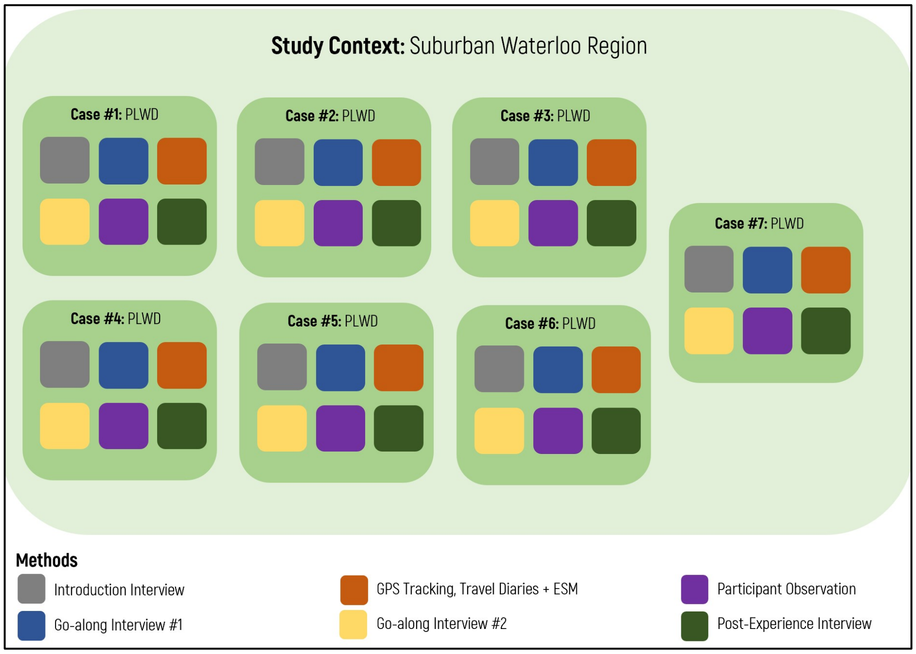
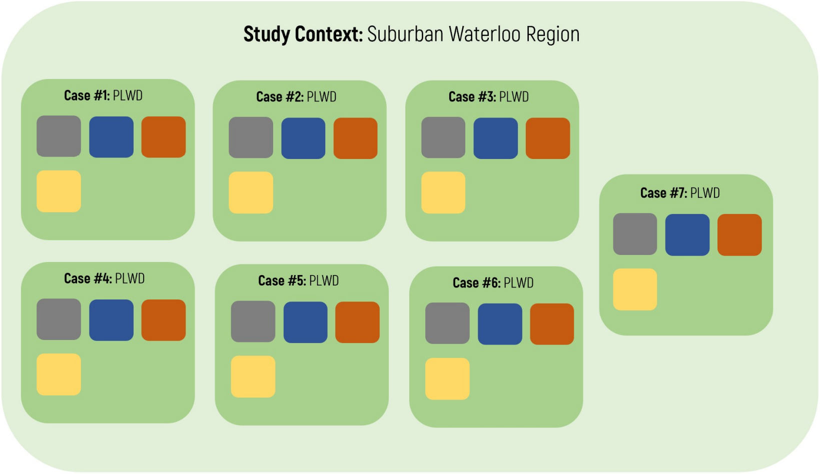
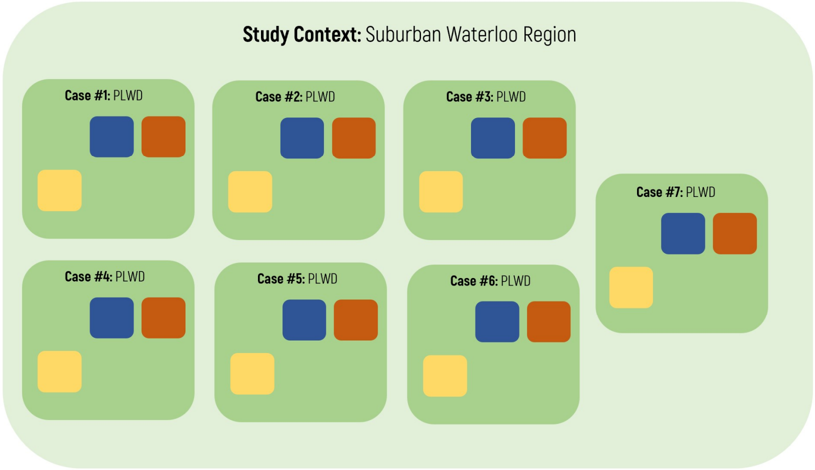
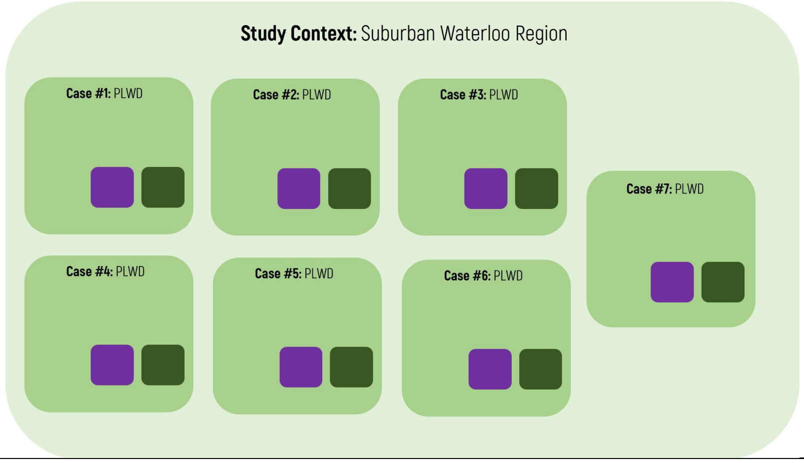


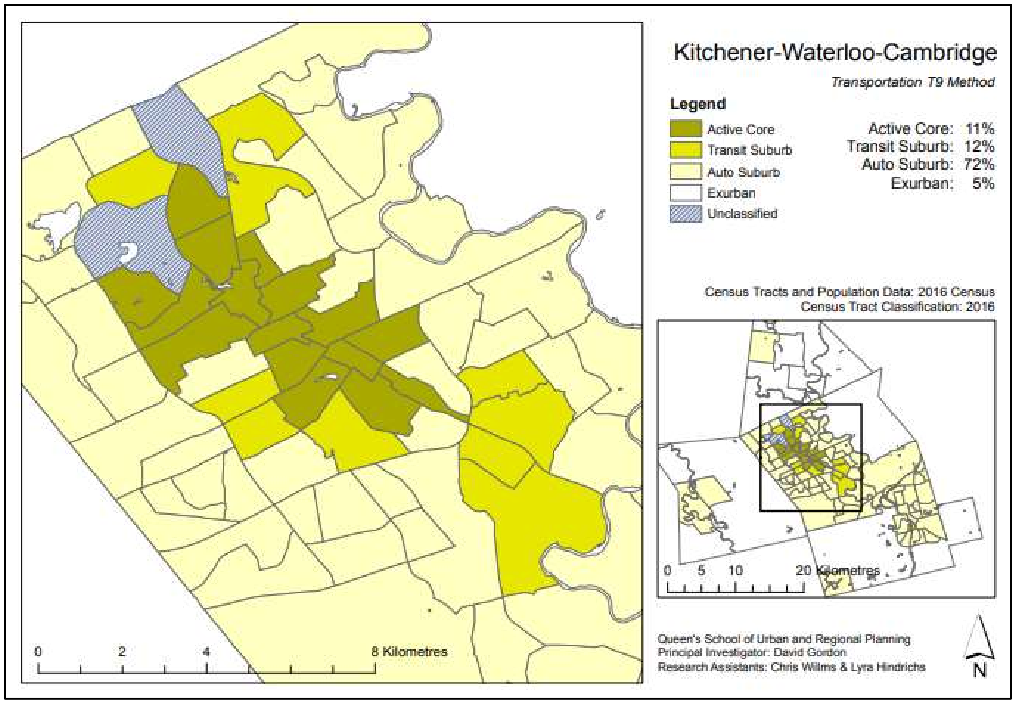
Figure 2.2: Case Study Methodology by Objective/Chapter

Chapter/Objective	Visual Depiction
CHAPTER 3 **Research Objective:** To understand how PLWD experience their suburban neighbourhoods, and how these everyday practices shape/are shaped by their past, present, and future(s), as well as their personal relationships.	
CHAPTER 4 **Research Objective:** To identify how and what PLWD identify as socio-spatial barriers and supports to mobility in their familiar suburban neighbourhoods.	
CHAPTER 5 **Research Objective:** To identify how and what PLWD identify as barriers and facilitators to accessing the planning process.	

2.3.1 Context

The context for this case study was the suburban neighbourhoods of the Regional Municipality of Waterloo, located approximately 100km west of Toronto, Ontario, Canada. The Region is made up of three cities (Waterloo, Kitchener, Cambridge) and four townships (North Dumfries, Wellesley, Wilmot and Woolwich) with a population of 601,220 as of December 2018 (Region of Waterloo, 2019). In the Region, the number of PLWD was projected to increase 187% between 2011 and 2036, from 6,365 PLWD to 18,314 (Hopkins, 2010). The Region also has a substantial proportion of neighbourhoods classified as 'suburban', making it an ideal location for the research (Gordon, 2019). See **Figure 2.3** below:

Figure 2.3: Suburban Land Use Typology Map



2.3.2 Cases

2.3.2.1 Case Selection + Recruitment

I sought to investigate the experiences in public spaces of PLWD living at home in suburban areas, and treated each individual participant as a 'case' for the purposes of the overall thesis. In terms of sampling and case selection, I acknowledge that the recruitment of participants in this population willing to do this research is difficult (Phillipson & Hammond, 2018). There is often also difficulty with the ethics and consent process, as well as needing substantial time to build rapport relationships that result in meaningful research interactions (Keady & Lars-Christer Hyden, 2018; Phillipson & Hammond, 2018). Before beginning this research, I spent substantial time researching how to do research with PLWD, in addition to consulting with leading academics.

The cases (participants) were sought in an information-oriented way (as opposed to random sampling), in order to "maximize the utility of information from small samples and single cases," (Flyvbjerg, 2006, p.230) The participants (cases) were selected because they were living with dementia, at home in a suburban neighbourhood, which was the phenomena under study. Instead of issuing an at-large call for volunteers (due to limited funds available for advertisement), I contacted community groups working with PLWD. Through the organizers (gatekeepers) of community support groups in the Region, I was invited to present to the group for volunteers to participate in the study individually. This was done by spending 1-2 hours on the phone discussing the study with the gatekeeper, going over the requirements and materials (including Information Letter, Consent Form, and Presentation). During the presentation to the group, I used a PowerPoint presentation, and interacted with the group by mingling, chatting with people about the weather, etc. (See Appendix A). Print outs of all the materials were provided (including the PowerPoint, the Information Letter and Consent Letter for the study, including versions addressed to both the potential participant and their care partner, so that participants could choose to consent on their own, or have their care partner consent for them (see Appendices A-E). I also always wore a large font visible name tag, with the University of Waterloo logo. Questions were invited during the presentation, and at the end, I passed out small slips of paper in which participants could indicate that they wanted to learn more about the study (see Appendix F). Seven people (6 men, 1 woman) indicated interest, however only 5 participants (4 men and 1 woman) were recruited through this method. Another participant was recruited by mail – the gatekeeper of the support group offered to mail out the recruitment materials to every person on the waitlist for the group (to protect confidentiality). Another participant was recruited through a poster that was advertised on to a curated list of folks interested in dementia-related issues in the country (through a dementia-focused listserv at the University of Waterloo) (See Appendix G). Finally, I recruited additional participants (n=10) for focus groups through the original gatekeeper from the support group. The participants who were part of the focus group were recruited from the original support group. Working with the gatekeeper again, he received the consent of the entire group to participate (including 10 extra participants, in addition to the original 5)[10]. The Information Letter and Consent letters were distributed to the group prior to arrival, and participants signed consent forms before the focus group with the gatekeeper (see Appendix H-I). Thus, a voluntary convenience sample of PLWD who were part of/on a waitlist for a support group or dementia-specific mailing list was used for this thesis (Farthing, 2016).

2.3.2.2 Case Descriptions – Participants

The seven (7) recruited participants (each considered an individual case) all lived in neighbourhoods classified as an 'Auto-Suburbs' by Gordon (2019) except one, who was defined as living in an 'Exurban' neighbourhood. They all self-identified as living with mild to moderate dementia, ranged in age from 57 to 81 and all lived in the community (as opposed to congregate or supportive care settings). This thesis originally sought participants living with early onset dementia, with the rationale as twofold:

(1) they are less likely to experience co-morbid conditions than older adults with dementia, meaning that it may be easier to understand issues (both in physical and social environments and as a result of broader factors like stigma) arising because of their cognitive impairment, rather than as a result of combined mobility or sensory impairments (Alzheimer's Society of Canada, 2019; Jefferies & Agrawal, 2009)[11]; and
(2) they might be more likely to be familiar with smartphone-based technologies.

While six out of seven participants were diagnosed with early onset dementia symptoms, one participant was diagnosed later in life, at age 80.

Table 2.2: Participant List

Pseudonym	Participant, Age at time of Fieldwork	Condition Causing Dementia Symptoms (self-reported diagnosis)	Neighbourhood Typology (Based on Gordon, 2019)	Care Partner
Don	Male, 71 years	Early onset Alzheimer's disease	Auto Suburb	Wife (Retired)
Lorraine	Female, 81 years	Alzheimer's disease	Auto Suburb	Husband (Retired)
George	Male, 65 years	Early onset Alzheimer's disease	Auto Suburb	Wife (Working)
Douglas	Male, 65 years	Early onset Alzheimer's disease	Auto Suburb	Wife (Working)
Alexander	Male, 58 years	Parkinson's disease	Exurban	Sister (Working)

---

[10] It should be noted that these extra 10 participants are only included in the focus group discussions, and did not complete any of the other research methods. Thus, they are not considered cases by this case study methodology.

[11] This is not to say that research involving PLWD who have other mobility and sensory impairments is not important. It is incredibly important to this researcher, however in terms of feasibility of this specific research, it is not possible under the time constraints. Future research in academia would enable me to continue to ask these questions.

Violet	Female, 57 years	Early onset Alzheimer's disease	Auto Suburb	Husband (Working)
Elizabeth	Female, 56 years	Early onset Alzheimer's disease	Auto Suburb	Husband (Working)

2.3.3 Data Generation

There were several data generation methods used with each of the seven (7) participant cases, with the goal of answering the research questions and objectives for this thesis. The term 'data generation' is used because data is not just waiting around for one to collect it. Data generation methods are informed by one's outlook on reality, and based on the relational ontology and social constructivist epistemology used in this thesis – it is acknowledged that the knowledge bases selected have been constructed (Mason, 1996 as cited in Farthing, 2016). The literature on successful research with PLWD that centres the experiences of PLWD discuss the need to move beyond traditional approaches like sit-down interviews (Keady, Hydén, Johnson, & Swarbrick, 2017; Phillipson & Hammond, 2018). To move beyond, Phillipson and Hammond (2018) found that irrespective of methodology, traditional methods (e.g. semi-structured interviews) were much more effective when combined with participatory approaches that included a visual or experiential component (Phillipson & Hammond, 2018). As will be elucidated below, I used several different kinds of methods, from sit down to go-along interviews, using passive and active tracking technologies as well as experiential approaches. Multiple methods, conducted in a specific order, were selected to ensure rigour (see Section 2.4 for more on information).

Additionally, Phillipson and Hammond (2018) identified successful researchers with PLWD who focused on "inclusion, empowerment, expression, flexibility, and communication when selecting methods" (p. 1). Each method description includes anecdotes on how they were adapted to meet individual needs. Consistent with other research with PLWD, the participants frequently questioned themselves and their own abilities (Genoe & Dupuis, 2013). To counteract these sentiments, one of the most common phrases I used with participants was:

> *"We are using all of these methods because we are not really sure which ones will work or stick. It's like we are taking a bunch of pasta, throwing it up against the wall and seeing what sticks."*

And, when something did not work, or a participant was nervous about using something, I would say:

> *"You know, if something does not work, that is my fault as a researcher. Never yours. It is my job to work with you to come up with something that works. It is all part of the process."*

Statements like these put people at ease, and made them laugh. Further, I ensured I made the time for repeat contact with participants, observations and engagement, as well as providing an appropriate, comfortable research environment (Phillipson & Hammond, 2018). This was a major goal throughout the data generation phase which took approximately 10 months, from April 2018 to February 2019.

2.3.3.1 Methods

The following is a list of the methods selected and used with each participant (n=7), the rationale for their inclusion and a brief summary of the protocol. This list also includes the types of accommodations that I made. That is because flexibility in research design is integral to planning research (Farthing, 2016). It is even more important for PLWD, in order to be responsive to different communication needs (Phillipson & Hammond, 2018). Further, there is chart summarizing the methods, time required, the manuscript chapters they were used in, and the research objectives they address.

Table 2.3: Summary of Phasing, Methods + Time Required for Fieldwork

Phase	**Method**	**Brief Description**	**Time Required**	**Research Objective Addressed**[12] (listed in condensed form here)	**Chapter No.**
1 - *Usually completed on the same day*	Introduction Interview	Seated, in the home of the participant. Either by themselves or with care partner	30 – 90 minutes *(however this does not include the time needed to introduce myself, get acquainted - which usually took another 60 minutes)*	(1) Socio-spatial experiences of the neighbourhood	3
	Go-along Interview #1 Experiential	Participants were instructed to take me on a walk of the neighbourhood, where they normally go. Care partners were not present.	40 minutes – 3 hours	(1) Socio-spatial experiences of the neighbourhood (2) Barriers + supports to mobility	3,4

---

[12] To recap, the research objectives are as follows: (1) To understand how PLWD experience their suburban neighbourhoods, and how these everyday practices shape/are shaped by their past, present, and future(s), as well as their personal relationships; (2) To identify how and what PLWD identify as socio-spatial barriers and supports to mobility in their familiar suburban neighbourhoods; (3) To identify how and what PLWD identify as barriers and facilitators to accessing the planning process.

2 – *Two-week period, with multiple visits*	GPS Tracking	Participants were given an information sheet (with photos, etc.) on how to use and charge the tracker. They then wore the trackers for two weeks.	2 weeks *(this included multiple visits and phone calls to troubleshoot the GPS tracker)*	(1) Socio-spatial experiences of the neighbourhood (2) Barriers + supports to mobility	3,4
	Travel Diaries	Participants were given a paper version of the travel diary and an information sheet on how to fill it out. Accommodations were made (please see above).	2 weeks *(concurrent with the GPS tracking)*	(1) Socio-spatial experiences of the neighbourhood (2) Barriers + supports to mobility	3,4
	Mobile Phone App	Participants were given an information sheet (with photos, etc.) on how to use the app. We also tested the app together. Unfortunately, only two participants used the app, however they had crashing concerns (due to old phones) and some were unable to take photos due to tremors.	2 weeks *(concurrent with the GPS tracking and Travel Diaries)*	(1) Socio-spatial experiences of the neighbourhood (2) Barriers + supports to mobility	Not used. But will use in a methods paper in future.
3 – *Usually completed on the same day*	Go-along Interview #2 Supports and Barriers	Participants were instructed to take me on a walk that was predetermined by their most common walk from the GPS tracking. They were instructed to identify at least three barriers and supports. Care partners were not present.	40 minutes to 2.5 hours *(after GPS tracking and travel diary sessions were completed)*	(1) Socio-spatial experiences of the neighbourhood (2) Barriers + supports to mobility	3,4
4 – *Completed on the same day*	Participant Observation	I attended open house meeting with participants as citizens. We looked at posters, interacted with staff, listened to	1 – 3 hours	(3) Barriers + facilitators to access at an open house	5

		presentations and gave feedback			
	Post Experience Interview	Immediately after the open house experience, conducted the interview in a secluded area	10 – 40 minutes	(3) Barriers + facilitators to access at an open house	5
5 – *Completed on the same day*	Focus Groups with entire support group	Conducted focus group with all members of the support group.	2 hours	(2) Barriers + supports to mobility	Not used. But will use in a future paper on methods.

2.3.3.1.1 Introduction Interview (semi-structured, sit-down interview)

Rationale: To get to know the participant, to understand their mobility history and their history in the neighbourhood. Introduction interviews were used to build rapport (Phillipson & Hammond, 2018), and get a lifecourse understanding of participants past, present and future practices in public spaces (Andrews, Evans, & Wiles, 2013).

Summary of Protocol: Prior to the interview, I printed out maps of the participant's surrounding neighbourhood at three scales (about a 400m radius, 1km radius and a 5km radius). Participants were asked where they would be most comfortable talking to me. They all said that their home would be best. Accordingly, I visited homes and conducted the interview with the questions listed in Appendix J. Sometimes the participant's care partner was nearby and participated in the conversation. Otherwise, it was a one-on-one conversation. I asked questions about the individual's childhood, where they grew up, and how they got around when they lived in different places throughout their life. I asked participants about their current mobility behaviours, and asked them to draw on a map what they thought their neighbourhood boundaries were. The final questions were about what they thought the future might look like for them, how they were preparing for it (if they were) and any concerns they might have as they change in the future.

Types of Accommodations Made: Generally speaking, participants did not have any issues with answering the questions. In one instance, a participant had significant issues with language, and so her care-partner was able to help complete her sentences, or make statements and then asked her if he was correct. Some participants had difficulty holding a pen to highlight where their neighbourhood was on a map, so I drew it for them under their guidance.

2.3.3.1.2 Go-along Interview #1 (Experiential)

Rationale: To understand the participant's experiences in their familiar neighbourhood. The go-along interview was used because of its ability to capture in situ experiences, and meaningfully understand socio-spatial experiences (Carpiano, 2009; Hand, Huot, Rudman, & Wijekoon, 2017; Lee & Dean, 2018). The method has also been used successfully with PLWD, and revealed more about everyday life (e.g. capturing behaviour and perceptions of place) than a traditional interview (Burton & Mitchell, 2006; Hung et al., 2017; Odzakovic, Hellstrom, Ward, & Kullberg, 2018). Further, all participants were walking in areas that they felt comfortable and familiar in, as opposed to new or unfamiliar settings. This is an important distinction to make as these are different brain processes, and as dementia symptoms frequently affect areas of the brain related to navigation and memory. Each of the participants voiced during these walks how they "just knew where to go" because this was an environment they were familiar with (to be differentiated from research where participants are taken on the same researcher-selected route).

Summary of Protocol: Participants were asked to take me 'on a tour' of their neighbourhood, and describe the route as they were walking, which is the common protocol used in go-along interviews (Carpiano, 2009). The go-along interview was audio recorded, as well as GPS tracked using a smartwatch. (This GPS tracking eliminated the need for a second researcher to plot the route during the go-along interview, and also made the experience more natural for the participant).

Types of Accommodations Made: None required.

2.3.3.1.3 GPS Tracking

Rationale: To understand the mobility patterns of the participants without researcher interference.

Summary of Protocol: Participants were given a GPS tracker as well as a set of instructions (with photos) on how to use it and charge it every evening (See Appendix K). I spent significant time with the participant and their care partner, demonstrating how to use the device. Literature on studying activity space in health research states that two weeks of monitoring is the recommended time period for capturing habitual patterns (Zenk, Matthews, Kraft, & Jones, 2018). Thus, participants used the tracker for two weeks, and this recommendation also guided how long the Travel Diaries and Experiential Sampling Method tools were used for.

Types of Accommodations Made: I made myself available via cell phone to participants, who would call if a button turned off, etc. All participants contacted me at some point using these methods. The GPS trackers were one piece of equipment that participants really liked using.

2.3.3.1.4 Travel Diary

Rationale: To understand the mobility patterns of the participants without researcher interference. Travel diaries were used in conjunction with GPS tracking in order to capture a fuller picture of information about mobility patterns. For instance, GPS tracking might tell you the location of the end of a route journey, but cannot tell you exactly which store or why the person went there. Further, GPS tracking can only differentiate based on speed, so while it is possible to discern walking vs. automobile trips, it is not possible to discern automobiles versus taking the bus for instance. Finally, GPS tracking and travel diaries were used to understand movement patterns from a broader timescale perspective.

Summary of Protocol: The researcher built a custom Travel Diary form (see Appendix L) that asked for the following information: what time did you leave, what time did you return, where were you going, how did you get there, who were you with, and did you notice anything that you liked or disliked. The last question was based on a suggestion from a participant.

Types of Accommodations Made: One participant had difficulty thinking of the word for the location they visited. In response, I created a customized paper multiple choice version, where the participant only had to colour in a bubble to indicate their selection. Another participant could not hold a pen, but used their smartphone a lot. In response, I created a customized Google form with the same questions, made it into an icon on her home screen on her smartphone, and she filled it out that way. Another participant did not want to fill in the chart, and instead I called her every evening, and she would dictate the answers to me. A fourth participant, when I arrived at his home to collect the GPS tracker and Travel Diary stated that they did not want to fill out the diary, so he did not do it. However, previously he had told me that he kept a meticulous calendar. So we went through his calendar together, and I recorded his answers for each day.

2.3.3.1.5 Mobile Phone App (Experience Sampling Method)

Rationale: To capture in-the-moment experiences without researcher interference, and participant-directed images. Initially conceived as photovoice, a mobile smartphone app was created to augment photovoice with Experience Sampling Method (Doherty, Lemieux, & Canally, 2014; Dunlop, Casello, & Doherty, 2015; Quinlan Cutler, Doherty, & Carmichael, 2018). Photovoice was a tool originally designed to understand the lives of women in rural China (Wang, 1999) and has been used effectively in urban planning to understand the lived experiences of marginalized populations (Harris, 2017) and older adult experiences of mobility (Chaudhury, Mahmood, Michael, Campo, & Hay, 2012). It involves giving participants a camera, and encouraging them to document their daily lives. Usually, participants are given instructions to take photos of dichotomous categories like: “features in your community that you like” and “features that you dislike”, or barriers and facilitators to movement for instance. Then, the researcher will conduct a follow up interview with the self-captured images to discuss individually with participants or bring the larger group together to discuss photos as a group. Participants can also be instructed to take photos of certain activities, which Genoe & Dupuis (2013) used with PLWD to understand their experiences of leisure activities. Genoe & Dupuis (2013) found photovoice to be an effective tool in capturing lived experiences of PWLD and encourage its continued use, as it has many benefits including: photos helped cue memory as well as helped participants plan for their follow up interviews, and helped participants share stories and captured significant meaning. They do however list the following limitations they encountered: ethical concerns, physical issues with using the disposable cameras (including operating them and their limited capabilities in terms of photo taking), forgetting the context of the photos (because they may have not remembered why they took it) and questioning themselves and their own abilities (worrying about taking a picture of the ‘wrong’ thing). In order to address some of the limitations of photovoice as described above, and to capture in situ experiences, I used Experience Sampling Methods, through the use of a simple smartphone application. This type of Experience Sampling Method can help people record their socio-spatial experiences, minimizing the need for participant recall and mitigating investigator interference effects (Doherty et al., 2014; Dunlop et al., 2015; Quinlan Cutler et al., 2018).

Summary of Protocol: Dr. Doherty and I designed a smartphone application using a service from the company Metricwire. It was designed to be simple to use, and involved the participant taking a photo in the app, and then answering a few questions about the current conditions, and their mode of transportation. The idea was to capture more information to help cue the participant at a later date. In addition, the app was designed to automatically record the location and time of the photo so the participant did not have to enter that manually. This method was designed to allow participants with a smartphone to record their experiences in their neighbourhood, either through photos or video recordings. The inclusion of video recordings was to be able to capture more than just one sensory experience of space. While photos are incredibly powerful, they provide a 2D representation of our reality, whereas video captures 3D, motion, as well as noise. Participants were also given a booklet with instructions in plain English and supplemented by photographs/example drawings and graphics on how to use the application. During a period of two weeks, participants were instructed to take at least 10 pictures of something that makes it difficult for them to get around their community and 10 pictures of something that makes it easier for them to get around their community. The data collection was scheduled to be during the two-week period of using the GPS tracker and Travel Diary. This was in an effort to be able to combine the ESM results with GPS tracking, in the hopes of producing more contextualized information about the participant's trip.

Types of Accommodations Made: Unfortunately, the majority of participants did not have a smartphone. Three participants did have a smartphone, however one was only comfortable using the telephone function on it (and despite training and encouragement from their partner, did not use it). Another participant used it but ended up only taking photos in the backyard (and since their phone was a first generation iPhone, the app would crash often and captured low quality images that obscured what was in the video). The third participant was only able to use the smartphone when it was laid flat on the table, making it nearly impossible to capture photos/videos while outdoors. One participant only had a flip phone. The last three participants did not have phones, but had partners who did. They were trained to use it together, however care partners found that asking their partners to take photos produced disagreements, and decided not to use it. Others forgot to use the app, despite notifications. The questions used were deemed understandable by participants (who had provided feedback on earlier versions). In future, I would purchase the same smartphone for all participants (with different operating systems and versions, they each had their own bugs), in addition to doing a training walk with all participants to get them comfortable using the technology. I should have spent more time (beyond the 1-hour introduction and multiple phone calls) working with participants to make sure they understood how to use it. Finally, in a future study, I would consider not combining this method with the GPS tracking/Travel Diaries as that might have been too much at once for participants.

2.3.3.1.6 Go-along Interview #2 (Supports + Barriers)

Rationale: To have participants self-identify barriers and supports on a second go-along interview. The go-along interview was used because of its ability to capture in situ experiences, and meaningfully understand socio-spatial experiences (Carpiano, 2009; Hand et al.,2017; Lee & Dean, 2018). The method has also been used successfully with PLWD, and revealed more about everyday life (e.g. capturing behaviour and perceptions of place) than a traditional interview (Burton & Mitchell, 2006; Hung et al., 2017; Odzakovic, Hellstrom, Ward, & Kullberg, 2018). Further, all participants were walking in areas that they felt comfortable and familiar in, as opposed to new or unfamiliar settings. This is an important distinction to make as these are different brain processes (Gärling, Böök, & Lindberg, 2013), and as dementia symptoms frequently affect areas of the brain related to navigation and memory (WHO, 2017). Each of the participants voiced during these walks how they "just knew where to go" because this was an environment they were familiar with (to be differentiated from research where participants are taken on the same researcher-selected route).

Summary of Protocol: I selected the second go-along interview route based on the most frequently travelled route by the individual participant, as identified after two-week GPS and travel diary tracking. Participants, during this second interview, were also given two prompts and asked to identify at least three of each of the following during the walk:

- Supporting/enabling built environment features ("something that you like, makes you feel safe, comfortable, or helps you find your way")
- Unsupportive/disabling built environment features ("something that you do not like, makes you feel anxious, scared, confused, or uncomfortable")

When participants identified a barrier or support during the second go-along interview, I took a photo and a video in which the participant narrated the experience.

Types of Accommodations Made: It turns out that most participants did not want to take the photo themselves, so I captured photos/ videos when they indicated that they wanted to.

2.3.3.1.7 Participant Observation – Planning Open House Visit

Rationale: Participant observation was used to capture authentic experiences, and avoid biasing the professionals running the open houses.

Summary of Protocol: I systematically examined community newspapers and municipal websites for advertisements for open houses in the Region to identify one near each participant's residence. Together, we did a site visit, then attended open houses with participants either individually or in pairs. We did not disclose to organizers that they were attending, and attended the sessions like any other citizen. This was to ensure that staff did not change their behavior based on the knowledge that the participant was a PLWD. They participated in the activities as presented (i.e. filling out comment sheets, listening to presentations, using post-it notes). I recorded the experiences, in addition to capturing images of the space/presentation items and sketching the layout of the room.

Types of Accommodations Made: None.

2.3.3.1.8 Post Activity Interview – Planning Open House Visit

Rationale: To capture how the participants felt and their experiences during the open house, in their own words.

Summary of Protocol: Immediately after attending the Open House, the researcher conducted a semi-structured interview with participants about their experiences. They were asked questions about the 1) presentation of information 2) communication with others 3) experience of the space. See Appendix M for a full list of questions.

Types of Accommodations Made: Some participants had difficulty answering the questions. Thus, I would recap one of the shared experiences that had just happened and asked them how it had made them feel.

2.3.3.1.9 Focus Group Interviews

Rationale: The rationale behind the use of the focus groups was to have more participants living with dementia comment on the photos captured by their peers. This group was also comprised of only people with early onset dementia, and gender stratified, which would provide a sample that has not yet been worked with in the literature. Further, the focus groups were meant to also be a form of photovoice, where participant captured images were then discussed by the group.

Summary of Protocol: I selected at least two photos from each of the five original participants with early onset dementia (one barrier and one support). These photos were selected based on their difference from other photos (meaning - I did not show 4 photos of a similar suburban residential street). The group (n=15) was split into 4 gender stratified smaller groups. Each smaller group had one facilitator (someone who works with the group on a regular basis) who had a supplementary question sheet (Appendix N). Each participant was given a package with 8.5x11 colour photos of each image (Appendix O). Each table also had an audio recorder. The image would be shown on the screen, and I would describe where it was taken. Then I would ask "Raise your hand if you would feel safe walking here by yourself", then after the total was calculated (and gender stratified) by the Research Assistant, I would ask "Raise your hand if you would not feel safe walking here by yourself", and the tallying process would be repeated. The participants were then instructed to talk to their group about why they voted yes or no. The facilitators helped by keeping participants on topic, and asking prompting questions like, "You voted yes – can you tell me a bit more about why you did that?" Then I would move on to the next image or video.

Types of Accommodations Made: None required.

Average Time Needed: The entire focus group took 2 hours.

2.4 Rigour

Rigour was established at multiple stages of this thesis, and through a variety of means, including through: (1) overall research design; (2) the process followed in terms of data generation; (3) through the analysis of the data based on research objectives; and (4) through reflexive practice on positionality. Further, this research has fulfilled the criteria for evaluating qualitative research according to Baxter & Eyles (1997) and Lincoln & Guba (1985) – please see Appendix P.

In terms of overall research design, this thesis carefully connected my relational ontology and social constructivist epistemology to theory, methodology, methods, and analysis. See **Table 2.1** – Building Blocks of Research for a summary. For instance, one example of these connections is that because of the relational ontology and social constructivist epistemology of this research, during the introduction and go-along interviews, participant observation, and post-experience interviews, the researcher paid attention to embodied and subjective experiences, human and more-than-human encounters, sense-scapes (incorporating sound, visual, olfactory, tactile experiences), personal histories, and the influence of larger socio-political structures on who belongs in outdoor space (Tornaghi, 2015). I also used multiple methods to engage in triangulation, which is defined by social constructivists who employ it as offering "the opportunity to deepen the understanding of the research question and to explore multiple realities," (Hastings, 2012, p. 1538). Obtaining data from diverse sources allows me as a researcher to expand my understanding of the research questions from multiple perspectives (Hand, Laliberte Rudman, Huot, Gilliland, & Pack, 2018; Hastings, 2012)

2.4.1 Timeline Rationale

I selected the methods and conducted them in a specific order, so as to ground the research in the participants' experiences (of the neighbourhood and the planning process) and form an understanding using data from diverse sources and settings. The order of methods was also selected to build rapport with participants gradually, and to move from tasks that might be perceived as 'easier' (take me on a walk in your neighbourhood) to more 'complex' (i.e. using the GPS and smartphone technologies). The research began with a traditional semi-structured introduction interview (ranging from 20 – 90 minutes), asking questions about the places they have lived in over time, their past and present mobility practices, and what they are concerned for in the future. This introduction interview became a way to understand lifecourse perceptions of the neighbourhood and participants' practices over time in public spaces (Andrews et al., 2013). This introduction interview was also a way to understand participants' perceptions of the neighbourhood while indoors, before understanding how the participant experienced the neighbourhood while physically moving in it, and being 'cued' to different aspects while outdoors (Finlay & Bowman, 2017; Hand, Laliberte Rudman, Huot, Gilliland, & Pack, 2018; Lee & Dean, 2018). During the first go-along interview, the participant was directed to be a tour guide of their neighbourhood (ranging from 45 minutes to 3 hours). The purpose was to shift the power dynamic from the researcher to the participant, doing the interview on the participants' terms (Carpiano, 2009; Finlay & Bowman, 2017). After the first go-along, two-week GPS tracking, travel diary recording, and experience sampling measurement was used to get another perspective of mobility patterns in the neighbourhood. The rationale for doing all three methods at once were twofold. First, it was to understand what was occurring before and after different ESM samplings. For instance, when a participant would fill out a survey in the mobile app, we would be able to plot that survey (and associated answers) along a GPS route (provided by the GPS tracking) as well as why they were on the route (discovered through the Travel Diary). Further, the rationale behind using both GPS tracking and Travel Diaries was to ensure that all trips were captured, in case a participant forgot the GPS in one instance or forgot to write down trips in the Travel Diary. I selected the second go-along interview route after reviewing each participant's GPS tracking and travel diary recording, by choosing their most commonly travelled to destination. The purpose of the second go-along interview was to ensure that the go-along interview data also included a route that the participant used on a regular basis, as a way to ensure rigour (Baxter & Eyles, 1997b). During the second go-along, I gave participants two prompts and asked them to identify at least three of each of the following during the walk:

- Supporting/enabling built environment features ("something that you like, makes you feel safe, comfortable, or helps you find your way")
- Unsupportive/disabling built environment features ("something that you do not like, makes you feel anxious, scared, confused, or uncomfortable")

The rationale for using different instructions for each go-along interview was to go beyond the tour guide instruction, by directing them to take me on their most commonly travelled route, and to have them purposefully define what was supportive or a barrier to them. Finally, I selected images and videos captured by the participants who had been recruited through the support group (n=5, two-three images/videos each) and presented them to a larger focus group of peers living with early onset dementia (n=15)[13]. The rationale behind using the focus groups was to understand if the supports/barriers identified by the original participants were also identified by the other focus group members. The last two phases of the research – participant observation at a public open house and post-experience interview with the participant – were done after the other research pieces in order to have built substantial rapport and trust with participants prior to this activity. These last two phases were used in combination to establish credibility by including both researcher-led and participant-led perspectives (Baxter & Eyles, 1997).

2.4.2 Analysis of Empirical Data

The empirical data collected were analyzed in three different ways, according to their corresponding objective. This is outlined below.

2.4.2.1 Manuscript #1 – Everyday Built Environments of Care

The research objective for this manuscript was: to understand how PLWD experience their suburban neighbourhoods, and how these everyday practices shape/are shaped by their past, present, and future(s), as well as their personal relationships. A constructivist grounded theory analysis approach was used to analyze the interview data, in which the semi-structured and go-along interviews were transcribed and followed open, axial and theoretical coding (Charmaz, 2014). Open coding involved examining the transcriptions line-by-line and summarizing sections of text using active gerund-based phrases like “Expressing fear for the future”. This strategy is favoured by Charmaz because it allows the researcher to see processes and actions by taking an active stance, ultimately moving the data forward analytically (Charmaz & Keller, 2016). The researcher (SB) also used as much detail as possible in these action codes to capture nuance and to centre participants’ voices and constructions of meaning (Charmaz, 2000 as cited in Mills, Bonner, & Francis, 2006). Focusing on actions, rather than themes was an important part of this step (Charmaz, 2014). Memo-writing for each open code was also employed, and used later in the analysis as well when investigating relationships between action codes (Charmaz, 2014). Through immersion in the over 1200 gerund-based action codes, researcher SB began to organize and interrogate them into categories (axial coding). This categorization was then peer-checked and tested by the second author (JD). Then the researcher SB built and tested the categories on the rest of the data during the theoretical coding phase, by re-examining each open code to ensure it was in the correct category. These steps involved examining

---

[13] Made up of 5 original participants and the extra 10 recruited for the focus group.

and re-examining the relationships between different patterns and themes from the data. This was again peer-checked by JD to ensure rigour. During axial and theoretical coding stages, the lens of care became an appropriate mechanism to understand the socio-spatial relations the researchers saw emerging. As a result, during the axial (and then theoretical coding stage) the authors decided to re-examine the themes through the new lens of care, sensitizing the data to this new perspective. The GPS and travel diary data were used to enhance understanding of some of the categories that emerged.

2.4.2.2 Manuscript #2 – Barriers + Facilitators to Mobility

The research objective for this manuscript was: to identify how and what PLWD identify as socio-spatial barriers and supports to mobility in their familiar suburban neighbourhoods. This manuscript used the data generated by the two go-along interviews, GPS tracking and travel diary data. Typically, go-along interview data is analyzed through traditional techniques like line-by-line coding or analyzing fieldnotes (Finlay & Bowman, 2017; Hand et al., 2017). However, these analysis techniques ignore the integral spatial information that is being experienced during the walk. In response, this paper used a novel technique to integrate the transcript with geolocated imagery. Go-along interviews were geocoded, and visual images of locations linked to quotes post-interview (either through researcher-participant captured photos or using Google Earth imagery). These images (with quotations) were treated as documents (Cannuscio et al., 2009) and analyzed for content based the dominant built environment features as described by participants (Fusco, Moola, Faulkner, Buliung, & Richichi, 2012). Using four of the thirteen go-along interviews as a test, researcher (SB) identified three built environment feature categories – land-use, urban design, and wayfinding. These themes were then confirmed using peer checking by the second researcher (JD) (Baxter & Eyles, 1997; Brown et al., 2015). The remaining images and corresponding quotes (n = 268) were coded into the three categories using qualitative data analysis software Atlas.ti. Corresponding quotes and images were also tagged with further descriptors of: (1) the participant's embodied and verbalized responses to the built environment (e.g. like, dislike, comfort, discomfort, neutral), (2) description of how they related to a particular place (e.g. socio-spatial relationships, memories, daily amenities, turning cue, or not applicable), and (3) further descriptors of the built environment features (e.g. green space, street crossing, trail). These images were printed and selectively coded within the three categories to identify enabling and disabling built environment features in suburban neighbourhoods for PLWD. They were further divided into sub-categories based on the built environment feature being described. Some photos were counted in two or more categories, as they related to both. For instance, one participant discussed being close to a drug store as important because it was close to their house (related to proximity and therefore put in the land-use category), in addition to it being a landmark for them (it is on the way to their bus stop) and therefore also placed in the wayfinding category.

2.4.2.3 Manuscript #3 – Adapting the Open House

The research objective for this manuscript was: to identify how and what PLWD identify as barriers and facilitators to accessing the planning process. This manuscript used the data generated by the participant observation at an open house meeting and the post-experience interview. To capture the experience, I used four diverse qualitative data techniques to improve the validity of the findings through methodological triangulation (Farmer, Robinson, Elliott, & Eyles, 2006; Hall & Rist, 1999). The data techniques included: an audio recording of the experience, photographs of the location and visual materials, post-experience fieldnotes and sketches, and a post-open house interview asking questions related to the framework.

To analyze the data generated, I used the framework method as it organizes data in a way that is helpful in answering direct research questions (Gale, Heath, Cameron, Rashid, & Redwood, 2013). The framework method pre-determines coding categories based on existing literature. I drew on deep engagement with the literature on what might affect the experiences of PLWD at open houses, including existing research in terms of communication, designing indoor spaces and the presentation of visual information to form the framework categories. I then coded the data with a research assistant, peer-checking to ensure credibility (Baxter & Eyles, 1997).

2.4.2.4 Data Left Out?

During this thesis, a significant amount of data was generated. Unfortunately, due to the limitations of three manuscripts, only a selection of the data was able to be used. The focus groups for instance, were not used because the data generated was about unfamiliar built environments. The ESM method did not end up working with a significant portion of this group of participants. The data generated from these two methods (as well as all the others) will however be used in a future methodology paper about doing research with PLWD in public spaces. The GPS data and Travel Diaries were used as supplementary data in two of the three manuscripts (Chapter 3-4), however the data generated has not been used to its fullest potential. In future work, this data will be examined in further detail, combining it with GIS mapping of road/building typologies, Official Plan designations, and comparing perceived versus lived spaces.

2.4.3 Positionality

All knowledge is embedded, situated and partial – presenting an inevitable bias in research (Haraway, 1988; Bhavnani, 1994; Bhavnani & Haraway, 1994 as cited in Mohammad, 2001). Being part of the social world means that we cannot be outside of it, or pretend that we are god-like by insisting on objectivity and neutrality (Mohammad, 2001). Then, the question becomes – how do we move forward with the creation of knowledge? Many scholars have suggested to do the opposite of the post-positivists (who obscured the nature of knowledge with their claims to objectivity and neutrality) by making this explicit and calling for critical self-reflexivity, but also recognizing that this must be combined with the "responsibility [of the researcher] to choose and affirm [their] political commitment through the types of representations [they] seek to make, irrespective of [their] social position, colour or gender," (Mohammad, 2001, p. 114). This is consistent with my social constructivist epistemology, and in this section, I affirm my commitment to providing a representation of living with dementia in suburban neighbourhoods that is led by the experiences of the people living it, while recognizing my role as a researcher in co-constructing that knowledge (Franke et al., 2019; Mills et al., 2006). I believe that as planning scholars and practitioners, it is our duty to ensure that every citizen has access to the neighbourhood that they live in, and this is fundamentally an issue of justice. I designed this thesis to centre the experiences of PWLD, and to strive towards understanding how to improve their experiences outdoors, and their access to the political process that shapes those places. I also make clear my background, and insider/outsider status during this research below.

Understanding my positionality in this research is an integral, as it influenced the development of the research plan, and execution of the fieldwork, analysis and representation of the data. It also influenced how participants viewed me as a researcher. I identify as a cis-gender, young, temporarily able-bodied, white woman, who grew up in relative affluence in Toronto. All of my participants were white, of Anglo-Saxon or Germanic decent, and were born in Canada, mostly in southern Ontario. By virtue of my also being white, and from southern Ontario with a broad knowledge of multiple municipalities (due to my experience as an urban planner), I was able to connect with participants about every place that they had lived. Participants also always asked why I was doing the research, and I told every single person about my grandmother (Nanny) and her story[14] of living with dementia. I also introduced myself as a planner, which seemed to also be reassuring to participants. By virtue of my personal experience with a PLWD, my professional background and knowledge of the geographic area, in addition to my spending significant time with participants (and often, their partners), I believe I was afforded some form of 'insider' status (Mohammad, 2001). Participants and care partners, I believe, felt like I understood part of their reality. That being said, participants did also perceive my 'otherness' at points, rendering me on the 'outsider' side. A few examples of this included: one participant commenting on how because he is a man, he does not get scared like I (a woman) would (a I could not understand what that was like because I am a woman), and that, since I was young, I could not possibly know what was good for a city council to do (despite my explaining my professional background).

During my PhD, I experienced a year with chronic, debilitating pain in my ankles and knees, which left me unsure as to if I would be able to walk one day to the next, or hour to the next hour. I would wake up screaming, and had to rely on crutches, driving (public transport was far too painful), and there were days where I could not do anything. That experience, which happened before my comprehensive exam, brought the work I had read in disability studies to life for me. I also learned first hand, through this experience, what internalized ableism meant. In my head, I was worried that my colleagues, friends/family, the people around me – thought I was faking my pain, especially considering it varied so drastically day to day and I did not have a diagnosis (despite multiple MRIs, blood samples, and trips to the rheumatologist). I now know, through readings in academia and through online communities like #disabledtwitter that I was experiencing internalized ableism; that I had to be productive, that my condition had to be constant – in order to be 'really' experiencing impairment/disability. The experience of episodic dis/ability has stayed with me, and I believe it has really cemented in me that bodies are messy, fluid, unpredictable, and constantly changing.

---

[14] I grew up in the Beach neighbourhood in Toronto, a place where everything you ever needed could be accessed on foot or by public transit – the park, the beach, the grocery store, school – everything. My parents both grew up in a suburb west of Toronto. My Canadian maternal grandparents (Nanny and Poppa) lived at the end of a cul-de-sac with a pool, grass to play baseball on and a huge flower, vegetable, and fruit garden. Their house had always been magical – it was a place of love and connection for four generations, including my dad's side of the family. I was so incredibly fortunate to have grown up with four grandparents and a great-grandmother, all of whom I was incredibly close to. My Poppa died when I was 13, and shortly thereafter, my Nanny was diagnosed with Alzheimer's disease. I watched as the place that was so magical for all of us became like a prison to her. Once she lost her ability to drive, she became isolated and her health and well-being suffered. I was in a liberal arts undergrad at the time, and I kept wondering – would it have been different if she had lived in the neighbourhood I had grown up in – the walkable place versus the car-dependant one?

My personal characteristics are not the only important item to acknowledge. I grew up surrounded by five grandparents, who all experienced/ are experiencing some disability throughout their lives, including mobility, sensory and cognitive impairments (including dementia, stroke recovery, and delirium as a result of a hospital stay). I have been a witness to watching how my grandparents were treated poorly by others by virtue of their age, their impairments and their ability to speak English. This, combined with the articles and books I have had the privilege to read, have cemented to me the ways in which societal prejudices about difference ("othering") manifest to the detriment of people I love. That being said, I am not a person living with dementia, and thus I cannot truly know what it is like to live with it. I am unable to truly turn the personal into the political, as I do not live with dementia.

Turning the personal into the political has been one of the most central tenants and greatest achievements of the disability rights movement. It has allowed for disabled folks to turn their lived experiences into a political movement to demand rights, as well as to produce critical research (Worth, 2008). Bartlett and O'Connor (2010) recognize the need in dementia research to make "the connection between personal experiences and broader societal practices… recognizing the personal as political" (p.77). The political power of the personal story is also the power of narrative, which can be used to expose grander oppressive practice, as well as individual experience (Bartlett & O'Connor, 2010, p. 89; Dupuis et al., 2016). The power of narrative is evident in books authored by PLWD, like Kate Swaffer (2016) and Christine Bryden (2005), which personally challenged my own views on not only what PLWD are capable of, but how they experience certain situations. First hand experiences from authors with dementia, like Bryden (2005) bring into sharp relief what would not be possible to tell through an empirically based study. Storytelling as a political tool for planning practice and scholarship has been highlighted by Sandercock (2003), as a way of connecting the personal to the political, a potential catalyst for change, a way of critically analyzing the notion of foundational stories of planning and policies, a tool used by academics "as explanation and critique" of practice, and a way to train planners (Sandercock, 2003, p. 204).

In contrast to this, geographer Worth (2008) wrote that often, having a personal experience of disability is a prerequisite for being an academic in the field of disability geography, and engaging with its debates. This is especially relevant as many researchers with an interest in PLWD are unlikely to have dementia themselves (although Swaffer and Bryden are notable exceptions). While the personal is a powerful tool, Worth (2008) highlights the two main risks associated with having this prerequisite. First, it creates "the assumption that a subfield that engages wholly with the personal is exclusionary,"

(p. 312) and the sub-discipline has "no strong points other than the passion of its researchers" (p.307). Worth (2008) suggests that non-disabled researchers be encouraged into the discipline, suggesting the use of emancipatory research methodologies, "as successful research depends on the ethical and political commitments of the researchers rather than 'their level of personal identification with the subject" (p. 311). In contrast to Worth's (2008) assertions, Goodley (2011) cites several other scholars who welcome those without a personal disability into the field. Goodley (2011) does warn that as a non-disabled researcher, one has to be aware of their own privilege and the power dynamic as a researcher, especially in regards to working with people with intellectual disabilities (p. 26-7). With that in mind, seeking relational stories from PLWD by non-disabled researchers has been done by authors like Lloyd and Stirling (2015) who have been successful in understanding some of the complex social and spatial relationships for PLWD in Australia. Shakespeare et al. (2019) (who identify as disabled, living with a mental health condition and having dementia) have called for PLWD and those without to work together to understand the complex multi-layered experiences of living with dementia. That is what I sought to do with my research as well. It was designed to place power in the hands of the participants, through method selection but also through my openness to be flexible in terms of executing those methods. It is why I spent so much time with people in places that were comfortable for them.

2.5 Reflection on Research Design

I learned an incredible amount doing this research. I also realized through this research, and interactions with participants, that I am one of the only researchers that ever spent this much time with them, and they felt like they actually knew me. The following are a few short reflections on lessons learned, and a reflection on skills developed during my PhD can be found in Appendix Q.

***Rapport and Trust* -** Central to research with PLWD is building rapport and trust. This started with my ethics application. When I submitted, I put my personal phone number on all of the materials. The Ethics Board said that was unorthodox and to remove it. I responded with the following and they allowed me to keep my cell phone number on the materials:

> That makes perfect sense, however I have provided my cell phone number for a few reasons. First, I have provided my cell number so that participants can reach me right away if they have questions about the mobile app for example. Second, I was never provided with a phone in my office at UW, and do not have a personal voicemail or extension. I do not want my participants to get confused when calling in to UW and not being able to find my name in the directory (because it does not exist). I also do not want the participants to always be calling my supervisor, then having my supervisor have to pass the message on to me. If I am comfortable with putting my cell phone number in the materials, is

> that alright from the Research Ethics Committee's perspective? I want to be able to minimize unnecessary confusion for my participants.

This inclusion of my phone number proved to establish trust with my participants and their care-partners, setting the stage for the rest of the research. Being able to communicate instantly allowed me to deal with any issues with the equipment, conduct alternative data collection methods when needed, and be available to go visit participants immediately. One situation that exemplifies this was when one participant texted me saying that another participant's tracker was acting up. I was able to troubleshoot with them via text message. Another example was when one participant had difficulty filling out the Travel Diary form. So instead, we arranged a phone call at a set time every day (over the two week period) in which she would tell me over the phone the information and I would record it in the Travel Diary. In another instance, I was able to visit a participant's home on the same day in order to switch out a tracker that was not functioning properly.

***Process Consent* -** Prior to undertaking any activity during this research, even when I had pre-arranged meetings with participants - I would always start off with, "Is this an okay time to conduct this activity? If not, no problem - I can always come back later." I did this upon showing up at someone's front door, but I also did it the day of the meeting (or the day before) vis telephone (or text, depending on the individual's preferences), as I know from previous literature (McKeown, Clarke, Ingleton, & Repper, 2010) and from lived experience with PLWD that sometimes we have good and bad days, and it is best to be flexible and provide options.

***Flexibility* -** As outlined in Section 2.3.3., I was very flexible with the methods being used, often working with participants to alter the method to best suit their situation or communication needs and preferences, without compromising the data. I also came prepared with potential alternatives for participants.

***Importance of empathy, reflexivity* -** This research was about people's experiences in their neighbourhoods, and as I told participants in my initial presentation – it was about telling me what participants liked and did not like about their neighbourhood. There were however, many difficult moments that came up in the interviews. There were instances were participants cried talking to me about how their lives had changed post-diagnosis, how their friends thought they were contagious. How they were scared of ending up like other friends they had. How to act in these kinds of challenging moments was not, to be honest, something I learned entirely from a book. What I did learn by reading were the diverse studies done by scholars like Dr. Sherry Dupuis, and accounts of PLWD by PLWD like Kate Swaffer. How to respond to those moments was also something I had learned from my own family, my grandparents, and my friends. I responded with empathy, by listening, by telling them their stories are important, that they are important. I meant every word that I said. The professional transcriber I used even commented on how I interviewed people, saying that I have a way of getting people to open up, making them feel comfortable, even in telling painful stories. There were days where I would get in the car or on my bike and cry. I would record myself, and I was constantly checking in with my own privilege and my own experiences. This constant reflection was integral to my research, and integral to how I worked with my participant partners.

Chapter 3 – Manuscript #1

Title: Everyday built environments of care: Examining the socio-spatial relationalities of suburban neighbourhoods for people living with dementia

Abstract

There has been a call from US policy advisors to expand research on people living with dementia (PLWD) from health and social sectors to urban planning. The World Health Organization projects the number of PLWD to increase from 47 to 132 million worldwide by 2050, with 60-80% of PLWD residing within the community (as opposed to congregate settings). For PLWD, being supported by their neighbourhoods in terms of access has many benefits: more social interaction, sense of worth, dignity and improved physical/mental health. As PLWD are likely to experience a 'shrinking world' effect, it is important to investigate the socio-spatial relationality between PLWD and their neighbourhoods. Using a relational care lens, this research seeks to understand the everyday practices of seven (7) PLWD in their suburban neighbourhoods using multiple methods (semi-structured and go-along interviews, GPS tracking, travel diaries). PLWD interact with their neighbourhoods through processes of caring for self in the past, present, and future, in addition to (re)organizing their newfound interdependent realities and being cared for through human and more-than-human encounters in public spaces. This research demonstrated the ways in which PLWD were living through adversity in the built environment ('hopeful adaptation'), revealing innovative practices and structural barriers in suburban areas. Being able to access one's neighbourhood is a right, and this research highlights how certain socio-spatial characteristics of suburban neighbourhoods can, through a relational care lens, become a simultaneously caring and careless place.

3.1 Introduction

Recent work examining the impact of place on health has called for more socio-spatial relational understandings of everyday life, particularly for disabled individuals, as a way to question why able bodies move with apparent ease (Hall & Wilton, 2017; Power, Bell, Kyle, & Andrews, 2019). In response to this call, this paper examines how disabled individuals, particularly people living with dementia (PLWD), experience their familiar suburban neighbourhoods in their everyday outdoor practices. Dementia is considered a disability, with a growing advocacy movement (Shakespeare et al., 2019). Activists living with dementia, through Dementia Alliance International (DAI), have recently demanded to be a part of the United Nations Convention on the Rights of Persons with Disabilities (CPRD). Supported by Alzheimer's Disease International (ADI), and putting forward a human rights-based policy, their demand was unanimously granted in 2016 (Shakespeare et al., 2019).

Dementia refers to a set of symptoms (e.g. declining issues with memory, spatial navigation, communication, depth perception, behaviours) caused by a variety of different diseases, the most common being Alzheimer's disease. It is a progressive condition, and there is no cure (WHO, 2017). With the projected number of people living with dementia (PLWD) to more than double by 2050 (132 million worldwide) and 60-80% of PLWD living within the community (as opposed to congregate living facilities), there has been a growing literature on their experiences in outdoor, public spaces. For PLWD, being supported by their neighbourhood in terms of access has many benefits: more social interaction, sense of worth, dignity and improved physical/mental health (Burton & Mitchell, 2006). PLWD are likely to experience a 'shrinking world' effect (when compared with similarly aged counterparts), limiting their access to the benefits of being supported in their neighbourhood. This could be due to a number of factors at all scales, from the individual (e.g., being concerned about one's changing abilities and declining sense of how to act in outdoor life (Bartlett & Brannelly, 2019)), to the socio-political (e.g., society's perceptions of PLWD as dangerous wanderers) impacting how PLWD and their care-partners and others view their actions (Blackman et al., 2003)).

The type of built environment one lives in further influences this access. In particular, a growing body of work identifies suburban built form as linked to poor health impacts for the general population, and in particular for older adults (when compared with urban, walkable areas) (Ghani, Rachele, Loh, Washington, & Turrell, 2018; Kerr, Rosenberg, & Frank, 2012; Levasseur et al., 2015). With no research in this context, it is integral to investigate the socio-spatial relational interactions between PLWD and their suburban neighbourhoods to better understand how place can support their health and wellbeing.

Existing research on experiences of PLWD in their neighbourhoods is nascent and fragmented, with studies either investigating social networks in a geographically defined area or focusing on PLWD's perceptions of the spatial. These calls for more socio-spatial relational understandings have been justified by critical disability studies (CDS) scholars and 'hopeful adaptation' scholars in health geography. The former focuses on investigating the disabling nature of environments in relation to the embodied experiences of impairment (Hall & Wilton, 2017). The latter calls on geographers to examine how people create "innovative" practices through adversity when living with illness, and to see identity as fluid (Power et al., 2019). While these scholarly justifications are related, I find that they are considered separate conceptualizations. This paper argues that a care perspective can bind these two together and serve as an analytical framework through which to interpret the socio-spatial practices of PLWD in suburban landscapes across time-scales. Care was selected because it focuses on understanding interdependencies at all scales, and is emotional, particular, relational, embodied, and contextual (Keyes et al., 2019; Williams, 2017). Care has been taken differently by different disciplines and scholars depending on their onto-epistemological positionality, however in this paper the geographies of care literature is drawn on, which calls for the expansion of studying care relationships as a complex socio-spatial network encompassing diverse scales and time-space, and between human and more-than-human others (Amin, 2002; Bowlby, 2012; Imrie & Kullman, 2017; Lawson, 2007; Williams, 2017). This paper addresses these theoretical calls to seek these "innovative practices" (Power et al., 2019) and "contexts that allow 'able bodies' to move with ease" (Hall & Wilton, 2017, p.740) through the lens of care to study of everyday life of PLWD in suburban neighbourhoods. The research aim is to understand the everyday practices of PLWD in their suburban neighbourhoods, and how their experiences shape/are shaped by their past, present, and future(s), and their relationships with human and more-than-human others.

This paper begins by outlining the existing research and gaps in research on PLWD and their neighbourhoods, and introduces an argument for adding 'care' as an analytical lens for understanding socio-spatial relational understandings of everyday life. Then it traces these experiences in suburban neighbourhoods according to the *in-situ* experiences of PLWD, through a constructivist grounded theory approach to analyzing semi-structured introductory and go-along interviews, and supplementing the themes with GPS tracking and travel diaries information. The results revealed how

PLWD care for themselves in their neighbourhoods through time, including how PLWD practice self-care, and their relationships with others in public spaces and how this impacts their experiences in their neighbourhoods. The paper ends with a discussion of potential structural (in)equities faced by PLWD in their neighbourhoods and innovative practices to overcome adversity, building up a theory about what it means to care for oneself and others, as well as being cared for in everyday suburban life.

3.2 Literature Overview

3.2.1 Existing Work on PLWD in Public Space

There is evidence that personal histories, social interactions/contexts, immediate environment and broader socio-cultural contexts influence the behaviours, performance and quality of life of PLWD, not solely the neuropathology of dementia (O'Connor et al., 2007). However, existing research on the impact of the built environment is nascent, with Keady et al. (2012) finding only 14 articles on the topic, and a subsequent review finding only 10 more (Biglieri, 2018). As a result, "the impact of people with dementia on cityscapes is not well understood," (Manthorpe & Iliffe, 2018, p.8). PLWD face unique challenges in accessing their surrounding neighbourhood, not experienced by similarly-aged counterparts. They are likely to experience a 'shrinking world' effect, in that their activity spaces are smaller than other older adults. A month-long GPS tracking showed that people with mild dementia travelled on average 400m from their homes and persons without dementia travelled an average of 1.5km (Shoval et al., 2011b) (See **Figure 3.1** for a visual representation of this in the Region of Waterloo). This idea of a 'shrinking world' for PLWD from a sociological perspective states PLWD's conceptual access to the world shrinks over time (Duggan et al., 2008), and is likely influenced by the personal, changing nature of their impairment, structural barriers in their built/social environments and the impact of broader socio-cultural-political structures (like stigmatization and fear associated with PLWD going outdoors alone) (Bartlett & Brannelly, 2019; Blackman et al., 2003; Duggan et al., 2008; Lloyd & Stirling, 2015; Neubauer et al., 2018). Other research has asserted that for PLWD, walking in one's neighbourhood is a way to resist that 'shrinking world' effect (Odzakovic et al., 2018) and that the neighbourhood can provide "a significant arena for people to draw upon their personal potential and capabilities in order to compensate for the limitations they experience" (Ward et al., 2018, p. 877). In contrast to focusing on capabilities, research done through a critical disability study lens on PLWD who go outside revealed an ontological vulnerability that PLWD were experiencing through “an awareness of failing knowledge about oneself or the ‘rules’ of outdoor life” (Bartlett & Brannelly, 2019, p.6). This diverges from an epidemiological study postulating the neighbourhood as cognitive reserve, in which certain built environment features were associated with less cognitive decline, such as proximity to community centres and public transport, suggesting that being enabled to continue activities because of the physical characteristics of the area one lives in could be a protective factor for dementia (Clarke et al. 2013; 2015). Overall, these studies present conflicting perspectives on how to view the neighbourhood for PLWD – as capable of supporting PLWD using a capacity-based approach or viewing it as a source of increasing ontological vulnerability or viewing certain kinds of neighbourhoods as more protective than others. They each represent the need for socio-spatial relational research, work that understands the realities of the impairment, acknowledges the structures that influence experiences, highlights innovative practices by individuals to live well in their current settings, and recognizes that some neighbourhoods might be more supportive than others (because of their socio-spatial characteristics).

Figure 3.1: Activity Space of Older Adults and PLWD - Superimposed over Region of Waterloo

©Google Earth, 2019

The research on the relationship between the built environment and PLWD has been concentrated in the past decade and a half, and the variety of disciplines engaged in this work is vast[15]. Like Corburn (2009), this paper argues that this is one of the collective strengths of this research, using a multitude of theoretical frameworks, methodologies, scales and perspectives to understand the experiences of people and place. However, the existing work can be considered fragmented, not sustained, and lacking systematic study. There have been attempts to understand the everyday life in the neighbourhood for PLWD, however, this knowledge has largely kept social and spatial studies separate. For example, in social studies, sociologists and gerontologists have examined everyday technologies (from smartphones to the built environment) that help support PLWD in outdoor spaces in continuing activities through examining the lived experience and meanings (Brittain et al. 2010; Duggan et al., 2008) and delving into life spaces for PLWD (Lloyd & Stirling, 2015). Duggan et al. (2008) found that built environments (BE) can be a source of identity and inclusion , and Lloyd and Stirling (2015) found four themes of particular salience regarding life spaces and mobility for PLWD: access to public space, social distance and proximity, changing meanings of space and objects, and imaginative co-presence. Brittain et al. (2010) found that BEs have the potential to be both therapeutic and frightening. Odzakovic et al. (2018) found four themes when conducting walking interviews with PLWD – "personal narratives as embedded within the neighbourhood; the support of selfhood and wellbeing through movement; the neighbourhood as an immediate social context; and restorative connections to nature" (p. 2). Another study concluded that the neighbourhood should be seen as a conduit of social health, showing the importance of 'ephemeral encounters' in supporting social engagement and instructed health practitioners to conduct mobile assessments (Ward et al., 2018). These sociologically based studies of the lived experience of the neighbourhood of PLWD focus on investigating how the neighbourhood can support PLWD to be socially/physically active, and the meaning that they attach to their neighbourhood and their social relationships. These studies, while occurring in geographically constrained areas, focus on the social, treating place as a container, and seemingly focus on agency of the individual over structural issues.

Conversely, research by planners and health practitioners have examined everyday life from a perspective that prioritizes the spatial. For instance, from an urban planning perspective, scholars like Burton and Mitchell (2006) in the UK made several findings with their walking interviews with older

---

[15] Including (in alphabetical order): anthropology, architecture, computer science, engineering, epidemiology, geography, interior design, medicine, nursing, neuroscience, occupational therapy, policy, psychology, public health, recreation and leisure, social gerontology, social work, speech pathology, technology studies and urban planning.

adults with and without dementia, including PLWD preferred less socially demanding trips; travelled to one location per trip; and feelings of anxiety, fear of embarrassment, and confusion were common among PLWD. Allied professions such as occupational therapy researchers have focused on understanding the difficulties of crossing the road as a PLWD and the trip to the grocery store in Sweden (Brorsson et al., 2011; 2013; 2014). An architect's study aimed to use the current evidence about the dementia-friendliness of buildings and work with planners and architects to develop a checklist designers could use (Fleming et al., 2016). However, the primary function was to create a tool for designers, and consultation with PLWD was limited. In addition, the study assumed that a trip started and ended at a car park, neglecting the public spaces that exist beyond. These studies lack a meaningful engagement with the social, including the influence of personal histories of PLWD. To bridge the gap between insights from the two main perspectives engaged in this work requires a socio-spatial relational perspective.

Simultaneously, there has been a growing body of work investigating the health impacts of living in suburban areas for people, and in particular for older adults[16]. These North American car-centric suburban areas (an under-researched area of inquiry in terms of everyday life (Keil, 2018)), have been identified by scholars as more difficult for older adults who experience mobility, sensory and cognitive impairments, with negative impacts on physical activity levels, social engagement, mental health, and barriers to mobility when compared with walkable urban centres (Ghani et al., 2018; Kerr et al., 2012; Levasseur et al., 2015). That being said, studying the nuance and context of a place is integral, as larger-scale statistical studies can ignore these richer understandings of experience (Loukaitou-Sideris, Wachs, & Pinski, 2019). Further, considering all PLWD studies so far have been in a European context (except one in Australia), the impetus to examine the suburban North American perspective is critical. Suburban spaces are not monolithic, nor are they universally 'bad' – this perspective obscures reality, disincentivizes research in these places, and reduces the suburban to a caricature (Keil, 2018). Rather, suburban areas result from the process of suburbanization, with complex forces and actors at all scales, and there is a need to understand how people (especially marginalized groups) make and (re)make the places they live in to adapt to them.

---

[16] It should be noted that while not all PLWD are older adults (in fact, 6 of 7 participants in this study were diagnosed with dementia before they were 65), dementia symptoms are more likely to affect older adults. This is why the literature on suburban areas for older adults is drawn on here.

3.2.2 Theoretical Gaps

Despite this growing body of literature on PLWD from diverse disciplines, these studies still fall into two categories – either focused on social factors in a geographically bounded place (like social networks and supports (Campbell et al., 2019; Ward et al., 2018)) - or on PLWD's responses to features in the built environment or spatially focused (Biglieri, 2018; Brorsson et al., 2011; Burton & Mitchell, 2006). While these are important avenues of research, it does not reflect what social scientists have known since Lefebvre in the 1960s – rejecting conventional views of space as a container, and instead positing that people make places and places make people, that this is a process that is fluid and occurs over time (Cummins et al., 2007; Graham & Healey, 1999). This socio-spatial relational thinking is multi-scalar, sensitive to temporality and dynamic/encountered/fluid, "endlessly coming into being," (Skinner, Cloutier, & Andrews, 2015, p. 787). Drawing on affect as a way to understand relationality, Andrews et al. (2013) discussed how we know the world through our embodied experiences – hybrid assemblages composed of human bodies and more-than-human objects (e.g. technology, flora, fauna, the built environment) that can be different between individuals. Further, our relationships with place are shaped by our histories, and our lives impacted by our relational connections between self, neighbourhood, friends, family and the world through time-space. This relational perspective allows researchers to examine macro- and micro-processes at diverse scales and richly describe "the nature of these relations and their consequences," (Skinner et al., 2015, p.788). A focus on a relational view of place can help counter policies based on the belief that health and wellbeing are results of physical determinism, in which the built environment is only what is constructed and designed (Corburn, 2009). A relational view of place is one that looks beyond forms to the social, economic, political and meaning-making processes that combine to make a space a place (Corburn, 2009; Cummins et al., 2007).

This relational view of place has been taken up in two intersecting disciplines that provide the theoretical justification for this research – critical disability studies (CDS) and 'hopeful adaptation' from health geography. First, in CDS, there has been a movement to not only examining the disabling nature of environments (i.e. the social model of disability), but also an individual's embodied relational dependencies on human and more-than-human actors. Scholars have acknowledged these experiences as fluid over time and seek to understand how they intersect with other identities (Goodley, Lawthom, Liddiard, & Runswick-Cole, 2019; Hall & Wilton, 2017). Disability is relational (Dear et al. 1998; Hall and Wilton, 2017) and for disabled persons, it involves a complex layering of actors, structures and personal, embodied impairment (Thomas, 2004b). Shakespere (2006) argues that in order to address these complex phenomena, we require different levels of analysis and intervention, from the medical to the socio-political. Hall and Wilton (2017) call on us to focus on relational dependencies for disabled people in space and "make explicit the specific relational connections and material contexts that allow 'able bodies' to act with apparent ease," (p.14). This relational perspective on disability acknowledges that "all persons (disabled and non-disabled) depend to a greater or lesser extent on human and non-human others for their capacity to act," (Hall & Wilton, 2017, p.13). These dependencies can be at all scales, including but not limited to technology, aspects of the built environment, transportation system, prosthetics, and diverse care relationships.

A second justification comes from health geography's proposed elements of 'hopeful adaptation,' understanding the "myriad, often non-linear ways that people seek and find health and wellbeing in spite of adversity" (Power, Bell, Kyle, & Andrews, 2019, p.1). Their four elements include: seeing health/health behaviour as fluid (rather than dichotomous enabling/disabling); needing to investigate socio-spatial relationality to situate the "entanglement between people's everyday battles and the wider structural constraints in which they reflexively engage;" seeing identity as a journey (i.e., not pre- versus post-diagnosis); and alerting practitioners/scholars to everyday innovative practices used to adapt to adversity (Power et al., 2019, p.5). Even though geographical and planning scholars have engaged with relationality as a theory for understanding everyday life through justifications from disability studies and hopeful adaptation, these two are still considered separately and are not adequate on their own. This paper argues that a care lens can bind these two together and serve as a robust analytical framework through which to interpret the socio-spatial practices of PLWD in suburban neighbourhoods across time-scales.

3.2.3 Using Care to Examine Everyday Socio-Spatial Relational Life

> *"[Caring] can be viewed as a species activity that includes everything we do to maintain, continue and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves and our environment, all of which we seek to interweave in a complex, life-sustaining web"* (Fisher & Tronto, 1990, p. 40).

This definition of care is purposefully broad, as it is intended to be a "situated engagement with the multiple and complex circumstances producing the need for care, but they also offer an explanation of how people are operating in the urban to repair our world" (Tronto, 1993, p. 825). This definition comes from a relational ontology and is emotional, particular, relational, embodied, and contextual (Lawson, 2008; Williams, 2017). In geography, the definition of care has been adopted and expanded through scale in diverse ways. For instance, it has encompassed examining close relationships between people in typical locations where 'care' happens (e.g. how care relationships are (re)produced between partners through home care, or between professionals and patients within an institutional facility), examining how people 'care for' the environment (Jones, 2019), and at the global scale (e.g. how the neo-liberalization of professional care work and global migration of care-workers affects their families and the ones they work for) (Lawson, 2007). Care has also been a lens to view everyday practices as acts of self-care in the urban environment (see Rosa's (2019) work with Roma women in Europe). Care has also expanded to describe everyday encounters in public spaces between strangers who "sustain forms of conviviality and kindness" (Imrie & Kullman, 2017, p. 6). Amin (2012) calls this an "expanded politics of care" in which the built environment can be an important part and precondition for interpersonal relations. Bowlby (2012) conceives of these interactions in public spaces as occurring across time-space. They discuss three timescales to examine: (1) individual life-course and intergenerational exchange; (2) individual and collective memory; and (3) daily body rhythms (Bowlby, 2012, p. 2108). While care has been critiqued for being paternalistic by disability and dementia scholars, the concept is not necessarily oppressive (Keyes, Webber, & Beveridge, 2015), and an ethic of care is a way of "centralising the experiences of people with dementia in order to design responses required to promote citizenship," (Brannelly, 2016, p. 306). A care lens focuses on interdependency, rejecting the false dichotomy between 'control' and 'protection' (Brannelly, 2016). It is also a concept argued to be key to relational citizenship for PLWD (Keyes et al., 2019). Relational citizenship combines a human rights approach, with a centralizing understanding of agency as expressed through embodied selfhood of PLWD (like bodily actions in relation to others) and a focus on interdependence (Kontos et al., 2016, 2017).

The focus on a relational socio-spatial care approach enables the researcher to examine disability in a relational way, that personal and embodied experiences of disability must be studied in tandem with broader societal impacts of disablism (through socio-cultural discourses and built environment barriers) (Goodley et al., 2019; Hall & Wilton, 2017; Thomas, 2004b). A care perspective encourages researchers to:

- Move away from the idea of it as asymmetry of care between the vulnerable person and generosity of the other (Rosa, 2019);
- Research the ordinary - what is visible but escapes our attention – and show how it matters (Laugier, 2015 as cited in Rosa, 2019);
- Go beyond individualist notions to see vulnerability as part of all people, and assume collective "responsibility towards the other (near and far, known and unknown)" (Rosa, 2019, p.199);

- Think of interdependencies (between people and people, and places, and objects) and reject the dependent/independent dichotomy;
- Examine both structure and agency, and recognize that they are not as discernable in everyday life; and
- Understand that disability is both embodied and a result of structural factors. A focus on individualism and autonomy fails to accommodate a diversity of embodied experiences.

This perspective allows us to get away from the dichotomous question of "Who cares for whom?" and instead ask "How does one (do we) care(s)?" (Rosa, 2019). As demonstrated below, this lens enabled this research to interrogate how people adapt to their existing environments, and (re)make their neighbourhoods into a place that is familiar and comfortable to them, how they care for themselves and their loved ones through their everyday practices in public space, and how ephemeral encounters with human and more-than-human entities care for them. This research found that PLWD care for themselves by negotiating their environments, dealing with changes to their abilities, as well as with societal and internalized stigma, in addition to caring for others by limiting their mobility to stay safe for their loved ones, for instance. Examining these realities produced situated understandings of everyday life for PLWD in sub/urban environments.

3.3 Research Aim

The original intent of the overall research project was to understand lived experience in neighbourhoods for PLWD. However, while using a grounded theory analysis approach to understand how socio-spatial relationality emerged, notions of care became apparent in the later phases of analysis, and it became an appropriate mechanism through which to interpret the data. This led to the intent of this paper to use that empirical data to build understanding of how care manifests in everyday practices in public spaces from the perspective of PLWD. Thus, the research objective is to understand the everyday care practices of PLWD in their suburban neighbourhoods, and how their experiences shape/are shaped by their past, present, and future(s), as well as their relationships with human and more-than-human others.

3.4 Participants and Methods

This research was part of a larger study, guided by a relational ontology and social constructivist epistemology, and using a case study methodology. The context being investigated is familiar suburban neighbourhoods for PLWD, all in the mid-sized Regional Municipality of Waterloo, Ontario. In Waterloo, the number of PLWD was projected to increase by 187% between 2011 and

2036, from 6,365 PLWD to 18,314 (Hopkins, 2010). The cases were defined as seven individual participants who were recruited through community organizations and self-identified as living with mild-to-moderate dementia. These participants ranged in age from 57 to 81 and all lived in their own home (as opposed to congregate living settings). The small sample size was appropriate given the case study methodology utilized by this research, however also reflected the challenges with recruiting this population, and with building the significant amount of rapport required to foster trust and familiarity as a researcher (Keady et al., 2017; Phillipson & Hammond, 2018). This included consistent, repeat contact with participants, observations and engagement, as well as providing a research environment centred on inclusion, empowerment and expression by being flexible and responsive to diverse communication styles (Phillipson & Hammond, 2018).

This project selected participants who lived in suburban neighbourhoods because of the lack of meaningful investigation of experiences in public spaces for PLWD in this setting (most existing studies are in urban or rural settings). To ensure that all participants lived in a suburban area, their neighbourhoods were examined using Gordon's (2019) typology. All participants lived in a neighbourhood classified as an 'Auto-Suburb' by Gordon (2019)[17] except one, who's neighbourhood was classified as 'Exurban'.

Table 3.1: Participant List

Pseudonym	Participant, Age at time of Fieldwork	Condition Causing Dementia Symptoms (self-reported diagnosis)	Neighbourhood Typology (Based on Gordon, 2019)	Care Partner
Don	Male, 71 years	Early onset Alzheimer's disease	Auto Suburb	Wife (Retired)
Lorraine	Female, 81 years	Alzheimer's disease	Auto Suburb	Husband (Retired)
George	Male, 65 years	Early onset Alzheimer's disease	Auto Suburb	Wife (Working)
Douglas	Male, 65 years	Early onset Alzheimer's disease	Auto Suburb	Wife (Working)
Alexander	Male, 58 years	Parkinson's disease	Exurban	Sister (Working)
Violet	Female, 57 years	Early onset Alzheimer's disease	Auto Suburb	Husband (Working)
Elizabeth	Female, 56 years	Early onset Alzheimer's disease	Auto Suburb	Husband (Working)

To address the research aim, the researchers selected several methods to form an understanding of experiences in suburban public spaces. This is common with other research with PLWD and reflects other successful research centering the experiences of PLWD, which have shown that traditional

---

[17] This typology categorizes census tracts into four categories based on transportation data: Active Core, Transit Suburb, Auto Suburb and Exurban.

methods (e.g. semi-structured interviews) were more effective when combined with participatory approaches that included a visual or experiential component (Phillipson & Hammond, 2018). Experiential methods included multiple go-along interviews (Carpiano, 2009), participatory GIS (involving GPS tracking) and travel diary recordings (Hand, Laliberte Rudman, Huot, Gilliland, & Pack, 2018). To ground the research in the participant's experiences of place, data generated from diverse methods were selected and conducted in a specific order. The diverse qualitative methods captured meanings and interpretations of place over time, and were complemented by participatory geospatial techniques "to address spatial, social, perceptual, and other elements of person-place transactions" (Hand et al., 2017, p.e48).

The research began with a traditional sit-down semi-structured introduction interview (ranging from 20 – 90 minutes), asking questions about the places they have lived in over time, their past and present mobility practices, and what they are concerned for in their future. Introduction interviews were used to build rapport, and get a life-course understanding of participant's practices in public spaces (Andrews et al., 2013). This introduction interview became a way to understand participant's perceptions of the neighbourhood while indoors, before understanding how the participant experienced the neighbourhood while physically walking in it.

During the first go-along interview, the researcher directed the participant to give a tour of their neighbourhood (ranging from 45 minutes to 3 hours). The purpose was to shift the power dynamic from the researcher to the participant, doing the interview on the participants' terms (Carpiano, 2009; Finlay & Bowman, 2017). The go-along interviews were used because of their ability to capture and meaningfully understand in situ socio-spatial experiences (Carpiano, 2009; Hand et al., 2017; Lee & Dean, 2018). The method has also been used successfully with PLWD and revealed more about everyday life (e.g., capturing behaviour and perceptions of place) than a traditional interview (Burton & Mitchell, 2006; Hung et al., 2017; Odzakovic et al., 2018). After the first go-along interview, GPS tracking and travel diary recording for two weeks was used to ascertain a fuller picture of mobility patterns in the neighbourhood, from a broader timescale perspective.

The second go-along interview route was selected by the researcher (SB). She directed participants to take her to their most common destination as defined by the GPS tracking and travel diary recordings. The purpose of the second go-along interview was to ensure that the data included a route that the participant used regularly, as a way to ensure rigour (Baxter & Eyles, 1997). Due to the relational guiding perspective of this research, during the introduction and go-along interview, the researcher (SB) paid attention to embodied and subjective experiences, human and more-than-human encounters, sense-scapes (incorporating sound, visual, olfactory, tactile experiences) (through observing the participant) as well as personal histories, and the influence of larger socio-political structures on who belongs in outdoor space (through the design of the introduction interview questions, as well as paying attention to how participants described their past, present and future) (Tornaghi, 2015). The Office of Research Ethics approved this research protocol at the University of Waterloo.

3.4.1 Analysis + Approach

A constructivist grounded theory analysis approach was used to analyze the interview data, in which the semi-structured and go-along interviews were transcribed and followed open, axial and theoretical coding (Charmaz, 2014). Open coding involved examining the transcriptions line-by-line and summarizing sections of text using active gerund-based phrases like "Expressing fear for the future", which is favoured by Charmaz because it allows the researcher to see processes and actions by taking an active stance, ultimately moving the data forward analytically (Charmaz & Keller, 2016). The researcher (SB) also used as much detail as possible in these codes to capture nuance and to centre participants' voices and constructions of meaning (Charmaz, 2000 as cited in Mills et al., 2006). Focusing on actions, rather than themes was an important part of this step (Charmaz, 2014). Memo-writing for each open code was also employed, and used later in the analysis as well when investigating relationships between action codes (Charmaz, 2014). Through immersion in the over 1200 gerund-based action codes, researcher SB began to organize and interrogate them into categories (axial coding). This categorization was then peer-checked and tested by the second author (JD). Then the researcher SB built and tested the categories on the rest of the data during the theoretical coding phase, by re-examining each open code to ensure it was in the correct category. These steps involved examining and re-examining the relationships between different patterns and themes from the data. This was again peer-checked by JD to ensure rigour. During axial and theoretical coding stages, the lens of care became an appropriate mechanism to understand the socio-spatial relations the researchers saw emerging. As a result, during the axial (and then theoretical coding stage) the authors decided to re-examine the themes through the new lens of care, sensitizing the data to this new perspective. The GPS and travel diary data were used to enhance understanding of some of the categories that emerged.

3.5 Findings

The findings reported here focus on understanding the everyday care practices of PLWD in their suburban neighbourhoods. They are separated into three major parts, the first concentrating on how PLWD's outdoor experiences are shaped by their past, present, and perceived future(s), and their engagement in self-care over these temporal dimensions. In care research in public spaces, the examination of timescales has been deemed crucial, calling for examining aspects like individual life-course, individual memory, and daily body rhythms, which are included in this section (Bowlby, 2012). The second part of the findings focuses on how PLWD′s relationships with others are practiced and impact their experiences in public spaces. This second overarching theme is inspired by the care research emphasizing interdependence and suggesting scholars consider how an individual cares for themselves, others, and is cared for, instead of assuming that care is unidirectional (from caregiver to recipient) (Lawson, 2008; Rosa, 2019). The third part of the findings examines encounters in public space as care (Amin, 2002; Ward et al., 2018) showing how small interactions with human and more-than-human others can foster a sense of inclusion in the community.

3.5.1 Context Vignettes

To understand socio-spatial relationality, context is integral (Andrews et al., 2013). Individual life courses have a profound impact on someone's present self, and this is no different for PLWD. This section is thus divided into small snapshots of personal histories and how this influences the individual's everyday practices in their suburban neighbourhoods.

Violet grew up in a suburban area of a large city, relying on driving, walking and the occasional public transportation ride. She then moved to a suburban area of Waterloo Region (20 years ago), and relied on driving until having her license taken away. Violet does not take public transportation, nor does she desire to learn how to take it, and this seems related to her lack of previous experience with it. She describes her neighbourhood as familiar, which makes her feel safe and not at risk of getting lost. Her familiarity comes from living in the same place for 20+ years. The prospect of moving scares her because she would have to learn again.

Elizabeth grew up in a large suburban municipality, relying on driving, walking, and public transportation. After moving out of province for work, and to a few different cities, she settled with her family in her current house in the Region and has been there for 20 years. Within a year of moving to the Region, she experienced an adverse health event and as a result, did not "learn" her neighbourhood. She still feels like she might get lost in it. She has, however, been relying on public transportation since she moved to the Region, but using it makes her increasingly nervous since her dementia diagnosis.

Alexander lives in the same town he grew up in, approximately 250m from his childhood home. He moved back to that location from a different suburban area in the same region because of the sense of familiarity, and the prospect of accessing services on foot after losing his license. Alexander also had grown up driving everywhere and had to teach himself how to use the bus. After a career in manufacturing jobs, Alexander says it is part of the reason he enjoys walking in industrial areas – because it makes him feel like he has a purpose.

Douglas grew up in a walkable small rural town, where he remembers his grandfather's house with the big porch that enabled him to connect with all of his neighbours. He compares this past with his present suburban neighbourhood with no porches, and a lack of social interaction. He also spoke about how hobbies from childhood have influenced his activity space, as the hobby shop is one of his landmarks in his neighbourhood, even if he only visits it once per year. He also grew up with dogs, and has three who he credits with getting him outside. When he was working, he described walking as a way to think creatively or work through a problem, and that this is still true for him today.

Lorraine grew up in a suburban area of a large city, using public transport, cycling and walking as her main modes of mobility. After moving to a suburban area of the region in her early 30s, she still relied on these modes and driving. She is an avid watcher of change in the area, pointing out new neighbours and housing developments. Her history as a community activist in the dementia realm (one of her relatives had it) and in the public space realm (including leaving notes for homeowners who do not shovel in winter, and advocating for more benches at bus stops) informs how she approaches having dementia. She has joined dementia support and recreation groups, taught herself to ride the bus and continues to be involved in activism.

Don grew up on a farm in the Region and has only lived in his current suburban home for about 5 years. Despite this short time, he says there is a sense of familiarity to it because he used to 'go into the city' (i.e. his current neighbourhood) for a night out when he was younger. Don calls himself a determined, confident person "who just goes" and he thinks that this outlook on life has enabled him to keep walking outside alone. Don also enjoys greenspaces such as streets with substantial tree canopies, natural areas and parks because he says it reminds him of growing up in the country and that feels comfortable.

George grew up in a suburban area of a major city, walking, riding his bike and taking transit. After moving to a mid-sized city, living in a small town in Europe, and then moving to another suburban area in the region post-diagnosis, George has learned his new environment over the past 5 years by using the same mobility methods he used in his youth. He states that his lifelong love of nature, mountain biking and hiking in Europe have influenced where he likes to walk (along a river). His professional career in the construction industry and living in Europe influences the routes he selects, choosing to walk around a historic downtown in the region that has similar stonework buildings and historic homes as his home in Europe.

A common thread throughout each of the stories was the impact of familiarity on a PLWD's sense of comfort as described during the interviews. This familiarity could be because of living in one place for a long time. It could also be due to having lived in a similar, geographically different place in their lifetime, or experiencing their current home location by driving through it in younger years. Examining individual life-courses in geography is not new, as we know that history impacts a person's current practices. However, by applying a care lens to these findings of (re)produced familiarity through time, we can think of these histories as past selves caring for present-day selves, as the former produced that familiarity considered such a support today.

3.5.2 Part 1: Self-care in Place Over Time

Care through time, and considerations of temporality, as shown above, are integral to socio-spatial relational experiences of the everyday for PLWD. Dementia, like many other chronic diseases, is episodic and fluid, with good and bad days. It is also like other degenerative diseases in that its symptoms will progress. Dementia was referred to by participants as a 'slow death' with the unpredictable nature and timing of decline. The temporal, changing nature of living with dementia and its impact on participants' future was a source of fear; however, many discussed (often with humor) how they are caring for their future selves, as their symptoms change. In terms of fear, many expressed concern over moving into a congregate living facility (Lorraine) or how their mobility will shrink:

> *"At some point I shouldn't be riding a bike…Maybe progress so that that wouldn't be safe and that will cut back a lot, and then I suppose the bus will become more and more difficult…So all those will shrink."* (George)

Others described fear of other progressive symptoms, like declining depth perception abilities and its potential to negatively impact on their safety near/using high-traffic roads near their homes (Violet, Lorraine), declining spatial memory – including a fear of getting lost (Lorraine), as well as the prospect of forgetting oneself/others and not being able to speak or move (Elizabeth, Lorraine). Besides describing fears outright, some participants talked about fear in the context of others they had known – like discussing those who went 'downhill fast' and became violent (Douglas). Participants noticed temporal changes in themselves, engaged in self-care practices in the present, as well as caring for their future selves through present actions.

3.5.2.1 Noticing Frictions[18]

For the PLWD in this study, their everyday lives were changing. They were beginning to notice the frictions between the changes in their everyday lives and the world around them (Fleet, 2019). Many reflected on the impact that decline had on their memory, abilities, and sense of time which affected their sense of self, and ability to navigate their familiar neighbourhoods daily (Don, Douglas, Lorraine, Elizabeth). The most common and prominent change was the loss of their driver's license, shrinking their life space in their car-centric neighbourhoods. Over half of the participants expressed a newfound fear of getting lost in unfamiliar places, outside of their familiar neighbourhood (Don, Douglas, Alexander, Elizabeth). Other participants noticed changing abilities within themselves that affected their experiences in public spaces, including impaired depth perception and risk analysis (i.e. when crossing a busy road, which happened often due to their suburban built environments (Violet, Alexander, George)), and constantly having to be 'on alert' and being easily startled (which did not happen previously) (Don, Violet). Some described how feeling panicky (Elizabeth) and losing confidence in oneself (Don) makes walking around more difficult, and almost prohibitive. Participants also noticed increased difficulty with performing public space related tasks that were once easy, including riding a bike, gardening, grocery shopping and walking. For one participant, who found all the steps associated with grocery shopping difficult (e.g., making a list, travelling to the store, finding the items, and returning home), she noticed she has become increasingly reliant on the discount retailer beside her apartment, as it allows her to make these mistakes and rectify them quickly:

> *"The other night we were having something and I don't even eat ketchup but [husband] wants ketchup. And I realized I had it on the list and I thought I bought it but it wasn't there.*

---

[18] I first heard the concept of 'Noticing Frictions' in a presentation by Chancey Fleet, in October 2019 at the #A11y IRL (Accessibility in Real Life) Conference in Toronto, Ontario, Canada.

> *So, I just grabbed my purse, ran over and bought a bottle of ketchup… I am very happy it's here." (Lorraine)*

This retailer has helped facilitate an adaptation to her changing ability because of its proximity. The practice of walking, while still done by all participants on their own, was described as more difficult than before, describing preparation for a walk as an involved task, needing to think in steps, and lacking the motivation to get out of the house (George, Douglas, Don). Some talked about how their world was smaller than before because of their changing abilities, and expressed frustration at it (Lorraine, Douglas, Elizabeth), with some blaming the built environment for being car-centric and lacking amenities within walking distance (Douglas). One participant discussed the "mind tiredness" and exhaustion from engaging socially since being diagnosed, which therefore changed and limited his interactions with others (George).

3.5.2.2 Present Day Self-Care

Participants' routes were guided by comfort, but also by purpose – many walked to get to a location, and some walked just to get outside. Examples included travelling to the library, walking the dog, and purchasing items. To seek comfort, participants would select specific routes to avoid noisy, smelly, fast-moving arterial roads, and walk along quieter residential or mixed-use streets, even if it took longer. They also avoided certain road junctures like roundabouts, and complicated/busy intersections (e.g. all way, three lanes, with turning lanes and large trucks), preferring instead to use medians (so that they only had to pay attention to one direction of traffic at a time), taking a longer route altogether, or just not travelling beyond that street. Participants also were likely to engage in jaywalking, in order to avoid walking long distances to intersections. Some participants also avoided streets with poor sidewalks or those without them, or sought streets with buffer zones between the road and the sidewalk, because they perceived these to be safer and/or more comfortable. In parking lots, participants purposefully walked on any pathways, as they were perceived as safer than walking across the lot. Participants planned routes around avoiding hills and certain greenspaces (perception of crime) as well as time-based constraints (e.g. going to commercial areas only at off-peak hours, not walking during rush hour, and not walking at night). Temporal constraints included the seasons, with participants discussing that winter limits their mobility, in terms of a lack of snow removal from sidewalks and discomfort in being cold. Participants also limited their own activity space based on what was familiar, stating that they would not go beyond certain boundaries, take different buses, or go to other parts of the region by themselves, for fear of getting lost. This self-imposed boundary creation by avoiding certain built-environment features or areas is a limitation for participants, but it can also be thought of as an act of self-care. They are ensuring (for themselves) that they do not get stressed out or panicked by staying within these realms.

Besides creating these boundaries and limits, participants also demonstrated embodied tactics for negotiating these more stressful locations (as described above). Participants would become hyper-vigilant, and this was embodied in their speech and actions, often checking traffic multiple times. Violet spent considerable time breaking down the steps for crossing a street. Upon approaching the edge of the sidewalk, and she would look both ways twice. Then she would wait for a car going 20km/h to come to a complete stop, make eye contact, look both ways again, and then step off the sidewalk. Each step was pronounced, and done at each intersection. Other research has indicated that for PLWD, their ability to negotiate several inputs of information at once is depleted (Brorsson, Ohman, Lundberg, & Nygard, 2014), and this participant dealt with that by making sure every step she took was slow and methodical.

Further to participants engaging in present day self-care practices, their lived experience outdoors was impacted by prescribed self-care recommendations from medical professionals. For Don, his doctor ‘prescribed’ three physical activity sessions and three organized social groups per week, which encouraged the participant to get out and walk more. For Elizabeth, it was the opposite – after getting lost while on the bus (but then calling her husband and figuring out how to get home via bus again), her doctor recommended that she not go by herself for a walk again. This had a serious impact on her outdoor life and she lamented that because of it, she does not go outside often. This is further complicated by her experiences in public spaces in which people mumble and talk quickly, which confuses her, and then she believes that they do not understand her disabilities.

3.5.2.3 Planning for Care in the Future

Participants demonstrated how they are caring for their future selves in terms of their mobility and housing. On a go-along interview, George showed me the congregate living facility that he wants to move to when he gets to “that stage”, having selected it because of its proximity to a lively town square, coffee shops, library and stone masonry buildings – “That would be a nice, home where you still get out and see things”. Don and his care partner discussed that they moved to their current residence because of the diagnosis of dementia – they wanted to walk to amenities to make up for the (eventual) loss of a driver’s license. For other participants, it was about figuring out how to be mobile now and to prepare for the future. Some participants discussed learning how to use public transport (because of the loss of their driver's license), hoping they could learn before it was too late and not have to rely on drives from others (Lorraine, Elizabeth, George, Alexander), as well as preparing for the future by looking into paratransit vehicles (George, Violet, Elizabeth, Alexander).

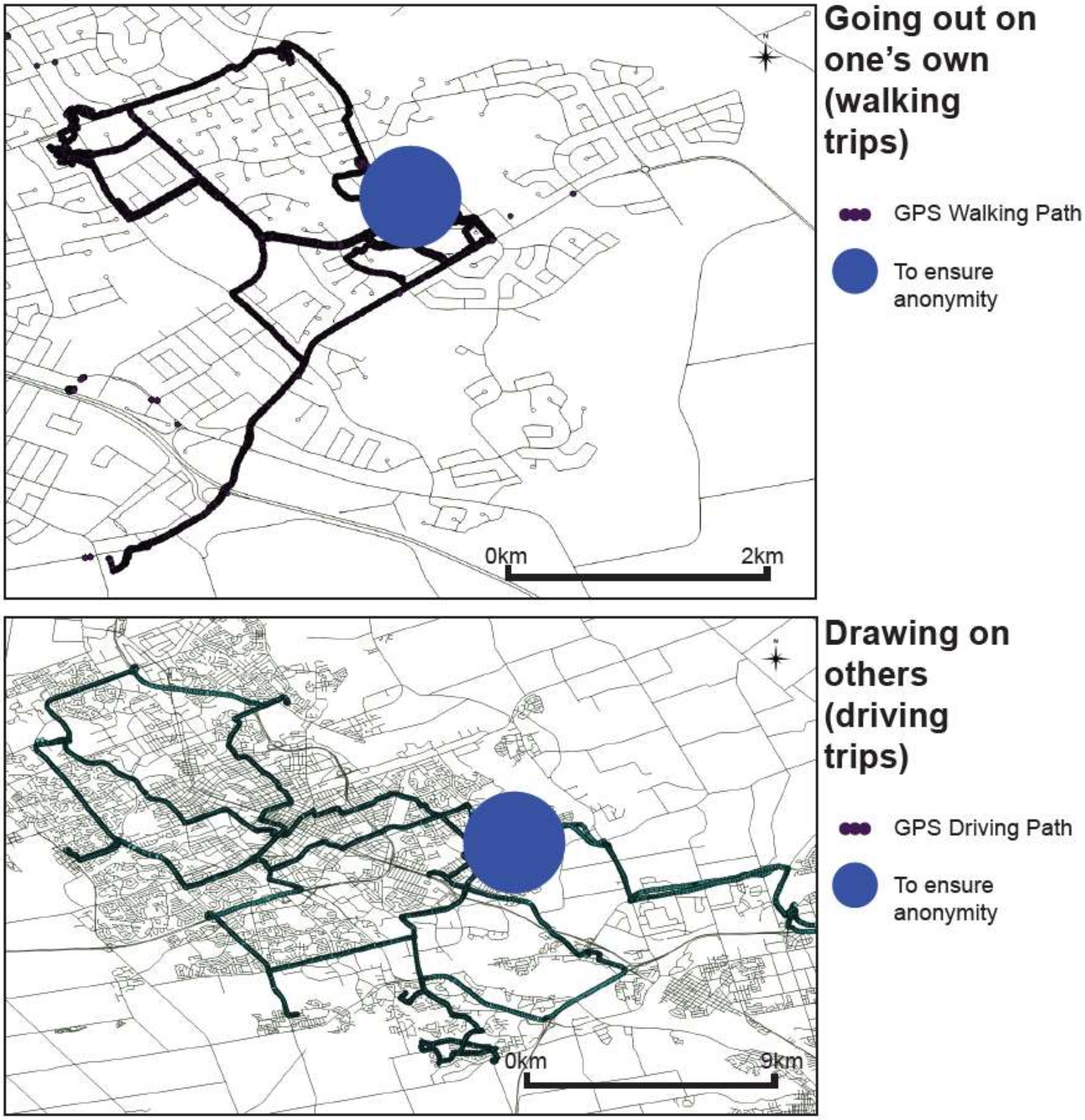
Another strategy was the consistent physical act of walking in one's neighbourhood – remaining physically active was seen as a way to stay in shape and ward off the progression of dementia symptoms (Don). Douglas described and guided the researcher on his daily walking loop that he takes with his two dogs as a way to prepare himself for a future time if he gets lost; his rationale being that the dogs will know the way home, and his partner will know where he is because that is his daily habit, training himself in the present for the inevitable decline in the future. Further, he discussed it being imprinted in his brain - "But it is like I have to have a habit. If I want to walk, I have got to make sure I remember that walk all the time". Similarly, Don discussed "keeping the cobwebs off" the little box that is his neighbourhood by going out regularly for walks: *"*Like in this little box is that and I keep the cobwebs off that box. So I can look in and see what I need, where I am going, whatever you know". This suggests that either consciously or unconsciously, participants understood the embodiment of their familiar knowledge of the neighbourhood in a broader way. All participants engaged in some form of habitual walking (as evidenced by their GPS tracking), ranging from once a week to once a day. This 'fighting against the shrinking world' through walking is echoed in previous studies (Odzakovic et al., 2018). Other participants turned to technological solutions to adapt their present (and future) experiences in public spaces. This included using smartphones with GPS directions and bus schedules (George) (although some were scared to use a smartphone at all (Lorraine)), considering wearing a medical alert bracelet (Lorraine), educating themselves (PLWD and care partners) about dementia (Lorraine, Douglas), and keeping detailed phone contact lists with photos of individuals at different ages (George). These technologies represent a spectrum of adaptations.

Last, some participants did not want to talk about the future, preferring to live in the moment (Violet), or exhibited internalized ableism - "When the Alzheimer's gets me to the point where I don't know where I'm going – then I shouldn't be going anyway. Without somebody on your arm, or a long chain and a buckle" (Don). This negative perspective on the future could be interpreted in a few ways: the participant is being realistic, understanding how they may need to be more interdependent in the future, and/or they are experiencing internalized ableism, in which they believe that their disabilities will become so 'bad' that they deserve to be limited in movement, rather than questioning why the environments around them are not made for those disabilities. The preference for living in the present, along with the strategies for planning for care in the future can all be considered acts of self-care in place.

3.5.3 Part 2: Care Interdependence in Place

PLWD are frequently framed as dependent – on the healthcare system, their families/friends – by society and by a large majority of the literature. However, through understanding this work through a lens of care, it emerged that the participants living with dementia have created an interdependent network to facilitate their mobility in addition to caring for others in their everyday outdoor practices in several diverse ways. The biggest change in the participant's everyday lives was no longer being able to drive. Due to living in a car-dependent suburban environment, it altered how participants interacted with their neighbourhoods, shrinking their activity space. They often had to learn how to navigate on foot and take public transport. PLWD also created and relied on a complex interdependent mobility network, made up of walking (all participants) and public transport (Alexander, Lorraine, Elizabeth, George) trips on their own and drives from family and friends. For instance, George walked on his own to the library and recreation centre, but relied on drives from his wife and daughter to his place of worship, and paratransit services to attend specialized recreation sessions. Lorraine walked on her own to a neighbourhood grocery but relied on the bus to travel to her recreation class and her husband on drives to the pharmacy. Participants often described how much farther they could travel when someone drove them (compared with walking). When comparing participants' trips on their own and trips facilitated by family and friends (mostly driving) using the two-week GPS data, the participant's activity space varied greatly between the two. Including trips facilitated by family and friends enlarged activity space significantly for each participant (see **Figure 3.2** below for an example vignette from Douglas). While one might think of solo trips as the ultimate in understanding mobility, a care lens and focus on adaptation highlights the importance of how the individual (often with their partner) has built up a care network of family and friends to facilitate their mobility. Participants travelled on their own (walking and public transportation), but also had combinations of partners, place of worship friends, exercise buddies, children, paratransit and carpooling to take them to and from social and exercise activities, appointments, and shopping locations.

Figure 3.2: Mobility Vignette - Douglas: Going out on one's own (walking) vs. Drawing on others (driving)



In addition to thinking of mobility patterns as interdependent, participants also revealed how they care for others in their everyday practices. This included caring for neighbours through purchasing groceries and facilitating their mobility by having their partners drive them places (Lorraine), shoveling snow for older neighbours (Douglas), and a general sense of 'looking out for one another' in the community (Don). Participants often lived close to children or siblings and would make a point of visiting them or, at least, passing their house and/or place of work (Don, Alexander, George). Many participants cared for their partners by doing errands on their own during the day (while their partner was at work), like buying groceries and snacks and walking the dogs (Lorraine, Violet, Douglas). Another participant cared for his partner by regulating his own behaviour; by not veering off his daily walking route, so that the partner would always know where he was (Douglas) or by promising to wear reflective gear so that he would be more visible to cars while walking (Alexander). Others expressed this by carrying a cell phone when they went outdoors (all, except Don). They cared for their partners by going for walks and taking part in a hiking group (George), restricting nighttime outdoor activities to spend more time with their partner (Douglas) and encouraging their partner to get outside (Lorraine). Douglas cared deeply about the safety and comfort of his dogs, designing a walking route that prioritized shade, away from busy roads and coyotes, and was an easy-to-remember loop. Participants also worried about the state of the built environment for others, through expressing concerns for children and women's safety near busy roads (Don, Douglas) and for older adults regarding cracked, narrow sidewalks (Lorraine), with one participant taking it upon herself to write homeowners/businesses notes when they did not clear their sidewalk of snow in winter (Lorraine).

3.5.4 Part 3: Encounter as Care

This final theme departs from the previous because it documents how encounters with human and more-than-human others for PLWD make them feel cared for in their neighbourhoods. During the go-along interviews, all participants said hello to at least one passerby who they did not know, sometimes commenting on the nice weather, cooing at a baby in a stroller, or talking about the previous night's football game. The researcher noted that after the experience, they seemed to have more 'pep in their step', suggesting these ephemeral encounters made them feel good. Some participants also described the great cultural and social events put on by their towns as something they enjoyed (Alexander, George). Human encounter was also something sought by participants from diverse service establishments. This included going to cafés where the staff and other patrons are friendly and welcoming (Don, Elizabeth), a bus driver who says hello and waits until you are seated before moving (Alexander), and visiting a seniors' community centre with a cafeteria or certain pharmacy because they know him (George, Alexander). Encounters with neighbours and acquaintances were also a key component of the caring encounters experienced by participants. These encounters, which included everything from a quick hello to a conversation during the go-along interviews, happened closer to the participant's home (compared to the stranger/people in service encounters), and were something that participants sought:

> *"There's a lot of nice, lot of people out. Older than me and younger than me that they're walking their dogs or their kids and I get to say hello to somebody. That's a human. I do talk to my dogs but they don't tell me anything back. Good listeners." (Douglas)*

Some participants lamented that they did not know their neighbours as well and wished they saw people out more often. They attributed this to a lack of porches, the distance between homes, and a car-centric lifestyle (Douglas, Elizabeth). Many talked about visiting friends/family, and pointing out favourite spots to go with these folks (like parks, community centres, cafés, places of worship, etc.). Participants always mentioned the role of the support group in their lives and the diverse destinations that they have visited with them. Sometimes the places discussed were only accessible via car, suggesting a requirement for that transportation mode.

Participants also sought encounter with more-than humans, including flora, objects, and fauna. In terms of flora, participants selected routes to pass certain gardens, and areas with a large tree canopy (Elizabeth, Lorraine, Don, George). During the go-along, Elizabeth stopped to look at the 'little library' in front of a person's home, and upon taking the time to borrow a book, exclaimed what a wonderful experience it was . The fauna included participant's own pets who gave some the motivation to get outside (Douglas, George), as well as encounters with other people's pets (stopping to say hello to friendly dogs), birds nesting, ducks on a pond and in a river. These human encounters experienced in the neighbourhood ranged from less familiar (strangers) to more familiar (family/friends), however, when combined with the more-than-human encounters, they form an important complex network of feeling connected to one's community, and to feeling cared for. These caring encounters with strangers, people serving them, acquaintances, friends/family, animals and natural areas make PLWD feel connected to their community.

3.6 Discussion

Scholars in both critical disability studies and 'hopeful geography' stress the need to understand people as fluid beings, with relationships and abilities as changing over time. PLWD are constantly experiencing change in their abilities and sense of self, and reflect on this in terms of their recent past and present. Research from previous studies on the outdoor behaviour of PLWD reveals that the PLWD is more aware of their changing abilities than their care partner (Bartlett & Brannelly, 2019). This noticing frictions (Fleet, 2019) and how participants have adapted (or not) their 'daily body rhythms' (Bowlby, 2012) in outdoor practices can be considered an act of self-care (or lack thereof), and give insight into structural barriers in their suburban neighbourhoods. The changes in experience and perceived abilities over time for the participants show how their suburban landscapes have become increasingly inaccessible to them, especially following the loss of their driver's license. It also indicates that the unpredictable nature of dementia symptoms means it is difficult to maintain "one's world so [they] can live in it as well as possible" (Tronto, 1990, p.40).

PLWD in this study have (re)made themselves and changed their interactions with their surroundings to be accessible in some way. They have done this through practices of caring for oneself in the past, present and future. Participants have mostly chosen to live in a place that is familiar to them, based on their historical past, be it through living in the same place for 30+ years, or through familiar architecture, but a different location. In the present, PLWD have engaged in self-care by limiting activity space to what is familiar, selecting certain routes to avoid stressful streets, and altering their actions in public space to be more careful than previously. Altering actions to deal with uncomfortable environments was also observed through a study in the UK with PLWD (Ward et al., 2018). Participants taking different measures to ensure that they are walking in comfortable places is congruent with other relational walking behaviour research with adults (Dean, Biglieri, Drescher, Glover, Casello, under review). Self-care was also exemplified through daily practices to prepare for their future selves, and the inevitable decline that they will experience; for instance, through daily habitual walking practices, or selecting a future supportive living facility for its proximity to a familiar, preferred location. This habitual walking is congruent with other research with PLWD that found walking was a way to resist the inevitable shrinking world effect (Odzakovic et al., 2018). These acts of past, present and future self-care in space – (re)making their activity spaces and using new practices to fit their changing needs and abilities – can tell us a lot about poor urban design and land use policy, but it also tells us how PLWD are innovative in how they negotiate and are preparing to negotiate these suburban environments.

There is a need to think about how to learn about these innovative practices, and how to build on them, and to enable movement as practitioners. Self-care practices open up spaces of interaction and encounter in other research (Rosa, 2019) which is also true for PLWD – when they can go outside, they are more likely to encounter others and thus feel included. A further dimension that impacted the self-care practices of PLWD were societal conceptions of dementia as a tragic, inevitable decline in which one should disengage from society (Mitchell et al., 2013; Swaffer, 2015). This was clear in two ways, first through 'prescribed self-care practices' in public spaces by a physician, through the dichotomous examples provided (from recommending walks outside to stating the participant should never go out alone), and the power of a medical professional in dictating how to care for oneself in terms of outdoor activity. This demonstrates a need for physician education in the stigma surrounding the condition and balancing safety with continued inclusion and engagement in public spaces. The second way was how some participants preferred to only live in the present (as opposed to thinking about the future) and conceived of their future selves negatively, suggesting internalized ableism, largely perpetrated by societal conceptions of the condition. PLWD are well aware of the dominant discourse surrounding dementia, and it influences their practices in terms of caring for themselves in the present and future. This speaks to broader socio-cultural-political relations and the need to address these discourses to not only make PLWD feel like they belong in society, but to support their inclusion in public spaces across the dementia journey (Kontos et al., 2018).

A care lens challenges the narrative of dependency for PLWD through understanding their experiences with human and more-than-human others as interdependence in place. First, a care lens perceives mobility as a complex relational network and explains how family and friends care by supporting the inclusion of the PLWD in the community by aiding them to be mobile. Another way to interpret this finding – from a perspective that incorporates the spatial component – is a comment on how drawing on others for drives might only exist because of the car-dependent built environments in which these participants find themselves (revealing structural issues). However, it is understanding these tactics (that PLWD use to adapt to their neighbourhood) which unpacks the messy nature of everyday life – many people rely on multiple transport modes, diverse supports and socio-spatial care relations through which they access public spaces. Further, this section demonstrated how PLWD provide care to others in everyday spaces, confronting hegemonic conceptions of dependency, perpetrated by media and academic research. Confronting this hegemonic misconception could combat stigma, and challenge why interdependence is undervalued in society. The very documentation of their innovative practices challenges (and highlights) the impact of stigmatization directly on PLWD's mobility and the perception of the design of suburban neighbourhoods more generally.

This research builds on the expansion of care, to include how human encounters in public space can be considered a form of care (Amin, 2002). The findings from this work follow research in the UK with PLWD contending the importance of neighbour relations and other proximate strangers for social health (Ward et al., 2018). Participants all spoke about greeting people when they were outside, taking time to mention seemingly mundane encounters as important to them. This is congruent with findings from the UK which indicated how important these fleeting, ephemeral encounters were to one's sense of inclusion in the neighbourhood as a PLWD (Ward et al., 2018).

3.7 Conclusion

PLWD are often excluded from everyday life in public space (Bartlett & Brannelly, 2019). This study on the ordinary practices (Laugier, 2015 as cited in Rosa, 2019) of PLWD demonstrated how they (re)make their world to adapt in it. They do this through processes of caring for self in the past, present, and future, besides (re)organizing their newfound interdependent realities and being cared for through human and more-than-human encounters in public spaces. This research demonstrated how PLWD were living through adversity in the built environment ('hopeful adaptation'), revealing innovative practices. However, it is integral to recognize that despite these innovative practices, PLWD face structural barriers in suburban landscapes, like physical inaccessibility and socio-cultural barriers like stigmatization and car-focused cultures. Being able to access one's neighbourhood a right, and it is vital to identify these barriers, and augment these innovative practices to build more inclusive neighbourhoods.

This research adds to the literature on relational space, showing how the neighbourhood is not a container, but made up of dynamic socio-spatial relationalities that are being (re)negotiated over time by PLWD. When combined with insights from disability studies and hopeful adaptation (i.e. fluidity, the messy interplay of agency, structure, and embodiment, life-course approaches), and viewing ordinary practices through an expanded notion of care, relational place research can build a more nuanced understanding of everyday life. Viewing ordinary practices through a relational care lens emphasizes that we are all simultaneously vulnerable and have a responsibility for other(s) in the community (Rosa, 2019). The research also adds to the geographies of care literature by expanding through scale to study the neighbourhood, but also focusing on socio-spatial relationships at the most personal level (i.e. self-care practices) to the societal level (i.e. how perceptions of stigma impact the everyday practices of PLWD) through time (by examining the past, present, and future). It adds to research disputing everyday life in the suburbs as monolithic and timeless by showing the dynamic interplay of impairment, embodiment, and social and structural barriers over time (Keil, 2018).

Navigating the complicated socio-spatial relationships that people have with their neighbourhoods is one way to understand how the neighbourhood can be an un/equal place of care. The suburban neighbourhoods experienced in this study existed on a spectrum in terms of this complex network of care, suggesting inequities. Ward et al. (2018) echo the call by Cooper et al. (2016) to conduct research to investigate the health inequities that exist between PLWD, and further add “an environmental dimension by underlining how differing relationships with the neighbourhood can lead to diverse outcomes and potentially to inequalities in social health,” (p.878). The lens used in this paper is an in-situ way to examine inequities in these complicated human experiences in suburban landscapes. Working with PLWD to understand these complex present interactions, histories and futures in the context of a care lens is very useful to understand potential (in)equities in the built environment. PLWD are constantly engaged in self-care by negotiating their surroundings, dealing with changes to their abilities and selves, as well as with societal and internalized stigma, in addition to caring for others by limiting their mobility to stay safe for their loved ones, and performing household chores.

This perspective of care has allowed this research to reject the dichotomous question of “Who cares for whom?” and ask “How does one (do we) care(s)?” (Rosa, 2019). By answering the latter, this research has interrogated how people adapt to their existing environments, and remake their neighbourhoods into a place that is familiar and comfortable to them. It demonstrates how they care for themselves (like creating an interdependent mobility network) and their loved ones through their mobility practices and how ephemeral encounters with human and more-than-human entities care by supporting PLWD’s inclusion in neighbourhoods. The complex interdependent network of care described here are theorized to be supportive in various ways and along a spectrum, suggesting that their suburban neighbourhoods are not universally careless. Rather, these suburban neighbourhoods and their systems of encounter and impact on everyday practices can be simultaneously caring and careless in diverse ways, like at certain locations, through different embodiments in space, and changing abilities and perceptions through time.

A socio-spatial relational care lens reveals the dynamic, messy interplay between people and place, and human, and more-than-human materialities through time. Thinking of these relationships through a care lens balances human agency and self-care practices, relationships with human and more-than-human, understanding power structures (like stigma and internalized ableism) and the built environment, while also being sensitive to time space. Examining these realities can help us build contextualized understandings of (in)equities for PLWD in suburban environments. This research shows how using a socio-spatial relational care lens could lead toward more nuanced, contextual understandings of place. By emphasizing interdependence, it can lead to a better understanding of everyday life in suburban spaces and give us insight into adaptive practices (agency) and structural issues (built environment, stigma) that affect the quality of neighbourhood-level decisions. It contributes to the larger project of theorizing suburban space in terms of everyday life and socio-spatial supports for and barriers to wellbeing for vulnerable populations.

Chapter 4 – Manuscript #2

Title: Fostering mobility for PLWD in suburban neighbourhoods through land use, urban design and wayfinding

Abstract

The World Health Organization calls dementia the leading cause of dependency and disability among older adults, and globally, the number of people living with dementia (PLWD) will see a nearly 150% increase from 2015 to 2050. Contrary to popular belief, most PLWD live in the neighbourhood as opposed to congregate living settings (Alzheimer Society of Canada, 2010), and research on built environment facilitators/barriers to mobility for this population is nascent (Biglieri, 2018). This research investigates how PLWD experience elements of their suburban public spaces as enabling/disabling to their mobility. Thirteen go-along interviews with seven participants produced a total of 268 images that were generated and analyzed into three categories: land-use; urban design; and wayfinding. While this research highlighted barriers for participants, their suburban neighbourhoods were often perceived as enabling in diverse ways, highlighting the need for a more nuanced understanding of everyday life in suburban settings.

4.1 Introduction

Most older adults have expressed their desire to age-in-place (Binette & Vasold, 2018). With that comes the need to consider how built environments can support this process. Maintaining continued access to one's neighbourhood depends on one's mobility, defined "as being able to safely and reliably go where you want to go when you want to go, and how you want to get there," (Satariano et al. 2012, p. 1508). It is directly related to one's quality of life, sense of independence, social participation and physical health (Franke et al., 2019; Webber, Porter, & Menec, 2010). For older adults, this is more acute, as the World Health Organization (WHO) recognizes mobility as integral to ageing well (Franke et al., 2019).[19] Mobility includes access to places like shops, healthcare, public services, recreation and family/friends. It is the variable that most influences the capabilities of persons over 60 to perform self-care and take part in the life of their households (Tellez, Krishnakumar, Bungener, & Le Galès, 2016). It depends on several factors, ranging from the personal level (physical, sensory, cognitive impairments, personal histories, gender) to the contextual (built, social and political environments) (Franke et al., 2019; Webber et al., 2010).

One cognitive impairment that has a significant effect on mobility is living with dementia, a set of symptoms that will affect 150 million people globally by 2050. People living with dementia (PLWD) make up a significant portion of older adults, and dementia is cited as a primary determinant of dependency among this population (World Health Organization, 2017). Dementia is an umbrella term used to describe progressive symptoms that affect cognition like impaired memory, confusion navigating space, inability to focus, reduced visual perception, and difficulty with communication, activities of daily living, reasoning and judgement. Approximately 60-80% of all PLWD have Alzheimer's disease (AD), and there are no known treatments to reverse the symptoms (WHO, 2017). Accordingly, much of the efforts to date have focused on maintaining quality of life and supporting PLWD, including work on the role of environments in shaping quality of life for PLWD.

Most research on environmental support for PLWD focuses on institutional care settings (Chaudhury & Cooke, 2014; Chaudhury, Cooke, Cowie, & Razaghi, 2017; Faith, Rooney, Hadjri, McAllister, & Craig, 2015). This is problematic as the majority of PLWD do not live in care settings. In Canada, over two-thirds are living in the community and in the United Kingdom, this is estimated at 80% (Alzheimer Society of Canada, 2010). This gap in knowledge about how community-dwelling

---

[19] It should be noted that while most older adults develop dementia, not all people living with dementia are older adults. This is evident in the sample, which included six participants with early onset dementia (diagnosed before 65) and one who was diagnosed after 65.

PLWD experience public space is exacerbated by the North American reality of predominantly suburban neighbourhoods and older adults' desire to age-in-place (Binette & Vasold, 2018). Extant research acknowledges that suburban communities pose additional challenges to older adults, particularly regarding mobility (Ghani et al., 2018; Kerr et al., 2012). Research has called for increased walkability (through density, street connectivity, land use mix, etc.), improved public transport systems, and access to comfortable, safe streets, and amenities to improve mobility for older adults (Cerin, Nathan, Van Cauwenberg, Barnett, & Barnett, 2017; Loukaitou-Sideris et al., 2019; Nathan et al., 2019). For PLWD, the impact of suburban neighbourhoods on their mobility is unclear.

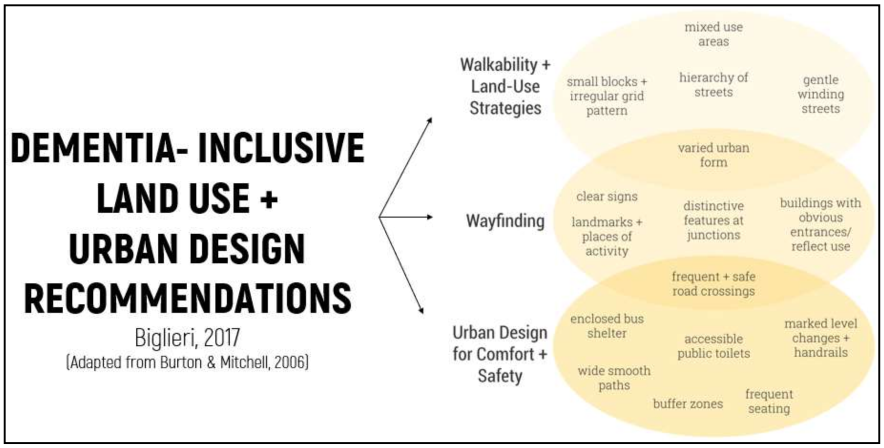
The small but growing body of research on examining the built environment (BE) for PLWD indirectly supports the allied body of research on older adult mobility. This is due to most studies on older adult mobility often excluding PLWD or aggregating their results, obscuring them. It is important to do this work with PLWD, because dementia has a significant effect on QOL, and should be considered separately in research (Tellez et al. 2016). To date globally, there is a paucity of research that examines the role of the built environment in the mobility of PLWD. Accordingly, this paper sheds light on the environmental barriers and supports to mobility for PLWD through an empirical study of community-dwelling PLWD in suburban communities in Waterloo, Canada. This paper first outlines the existing knowledge on planning BEs that support PLWD, uses an analytical framework to untangle the role of built form in mobility, analyses extensive empirical data, and concludes with evidence-based recommendations for future planning research, practice and policy that can improve the mobility of PLWD, and therefore, their QOL.

4.2 Background

Mobility outside the home for PLWD is often conceptualized in terms of risk to the individual (Manthorpe & Iliffe, 2018), and many studies focus on using technologies to track and ensure their safety when outside on their own (Liu, Cruz, Ruptash, Barnard, & Juzwishin, 2017; Pot, Willemse, & Horjus, 2012). Work on how vulnerability is felt outdoors by PLWD and their care partners revealed "an awareness of failing knowledge about oneself or the 'rules' of outdoor life," (Bartlett and Brannelly 2019, p.4). This failing knowledge might explain the 'shrinking world', described both physically and socially for PLWD and their care partners (Duggan et al., 2008), and demonstrated empirically through GPS activity-space research that found PWLD travel on average 400m from their homes and those without dementia travelling 1.5km (Shoval et al., 2011).

The seminal study on the built environment and PLWD was conducted in the United Kingdom by Burton & Mitchell (2006). They found accessing local streets had positive impacts on PLWD - a sense of freedom and autonomy, dignity and a sense of worth, physical exercise, psychological wellbeing, and social interaction. Their walking interviews with people over 65 with and without dementia resulted in recommending six principles for built environment design – familiarity, legibility, distinctiveness, accessibility, comfort and safety. They also created 17 core recommendations from all scales (from street layout to furniture) to incorporate into new developments or retrofit old ones. Biglieri (2018) further analyzed Burton and Mitchell's (2006) findings and recategorized the recommendations for planning practitioners into three overlapping categories (see **Figure 4.1**). The 17 recommendations listed have all been validated by at least one academic article (Biglieri, 2018).

Figure 4.1: Summary of Burton & Mitchell's (2006) Findings by Biglieri (2018)



Since Burton & Mitchell's (2006) publication, additional research in planning for PLWD included creating a 'dementia-friendly'[20] checklist for buildings (Fleming et al., 2016). However, consultation with PLWD was limited to two individuals and the study assumed that a trip started and ended at a car park. Research from Sweden has focused on trip planning, everyday technologies, and experiences of crossing the street. In this research, they found crossing the road was a complicated endeavour, with multiple layers of issues (i.e. the layout of the street, weather, vehicles and other pedestrians/cyclists). Similar to previous research with others with cognitive impairments, PLWD

---

[20] 'Dementia-friendly' is a contested term in the dementia studies literature and among activists living with dementia. It is used here because that is how Fleming et al. (2016) define their work. For more information on the critiques of this term, see Section 1.2.2.

could not keep track of all the inputs and problems would ensue (Brorsson et al., 2011; Brorsson et al., 2014; Gaber et al., 2019).

While these studies focus on understanding perceptions of comfort in the built environment, a significant gap exists in research on wayfinding for PLWD. Since dementia is often described as a series of symptoms (i.e. spatial disorientation in familiar environments, issues with language, depth perception issues and confusion), it is important to understand how PLWD orient themselves in space and the influence that environments have on that process (Burton & Mitchell, 2006, p.29). Most studies on spatial cognition find that any simplistic explanation of how the brain orients the body in space will fail, as cognitive mapping is a dynamic process involving episodic and semantic, short- and long-term memory (Gärling, Böök, & Lindberg, 2013). Some scholars suggest the cognitive map is more like an orienting schema. This research adds to the growing body of literature inspired by Lynch (1960) on examining how people build cognitive maps, and solve wayfinding problems (Mondschein & Moga, 2018). It would also add to work on why certain built environment features are more memorable than others in terms of navigation for the general population (Gärling, Böök, & Lindberg, 2013). It isnecessary to understand how/why PLWD relate to certain places (socio-spatial relationality and embodied experiences) to understand if there are BE features/places that are more likely to be retained.

In terms of research on wayfinding for PLWD, most research has either taken place in a laboratory environment (Blackman, van Schaik, & Martyr, 2007), as an indoor wayfinding test (Marquardt, 2011; O'Malley, Innes, & Wiener, 2017; Rainville, Passini, & Marchand, 2001; Passini, 1998) or as an outdoor walk in an unfamiliar place (O'Malley, Innes, & Wiener, 2018; Seetharaman, 2018). The outdoor walks were conducted in unfamiliar places or guided, meaning that their findings do not tell us about how PLWD navigate in familiar places. Gärling, Böök, & Lindberg (2013) note that the two cognitive processes are related but different. A UK study conducted on navigating familiar environments found participants got disoriented most often at intersections if there were excessive stimuli (such as traffic, loud noises or visually complicated) and found interpreting maps difficult (Mitchell, Burton & Raman, 2004). They preferred short, narrow, slightly curved streets, lively mixed-use environments, and varied urban form. In terms of landmarks, they tended to look for distant and close ones to orient themselves (e.g. historical/civic buildings, distinctive structures, places of activity, and places of personal significance) and used them as orientation cues (e.g. aesthetic features like attractive gardens and practical features like benches) (Mitchell, Burton & Raman, 2004). However, this study has not been replicated, and it was done in a European context.

This paper investigates the North American suburban context, reflecting the paucity of research in this area.

Since legislation like the Americans with Disabilities Act (ADA) in the United States, and the Accessibility for Ontarians with Disabilities Act (AODA) in Ontario, Canada, accessibility is seen as a “self-evident, common sense good” (Hamraie 2017, p.5), and easy to understand, like ramps for those using a wheelchair (Imrie & Hall, 2001). However, there is less consensus on what enables mobility for PLWD – making it necessary to conduct this research with diverse populations in diverse settings to build an evidence base that is context-specific and intersectional. Building this base requires participatory methods and designing “with and by misfitting bodies” instead of designers making decisions based on a set of principles/values (Hamraie, 2013, p.23). To build this evidence base, this research uses an older adult mobility framework to examine the built environment barriers and supports to mobility (Franke et al., 2019), and centres the research on the lived experience of the participant. This study is guided by the following:

Research Question: What are the built environment barriers and supports to mobility as identified in familiar neighbourhoods by PLWD in suburban Canada?

Research Objectives:

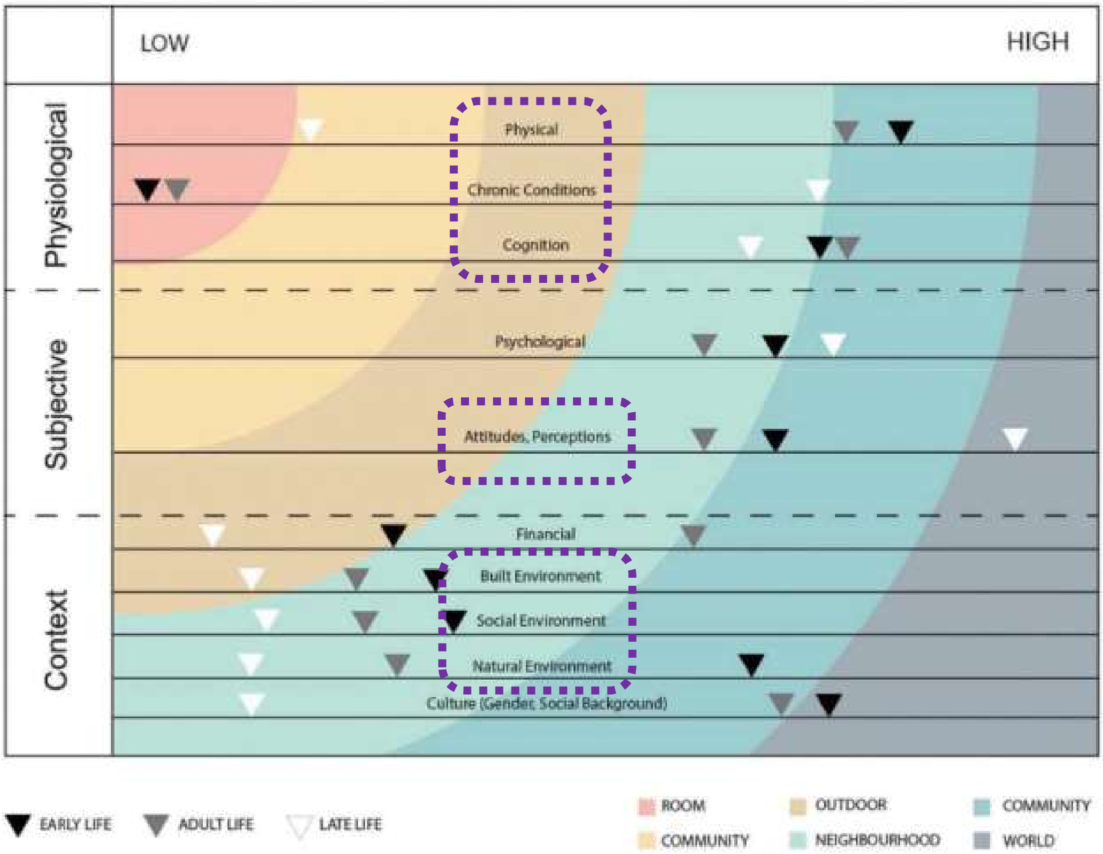
(1) Identify built environment features that PLWD like, make them feel safe, comfortable or dislike, make them feel anxious, afraid or confused.
(2) Identify built environment features that help PLWD navigate their familiar built environment.

4.2.1 Conceptual Framework – Mobility

To address the research question, this study used the interdisciplinary conceptual older adult mobility framework developed by Franke et al. (2019), which adapted the original developed by Webber, Porter, and Menec (2010). The former added key components to the framework, including subjective experiences, temporal dimensions, seeing the environment as built, natural and social and conceptualizing mobility as reflected along a spectrum. Franke et al.’s (2019) framework focuses on three aspects as influencing mobility at scales ranging from the home to the community to the globe: Physiological (physical, chronic conditions, cognition), Subjective (psychological, attitudes, perceptions) and Context (financial, built/social/natural environments and culture). The stated purpose of this framework was to inform clinicians and community workers on how to identify mobility changes in individuals over time, however, they call on scholars from diverse disciplines to study different components of the framework.

This paper focuses on the latter, by investigating components of the framework to help planners and urban designers consider how to alter the built environment to enable mobility.[21] However, the complexity of mobility within this framework is recognized, as is the agency of people to (re)make their built environment to be accessible to them through diverse means such as technology, exercise, and social networks. Using the conceptual mobility framework developed by Franke et al. (2019) – this paper concentrates on how the *built, social and natural environments* component of the framework at the *neighbourhood level* affects *subjective attitudes/perceptions* of these environments for a group of people with *physical/chronic and cognitive conditions* (See Figure 4.2). This study will identify how those built environments could be adapted to enable mobility for PLWD in suburban settings.

Figure 4.2: Aspects under study as identified in the Franke et al. (2019) Mobility Framework



---

[21] Further, this research is part of a larger project which reports on these complexities in Chapter 3.

4.3 Materials + Methods

This research was part of a larger study that explored the everyday lives of PLWD in their neighbourhoods. The overall study with each participant included an introductory interview, two go-along interviews, two-week GPS tracking and travel diaries, and field research at local public planning consultations. The Office of Research Ethics approved this research protocol at the University of Waterloo. Participants were recruited through community organizations and self-identified as living with mild-to-moderate dementia. These participants ranged in age from 57 to 81 and all live in the community (as opposed to congregate or supportive care settings). All participants lived in a neighbourhood classified as an 'Auto-Suburb' by Gordon (2019) except one, who lived in an 'Exurban' neighbourhood.

Table 4.1: Participant List

Pseudonym	Participant, Age at time of Fieldwork	Condition Causing Dementia Symptoms (self-reported diagnosis)	Neighbourhood Typology (Based on Gordon, 2019)	Care Partner
Don	Male, 71 years	Early onset Alzheimer's disease	Auto Suburb	Wife (Retired)
Lorraine	Female, 81 years	Alzheimer's disease	Auto Suburb	Husband (Retired)
George	Male, 65 years	Early onset Alzheimer's disease	Auto Suburb	Wife (Working)
Douglas	Male, 65 years	Early onset Alzheimer's disease	Auto Suburb	Wife (Working)
Alexander	Male, 58 years	Parkinson's disease	Exurban	Sister (Working)
Violet	Female, 57 years	Early onset Alzheimer's disease	Auto Suburb	Husband (Working)
Elizabeth	Female, 56 years	Early onset Alzheimer's disease	Auto Suburb	Husband (Working)

This paper uses the two go-along interviews (Carpiano, 2009; Lee & Dean, 2018), and is supplemented by data from GPS tracking and travel diaries. During each go-along interview, participant observation was conducted, paying attention to participants' embodied reactions to the surrounding environment (Hand et al., 2017). During the first go-along interview, participants were instructed to take the researcher on a 'tour' of their neighbourhood and follow a path they would normally take. The researcher selected the second go-along interview route based on the most frequently travelled route by the individual participant, as identified after two-week GPS and travel diary tracking. Participants, during this second interview, were also given two prompts and asked to identify at least three of each of the following during the walk:

- Supporting/enabling built environment features ("something that you like, makes you feel safe, comfortable, or helps you find your way")

- Unsupportive/disabling built environment features ("something that you dislike, makes you feel anxious, scared, confused, or uncomfortable")

When participants identified a barrier or support during the second go-along interview, the researcher took a photo and a video in which the participant narrated the experience.

4.3.1 Data Analysis

Typically, go-along interview data is analyzed through traditional techniques like line-by-line coding or analyzing fieldnotes (Finlay & Bowman, 2017; Hand et al., 2017). However, these analysis techniques ignore the integral spatial information that is being experienced during the walk. In response, this paper used a novel technique to integrate the transcript with geolocated imagery. Go-along interviews were geocoded, and visual images of locations linked to quotes post-interview (either through researcher-participant captured photos or using Google Earth imagery). These images (with quotations) were treated as documents (Cannuscio et al., 2009) and analyzed for content based on the dominant built environment features as described by participants (Fusco et al., 2012). Using four of the thirteen go-along interviews as a test, researcher (SB) identified three built environment feature categories – land-use, urban design, and wayfinding. These themes were then confirmed using peer checking by the second researcher (JD) (Baxter & Eyles, 1997; Brown et al., 2015). The remaining images and corresponding quotes (n = 268) were coded into the three categories using qualitative data analysis software Atlas.ti. Corresponding quotes and images were also tagged with further descriptors of: (1) the participant's embodied and verbalized responses to the built environment (e.g. like, dislike, comfort, discomfort, neutral), (2) description of how they related to a particular place (e.g. socio-spatial relationships, memories, daily amenities, turning cue, or not applicable), and (3) further descriptors of the built environment features (e.g. green space, street crossing, trail). These images were printed and selectively coded within the three categories to identify enabling and disabling built environment features in suburban neighbourhoods for PLWD. They were further divided into sub-categories based on the built environment feature being described. Some photos were counted in two or more categories, as they related to both. For instance, one participant discussed being close to a drug store as important because it was close to their house (related to proximity and therefore put in the land-use category), in addition to it being a landmark for them (it is on the way to their bus stop) and therefore also placed in the wayfinding category.

All participants were walking in areas they felt comfortable and familiar in, as opposed to unfamiliar settings. This is an important distinction to make as these brain processes are considered different (Gärling, Böök, & Lindberg, 2013), and dementia symptoms frequently affect areas of the brain related to navigation and memory. All participants during these walks said how they "just knew where to go" because they were in a familiar environment. In terms of limitations, this study was conducted without a control group of participants, so it is not possible to make comparisons between these groups. Further, the participants were all Caucasian, Canadian-born, and lived in similar suburban landscapes during their lifetime, so the results reflect that certain part of the population.

4.4 Results

In 1960, Lynch wrote the following in *The Image of the City:* "A good environmental image gives its possessor an important sense of emotional security. He [sic] can establish a harmonious relationship between himself and the outside world. This is the obverse of fear that comes with disorientation; it means that the sweet sense of home is strongest when home is not only familiar but distinctive as well," (p. 4-5). All participants whose experienced comfort produced by their sense of familiarity, and talked about how they "just knew" where to go in their neighbourhood - "I just know this. I've learned it so many times," (George) and "Yeah. Well especially in my area, because I know this area...Because we've been here so long that it seems really easy for me," (Violet).

Some participants had difficulty stating how they knew where to go - "...I mean what can I tell you. I don't use, I don't use [land]marks like that very often. I know my route. I have known my way around this," (Don). However, these strategies became clear when the researcher asked why they were turning or asked participants to point out things they thought were important. Another common theme participants discussed were fears associated with being taken out of the environment that they know so well. "Yeah, it is. Like I said, if you took me out of the comfort zone, like if we went to the city, well then I could be a little confused," (Alexander) or fears associated with moving "…that would be hard for me. Because I would have to start again," (Violet). Another participant related his familiar environment to a box he keeps the cobwebs off of:

> *"Like in this little box is that and I keep the cobwebs off that box. So I can look in and see what I need, where I am going, whatever you know...Home Hardware is that box.... And you know I have got everything I need. I have got Canadian Tire. You know I got Home Hardware, and half a dozen other little things places to get things." (Don)*

For this participant and others, it seems the edges of their familiarity form the boundaries of their mobility when they are outdoors by themselves: "Where I walk is generally places I know," (Lorraine). That sense of familiarity is a common finding in studies on PLWD and their environments. The question becomes – what influences the size of that metaphorical box, and the limits within which PLWD can be enabled to move by themselves.

In all, 268 photos and corresponding quotations were generated from seven participants in thirteen go-along interviews (two per participant, except for one who declined to take part in a second go-along interview). These photos were separated into three categories of (1) land use - *67 images* (including street networks, and essential land-use characteristics and components like greenspace and mixed-use zones); (2) urban design - *170 images* (including streetscape features, architectural styles, building massing, and landscaping); and (3) wayfinding - *90 images* (including landmarks, and signage as identified by participants). These images were further separated into subcategories based on the content of the photo then discussed in terms of barriers and supports to mobility.

4.4.1 Category 1 – Land Use

A total of 67 images and quotations were sorted into the category of land-use. The first subcategory consists of ***proximity to destinations*** like: places to purchase items; natural places (e.g., parks, trail systems, and walking around the block), places for organized recreation (e.g., recreation centres and parks); places to socialize (e.g., friend's houses, part-time job), places to eat, drink and linger (e.g., restaurants, cafes); and places to access services (e.g., doctor's offices, banks). See **Table 4.2** for a list of most common destinations, and transportation modes as defined using the Travel Diaries. This proximity was integral to participants, as they had all stopped driving because of their diagnosis of dementia. They relied on walking, drives from family members and friends, and for a select few - on pre-arranged taxis, public transport and cycling. As a result, participants frequently discussed proximity to their current home location as an important support (or lack thereof as a barrier). Proximity is also a relative term - for some, the walk to amenities was 200m, for others 3.5 - 4km (from the GPS tracking data).

Table 4.2: Summary of trips to destinations over two weeks

Destination Type	Total No. of Trips over two weeks by all participants combined	Percentage of Overall trips	Most Common Transportation Mode Used
Places to purchase	33	31%	Driving (someone else)
Natural places	19	18%	Walking
Places for organized recreation	17	16%	Driving (someone else)
Places to socialize	15	14%	Driving (someone else)
Places to eat, drink, linger	10	9%	Driving (someone else)

Places to access services	6	6%	Driving (someone else) + Walking
Unknown	6	6%	Driving (someone else) + Walking
Grand Total	**106**	**100%**	

The second subcategory was ***street networks***, with participants expressing a preference for a reliably connected street pattern (without dead ends or winding) combined with the ability to see far in the distance. Many participants discussed straight, connected streets as a support to mobility and accessing their neighbourhood (Douglas, George) while angled, dead-end or curved streets produced a sense of frustration for participants (Lorraine, Douglas, Don). Straight streets allowed for greater visibility: "I am saying is it easier to know where you are going because you can see really far ahead of you," (Douglas). Further, participants liked street designs where their walks did not have many decision points, like Douglas, who only had to turn three times to reach amenities 4km away (see **Figure 4.3**). There were, however, conflicting views on the best kind of street network, as one participant guided the researcher on an approximately 900m loop, and when asked why - "because it goes right down and around. I can go back…so this is a kind of loop I do," (Elizabeth – **Figure 4.4**). One way to overcome proximity barriers associated with typical suburban loop and lollipop design was through a pedestrian walkaway between a participant's subdivision and the arterial road on the edge, eliminating the need to find a road exit from the subdivision (see **Figure 4.5**).

The third subcategory, related to the street network, was preferring to use a ***trail system*** for walking. Often trails integrated into the participant's neighbourhood by connecting their house to amenities. Trails were an opportunity to avoid the noise of a road and preferred for the opportunity to be in nature (see **Figure 4.6**). They were also used as shortcuts and perceived as straight forward, in that they could follow the trail to their desired location, minimizing the need to make decisions at intersections, and decreasing opportunities to veer off. There were however barriers to using trails, like poor maintenance (in winter/spring months) and trails being non-continuous (in one case switching between different sides of a road).

The final subcategory is ***land-use segregation.*** All participants cited their suburban single-use residential zones (majority single-detached dwellings with commercial land uses on the edges) as quiet, safe and familiar. Mixed-use zones (often classic 'small town' downtowns, with 2-3 storey buildings and small storefronts) were also cited as supports, and enjoyable places to walk through. This was in contrast to single-use commercial zones, often characterized by loud, traffic-heavy arterial roads, and parking lots, which seemed to put participants "on alert".

Figure 4.3: Simple walking route

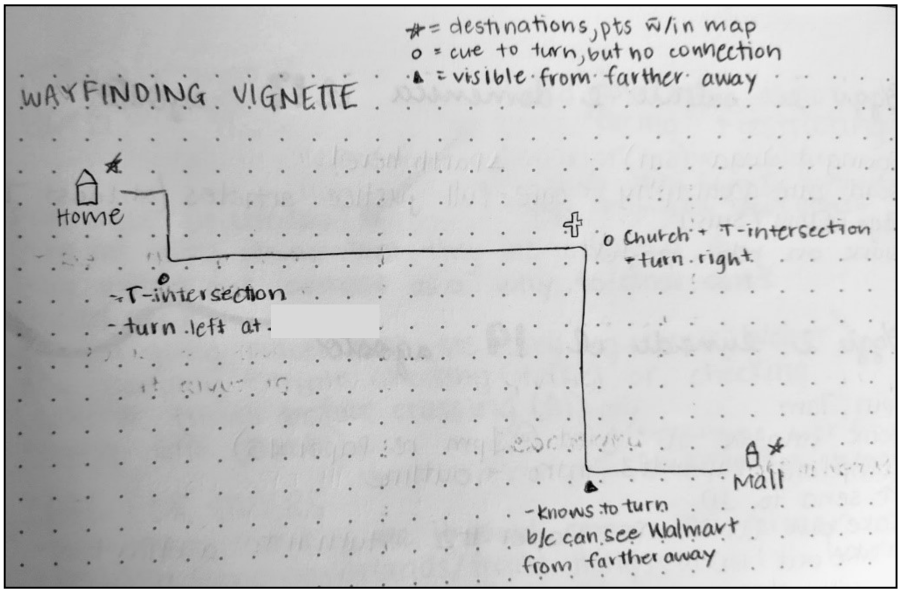
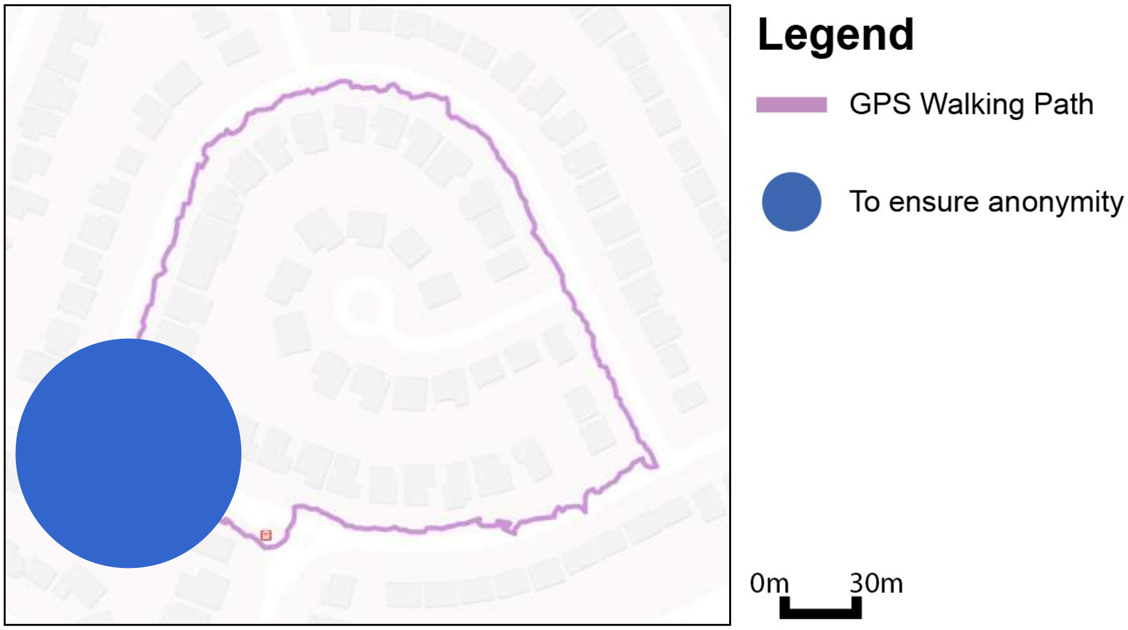
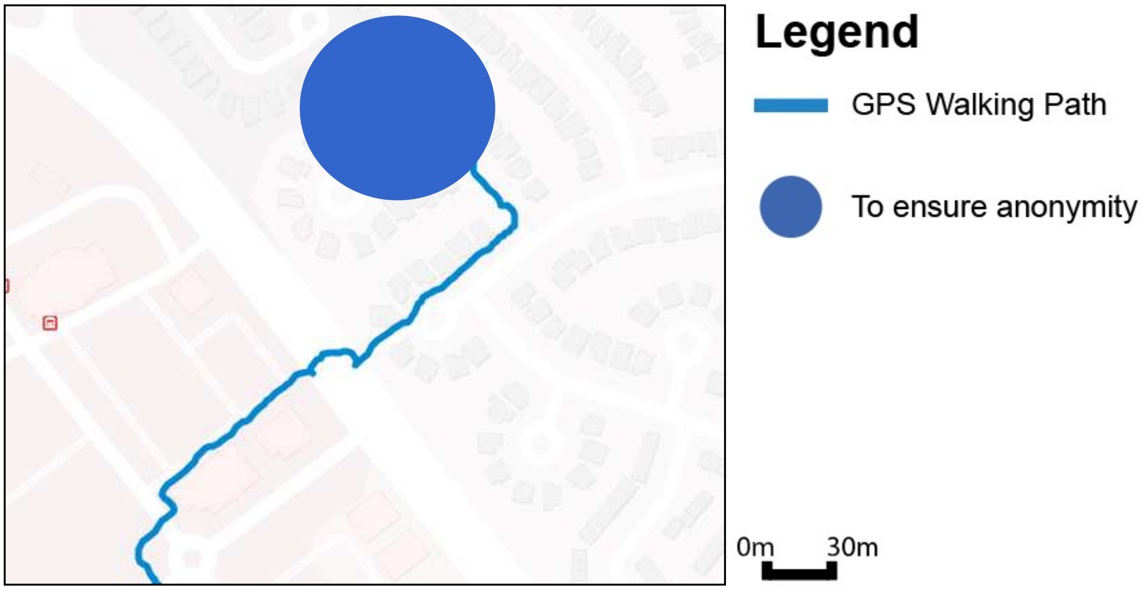


Figure 4.4: Preferred Loop Walking Path



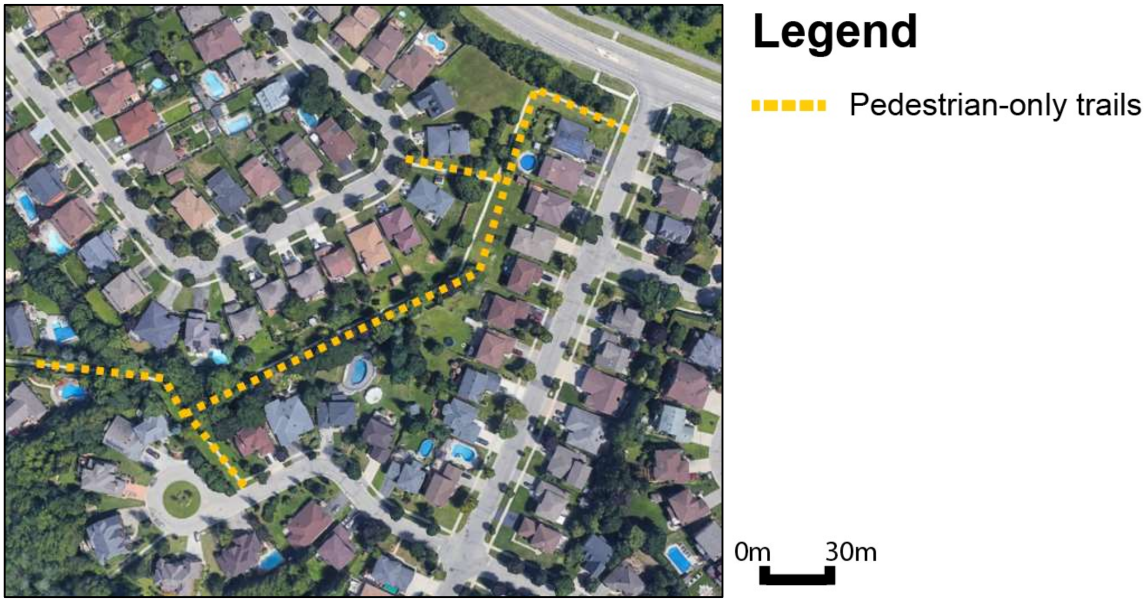
©Google Maps, 2019

Figure 4.5: Pedestrian path to exit the subdivision



©Google Maps, 2019

Figure 4.6: Preference for trails



©Google Earth, 2019

4.4.2 Category 2 – Urban Design

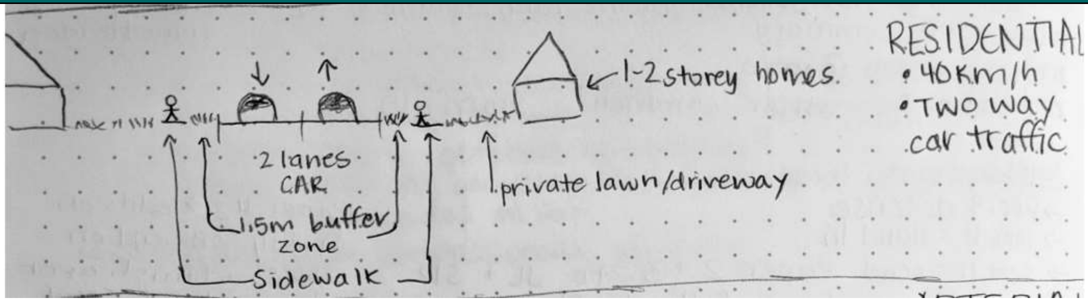
A total of 175 images were sorted into the category of urban design, with the subcategories being: streetscapes; street crossings; trails and parking lots. Many of the built environment supports identified in this category were described as comfortable, quiet and safe, while participants described built environment barriers as loud, with a lot of car traffic.

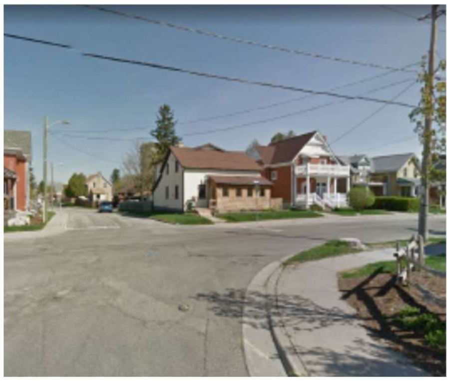
4.4.2.1 Streetscapes

The two streetscapes commonly selected during all of the go-along interviews were residential and arterial roads. While residential roads were most likely to be described as a comfortable streetscape, mixed-use areas in historical downtowns were also cited as supportive. All participants stated how comfortable their suburban single-use residential neighbourhoods were, often highlighting the quiet, few cars, sense of safety, and familiarity. Streetscapes identified as uncomfortable were most likely to be arterial roads or highways, and were only used out of necessity to access amenities in their neighbourhood - "I need to get where I am going so I come… But it is not my favourite way to walk… it is close to so much busy, smelly, traffic," (Lorraine). "No, I mean I go… But it's like a [highway] in the middle of town…they're not supposed to be going this fast but they always go that fast… zoom… cause it's straight right," (Douglas). See **Table 4.3** for cross-sections and sample imagery. During the go-along interviews, participants were 'on alert' when on arterial roads compared to residential ones. This is not only important because of their sense of comfort/lack thereof, but because PLWD are more likely to become overwhelmed by noise and activity, which will restrict their activity space and perhaps cause them to make mistakes while navigating (Brorsson, Öhman, Cutchin, & Nygård, 2013; Mitchell, Burton, & Raman, 2004).

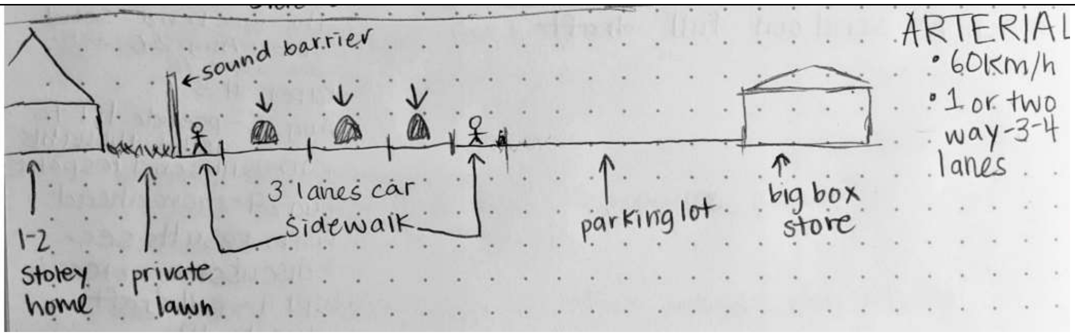
Table 4.3: Sample cross sections and photographs for major street types

<table>
<tr><th>Streetscape Type</th><th>Streetscape Cross-Section(s) and Captured Imagery</th></tr>
<tr><td>Residential</td><td>





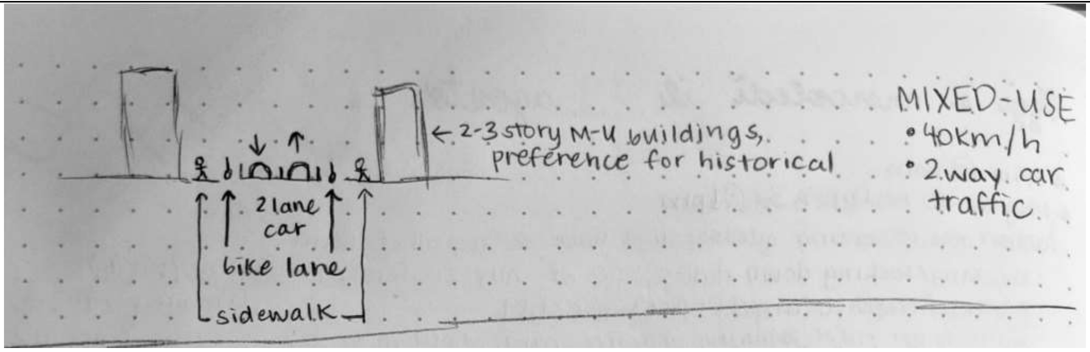
</td></tr>
<tr><td>Arterial Roads</td><td>

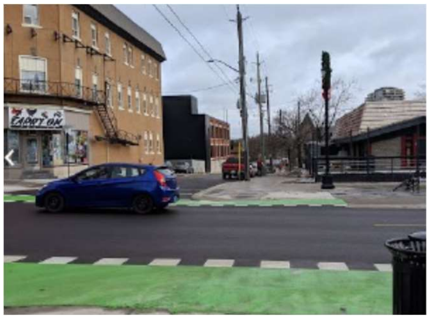


</td></tr>
</table>

<table>
<tr>
<td></td>
<td>



</td>
</tr>
<tr>
<td>Mixed-Use</td>
<td>




</td>
</tr>
</table>

4.4.2.2 Street Crossings

Street crossings were one of the most common themes that arose during the go-along interviews, combined with negative sentiments. All participants in one of their go-along interviews crossed a street they deemed unsafe, uncomfortable or disliked. There were, however, instances at other intersections where participants seemed at ease. These were often well-designed protected pedestrian infrastructures or quiet residential streets with low levels of traffic. One participant described an increased feeling of stress and panic since her diagnosis, even when crossing residential streets: "I feel a bit nervous… Because I just worry that they are going to, I don't know. Not slow down for me, and so I kind of feel a bit panicky…That is a new thing too is panic… I get panicky and freaked out yeah," (Elizabeth).

Jaywalking. Participants preferred to cross roads with pedestrian protective infrastructure (e.g. street lights, crosswalks, stop signs). However, nearly all participants engaged in some form of jay-walking, often because they perceived the protective crossing infrastructure as being too far from their desired path. This is problematic because PLWD might experience impairment in terms of depth perception and risk-taking. Therefore, it might be said that this kind of jaywalking behaviour can be even more risky for someone living with dementia, especially with roads that have cars going 60km/h and above. Participants decided to jaywalk on residential streets (2-lane, 40km/h), mixed-use streets (2-lane, 40km/h, more traffic), 3-lane one-way arterials with speeds over the 60km/h limit and 80km/h highways. The decision to jaywalk was a calculated one - one participant crosses an 80km/h 2-lane highway to stay on a protected trail that switches sides of the road to avoid the traffic noise while walking (George). In most jay-walking situations on arterial roads, participants ran across, and while they said the crossing was fine – the researcher noticed that they had to concentrate, and looked uncomfortable prior to and during the crossing, besides often expressing relief once it was over.

Other participants crossed 60-80km/h 4-lane roads and stopped in the middle on a median, to avoid walking the extra 100m - 370m to protected infrastructure crossings (Alexander, Violet). "I will just wait for traffic to clear and then I will just walk across. Stand in the middle median thing…I don't care then after that… because I am halfway and then I can watch the traffic as it comes straight through there like it does," (Alexander). This use of a median over protected infrastructure is congruent with findings from Brorsson et al. (2013) who found that when using zebra crossings, PLWD were stressed about negotiating cars coming from multiple directions (experiencing cognitive overload). With a median, PLWD only have to pay attention to one direction of car traffic, as opposed to multiple.

Protected Infrastructure. While participants preferred to cross at protected pedestrian infrastructure, there were several features highlighted that they did not like, avoided on purpose, or made them feel uncomfortable. Participants frequently used suburban arterial road intersections, and even though there was always some protective infrastructure in the form of street lights, participants were often 'on alert'. They were most often characterized as busy intersections with a lot of car traffic, high speeds, cars coming from multiple directions and a lot of noise: "It is so noisy," (Lorraine). Roundabouts were also avoided, however, some roundabouts in the area had protected pedestrian walking paths across ingress/egress points, with a median. This was perceived as safer than the actual roundabout: “I like how they have this…the pathway…so I don’t go around that thing,” however the participant behaved carefully at these crossings: “I do wait until someone stops,”, and adds that a stoplight would feel safer (Violet). Some participants saw a lack of protective infrastructure as forcing them to remain on ‘their side’ of an arterial road, thus limiting their mobility: “But I could probably be a little bit more adventurous as I say, but I don’t like to cross without a street light on the big streets, so that is why I am sort of stuck on this side of a [4-lane, 60km/h road],” (Lorraine).

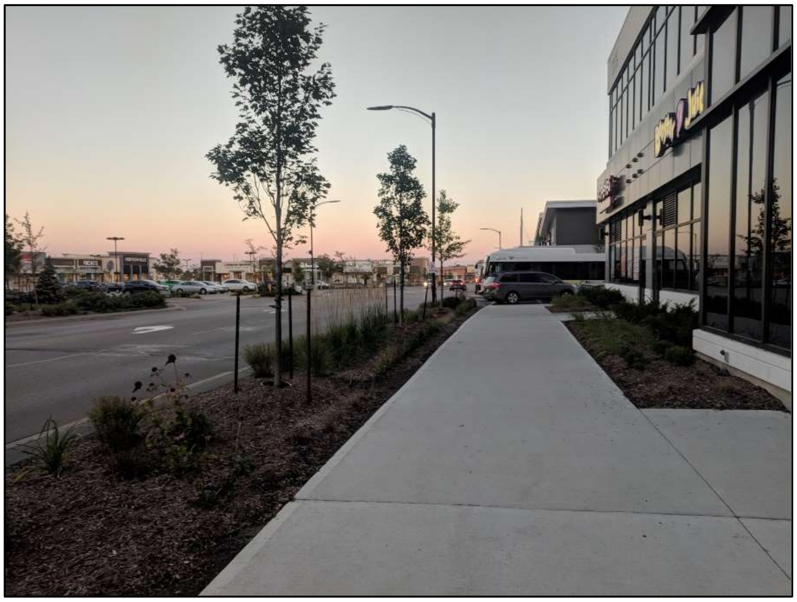
Suburban arterial intersections considered supportive were those with streetlights with buttons to stop traffic (Douglas), zebra crosswalks clearly delineated with a crossing guard (Douglas), stop signs with little traffic (Alexander), and any intersection with fewer cars (George). Some participants suggested that pedestrian crossing indicators at intersections (e.g. walk signal) should be placed at pedestrian height - “because most older people walk like this [crouched over, with their head down],” (Lorraine). There was however one downtown plaza that felt comfortable to a participant even though it had seven streets feeding into the area, because of the lower speed of cars and fewer of them (George).

4.4.2.3 Parking Lots

A central feature of suburban landscapes and accessing amenities is a parking lot. Parking lots were perceived as sometimes being overwhelming with the cars “coming around here and across there and then through there and it just [makes me feel] nervous. I don’t come. If I can get here, I don’t come then [at busy times]…[describing the atmosphere near a fast food drive thru] it scares me kind of…cause there you’ve got all sorts of cars coming in for that. And it can be really crazy,” (Elizabeth, see **Figure 4.7**). While some participants did not explicitly say they were fearful of these areas, they described being “all ears and eyes… I do not trust a person coming out of a parking spot,” (Douglas) and another saying “You have to be aware. I mean you are not aware - you are liable to be dead… and it won’t be the guy’s fault either,” (Don). Participants described going to these commercial areas with their large parking lots at certain times of the day to avoid the busyness (Douglas, Elizabeth, Violet). There were however different infrastructures within these commercial areas that participants deemed supportive including: accessible parking spots (Lorraine), shaded areas (Violet), speed-reducing measures (Douglas), protected pedestrian pathways through parking lots from spots to stores vis-a-vis painted lines (Douglas, Elizabeth, Violet), wide sidewalks with greenery on either side (Violet, **Figure 4.8**) and raised sidewalks in front of stores (Violet).

Figure 4.7: Unsafe parking lot

Figure 4.8: Protected pedestrian pathways in parking lots



4.4.3 Category 3 – Wayfinding

A total of 82 images were sorted into the category of wayfinding, fitting into two subcategories: landmarks and signage.

4.4.3.1 Landmarks

As mentioned, wayfinding in familiar environments depends on one's cognitive orienting schema. This section investigates the proprieties of landmarks that PLWD use in familiar environments and is organized based on how the participant uses the landmark, their connection to it and the built environment feature qualities of those landmarks.

4.4.3.1.1 Destinations as Landmarks

Many participants discussed different destinations as landmarks, which seemed to form the anchors of their cognitive map. These destinations were places participants guided the researcher to or discussed during the go-along interviews. They were prominent in participant's minds, as they had some kind of social connection with each location. The destinations relate to the 'proximity to' land-use category.

Places to purchase/browse. Many of the destinations identified by participants were places that they made regular purchases. For instance, some participants frequented their local pharmacy to pick up prescriptions (Lorraine, Alexander, Elizabeth, Don) and for one participant, feeling "being known" by the staff was important (Alexander). Other entities highlighted by participants include grocery shops, butcher shops/delis, the bank[22], the liquor store, and bus stops (Alexander and Elizabeth). Participants also pointed out stores they liked to browse in, as opposed to making regular purchases. This included a series of thrift stores for one participant (George) and an eclectic store where "everything has a story. It's made by people who rent out space. A lot of stuff comes from all over the world," (Elizabeth). Most participants also identified entire commercial plazas as landmark destinations, conceived of as having everything you could ever need: "You could have a house right there. Never have a car. You can get everything you want right here," (Don). This is likely because of a social connection to one or more individual stores within the plaza (e.g. Walmart for Violet, Tim Horton's for Don), but also because of its difference from the rest of their low-rise single-use residential neighbourhood.

Places of purpose. None of the participants in this study worked full time, despite many being under the age of 60. Some landmarks identified by participants were related to feeling a sense of purpose. For one participant, this was a part-time job in an industrial zone (Alexander), for the other

---

[22] Some participants explicitly said they no longer go to the bank - their partner does for them (Violet, Douglas).

three male participants, it was the local hardware store that they could walk to if they needed something while working on a home improvement project (Don). For two of the female participants, destinations of purpose included a discount store to purchase groceries for the household.

Places to recreate. There were different destination landmarks mentioned by participants as places for recreation. For some, this was the local community centre where one participant does Tai Chi and socializes (Lorraine), and another does group fitness classes (Don). Don takes his grandchildren to play at a park with a swimming pool, while George takes grandchildren to a zoo in a park (Don, George). For another, it was a commercial gym where one participant works out on her own (Violet). For two other participants, this was the local library where they could access books, puzzles and games (Lorraine, George). For another, this was choir practices at her local place of worship (Elizabeth). All participants also mentioned a day-program they attend with other people living with dementia. However, since they travel there by private vehicle driven by others or pre-arranged taxi, often participants did not describe the physical landmark but knew it because of their experiences at the program.

Places to linger/socialize. This included going to a place to be around people, frequently strangers or acquaintances. For one participant this meant attending the local seniors' community centre club, where he engaged in programs and accessed affordable food/beverages (George). For Don it was about visiting the local Tim Horton's café that had friendly people and workers who looked after you: "And these guys in this Timmie's is, they look after like when older people go in there…they look after them. They make sure that, like they don't just, like if you go away and leave something there, they are running down the street saying hey! That kind of stuff you know?… Go over there and sit beside somebody. It is very friendly…because it is lots of mature people. Older in other words," (Don). Another landmark was the town hall plaza because of its association with events that bring people outside - "They do art shows in here and crafter sales. Ah, they turn it into many things. Throughout the summer there's night fun kids' stuff, a musician - the city puts it on in front of the city hall…kids love it," (George). Another participant talked about stopping near a splash pad and watching kids "Sometimes I just sit there and laugh, and these little kids come up and ask what are you laughing at," (Violet). For others, they identified places associated with family members, including children's houses (Don) and sibling's workplaces: "This is just where if I'm bored and got nothing to do, I'll come up and say hi. Blah, blah and leave again," (Alexander). Even if the family member is not home, Don mentioned how he walks by anyway, to have something to talk about later with his grandchild, "It is like… you say hey, nudge nudge - I walked by your place the other day or say something to [his grandchild] - young guy, where were you? I was over here looking for you and there you were, gone. What the heck, blah blah, just jab him a couple of times. So I use things to mix into the conversation, so I can do that poke, jab type of humour," (Don).

Preferred places to eat included an accessible coffee shop with ramps and automatic doors (Elizabeth), a cheap neighbourhood diner, McDonald's (Alexander) and even a local seniors' centre with affordable food and beverages (George). Accessibility, good taste and affordability were key factors - as Alexander stated about the McDonald's "It's where I get my little cheeseburgers, something cheap. And I like em cause they're fresh. It's quick and simple. Good for your waistline. I mean, like for 5 bucks, you can get two cheeseburgers and stay under 5 bucks so you're doing okay and you still get pickles on". These places had large, recognizable signs on the front of the location, making them perhaps more identifiable by participants.

4.4.3.1.2 Leprechauns, Little Libraries + Gardens: Homes and Front Yards as Landmarks

Suburban landscapes with their predominant subdivision style developments are often characterized by their sameness. As a result, participants repeatedly identified private homes that stood out as landmarks during their walks. Seeking 'unique' gardens or garden elements was common, with examples including a stone garden, vegetable garden in a front yard, a community garden, a well-developed rose bush, a small chair for a leprechaun, and a large bird ornament. 'Little libraries'[23] were also seen as landmarks to be engaged with by participants - and on one walk, Elizabeth ended up selecting a book to take home (**Figure 4.9)**. Houses were identified as unique for reasons like a large red RV parked in one driveway year-round (**Figure 4.10**), solar panels on a roof, a large porch in a neighbourhood that had none, a front façade covered in ivy and a well-manicured larger home that was distinct from the rest of the area. For Douglas, the defining feature on one house was a balcony that nearly always had an older couple sitting on it who would wave: Douglas: "Good weather you will see them, him and her." Researcher: "That matters." Douglas: "Yeah." (**Figure 4.11**). While these characteristics might not seem distinct in isolation, it shows how PLWD create landmarks for themselves based on the difference from the rest of the built form in the neighbourhood.

---

[23] 'Little libraries' are neighbourhood book exchanges. Homeowners erect a small case on their property and invite members of the community to borrow, take, and leave books. For more information about this international network, please see https://littlefreelibrary.org/

Figure 4.9: Little library landmark

Figure 4.10: RV as landmark

Figure 4.11: Balcony social encounter as landmark

4.4.3.1.3 Rivers, McDonald’s + City Hall – Landmarks as Compasses

Some landmarks were identified by participants from farther away, and they often acted as an orientating mechanism - giving the participant information about where they were in the grander scheme of things. They identified landmarks that function as the Eiffel Tower does in Paris, like a compass. For instance, one identified their apartment complex during the go-along interview, saying that it was visible anywhere in the neighbourhood (because it is the only high rise in a low-rise area) (Lorraine), a city hall clocktower or church spire (George). The city hall tower could also be heard from farther away - a soundscape landmark, “That’s city hall. They have electronic chimes in there every hour. Hear ‘em from our house,” (George) (**Figure 4.12**). For others, these compass-like landmarks were visible in certain landscapes. Don identified the ‘big white house’ on a street in his neighbourhood as a way of orienting himself to different routes he can take while walking his dogs. Other participants used landmarks to discern when they were getting close to where they wanted to go. This ranged from George being able to see the downtown area because of the tall historical buildings in a natural landscape and pedestrian bridge crossing the river to Douglas and Violet identifying the Wal-Mart sign and Alexander identifying McDonald’s as something recognizable from far away and used to know that they are travelling in the right direction. “Like I said, there’s McDonald’s, can’t miss it,” (Alexander). Most of the landmarks that participants identified from farther away were single buildings or built environment features. George used a river as an orientating landmark, which guides him from near his home to the central business area. When asked if he follows the river on his walks, “Yeah - you can’ t go wrong with a river. They don’t move [giggles]. It takes them a long time to change their minds… you’ve got compass points built into the landscape…wonderful landmark, baring, locator - terrific,” (Don) (**Figure 4.13**).

Figure 4.12: City Hall as orientating landmark (visible and audible from farther away)

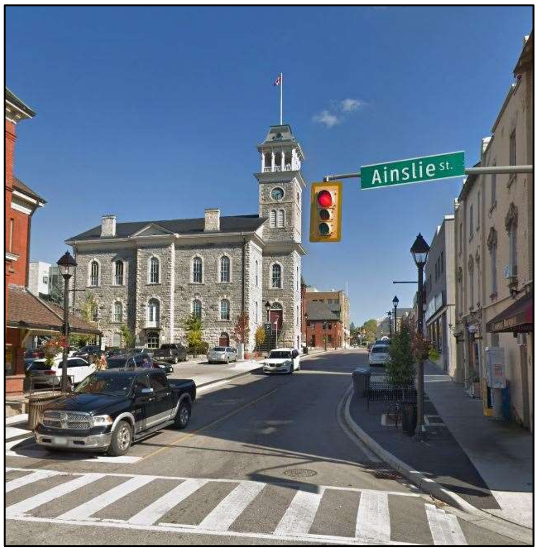
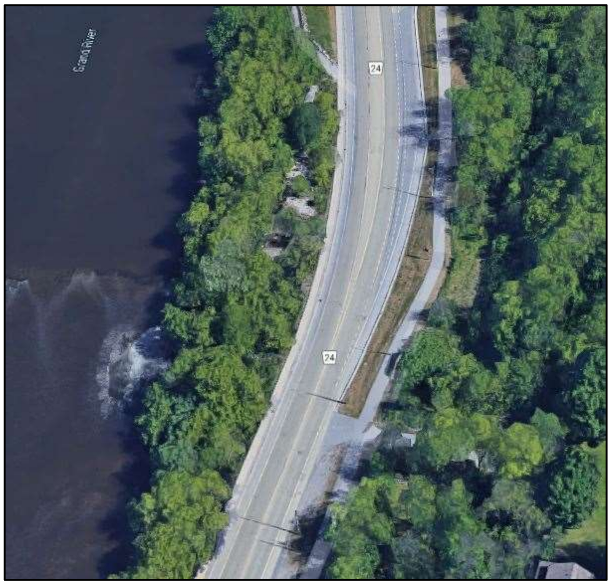


Figure 4.13: River as orientating landmark



4.4.3.1.4 Go Right at the Church – Directional Landmarks

Some participants identified built environment features that were not destinations, but seemed to provide information about what to do next or were recognized on the way to a final destination. Participants identified stores and restaurants that they do not frequent, however, used them to provide information about changing direction. Violet identified places like a restaurant with a big red sign, then a pet store that acted like beacons, showing the way home to her house. Alexander identified a restaurant without a prominent sign, but in the shape of a long bungalow style home in a suburban industrial/agricultural area as his cue to get off the bus (**Figure 4.14**). Douglas uses a small commercial plaza as an indication to turn but says he never uses the stores there. Alexander identified a pond with ducks that indicates he is on his way to a destination - where he “stop[s] and check and see how many ducks are in my pond”.

Few participants identified historic landmarks, which makes sense because most participants live in North American suburban landscapes. This included identification of a historic district that provided information to the participant about the direction of his house (George). Other participants identified historic landmarks during the go-along, like a cenotaph associated with community Remembrance Day[24] events (Alexander), and a perceived ‘odd’ church because of its architectural features (Lorraine). Only one participant identified public art during the go-along interview, viewing it both negatively and neutrally (George).

In terms of intersections, one participant used a church, combined with a T-intersection as an indication to turn right to continue on his journey (Douglas, see Figure **4.15**). Intersections like a dead-end and crosswalk for children to go to school were perceived as a landmark for their proximity to their homes (George, Douglas). Further, entrances to trails from streets all served as landmarks for participants, directing them to use the trails (Violet, Douglas, George). This included a walkway between the neighbourhood and the arterial roads on the edge of the subdivision; and an entrance to a pedestrian-only path and entrance to a naturalized area. Last, when lacking distinct landmarks (in a suburban industrial zone), one participant mentioned that he “just kind of keep[s] track,” of features as he passes them, like a group of parked school buses and long-haul trucks or a waste management building (Alexander).

---

[24] Also known as Veterans Day in the United States.

Figure 4.14: Restaurant as cue to exit the bus

Figure 4.15: Church as directional landmark

4.4.3.2 Signage

When participants observed directional signage, they deemed this type of navigational tool as supportive. Signage combining words, arrows and simple symbols was easily interpreted (George, Elizabeth). Other signs were more difficult to interpret as they were mostly symbols, rather than descriptions of the destinations (Don) **(see Figure 4.16).** Don and Douglas suggested more signage in neighbourhoods as something that would help them navigate to major areas, like the local school or the central business district, and Elizabeth said: “I wish that more places would have signs up,”. Finally, Douglas suggested that signage could also warn drivers to slow down in residential areas because PLWD lived in them.

Figure 4.16: Signage in need of more description

4.5 Discussion

To enable mobility for PLWD, this research looked at their perceptions of different built environments (Franke et al., 2019), then categorized the findings based on different built environment features: land-use, urban design, and wayfinding. In terms of land use and urban design, the findings are consistent with much of the literature on the need for building human-scaled, comfortable, pedestrian environments for vulnerable users like older adults, disabled individuals, and children (Gehl, 2010). However, when considering increased risks to crossing or using roads safely for PLWD because of impaired depth perception and judgement, and being more easily overwhelmed by noise/activity, these recommendations become imperative to mobility for this group. In terms of the wayfinding category, there is much less literature from an urban planning perspective to create legible built environments for PLWD. This research shows it is important to investigate not only Lynch's (1960) 'public images' (what is most recognizable by a larger group) but also the perspectives of those of marginalized groups, especially PLWD who experience specific issues related to navigation. While this research separated the findings into three categories, they are also intrinsically linked components. For instance, without the proximity produced by mixed-use nodes in relation to residential zones (land-use), people might have fewer landmarks to situate within their cognitive map (wayfinding), and fewer destinations to access. Then, even with all of those elements, if the street crossing is perceived as unsafe, too far away, inconvenient, or prioritizes cars instead of people, PLWD are unlikely to find it as supportive to their mobility (urban design).

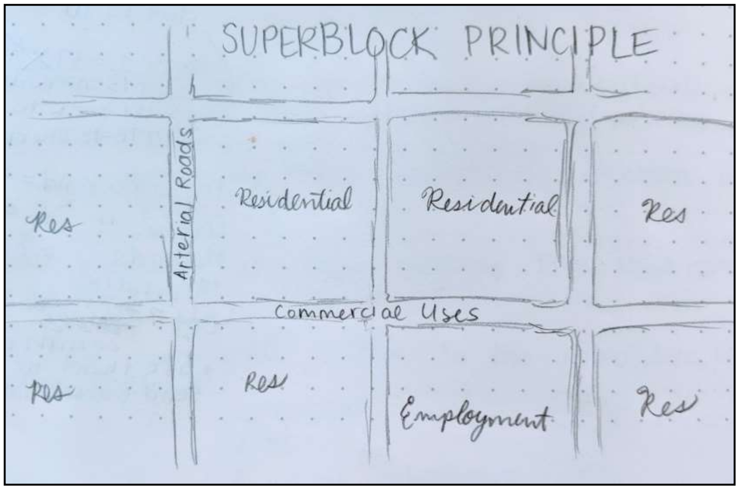
4.5.1 Category 1 – Land Use

Perhaps unsurprisingly, participants cited the proximity of amenities they had a social connection to, green spaces, and trails, as well as a grid network of connected streets as supportive. This is consistent with the literature on the need for mixed-use nodes within neighbourhoods for PLWD, and with research on older adult mobility more generally (Loukaitou-Sideris, Wachs, & Pinski, 2019; Kerr, Rosenberg, & Frank, 2012; Burton & Mitchell, 2006). In many of the suburban landscapes in which people lived, there were some destinations accessible on foot, mainly in the form of commercial plazas, and parks. Barriers were often the opposite of these features including amenities located out of walking distance, slanted/curved streets and dead ends/ interrupted street patterns. While participants felt the proximity to destinations trumped comfort, minimizing these negative overstimulation effects from cars and arterial roads would be beneficial for PLWD. This is also consistent with Mitchell, Burton & Raman's (2004) findings in the UK, which showed an increased level of stress in these types of overstimulating situations. Overall, the findings fit with those made by Burton & Mitchell (2006) in their original study. However, participants in this study highlighted green spaces like parks and naturalized areas as important to them, in addition to using pedestrianized trails instead of roadways. Another unique finding of this research was not that the proximity of amenities was important, but the participants' rationale for needing them was. All participants discussed familiarity within their neighbourhoods and the fear of leaving that area as important. This is a form of self-imposed mobility limitations, and is influenced by whether or not they have destinations that they can walk to already. Finally, the single-use residential suburban neighbourhoods that participants lived in were cited as supports by every participant for their quietness and familiarity. This challenges the idea of suburbs as definitively unsupportive places to grow older for this group of participants (who have lived for many years in their suburban neighbourhoods) (Golant, 2019).

4.5.2 Category 2 – Urban Design

Residential zones in suburban areas were described as supportive because of the quietness, low levels of traffic, safe crossings, comfortable streetscapes (e.g. buffer zones, shade, historic houses and gardens to look at etc.). These residential single-use zones generally follow the 'superblock' principles that dominate much of suburban community planning in Ontario (Filion, 2018). The by-product of single-use zones are the arterial roads and commercial zones that are located on the edges (see **Figure 4.17**). Participants had to cross these arterial roads to access destinations, posing several barriers, including un/safe jaywalking practices, discomfort walking because of noise and cars, and unsafe pedestrian crossing infrastructures. Participants did, however, minimize their contact with these uncomfortable streetscapes. For instance, they walked parallel to the busy arterial on a quieter side street or followed a protected pedestrian trail that ran alongside the road. Besides encouraging traffic calming practices, building wider sidewalks and buffer zones, planners could consider running parallel routes to major traffic-ways. Further, through policy, planners should encourage more medians within street crossing infrastructures, as only having to give attention to one direction of traffic at a time was considered easier for PLWD. Parking lots are another area for improvement. As an often unavoidable feature of suburban landscapes, with cars moving in unexpected ways, and often lacking demarcated places to walk – parking lots can put PLWD on edge, considering symptoms of being sensitive to noise and sudden movements, as well as having impaired depth perception. Separated sidewalks, predictable car lanes, and traffic calming measures can ease these concerns. Creating safer, predictable, quiet landscapes through these simple considerations could improve the ability of PLWD to process their environments and not become overwhelmed, in addition to making it more comfortable for all pedestrians.

Figure 4.17: Superblock sketch



4.5.3 Category 3 – Wayfinding

> *"There may be little in the real object that is ordered or remarkable, and yet its mental picture has gained identity and organization through long familiarity," (Lynch, 1960, p.6).*

This section reveals the landmarks and wayfinding strategies that PLWD use in familiar spaces, answering O'Malley, Innes, & Wiener's (2017) call for more qualitative research on orientation strategies of PLWD and which cues they select to navigate (p.325). Social connections to the landmarks within their ‘orienting schema’ was integral for PLWD, as these featured more prominently during the go-along interviews (landmarks as destinations). This could suggest that socially-associative places for PLWD are more resilient to resisting dementia symptoms associated with declining navigation skills. It further emphasizes the need to ensure destination elements like green spaces, community centres, places of employment, groceries, hardware stores and restaurants are within walking distance of residential areas.

Similar to findings from (Mitchell et al., 2003), landmarks were often identified at junctions and decision-making situations, suggesting that participants have created these landmarks to situate themselves in these suburban environments of sameness. These kinds of landmarks might be described as directional or beacons in the psychology literature, as participants use them to navigate to other places, or mention them as salient and not use them as end destinations (O’Malley et al., 2017). The issue with smaller landmarks like special gardens and lawn ornaments is that most of these qualities could be considered ‘non-permanent’. For instance, the leprechaun chair might be removed, the rose bush could die or the RV owners could move. In terms of planning guidelines, implementing policy to ensure small landmarks on private property could be considered unreasonable, however, it is possible to require varied architectural forms for greenfield development and encourage individual homeowners to ‘be unique’. For heritage policies, stringent urban design/landscape guidelines might be revisited in the hopes of allowing homeowners to create ‘unique’ features on their own that are distinct. This research also shows that for these participants, suburban landscapes are not as monotonous as they seem. These landmarks were used in a variety of ways by participants - most commonly as something pleasant to walk past, but also as an indication that we were on the right path towards an end-goal (e.g. “and there’s that stone garden I always see”), or as a cue to change direction (e.g., turning right at the red RV). While this research showed that participants are resilient, through creating landmarks with small distinctive features in the landscape, it was clear that more obvious landmarks (like distinctive intersections, historical monuments, commercial nodes, etc.) are more permanent, and might serve as better landmarks for PLWD. This is congruent with previous work with PLWD in unfamiliar environments (O’Malley et al., 2018; Seetharaman, 2018).

The psychological typology of landmarks as serving different functions within one’s ‘orienting schema’ (including as destinations, orienting cues, associative cues and beacons) should be a consideration for planners and policymakers. While one cannot predict with 100% accuracy what PLWD will select as landmarks, research like this can give us insights into what people might use for different navigational purposes. For instance, planners might consider requiring building these kinds of landmarks within the neighbourhood, protecting these types of landmarks within viewscapes, or enhancing natural features like rivers, waterfronts etc. to be more visible from elsewhere in the community or city. For instance, protecting views of the CN Tower in Toronto or the Eiffel Tower in Paris might not only be a historical view issue, but also an issue for navigation. When planning for suburban greenfield areas, planners should consider testing designs to make sure they have planned easy, comfortable walking routes to destinations within their development, providing distinct features at intersections, minimizing the number of turns required, putting in a trail system, and using legible signage. Doing simulated walk-throughs of proposed developments is now accessible through virtual reality technologies, and planners should test routes within their developments to ensure that there are adequate landmarks and accessible signage.

City planners, according to Lynch (1960) should aspire to model an environment which relies on what he calls group or public images - "areas of agreement which might be expected to appear in the interaction of a single physical reality, a common culture, and basic physiological nature" (p. 7). However, this focus on what is perceived by a majority in the group has strong potential alienate others, especially the marginalized. Hamraie (2013) calls upon built environment scholars and practitioners to do the research with marginalized groups to understand what their needs in space, then compare across groups. In retrofitting older suburban areas, planners should do this kind of research with individuals to understand which routes they select and why. It would help municipalities to direct investment to particular intersections and streets to make them more comfortable and safer, but also to upgrade them through signage or more distinct permanent features. One might even conduct research into navigation strategies by neighbourhood residents and compare across groups. This kind of information could create community-based wayfinding plans, where community members work together to make wayfinding in their community easier for all groups. What this research with PLWD tells us is that connectivity in neighbourhoods is not just about the number of parallel streets and intersections – it is about the quality of the neighbourhood in terms of good destinations, comfortable streetscapes and memorable landmarks (orienting, turning cues, and beacons) that help people find their way. It is also important to investigate the different types of landmarks that PLWD use because planners need to think of landmarks beyond Kevin Lynch's "public images".

4.6 Conclusion

To use a metaphor from Dementia Alliance International member Peter Mittler, there is a need to build ‘cognitive ramps’ for PLWD (Graham, 2017). In their work on how to make universal design more social justice-oriented, Hamraie (2013) argues that building an evidence base would have scholars and practitioners shift from value-based design to designing “with and by misfitting bodies more generally” (p. 23). This paper has done that by working with PLWD and adding to the existing evidence base by identifying socio-spatial barriers and supports to mobility. It describes different PLWD’s reactions to and preferences for built environment features in their familiar neighbourhoods.

Using Franke et al.'s (2019) mobility framework enabled this research to identify BE barriers and supports to mobility in terms of land use, urban design and wayfinding for PLWD in their familiar suburban neighbourhoods. The results from this work challenge assumptions of the suburban neighbourhood as a definitively bad place to grow older (Golant, 2019). Many aspects of their suburban neighbourhoods were considered supportive of mobility by participants, such as the sense of quiet, familiarity and comfort produced by their mostly residential neighbourhoods. Suburban neighbourhoods are also not impossible to navigate for PLWD. The familiarity of one’s own neighbourhood is a powerful support. Participants also created landmarks for themselves in a variety of different ways, such as identifying landmarks in monotonous landscapes (e.g. special gardens, noticing certain types of cars parked). Many participants also found ways to avoid land-use and urban design barriers, like choosing to jaywalk or selecting parallel residential streets over arterial ones. That being said, it is integral to note that there were several barriers within suburban neighbourhoods that prevented PLWD from travelling as far as they wanted, like roads limiting movement by not having protected crossings or lacking sidewalks. There are several recommendations to retrofit or when building new that can ensure creating built environments that facilitate mobility for PLWD. While this sample is not representative of all PLWD, it can give planners and designers insights into how to enable the mobility of PLWD in a North American suburban context. Future research should investigate the different mobility experiences of PLWD based on gender, time since immigration and ethnicity.

Chapter 5 – Manuscript #3

Title: The Right to (Re)shape the City: Examining participation at open houses among people living with dementia

Abstract

Problem: The number of people living with dementia (PLWD) is set to increase to 132 million by 2050, with the vast majority expected to reside in community. Limited research on the impact of the built environment on PLWD has focused on planning outcomes, with no research on access to the planning process that shapes the places they live in.

Research Strategy: I accompanied seven participants living with dementia (individually or in pairs) to open houses, a commonly-used planning process tool, in Waterloo, Canada. To capture the experiences, I used audio recordings, fieldnotes and sketches, photographs and a post-experience interview with participants.

Findings: The sense of inclusion participants felt in attending the open houses was unexpected. Accessibility of open houses for PLWD can be improved however, by ensuring respectful, and patient communication (not rushing attendees, using plain language), providing clear, concise presentation materials (less is often more, offering in-the-moment feedback opportunities) and using a familiar, comfortable physical location (sensitive to over-sensory stimulation through acoustics and lighting).

Takeaway for Practice: The open house is already well-suited to the accessibility needs of PLWD, with peripheral, circular layouts allowing participants to learn at their own pace and interact one-on-one with practitioners. However, the recommendations that would make this process tool more accessible to PLWD are easily implementable, and by educating planners in these techniques, there could be an opportunity for the profession to help dismantle the stigma associated with dementia. The commonly used planning process tools need to become universally accessible, so that PLWD and other disabilities can attend any meeting they choose in their community.

5.1 Introduction

(Re)shaping the city through engagement in the planning *process* is a citizenship right. However, debates about civic participation in planning neglect a fundamental question about who has physical access to the engagement processes and how to best engage theses excluded groups. This paper focuses on the experiences of people living with dementia (PLWD), a cognitive disability, as a population who has historically been overlooked in attempts to make public engagement inclusive. Dementia is a disability (Shakespeare, Zeilig, & Mittler, 2019) and the World Health Organization (2012) calls dementia a major cause of "dependency among older people worldwide," (p.2). Globally, the number of people living with dementia (PLWD) is projected to increase from 47 to 132 million by 2050 (WHO, 2017). Recently, PLWD have begun to be sought to comment on policy related to their own health/social care (Edick, Holland, Ashbourne, Elliott, & Stolee, 2017; Nedlund & Nordh, 2015; Public Health Agency of Canada, 2018), however they are not included in the planning *process* that shapes the communities they live in (Lin & Lewis, 2015). This absence of intentional engagement is likely due to hegemonic misconceptions about PLWD which presume incapacity, perpetuating widespread stigma, and seeing PLWD as passive care recipients instead of citizens with voices to be heard (Bartlett & O'Connor, 2010; Mitchell et al., 2013). To date, these calls for increased engagement of PLWD have not been heeded in planning research or scholarship. Current planning-specific research focuses on the impact of planning *outcomes* on PLWD, rather than how to include PLWD in the planning *process.* PLWD deserve to be engaged in discussion about places where they live, and the adaptation of a planning *process tool* could challenge that stigma. In the dementia studies literature, there is evidence that communication, physical/sensory environments, and visual mediums should be considered (Dupuis, Gillies, et al., 2012), however research has never been conducted in a public engagement setting related to city-building. This research explores experiences at a common planning engagement forum, the public open house, to understand how to adapt this commonly-used planning *process tool* for PLWD. The aim is to illustrate how accessibility in the planning process for PLWD is a way for planners to help them in actualizing their innate citizenship rights regardless of their disability.

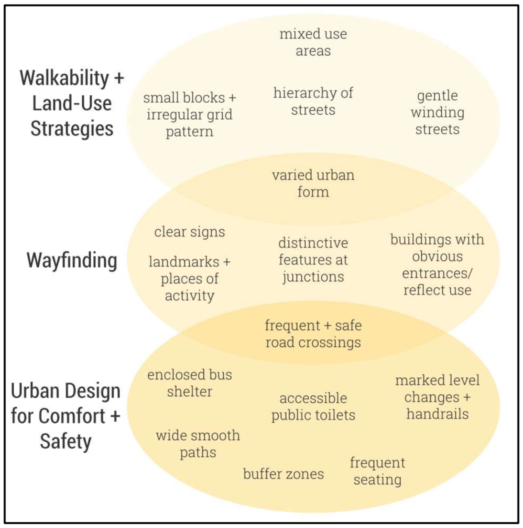
To conduct this work, I attended public open houses with PLWD individually or in small groups and used several data collection techniques (audio recordings, fieldnotes and sketches, interviews) to gather experiential and perceptual data from participants. The observations collected led to a number of recommendations to make the open house more accessible to PLWD, specifically the need for staff's approach to be respectful and patient (communication), to create a legible, familiar, and comfortable environment (physical/sensory environment), and to produce clear, distinct information visually through diverse presentation mediums (presentation of information). The aforementioned categories correspond to the research framework, however, unexpected findings included: the paradox of selecting versus future thinking, the need for a clear cohesive message about the topic and desired outcomes from an open house, and the comfort participants felt with me. Further, considering the stigmatization from society faced by PLWD, perhaps the most important finding was participants feeling like their voice mattered, suggesting a sense of inclusion, and citizenship, underscoring the importance of investigating accessibility for this group.

5.2 Background

Dementia is an umbrella term describing progressive symptoms affecting memory, cognitive abilities and behavior, and consists of issues related to spatial navigation, judgement, and visual perception (WHO, 2017). Approximately 60-70% of all PLWD have Alzheimer's disease, with no known treatments to reverse the symptoms (WHO, 2017). Estimates show that two thirds of PLWD live in community as opposed to congregate living (Alzheimer Society of Canada, 2010). PLWD are likely to experience a 'shrinking world' effect, making it essential to investigate the relationship between PLWD and the accessibility of the built environment, thus focusing on planning *outcomes* (Duggan et al., 2008; Shoval et al., 2011).

Research on PLWD and planning *outcomes* began with the seminal work done by Burton and Mitchell in 2006, which developed seven principles for design (familiarity, legibility, distinctiveness, accessibility, comfort, and safety) and 17 land-use and urban design recommendations that can be grouped into three thematic categories of: walkability and land-use strategies, wayfinding, and urban design for comfort and safety (**Figure 5.1**). Research is sparse, with fewer than 20 studies worldwide, concentrated in the UK, Sweden, and Canada (Biglieri, 2018), such as examining PLWD travelling to grocery stores (systematic observation), crossing the street (video analysis), and understanding socio-spatial lived place (walking interviews, social network mapping, home tours) (Brorsson, Ohman, Lundberg, & Nygard, 2014; Brorsson, Öhman, Cutchin, & Nygård, 2013; Ward et al., 2018). This type of work ultimately leads to the creation of design principles and recommendations, helping planners understand best practices for design and land-use policy. However, this is only one part of building a just city. Just outcomes will not suffice alone, one must concurrently consider justice in access to the planning process itself as well (Fainstein, 2010; Yiftachel, 1998).

Figure 5.1: Summary of Burton & Mitchell's (2006) Findings by Biglieri (2018)



5.2.1 Accessing the Planning Process as a Citizenship Right

The right to the city, and to (re)shape the place one lives in is a well-established concept in planning (Fainstein, 2010; Lefebvre, 1996). One of the ways people shape their cities is through engagement in the public planning *process* (Corburn, 2009), and ensuring this public engagement is inclusive of all people is central to professional planning codes of practice/ethics (American Institute of Certified Planners [AICP], 2016; Ontario Professional Planners Insitute [OPPI], 2019)[25]. Various levels of measuring intent behind the planning process were described by Arnstein's (1969) Ladder of Participation, and has been debated ever since – including disputes over collaborative versus communicative planning, questions of citizen-power and control, how to create redistributive process and even questioning the validity of including the public in any discussions on urban policy-making (Lord, Mair, Sturzaker, & Jones, 2017; Slotterback & Lauria, 2019). These higher-level debates, while integral to any discussion on public engagement, neglect a fundamental, basic question – are public engagement tools used in the planning process accessible to all people? Examining the

---

[25] ***OPPI Statement of Values*** – "To foster public participation. Members believe in meaningful public participation by all individuals and groups and seek to articulate the needs of those whose interests have not been represented." And OPPI Professional Code of Practice "1.4 identify and promote opportunities for meaningful participation in the planning process to all interested parties" (Ontario Professional Planners Institute, 2019).
AICP Code of Ethics - "We shall give people the opportunity to have a meaningful impact on the development of plans and programs that may affect them. Participation should be broad enough to include those who lack formal organization or influence" (AICP, 2016).

accessibility of these tools is a response to recent calls to acknowledge the vital role of compassion, emotional intelligence and relationality in planning practice (importantly, in public engagement) (Lyles & Swearingen White, 2019) by attending to the real-life experiences of PLWD and their interactions with planners in these forums. There has been no investigation into whether/how commonly used planning *process* tools are accessible to those with cognitive or intellectual impairments, with scholars focusing on more innovative participatory methods like go-along interviews and photovoice to engage these groups in the planning process (Mathers, 2008; Mathers, Thwaites, Simkins, & Mallett, 2010). For PLWD, despite the lack of research on the accessibility of engagement formats, there are a growing number of municipally-led Age- and Dementia Friendly City (AFC and DFC) policies that continue to be put forward (Williams-Roberts et al., 2015).

Engagement in the planning *process* is one example of involvement in participatory democracy, and thus, one way to express social citizenship. A key feature of citizenship in a democracy is guaranteeing 'vote and voice' through three principles: congruence (match between being affected by policy and having the right to comment on it); responsiveness (ability of a government to respond to citizen comments); and representation (providing opportunity to express opinions (in)directly) (Sonnicksen, 2016). However, for PLWD, there is the societal idea that they should not be able to vote or access government processes due to a perceived lack of cognitive capacity, and are not seen as 'citizen-enough' (Bartlett & O'Connor, 2010). This intense stigmatization stems from perceptions that PLWD are not 'in control' (Dear, Wilton, Gaber, & Takahashi, 1997), and often manifests into intentional exclusion from social and political spheres (Mitchell et al., 2013; Swaffer, 2014). However, by challenging these conceptions, and enabling PLWD to express citizenship through engagement in the planning *process* moves towards an explicitly political and democratic conceptualization. This goes beyond thinking of PLWD through a biomedical lens (sufferers of a deadly disease, already considered gone), and a personhood lens (with the ability to provide insight on their lived experiences). Having a voice in the city-building process is one way to express social citizenship, a lens which focuses on examining power relationships seeing them as active social agents (Bartlett & O'Connor, 2010)[26]. This push toward conceptualizing PLWD as political citizens is closely related to the 'dementia is a disability' activist movement. An activist living with dementia, Swaffer (2014) states, "We want to access services and to participate in the

---

[26] It should be noted that while there has been a change in how PLWD are viewed in health/social care discourse, the biomedical and personhood approaches still persist in many health and social care areas of practice and scholarship concerning PLWD.

community the way everyone has a right to expect, and to have our disabilities respected with acceptance, support and enablement," (p.714).

While there are currently international laws asserting the right of PLWD to be presumed capable, it does not mean immediate inclusion or being enabled to participate "in the communities, towns and cities in which they live," (Bartlett & O'Connor, 2010, p.45). This is evident through municipal policies like DFCs, (aimed at making communities dementia-friendly mostly through social interventions, like training service providers) which do not necessarily see PLWD as citizens. Paternalism is a significant critique of DFCs:

> [A DFC is]… merely a society that supports or takes care of its members. It is not a society that truly sees PLWDs as equal contributors… With positive attitudes, people may agree PLWDs deserve to live a meaningful life, but without positive beliefs, they may not believe PWLDs can actually live a meaningful life. (Lin & Lewis, 2015, p. 242)

Thus, any research into the accessibility of the planning *process* for PLWD must start with the belief that PLWD have meaningful suggestions to contribute to the conversation of city-building, and this necessitates addressing the stigma that constructs PLWD as lacking capacity (Mitchell et al., 2013). This research aligns with others who assert that the meaningful inclusion of perspectives from marginalized groups will lead to more 'just' cities (Fainstein, 2010). As planners, we need to think about how we create our planning engagement processes in order to understand what allows some to participate and place barriers in front of others (Yiftachel, 1998) in order to also fulfill the three principles that guarantee the 'vote and voice' of political citizenship (Sonnicksen, 2016). Practitioners are also beginning to be open to these ideas - Przydatek (2014) found planners willing to consider Burton and Mitchell's (2006) principles, and Hockey et al.'s (2013) survey of planners acknowledged the most marginalized older adults are not being heard through their processes. There is an opportunity for planners/planning scholarship to show leadership in furthering the evolution of the concept of citizenship for PLWD, from advocating for one's own care and national care policy (Bartlett & O'Connor, 2010; Bryden, 2005; Swaffer, 2014), to expressing citizenship through being physically present in public and domestic spaces (Bartlett, 2016; Phinney, Kelson, Baumbusch, O'Connor, & Purves, 2016) to having a voice in the political *process* of city-building.

5.2.2 Participatory Planning Tools – Accessible to Whom?

With the communicative and collaborative turns in planning theory, there has been a shift in seeing a key role for the planner as the skilled facilitator helping communities define their own vision through an examination of values and principles in case studies (Healey, 1996; Innes, 1995). This work has also included critiques of the planning *process* as being exclusionary towards marginalized populations. What constitutes a well-designed process in terms of public engagement is multifaceted and ranges from the macro to the micro scale – from overall design to individualized interactions with the public. Bryson, Moynihan, Quick, Slotterback, & Crosby (2012) summarized the extant literature and provided 12 guidelines for practitioners from managing power relations and establishing clear rules to using evaluation measures and utilizing multi-media approaches. Among the 12 guidelines is one that argues for inclusive practices: "Using inclusive processes to engage diversity productively" in which they state the importance of creating a process that brings people to the discussion who are "normally excluded by institutionalized inequities" (p. 29). De Souza Briggs' (1998) argument is particularly salient here as they argue that while what constitutes good values in terms of public engagement, as well as the overall evaluation, intent, framing and connection from stated purpose to decision-making of the process is important, it is how interactions play out at the microscale of the tools used, that affects how people participate in the planning *process.* Existing microscale research has included, for instance: the micro-politics of deliberation within community groups (Barnes, Knops, Newman, & Sullivan, 2004), participatory budgeting in low income communities (Meléndez, 2018), and effectiveness of visualizations in local climate change planning processes (Schroth, Pond, & Sheppard, 2015). However, these types of research assume process tools are already accessible to members of the public. This is especially significant because in not dealing with the microscale, current planning participation discourse neglects an inquiry into how disabled individuals access the planning *process*. While alternative tools like photovoice have been used with people with cognitive impairments, the typical *process tools* used in practice remain understudied (Mathers, 2008; Mathers et al., 2010; McClimens et al., 2014).

5.3 Methods – Understanding the Experiences of PLWD at Open Houses

Instead of conceiving of a new 'method' of garnering public feedback, I decided to explore experiences of PLWD at an existing, widely used *planning process tool* (the open house), and analyze those findings to understand how to make it more accessible. An open house is typically used by municipal staff or private planning consultants (herein referred to as 'staff') to garner feedback from the public regarding a variety of topics at a variety of scales, from infill developments to city-wide plans. An open house is usually informal and has a few key components, like visual presentation boards, staff available to answer questions one-on-one, and a method of formalized feedback

(Swerhun & AvRuskin, 2012). This research asks: *What are the barriers and facilitators to participation for PLWD at open houses in terms of communication, physical/sensory environment and presentation of information?* To answer this question, it is necessary to first examine the barriers to conducting research with PLWD, including difficulty in recruitment and the ethics/consent process, the time needed to build relationships resulting in meaningful interactions, as well as the need to move beyond traditional approaches (e.g. semi-structured interviews) and combine them with participatory approaches (Keady, Lars-Christer, Johnson & Swarbuck, 2018; Phillipson & Hammond, 2018). They identified successful researchers as those who focused on "inclusion, empowerment, flexibility, and communication when selecting methods," and made time for repeat contact with participants, observations and engagement, as well as provided an appropriate research environment (Phillipson & Hammond, 2018, p.1).

Research methods used to examine the micro-scale of public participation are similar to those used in social science research with PLWD, like experiential observation and post-activity interviews (Hung et al., 2017; Keady et al., 2018; Lacey-Avon, 2016). For instance, examining participatory budgeting sessions with video-capture to conduct discourse analysis (Meléndez, 2018), and examining public forums using case study analysis (including participant observation of the forums and post-activity interviews with participants) (Barnes et al., 2004). These methods and principles were something that I emulated. This research is part of a larger study, and it demonstrates the difficult nature of recruiting from this population group, and the time required to build meaningful research interactions. Before attending any open houses, I spent on average 10 hours with each participant, building trust and becoming familiar with their diverse communication styles, allowing me to adapt questions to help the participant express their perspectives in an accessible way.

Before examining the accessibility of the open house, I examined existing work with PLWD that may affect their experiences. This background work outlines the themes used during the subsequent framework analysis of the data (Gale, Heath, Cameron, Rashid, & Redwood, 2013). First is research on communication with PLWD, including best practices and communication training programs in care settings, as well as evidence that the latter reduced agitation in PLWD (Livingston et al., 2014; O'Brien et al., 2018; Wilson, Rochon, Leonard, & Mihailidis, 2012). While there are often 'Tips' authored by Alzheimer's associations, not all have empirical research backing (O'Brien et al., 2018). Yet, important considerations offered include: ensuring the PLWD feels respected by taking the time to listen to their opinions (Hung et al., 2017), and treating the PLWD as a unique individual (Downs & Collins, 2015). This research will expand that knowledge to a non-care setting, where the staff will not have prior knowledge that the person is living with dementia. Second, the physical/sensory environment of the open house deserves study, as it has been shown that the design of care home settings can influence a PLWD's mood, wellbeing, food intake, and influence how well people wayfind (Chaudhury, Cooke, Cowie, & Razaghi, 2017; Hung et al., 2017; Keller, 2007; O'Malley, Innes, & Wiener, 2017). For instance, PLWD can be sensitive to noise and light, and if mismanaged, can cause over- or under-stimulation (Dewing, 2009), and a systematic review of the design of the interior of congregate living facilities discussed the need to prevent sensory overload (Chaudhury et al., 2017). Although not previously researched, these studies point to the potential importance of the environment for supporting engagement of PLWD. Third, the presentation of the information at the open house is significant, as this determines if staff have presented information in a way that is understandable to the public and garners productive feedback (Hodge & Gordon, 2014). An open house uses visuals to depict information, which could pose an issue for PLWD, as one of the dementia symptoms that may be experienced is difficulty thinking abstractly (Alzheimer Society of Canada, 2018). However, these visual depictions of space can be related to visual art, which has been used as a form of life enrichment, therapy (art-making, art-viewing), as an effective arts-based method for engaging in research with PLWD, and as having the potential to increase communication and engagement (Dupuis, Whyte et al., 2012; Rosenberg, 2009; Young, Camic, & Tischler, 2016).

5.3.1 Participants

Participants were recruited through community organizations and allied networks that serve PLWD in the Regional Municipality of Waterloo, Canada. Six of seven participants have early onset dementia (diagnosed before the age of 65[27]), all self-identified to be in the earlier stages, live in the community and are identified by pseudonyms in Table 5.1. These participants were part of a larger research project I conducted on investigating PLWD's experiences in their neighbourhoods. This research project received ethics approval and used process consent[28] (McKeown, Clarke, Ingleton, & Repper, 2010).

---

[27] Since dementia is a set of symptoms, participants had been diagnosed with different diseases that cause those symptoms. The majority of participants were diagnosed with Alzheimer's disease, however other causes can include vascular dementia, Lewy-body dementia, and Parkinson's disease.

[28] Process consent is a form of consent in which the researcher asks the participant for verbal consent throughout each stage of the research. Since this research was part of a larger research project, participants signed a Consent Form at the beginning of the overall study, but for each separate activity (such as going to the open house, participating in the post-open house interview), the researcher explained the activity and asked for oral consent, making sure to explain to the participant that they had the option to refuse prior to continuing.

Table 5.1: Open House Meeting Descriptions + Participants

Subject of Open House	No. of People Present	Participant(s)	Condition Causing Dementia Symptoms (self-reported diagnosis)	Pseudonym
Proposal for redevelopment of a downtown street and public parkette	20	Male, 71 years	Early onset Alzheimer's disease	Don
		Female, 81 years[29]	Alzheimer's disease	Lorraine
Neighbourhood Plan – first open house meeting	75	Female, 81years	Alzheimer's disease	Lorraine
Proposal for improving a thoroughfare under a bridge	12	Male, 65 years	Early onset Alzheimer's disease	George
Proposal for a new park	15	Male, 65 years	Early onset Alzheimer's disease	Douglas
		Male, 58 years	Parkinson's disease	Alexander
Proposal for expansion of a cultural facility	20	Female, 57 years	Early onset Alzheimer's disease	Violet
		Female, 56 years	Early onset Alzheimer's disease	Elizabeth

5.3.2 Protocol

I systematically examined community newspapers and municipal websites for advertisements for open houses in the Region to identify one near each participant's residence. Together, we did a site visit, then attended the open house and did not indicate we were there to conduct a study. This was to ensure that staff did not change their behaviour based on the knowledge that the participant was a PLWD. To capture the experience at the open house, I used four diverse qualitative data techniques to improve the trustworthiness of the findings through methodological triangulation (Farmer, Robinson, Elliott, & Eyles, 2006; Hall & Rist, 1999; Hastings, 2012). The data techniques included: an audio recording of the experience, photographs of the location and visual materials, post-experience fieldnotes and sketches, and a post-open house interview asking questions related to the framework (**Table 5.2**).

---

[29] This participant went to two meetings – because they had such a good time at their first meeting, they wanted to go to a second with me.

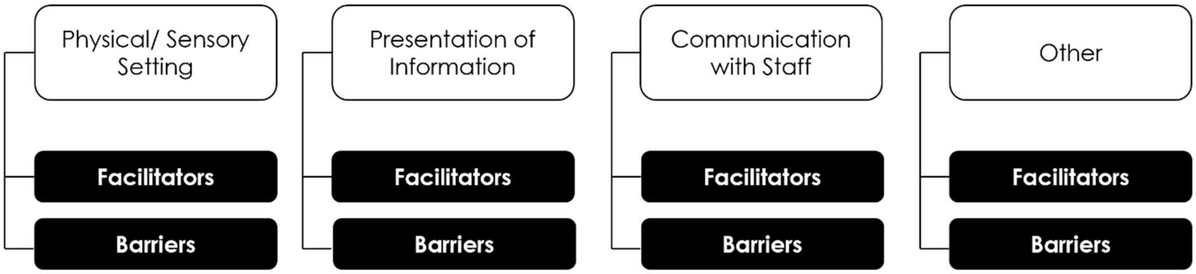
Table 5.2: Data Generation Table

Data Generation Technique	Protocol	Rationale
(1) Audio recording of the Open House meeting	• An audio recording was started at the entrance into the open house meeting and ended upon the exit from the building	• It was used to help the researcher recall certain instances and to review and develop a better understanding of the material.
(2) Photographs of the Open House location and visual materials	• The researcher took photographs with a cell phone camera of visual materials (poster boards, presentation slides, handouts, comment sheets)	• This was used to augment the audio recordings and fieldnotes during data analysis for a visual reminder of the experience.
(3) Fieldnotes	• The researcher hand drew a map after every open house and recorded the movement of participant(s), staff and members of the public. • Researcher also recorded the number of people present and other observations about the research objectives	• Recording fieldnotes after the meeting was used to capture this information not voiced on the audio recording.
(4) Post-Open House Interviews with Participant(s)	• The researcher conducted an interview with the participants as soon as they left the open house. The researcher asked questions about overall impressions; the physical/sensory setting; if the information was too little, too much or just right; if they felt like their voices were being heard; the attitudes of the staff towards them and the presentation of visual materials.	• The previous three methods of data collection involved the researcher collecting the data based on their own observations. • This post-open house interview was an opportunity for the participant(s) to express in their own words their experiences at the meeting.

5.3.3 Data Analysis – Framework Method

I used the framework method as it organizes data in a way that is helpful in answering direct research questions (Gale, Heath, Cameron, Rashid, & Redwood, 2013). I attended all meetings personally with participants and reviewed the data several times. Based on this knowledge, and deep engagement with the literature on what might affect the experiences of PLWD at open houses, I developed an overall coding framework, which was outlined previously and in **Figure 5.2**.

Figure 5.2: Framework Method Code Diagram



5.3.4 Limitations

One potential limitation was my presence at the open house, and while I attempted to not interfere with the experience, I did interact with participants and staff in as limited a way as possible. Research participants were also all of Caucasian descent, with English as their first language. While I was able to analyze body language in the moment, I was not able to closely review the interactions (since they were not videotaped). Another potential limitation is that I selected the open houses, and while participants had the opportunity to refuse, their interest (or lack thereof) in the topic might have influenced how invested they were in the topic of the open house. Lastly, there sometimes was tension between analyzing the transcriptions, fieldnotes, and photographs, then comparing it with post-experience interviews, however the purpose of having multiple methods is to understand the issues from different perspectives, rather than to confirm or deny observations and answers. While the post-experience interviews may not have yielded as many results, it is imperative to include and center the perspectives of PLWD along with the researcher-led data.

5.4 Findings + Discussion – Tweaking the Open House

The findings from this research demonstrates that there are several accommodations that could be made to an open house to make it more accessible to PLWD. The accommodations suggested here by insights from participants are minor in nature and could be implemented quickly by planners, and with little cost.

5.4.1 Communication – Staff's Approach Towards PLWD Matters

Staff interaction was most cited by participants, which is congruent with the literature that discusses the importance of respectful social interactions for PLWD (Hung et al., 2017). When asked if staff were easy to understand during the post-activity interview, all participants would state they had no difficulties. However, through observation it was noted that when staff did any of the following, participants tended to frown, cross their arms, and either stop talking, or go back to talking about prior topics: spoke quickly or over the participant, used planning jargon such as “the technically preferred plan is on that side if that’s what you are gravitating to”, and/or put unnecessary pressure on the participant to ask a question ("S: So are you just going to ask me something?" "P: Uh I don't know I forgot, it probably wasn't important"). Conversely, when staff used less specialized language, spoke at a slower cadence, approached participants in a respectful and friendly manner without rushing, participants would nod and ask follow up questions related to what staff had just spoken about. For instance, in comparing service in a café to the open house, George remarked:

> They [café staff] were saying ‘What do you want? Have you decided yet? Can I help you?’ You're not helping me interrupting me looking at the sign. So he [planning staff] was great. Yeah I complimented him on that. It's not a very pleasant thing when they are rushing you through because of their timetable.

Staff who took their time with participants, engaged not only by listening but also by probing further, trying to find common ground by asking how one relates to the site in question, and offering more information were perceived well by participants: “Oh sure, well they did due diligence on being completely welcoming…they have their expertise and yet didn't intimidate with it” (George). For PLWD, research shows that for even those in later stages, they may not remember what exactly was said, but they remember how someone made them feel (Bryden, 2005). This was evident for participants. For instance, Lorraine said, “I’m trying to remember exactly what he said and I don’t. But I didn’t feel anyone was talking down to me or anything like that.” When this type of respectful, un-intimidating and welcoming approach was used by staff, it was felt by participants. For instance, when staff spoke to participants without speaking ‘down’ to them or using ‘elderspeak’ (Eggenberger, Heimerl, & Bennett, 2013), by speaking to them like a ‘regular person’, participants seemed to feel more comfortable with them and would ask questions without prompting:

> I thought he was pretty neat, he just talked to us like a regular person. He just knew a little bit more than we did, that’s all. He was just a good person to talk to… I think he was just basically talking to us as people. He didn't have his planner hat on. (Lorraine)

Staff who took the time to connect what they were saying to the presentation boards by pointing, giving different real examples, and waiting for the participant to nod/assent before moving on was beneficial to participants, who would go from looking confused to engaged. In a few instances, staff were proactive and approached participants by asking “Do you have any questions?” and if the participant looked confused, they would follow up with "Would you like me to tell you a bit about the project?". This led to the participant opening up and beginning to ask questions and interact, whereas staff who walked away after the first question led to more confusion for the participant and a lack of response. This was a great way to orient the participants, as they often did not volunteer ideas until after the staff had provided explanations. Interestingly, the majority of open houses had such staff present, and the feeling of being heard seemed to be influenced by how staff interacted.

RECOMMENDATIONS FOR PLANNERS:

- Treat each person with respect. Give your full attention to the person and be aware of your body language (preference for open stances).
- Be patient by giving them space and time to understand information at their own pace. Do not make them feel rushed – sometimes it is better to be quiet while people think.
- Avoid jargon and ask if the person wants to have something explained, or volunteer a small piece of information about the board.

5.4.2 Physical/ Sensory Environment – Be Mindful of Sensory Stimulation + Room Set-Up

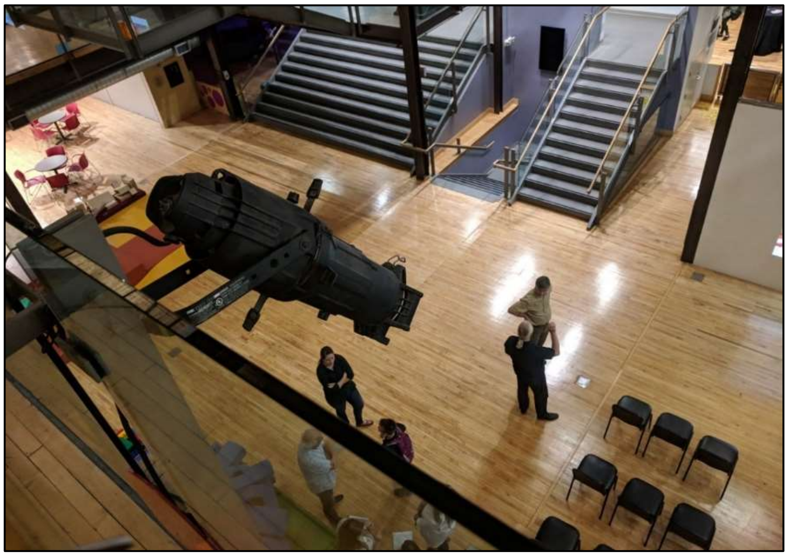
Consistent with literature on congregate living, noise and lighting were important considerations. One of the barriers cited by participants was a high level of noise (or threat of it), which can make concentrating difficult for PLWD, and as one participant remarked:

> R: If it was noisy how would that have changed your experience?
>
> P: I'd have left then. Control the environment or get out. (George)

Noise was influenced by the physical aspects of the room (linoleum flooring/sound reflective paneling vs. carpet and other noise controlling features) and number of people present. Most open houses were described as providing bright, consistent lighting, which is supported by literature as important in terms of engagement for PLWD (Chaudhury et al., 2017). Sensory overload was cited by some participants as a barrier to comfort level/comprehension, as some open houses took place in echoing auditory environments with various conflicting lighting sources (see **Figures 5.3-4**).

Figure 5.3: Poor sensory environment

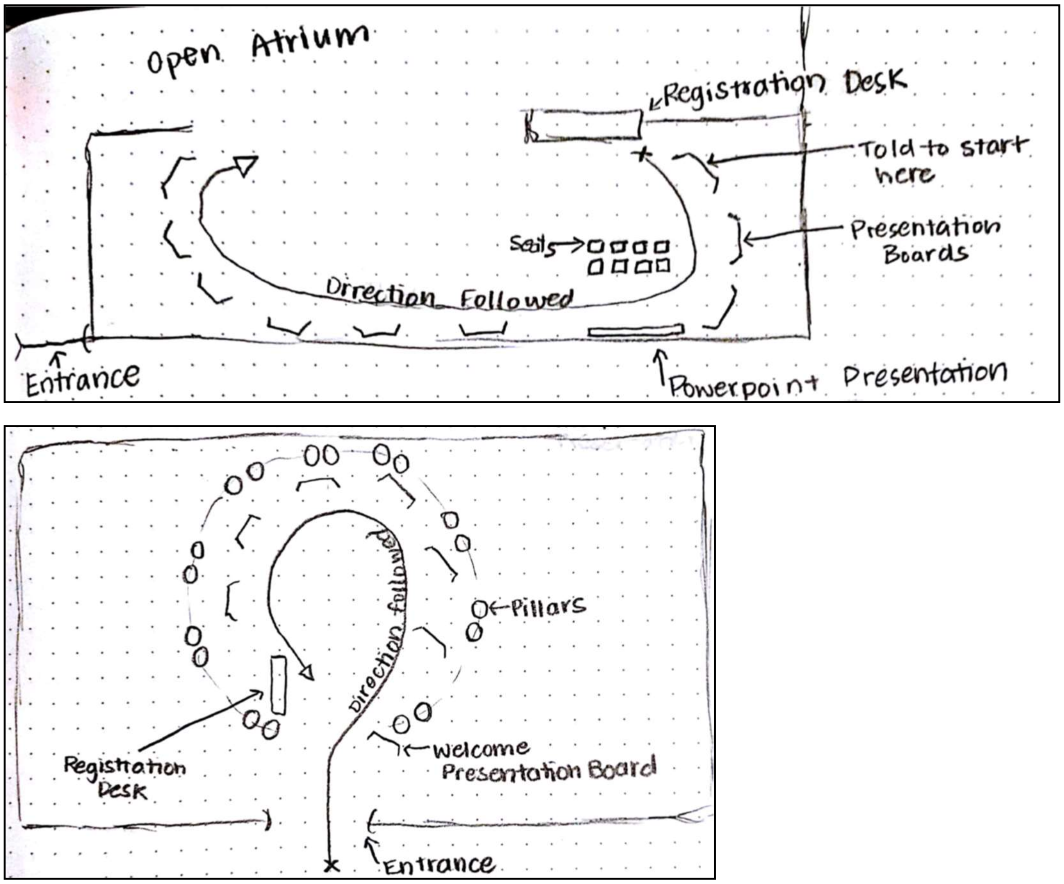
Figure 5.4: Poor sensory environment



Participants started to get restless around the one-hour mark, however, this depended on their engagement with the content, and if they felt they had something to contribute. One participant mentioned that anything longer than 1.5 hours would have been "too much" (Don). Additionally, if participants were looking at boards at their own pace and conversing, meetings were perceived as shorter. In long seated presentations (30-50 minutes), participants got restless, fell asleep, and/or admitted that they stopped paying attention. Being able to control one's own movement around the room, and being active (standing, interpreting visual information, conversing) seemed to result in enjoyment for participants, and seemingly more cognitive and physical engagement.

Legibility of an environment has been consistently found to be important for PLWD in terms of feeling comfortable, safe, and independent (Burton & Mitchell, 2006; O'Malley et al., 2017), and the findings were consistent with this principle. One barrier to legibility was the lack of signage outside/inside the buildings, however the set-up of Open houses was usually legible for participants, including presentation boards placed around the edge of the room in a peripheral circular layout (Figure 5.5). Participants liked not being the 'centre of attention' and the legibility of the layout meant they 'knew where to go' and were able to easily 'follow the story' of the poster boards. This layout made interactions less stressful by: enabling Staff to approach participants in a less confrontational way, allowing participants to move away if they chose to, and permitting them to move at their own pace. This was preferred by participants, as seated presentations forced them to learn at someone else's pace.

Figure 5.5: Sketches of peripheral, circular layouts



Familiarity is an established design principle for PLWD, in congregate living and public spaces (Burton & Mitchell, 2006). In the context of the open house, participants were more engaged and at ease if they had done a site visit (to establish familiarity with an abstract place), had a personal connection to the proposal (like lived experience as a football coach during an open house on a park development), and the location of meeting was at a place they recognized. For instance, one open house was hosted in the foyer of a church and one of the participants described it as a reassuring experience: "I just walked in and I felt like I was at home almost. Except for it wasn't so new" (Alexander). For PLWD, the ideal physical/sensory environment is to minimize aspects of an open house that can make it harder to concentrate, and create opportunities for breaks from conversation. This can be done by minimizing noise and ensuring consistent lighting, making the set-up of the room as legible, clear and familiar as possible and providing opportunities for participants to opt-in/out of a conversation.

RECOMMENDATIONS FOR PLANNERS:

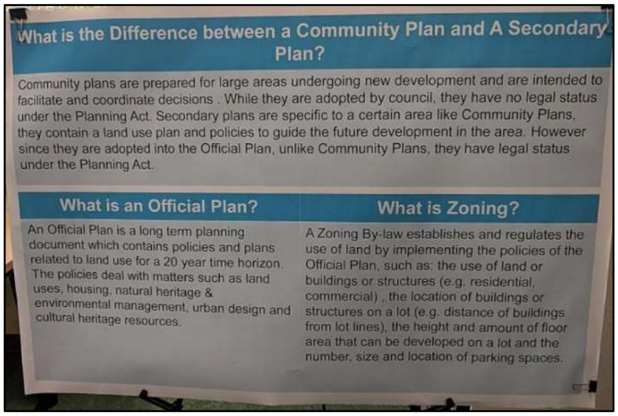
- Seek spaces that lower the potential amount of noise (e.g. carpeted floors, high ceilings). Ensure the space is evenly and well lit, with no reflections on the ground. Daylight is preferable.
- The location should be easy to find - use clear large format signage with arrows and photographs of the place you are indicating.
- Within the room, create signs that direct participants to boards, seating areas, commenting area, registration table, washrooms etc.
- Set up presentation boards in a peripheral circular formation. Clearly indicate the order and where to start.

5.4.3 Presentation of Information – Less is (often) more

Closely intertwined with the physical set-up of a room is the presentation of information (visual, auditory, and written). Typically, an open house includes: handouts, presentation boards, slideware presentation done by the staff, and different methods for providing feedback (e.g. comment sheets, post-its, drawing on maps, etc.). Research on the presentation of information to PLWD is sparse, and interaction with visual materials seems to be limited to arts-based methods, and few studies on wayfinding signage (Gresham et al., 2019). Common barriers can be separated into two broad groups – format and content.

In terms of format, common barriers across all materials included: being too difficult to read with four-line sentences and paragraphs (when bullets would be better), small font, blurry graphics, small posters, and being too text heavy (see Figures 5.6-8 for examples). In the absence of presentation boards, participants seemed to disengage from the open house, looking confused and stating that they did not feel consulted. Long presentations led to restlessness, a lack of attention, and decreased comprehension among participants. In terms of providing feedback, written comment sheets were the most common. Participants stated they had nothing to say at the end (despite engaged discussions throughout), and if they chose to write comments, would often write about the last thing seen, suggesting comments made earlier might have been forgotten. Another feedback collection method required participants to state preferences in front of a group. This made participants feel "awkward, uncomfortable," and not consulted[30] (Elizabeth).

Figure 5.6: Text- and jargon- heavy presentation board



What is the Difference between a Community Plan and A Secondary Plan?

Community plans are prepared for large areas undergoing new development and are intended to facilitate and coordinate decisions . While they are adopted by council, they have no legal status under the Planning Act. Secondary plans are specific to a certain area like Community Plans, they contain a land use plan and policies to guide the future development in the area. However since they are adopted into the Official Plan, unlike Community Plans, they have legal status under the Planning Act.

What is an Official Plan?

An Official Plan is a long term planning document which contains policies and plans related to land use for a 20 year time horizon. The policies deal with matters such as land uses, housing, natural heritage & environmental management, urban design and cultural heritage resources.

What is Zoning?

A Zoning By-law establishes and regulates the use of land by implementing the policies of the Official Plan, such as: the use of land or buildings or structures (e.g. residential, commercial) , the location of buildings or structures on a lot (e.g. distance of buildings from lot lines), the height and amount of floor area that can be developed on a lot and the number, size and location of parking spaces.

Figure 5.7: Presentation board with a blurry and confusing map

---

[30] It should be noted that this was the only meeting out of the five in which participants did not feel like their voice had been heard. It was probably a combination of how feedback was sought and the presentation of information, including no presentation boards, a handout that had nothing to do with the consultation, and a presentation that took up 90% of the open house on a topic other than the advertised one.

Figure 5.8: Presentation board with overcomplicated design

In terms of content, common barriers included: unlabeled visuals, overcomplicated drawings, jargon, unnecessary text and information, unrelated information[31] (making participants feel left out and confused), and too many visual boards (when there was too much information to remember, it led to fewer comments): "Yeah because that is just like telling me too many things, that I don't remember," (Lorraine). These barriers are contrasted with the fact that well-crafted visuals were consistently the most cited facilitator for participants, through being able to understand the diagram, relate it to a physical location, and get a better understanding by talking with staff. This increased engagement corresponds with literature on using visual art to engage PLWD (Young et al., 2016). Schematic drawings which provided enough information without overburdening the participant with unnecessary information were well received. **Figure 5.9** is the board spoken about in the following quote:

> Douglas: The drawing spoke.
>
> Alexander: It just spoke to me like it jumped out.
>
> D: Two baseball fields, got a nice green field, one that could be something else. You got the forest that the people walk through with their dogs and kids and everything. They planned it.
>
> A: Everything was right in place, for you to see what they were actually going to do.

---

[31] For instance, one hand-out was not relevant to the open house, instead it was a current listing of events in the building. This confused participants more, as they thought it was supposed to be related to the open house itself.

Figure 5.9: Presentation board with legible design

Figure 5.10: Presentation board with precedent images

Another facilitator was real photographs used for precedent images. Once the term was explained to participants, they had plenty to comment on (see **Figure 5.10**). This corresponds to research on wayfinding signage for PLWD – real life photographs are more legible than icons or diagrams (Biglieri, 2018): "Yeah, those boxes right away I knew that they had to be vegetable gardens. Right off yeah. The pictures and stuff were explanatory in what they were trying to say" (Alexander). There were also unique cases for each medium. One participant suggested that staff create a simple, easy to read handout to cue attendees by reiterating the purpose of the open house. For presentations, facilitators included providing relevant content, ensuring jargon-free language at a slower pace, visuals, and allowing people to ask questions frequently. Lastly, for feedback formats, sticky notes were effective for expressing in-the-moment thoughts, eliminating the need to recall every thought they had over the course of an hour or more (**Figure 5.11-12**). However, participants were most likely to share their opinions with staff verbally, as opposed to writing things down.

Figure 5.11: Presentation board with post-it notes

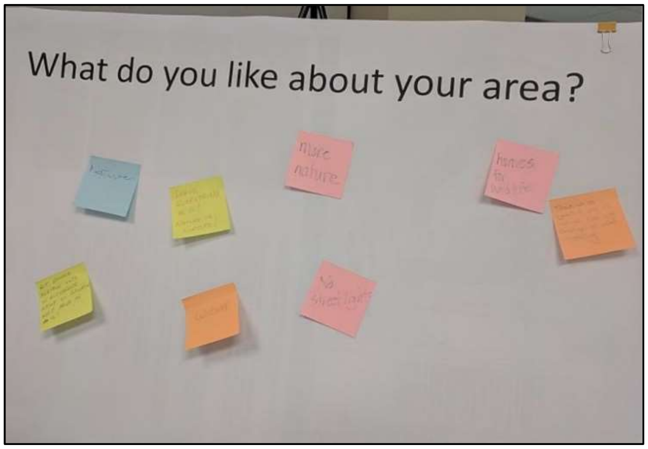
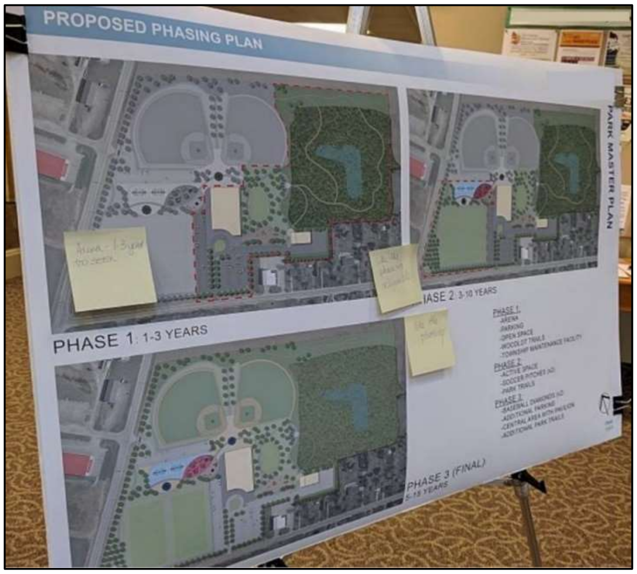


Figure 5.12: Presentation board with in-the-moment post-it notes



Striking the balance between too little and too much information is a difficult line to walk for practitioners. The case can be made that less detail and more concise statements, drawings, and directions might lead to better understanding. Additionally, strategies like repeating the purpose of the meeting through diverse presentation materials would be ideal for PLWD, as being cued to why we were at the open house made participants re-engage in discussions if distracted.

RECOMMENDATIONS FOR PLANNERS:

- All forms of information (handouts, presentation boards, feedback mechanisms, presentations, etc.) should be clearly and concisely written and presented visually (e.g. use short sentences, plain language, bullet points, large font, and appropriate, labelled, color graphics/photographs).
- Make the purpose and desired feedback a short and clear message. Restate in all materials.
- Presentation boards should tell a story, making it clear how they relate from one to the next.
- Gather feedback 'in-the-moment' from participants. (e.g. record information in a notebook as you speak with people, offer post-its/emoji stickers to comment directly on materials, or offer to write down their comments for them).

5.4.4 Contemplation, Clarity, Comfort + Citizenship – Unexpected Results

An emergent finding was the tension between the purpose of the open house as commenting on a specific design versus future thinking. Most open houses asked for the former whereas two asked abstract future questions. Specific discussions tended to be better understood, which is understandable as it seems it is easier in general for people to provide direct feedback on designs, rather than future think. The question becomes, how can we engage PLWD to think in a more abstract way about the future, considering that difficulty thinking abstractly is a dementia symptom that PLWD may develop? More research testing of a variety of methods, like virtual reality, participatory urban design charettes, online tools and other visualization methods could help shed light on this area (Gordon, Schirra, & Hollander, 2011; Mueller, Lu, Chirkin, Klein, & Schmitt, 2018; Radinsky et al., 2017).

The need for a clear, cohesive, and targeted message throughout the open house was evident. When the purpose of the open house was not clear, it led to confusion. The main question posed to the public was often "What are your comments?"- an open-ended question that does not provide adequate direction on the feedback desired. For instance, one open house presented 10 presentation boards and asked participants to "Give us feedback on this design" without offering alternatives or prompting the attendees to comment on certain aspects. This confused participants, however, when I suggested they look for things they did or did not like, they had a more engaged conversation. All of the open houses assumed attendees knew exactly what the staff wanted them to comment on. One way to combat this would be to reiterate in a simple, concise way the purpose and question(s) of the open house through all means of interaction and materials.

Another unexpected finding was the comforting role that my presence had on participants. My presence made some participants feel safe in a new place, provided them someone to ask questions to, and prompted them to engage. While my presence was important, it does not negate the other findings from this research, as many people go to open houses with a familiar person. However, a potential outreach program could pair planning students/practitioners with PLWD in the community as companions to attend community meetings of the person's choice for added support.

Finally, considering that PLWD are often confronted with stigmatization, and being presumed incapable in public discourse, perhaps the most important finding was the sense of inclusion, citizenship, and connection felt by participants in attending these open houses. Many talked about how good it made them feel to be included and asked for their opinions about their community. After their first meeting, one participant asked me if they could go to another, purely for enjoyment and connection to community they felt. Another said it felt good to "use their noggin" (Don) and share their knowledge. Another felt they had the opportunity to teach me, which is something they had not done in a long time:

> "I think they heard what we said." (Doug)
>
> "They made it very inclusive, you feel included in the process. Which is great yeah, because the small voice still needs to be heard." (George)

The language used by participants, like 'a small voice being heard' and 'feeling included' seems to not be the typical language of people being placated by a planning process, but rather people feeling like they were a meaningful part of that city-building process.

5.5 Conclusion – A Step Toward a More Inclusive Planning Process

Through examining the experiences of PLWD at open houses, this work has begun to answer a fundamental unanswered question of planning process research – are the engagement tools used by planners accessible to all people? It does this through a new way of studying the microscale of the open house with participatory methods to understand the needs of PLWD in a public context. The open house is already well-suited to the needs of PLWD, like having presentation boards set up in a circular peripheral layout allowing attendees to examine/learn at their own pace. With a few improvements, the open house could become an even more inclusive *planning process* tool for practitioners. This can be done by ensuring respectful, and patient communication (not rushing, using plain language at a slower pace), providing clear, concise presentation materials (less is often more, and offering in-the-moment feedback opportunities), using a familiar, comfortable physical location (taking care to note acoustics and lighting), and ensuring the purpose of the open house is reiterated throughout.

The majority of research with PLWD and the built environment has focused on how socio-spatial environments impact the lives of PLWD, dealing with planning *outcomes* (Biglieri, 2018;

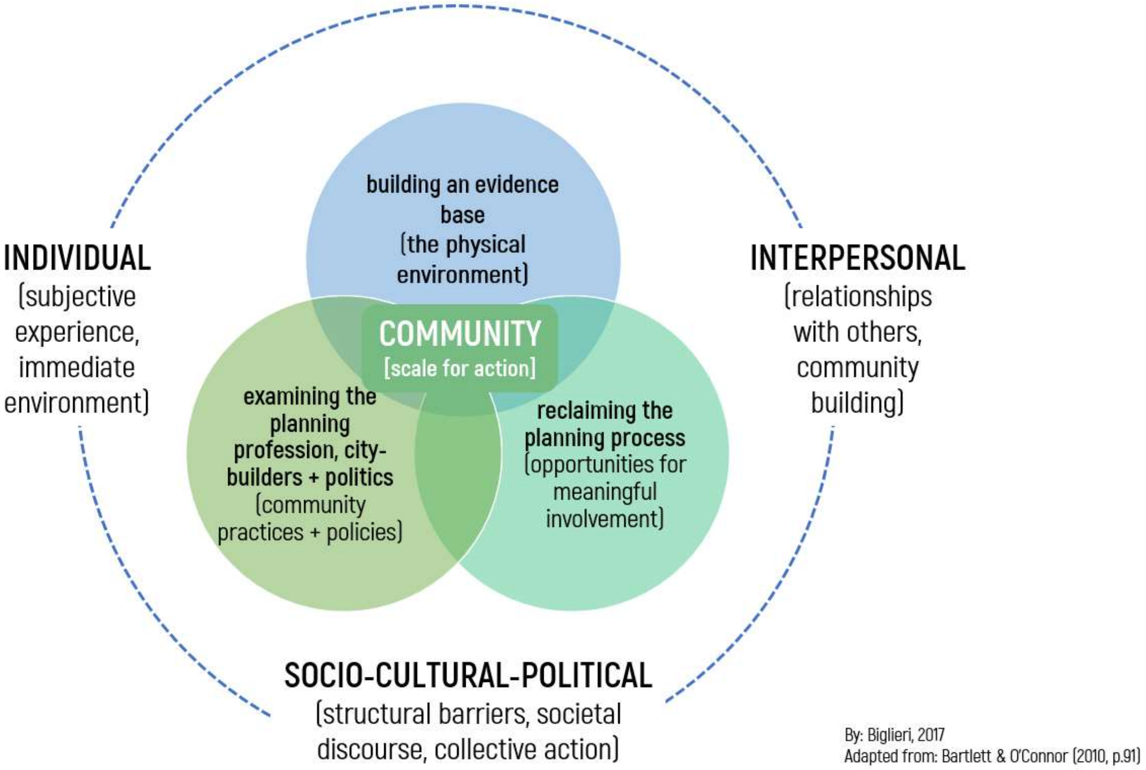
Brorsson et al., 2014; Mitchell & Burton, 2010). While there has been research on the impact of communication and physical design on PLWD, it has been in the context of care settings (Chaudhury et al., 2017; Hung et al., 2017), and the accessibility of the planning *process* for PLWD has not been examined. Dementia is a disability and PLWD are citizens of the places they live in. Further, participation in the planning *process* is a citizenship right. This work challenges the assumption that once diagnosed with dementia, "a person can, or should no longer participate in decision making at governmental level," (Bartlett & O'Connor, 2010, p.44). This research demonstrated that PLWD can not only participate in a government *process tool*, but with a few modifications, the tool can be made more accessible to PLWD. Equipping planners with these dementia-inclusive techniques in a rights-based (non-paternalistic) manner could combat the stigma associated with living with dementia by demonstrating *how* to enable a PLWD to exert their political power as a citizen in city-building conversations. Finding an advocate for this marginalized group is not enough (Fainstein, 2010), nor is creating a dementia-specific advisory group. The commonly used planning *process* tools need to become universally accessible, so that PLWD and other disabilities can attend any meeting they choose in their community.

That being said, creating recommendations to improve the open house will not necessarily encourage planning practitioners to 'move up' Arnstein's Ladder. After all, these open houses tended to sit somewhere between consultation and placation, with the public being asked for their ideas/opinions, without knowing how they may be used/not used (Arnstein, 1969). However, an open house is a *planning process tool* that can be used to facilitate the process of planning at any of those levels of intention, and in an evaluation of any planning process, many other considerations must be included to assess its success (see Blue, Rosol, & Fast (2019); Bryson et al.'s (2012) work for instance). Adapting the open house based on these findings is an example of a pragmatic, incremental approach that could be implemented by planners quickly, and without extra cost. This paper demonstrates the importance of seeing PLWD as citizens of the places they live in, and evolves social citizenship from walking in one's neighbourhood to engagement in the right to (re)shape the city as a political citizen through the planning *process*. The changes proposed from this study go beyond ensuring meetings are scheduled in locations and with services that are accessible (which is commonly understood as providing Americans with Disability Act (ADA) minimums for mobility and sensory disabilities) (Bryson et al., 2012). It adds to a growing body of knowledge on what compassion looks like in planning practice for this marginalized group (Lyles & Swearingen White, 2019) by demonstrating what accessibility in the public engagement process might look like for people with cognitive impairments like dementia. Finally, this research highlights the need to better understand what accessibility in the public engagement process might look like for others with cognitive or intellectual impairments.

Chapter 6 – Conclusion

The overall goal of this dissertation was twofold: (1) to advance our knoweldge of how PLWD experience their local suburban neighbourhoods, and (2) how planners can support PLWD. These research questions were developed based on the paucity of work in this geographic (i.e. suburban neighbourhoods) and analytical (i.e. socio-spatial relationality) area, combined with a necessitation of the work considering demographic trends, and the need to define spatial and process inequities experienced by this population group in order to build a truly ‘just city’ (Fainstein, 2010; Yiftachel, 1998). To achieve these goals, first, I created a framework for research on planning with PLWD (Figure 6.1). This framework outlined three major areas of action at the community scale: (1) planning outcomes “building an evidence base”; (2) planning process “reclaiming the planning process”; and (3) changing perceptions of practitioners “examining the planning professional, city-builders and politics”. These three areas are then influenced by three other scales – the individual, interpersonal and socio-cultural-political.

Figure 6.1: Relational Framework for Dementia-Specific Planning Scholarship + Practice



By: Biglieri, 2017
Adapted from: Bartlett & O'Connor (2010, p.91)

This framework guided the research objectives for the dissertation, which used a case study of seven (7) PLWD in Waterloo, Canada to address the following:

1. To understand how PLWD experience their suburban neighbourhoods, and how these everyday practices shape/are shaped by their past, present, and future(s), as well as their personal relationships. (Chapter 3, Manuscript #1)
2. To identify how and what PLWD identify as socio-spatial barriers and supports to mobility in their familiar suburban neighbourhoods. (Chapter 4, Manuscript #2)
3. To identify how and what PLWD identify as barriers and facilitators to accessing the planning process. (Chapter 5, Manuscript #3)

This concluding chapter will summarize the key findings from each manuscript (including how they interact with the original framework), outline the substantive, methodological, theoretical, and practical contributions of the dissertation, and finish with a discussion of the limitations and future areas of research.

6.1 Research Questions Revisited

This thesis consists of three manuscripts (Chapters 3-5), which answer the research objectives above, as well as corresponding to various aspects of the framework for dementia-specific planning scholarship and practice from Section 1.4. Chapter 3 addressed the first research objective, and added to the 'building an evidence base' part of the framework, with a deep engagement with the individual, interpersonal, and socio-cultural-political levels as outlined above. Chapter 3 used a care lens to combine justifications for examining the socio-spatial realities for marginalized groups from two groups of scholars – disability geography and 'hopeful' geography. With a constructivist grounded theory approach to analyzing 13 go-along and 7 traditional interviews with participants, Chapter 3 found that the complex socio-spatial relationalities of PLWD could be analyzed into three themes – self care in place over time including the past, present and future (encompassing individual/ socio-cultural-political levels); care interdependence in place (encompassing individual/ interpersonal levels); and considering encounters with others as a form of care (encompassing individual/ interpersonal/ socio-cultural-political levels). Chapter 4 addressed the second research objective, and added to the 'building an evidence base' portion of the framework by investigating individual subjective perceptions and embodied reactions of the built environment. Using mobility as an analytical framework, this paper analyzed the 13 go-along interviews with corresponding imagery to develop three major categories of barriers and facilitators – land use, urban design and wayfinding. The findings from this study demonstrates that PLWD do use their suburban public spaces, and identified barriers which exposes how these neighbourhoods were not built with their needs in mind (revealing socio-cultural-political structural barriers caused by planners/designers who planned for the 'normate') (Garland-Thompson 1997, as cited in Hamraie 2013, p. 8). Chapter 5 addressed the final research objective, and added to the 'reclaiming the planning process' portion of the framework by investigating individual subjective perceptions of a public open house with a field experiment. While the findings from this study created recommendations to make the open house accessible, it also challenged the misconception that PLWD cannot participate in democratic processes (Bartlett & O'Connor, 2010).

Overall, this dissertation shows the utility of this framework for guiding research with PLWD in planning scholarship. By using the community scale as a point of entry with a study of planning outcomes, process and perceptions of professionals, then examining it in tandem with the other levels (individual, interpersonal and socio-cultural-political), a fuller picture of how to support PLWD in public spaces can come to the surface. This dissertation argues that planning scholars and professionals can make a differential impact at the community level for PLWD, but only if their analysis and practice center the lived experiences of PLWD and incorporate the other three levels.

6.2 Contributions

6.2.1 Substantive

This dissertation makes four substantive contributions to the literature: through contributions to land use policy and urban design; how landmarks are perceived in wayfinding; created recommendations for an accessible planning engagement tool; and a socio-spatial account of everyday practices in public space for PLWD.

First, research into experiences in public spaces have concluded that there is a need for more walkable neighbourhoods (Kerr, Rosenberg, & Frank, 2012) and person-centered design (Gehl, 2010), especially for more vulnerable populations like older adults (Winters et al., 2015). For PLWD, the existing research on built environment features has largely focused on these aspects as well, however this research has mostly been based in Europe (Brorsson et al., 2014; Mitchell & Burton, 2006). Chapter 4 of this dissertation contributes to this discussion as it is the only study of its kind in North America, based in the predominant suburban neighbourhood form. In looking specifically at land use and urban design, I found that PLWD in their familiar suburban neighbourhoods have preferences for quiet, residential streets and appreciate walkable proximity to amenities. However, for PLWD, the loud arterial roads and unsafe intersections are more than an annoyance – some participants were physically excluded from parts of their own neighbourhoods due to these factors. This, combined with issues with depth perception and being startled easily, could indicate that what is considered an annoyance to most can become a dangerous situation and create literal borders for PLWD. When cities are planned for using what is perceived as ‘majority experiences’, we might not see these factors as dangerous, and do not treat them as such or account for them accordingly. This demonstrates the importance of documenting the experiences of PLWD, and considering them in order to drive sound decision-making and just policies.

Second, Chapter 4 added new information on how and what PLWD in suburban neighbourhoods identify not only as landmarks, but what role those landmarks play in their internal wayfinding system. This answers O’Malley, Innes, & Wiener (2017) who call for more social science research in familiar environments for PLWD that can identify how PLWD are using different landmarks (as destinations, turning cues, beacons, compasses, etc.), instead of just listing them as generic landmarks as previous literature has done (Mitchell, Burton, & Raman, 2004). Further, understanding which types of landmarks are easier to remember for PLWD could give insight into processing functions in the brain (Rosenbaum, Winocur, Binns, & Moscovitch, 2012). Using a psychology typology of landmarks in urban design and planning research is an exciting body of research, and should be continued (Mondschein & Moga, 2018) with PLWD who experience issues with spatial navigation.

Third, this dissertation added substantively to the literature on examining micro-scales of planning processes – i.e. how individuals experience different engagement tools like focus groups, and design charettes. By examining the micro scale of the open house from the perspective of PLWD, Chapter 5 is the only study to research if this commonly used tool is accessible to people with this cognitive impairment. This chapter finishes with recommendations for practicing planners on how to make their open houses more accessible to PLWD.

Finally, this dissertation added substantively through deep examination into socio-spatial relationships between PLWD and themselves, their friends/family, acquaintances, and how these relationships are shaped/shape their built environment over time. This is in contrast to previous studies focused on social aspects in a geographically defined place (Odzakovic et al., 2018). By meaningfully investigating all relations associated with the socio-spatial, Chapter 3 contributes substantively by outlining how understanding personal histories, how one perceives change in ability, self-care practices (past, present and future) and relationships with others in public spaces can bring to light innovative practices and structural inequities in access to the neighbourhood.

6.2.2 Methodological

This research makes four methodological contributions: a spatially focused method of analyzing go-along interviews; an alternative to mental map sketching; a new method for evaluating planning engagement tools in real time; and using care as an analytical frame for understanding everyday life.

Typically, go-along interviews are analyzed much like any other interview transcript or fieldnotes – through transcription, and then line-by-line coding (Finlay & Bowman, 2017; Hand et al., 2018). One study in the scoping review done by Hand, Huot, Rudman and Wijekoon (2017) connected photographs taken during go-along interviews to a transcript, but their analysis was still done through a line-by-line coding of the transcript, and the formation of categories based on the transcript (Van Holle et al., 2012). Chapter 4 used a novel way to analyze go-along interviews, in a way that still reaps the benefits of 'cueing' participants to talking about certain aspects of their neighbourhood that might get missed during a sit-down interview (Finlay & Bowman, 2017). Chapter 4 examined the transcript and gathered imagery from researcher captured or Google Earth photos whenever a built environment feature was mentioned or referenced. Then, the images were printed with the corresponding quotes and also tagged with further descriptors of: (1) the participant's response to the built environment (e.g. like, dislike, comfort, discomfort, neutral), (2) a description of how they related to a particular place (e.g. socio-spatial relationships, memories, daily amenities, turning cue, or not applicable), and (3) further descriptors of the built environment features (e.g. greenspace, street crossing, trail). These images were printed, and selectively coded within the three categories (land use; urban design; wayfinding) to identify enabling and disabling built environment features in suburban neighbourhoods for PLWD. The printed images were then categorized and sub-divided based on the built environment feature being described. The focus on the built environment feature/visual allowed for categories to emerge based on the BE feature, instead of based on the perception (e.g. like/dislike, etc.). This method is perhaps most useful for planning and urban design scholarship, as it provides visuals of the locations that are then tied to perceptions, instead of relying on the transcript to 'tell' everything about the context on its own.

Mental map sketching is one of the most common ways to study an individual's cognitive map, and is considered to be a reliable representation of this (McCunn & Gifford, 2018). However, with PLWD who may experience memory loss and communication issues, it was difficult for many participants to describe what their perceived neighbourhood was, or to draw it on a map. In one instance, when a participant was asked where they go during a sit-down interview with a map, they pointed in one direction and said "that way". Other participants had difficulty recalling the routes they used while in a sit-down interview as well. However, as soon as the go-along interview started, they were able to describe locations and salient landmarks as they were passed. It seemed to the researcher that once a participant was able to be cued to a certain environment by seeing it, they were able to discuss it. This concept of ‘cueing’ has already been shown to be effective in conducting research with PLWD – for instance in Genoe and Dupuis' (2013) study using photovoice, they found participants were more able to describe leisure activities through being cued with images that they had taken. PLWD might have difficulty recalling these places from memory, but then, when they are out in space, they know where to go, and can describe these feelings. This speaks to the importance of studying embodied reactions while in public space. Other scholars might consider using go-along interviews as a way to understand mental maps instead of relying on what people can remember or are able to draw on a page.

Previously, my research plan for investigating access to the planning process for PLWD was to create a ‘fake’ engagement session and have a group of only PLWD be led by a trained facilitator. While this might be useful in the future – it was first necessary to understand the ‘natural’ environment of an engagement session and the perceptions of the participants in that environment. Attending a real engagement session, gave participants the ability to interact with staff, other citizens, etc. without having to disclose that they had dementia, and it allowed for me to understand what in a real-life situation might be improved, based on participant’s perceptions and experiences. By capturing the meeting through a variety of inputs – audio recording, photos, sketching, and a post-experience interview – it was an unobtrusive way to understand how PLWD might feel about participating in the public planning process. This field experiment could be used with different marginalized groups (other than PLWD) as well, and could be used to give feedback to planners running engagement sessions, encouraging evaluation and better practice. For scholars, this method is an accurate way to evaluate the micro-scale of engagement practices, and could be used in combination with larger-scale examinations of accessibility and inclusion in the engagement process (i.e. examining if data collected at engagement sessions is used in final plans, etc.) (Slotterback & Lauria, 2019).

Finally, this dissertation used care as an analytical framework to understand the socio-spatial relationalities of everyday life in space at all levels, from the self to interpersonal to the community at large and socio-cultural constructions. This is an important methodological contribution, as it expands the examination of care into public spaces (Amin, 2002; Rosa, 2019), and demonstrates how as an organizing principle, it can upend the in/dependent dichotomy, and force people to consider all of humanity vulnerable, with a duty to care for others in public spaces.

6.2.3 Practical

This dissertation makes several contributions to planning practice, in the form of recommendations for land use and urban design policy, for the planning engagement process, and in terms of introducing a lens through which to view the everyday practices of marginalized people in space. In Chapter 4, I described specific prescriptions for planners in terms of land use, urban design and wayfinding supports and barriers for PWLD in suburban neighbourhoods. I also recommended the creation of 'community wayfinding plans', the idea of consulting with the most marginalized in order to form Lynch's *public images*, instead of relying on what the majority thinks public images are. This could be done by conducting several go-along interviews and asking participants to point out landmarks as they walk; using cognitive map sketching techniques, in which you ask participants to draw their neighbourhood and describe their routes to popular destinations on a blank piece of paper; or small group charettes in which you guide participants to identify Lynch's (1960) nodes, edges, paths, districts, and landmarks. Then, one could compare the results to understand how/if people use landmarks in similar ways. The next step would be to combine that information, and present it back to participants, and co-create a wayfinding plan with proposed improvements (like directional signs, more distinct features, etc.) to augment the communities' regular use of the space. By working with a community, one can truly understand collective socio-spatial meaning-making, without marginalizing certain groups. Further, a more detailed cognitive map has also been linked to an increased sense of place and connection to that place (McCunn & Gifford, 2018), meaning that a community wayfinding plan could be one way to improve people's sense of place and connection to their community.

In Chapter 5, I noted specific recommendations for planners (and any people hosting public engagement processes like open houses) based on the experiences of and insights from PLWD. The use of participant observation ultimately resulted in tangible, easy to implement, cost-effective recommendations to an already widely used tool – which could result in more widespread adoption by practice. These recommendations include the selection of a venue, communication between professionals and members of the public, and how visual information is presented, and feedback is sought. I anticipate incorporating these recommendations into a workshop and 'cheat sheet' that I hope to give to planners in the Waterloo Region, as a method of knowledge translation. This workshop can also serve as an opportunity to educate professionals about the negative stigma that is often used when members of society talk about dementia, and thus also represents an opportunity to address misunderstandings.

Finally, in Chapter 3, I demonstrated care to be an intersectional lens that can tell planners a lot about how and why people do certain things/take certain routes in public spaces. Thinking about movement in terms of the themes presented in Chapter 3 could reveal important information for planners, especially for more marginalized groups. For instance, by examining what people do for self-care in space, one might discover that Person X rides a bike to work because it is good for their health and is cheaper than alternatives, but that they also only select routes with protected bike lanes because they are scared of travelling on other types of roads. By examining how their movement is shaped by their relationships with familiar others could tell us how picking up children from school or volunteering in the morning before work requires them to use certain modes of transport. Lastly, by understanding relations with more distant others (e.g. greeting people on the street or waving at neighbours), we can reveal how/if people feel connected to and safe in their community. By looking at mobility in this manner, it is possible to reveal structural inequities, and then as planning practitioners begin to address these issues to create an inclusive city.

6.2.4 Theoretical

Together, these three manuscripts begin to illustrate the importance of examining everyday life for PLWD in public spaces through their socio-spatial relationships in order to build a more inclusive city. The first manuscript answered the first research question of this dissertation – how do PLWD experience their local suburban neighbourhoods? It focused on understanding socio-spatial relationships over time in place through a care lens, by asking "How does one (do we) care?" (Rosa, 2019) and speaks to the importance of understanding PLWD as complex individuals who are simultaneously engaged in caring for/being cared for by themselves, family/friends, others, and the built environment. Understanding their everyday innovative practices disrupts in/dependent dichotomies, and reveals structural and socio-political spatialized impacts of stigmatization. Chapters 4 and 5 dial in to the second research question posed by this dissertation – how can planners support PLWD? It focused in by researching the accessibility of planning outcomes and the planning process. When the manuscripts are considered together (examining everyday socio-spatial relational life through time, combined with planning outcome and process research with PLWD), they have two main theoretical impacts. First, the manuscripts challenge the Just City concept, by arguing for the explicit incorporation of insights from disability studies (supported by findings from this dissertation) in order to build a truly inclusive city. Second, the manuscripts expand notions of citizenship for PLWD into realms not previously considered.

6.2.4.1 Challenging the Just City

Leonie Sandercock suggested in her book *Towards Cosmopolis* that in order to build a just city, difference must not only be tolerated, but treated with dignity and respect. Sandercock believes that planning theory should connect with “other theoretical discourses – specifically debates around marginality, identity and difference, and social justice in the city – because these are debates which empower groups whose voices are not often heard by planners,” (Sandercock, 1998, p.110, as cited in Fainstein, 2010, p. 20). While the ‘Just City’ sought to engage with many of these debates (i.e. gender, race and class), it notably left out disability. Disability is a type of difference that is unexamined and undertheorized in planning theory and literature. To illustrate this example, the quintessential handbook on planning theory, *Readings in Planning Theory*. *Planning Theory & Practice,* by Fainstein and Campbell (2012) includes: foundations of planning theory (including utopian cities and Jane Jacobs), justifications and critiques of planning (i.e. examining capitalism and utilitarianism), normative frameworks (i.e. the science of muddling through, advocacy, participation), case studies of planning in action, and planning in a globalized world. While there are two substantial sections on understanding difference, through social justice (race, gender, class), the right to the city and how experiences in cities reveal structural inequities, disabled access is relegated to one sentence and a single footnote in Iris Marion Young’s chapter entitled "Inclusion and Democracy’. Further, this is best exemplified in literature reviews completed in the past few years on topics like walkability in the Journal of Planning Literature, concluding that “failing to capture diversity in ages and abilities in current walkable neighborhood research has potentially resulted in data-informed practices and guidelines that perpetuate the exclusion of spatially marginalized groups,” (Stafford & Baldwin, 2018, p. 25). Other systematic reviews of childhood mobility for instance, reveal a paucity of research considering disability as a form of difference (Ross & Buliung, 2018). If planning scholarship and practice wants to build inclusive, just cities, then these experiences have to be investigated, and their needs explicitly stated. With this, the question becomes – how should this research be conducted with disabled people? What scales do we look at? Is it all about barriers or are there embodiments of impairment that may not actually be changed with a built environment feature?

To answer these questions, I return to the rich critical disability studies scholarship (including notable geographies of disability work). The findings from the three manuscripts demonstrate how and why to bring these perspectives into planning theory concerned with building the ‘just city’. Difference is a socially contingent and inherently spatial phenomenon (Dear et al., 1997, p. 455). For those in the disabled community, space is something that they have always understood – it is something they live each day, often described as a material-discursive reality (Gleeson, 2013). Disability studies is a combination of the personal experience of impairment with the identification of broader structural, socialized barriers. Lessons from this scholarship were incorporated deep into the design, and findings of this dissertation, including: (1) space as a result of normative conceptions of the body; (2) the need to understand how stigma influences socio-spatial experiences (including rejecting bio-medical pathologizing of dementia) and (3) understanding disability/impairment as relational.

6.2.4.1.1 Questioning the ‘Normate’

Often, planners plan for people who look like them. This means that when we think about the design of cities, it is primarily geared towards the spatial needs and experiences of the ‘normate’ (Hamraie, 2013). Lewis (2011) notes that planning for impairments is rarely a feature of either planning theory or instruction across Canada, and “commonly used texts and reference standards also potentially reinforce perceptions that the bodies for which they design revolve around a range of average physiological norms,” (Harris & Dines, 1997; Imrie, 2000 as cited in Lewis, 2011, p.110). The result of these attitudes, and thus, decisions made on a local scale, are that the disabled body is denied a presence in our cities and communities (Imrie, 2010, as cited in Hamraie, 2013, p.8). If we are to understand that built environments reflect our society, the way we plan for and manage our cities effectively says that disabled people, and therefore PLWD, are not part of the public. The results from this dissertation demonstrate that PLWD are part of the public, and that they do/can participate in their suburban neighbourhoods by using public space and participating in the planning process. This research does show however, the limits of planning for the ‘normate’ in that it marginalizes PLWD in diverse ways – being unable to travel as far as they would like to, having to use alternative routes to ensure their own safety, as well as requiring certain changes and considerations to the design of planning engagement tools. Chapters 4 and 5 specifically demonstrate how to go beyond the ‘normate’ in planning outcome and process research, in order to build a just city. Considering difference in the pursuit of justice in the city has to question the assumptions made about the ‘normate’ body, by instead considering human experience as a spectrum, as well as examining intersectional experiences of marginalization.

6.2.4.1.2 Investigating Spatialized Stigma

Secondly, in the pursuit of the ‘just city’ one has to be able to recognize how stigma is spatialized, and how conceptions of capacity (or lack thereof) shape in/access to the built environment. Dear, Wilton, Gaber, & Takahashi (1997) discuss research on the hierarchies of acceptance for disabled bodies, highlighting the often spatialized component to this stigma and discrimination. For instance, PLWD are perceived to be ‘not in control’ of themselves, and thus are closer towards the bottom end of this hierarchy. PLWD face stigmatization through being labelled as ‘dangerous wanderers’ in the media, and in current research. When walking in one’s neighbourhood becomes framed as ‘wandering behaviour’, it pathologizes an everyday activity. Pathologizing people’s behaviour and looking at these actions through a biomedical lens is harmful (Dupuis, Wiersma, & Loiselle, 2012), yet persists in media (Bailey, Dening, & Harvey, 2019) and research. It is also harmful because PLWD and their actions are not considered intentional. In their research on long-term care, Dupuis, Wiersma, et al. (2012) found that because of this pathologizing of behaviour, staff in the home “rarely contextualized behaviors biographically or historically,” (p.170) leaving out the socio-environmental influences. Thus, pathologizing leads to thinking of PLWD at the individual level only, without regard for the broader social and physical environment. This medicalization is directly related to stigma about what PLWD are able to do, and affects their outdoor lives. As Wettstein et al. (2015) hypothesized, PLWD might have a smaller range of mobility (or life space) due to themselves and their caregiver "reducing their out of home behavior due to an awareness of lowered cognitive resources," (p.17).

With an awareness of how dementia is pathologized in the literature and media, in addition to the stigma surrounding the condition, I used research methods and analysis techniques to go beyond the individual, to understand the multi-layered diverse power geometries and socio-spatial relationalities that influence their embodied experiences in their neighbourhoods. Instead of trying to find an individual solution (like a GPS tracker or other technology device), I examined PLWD’s broader individual history, the context of their suburban neighbourhoods, and their socio-spatial relationships at all scales. This led to an understanding of how stigma is spatialized (such as doctors telling participants not go outside alone anymore), and internalized ableism (like participants saying they should not be allowed to go outside eventually). Further, by researching these broader contextual factors and assuming capacity of PLWD, I was also able to identify potential structural barriers to access (like land use, urban design, and wayfinding built environment features and aspects of planning engagement tools), in addition to the complex networks of care that they had built for themselves in their neighbourhoods. These lessons from CDS – identifying spatialized stigma and rejecting biomedical conceptions of the body – allows planning scholarship seeking the ‘just city’ to find spaces of resistance and adaptation (Tulle-Wilton, 2000 as cited in Brittain et al. 2010, p.276; Power, Bell, Kyle, & Andrews, 2019), and challenge understanding of how PLWD experience, produce and (re)produce space.

6.2.4.1.3 Toward a Socio-Spatial Relational Understanding of Disability

Last, in pursuit of the ‘just city’, planning scholarship has to move towards more socio-spatial relational understandings of everyday life (Corburn, 2017; Cummins et al., 2007; Graham & Healey, 1999). While this call tends to come from health impacts of place research, for planning scholarship, this has meant understanding planning as relations and processes, instead of objects and forms (Graham & Healy, 1999). A socio-spatial relational approach is particularly important to investigate for disabled individuals, as a way to examine the disabling nature of environments as well as the embodied experiences of impairment (Hall & Wilton, 2017; Thomas, 2004b). A personal experience of impairment can be static or episodic, it can be degenerative, cause pain or confusion for example, and as Shakespere (2006) notes, these effects are not always the fault of society, nor can these experiences always be generalized. There is thus, a need to “return to the realities of impairment,” (Shakespere, 2006 as cited in Goodley, 2011, p.28). Embodied experiences of disabled people can also be “powerful counternarratives to dominant representations of disability,” (Dear et al. 1997, p.457) and also “resists the reduction of the individual experience to social ordination,” (Gleeson, 2013, p.76). It is also often difficult to separate the two concepts when conducting research on the everyday lives of disabled people (Power et al., 2019). Hughes & Paterson (1997) argue that impairment (individual experience) and disability (impact of societal barriers) must be studied in tandem since together they form lived experience (p.334-5). This has translated to a movement to not only examining the disabling nature of environments (i.e. the social model of disability), but also an individual’s embodied relational dependencies on human and more-than-human actors. Scholars have acknowledged these experiences are fluid over time and seek to understand how they intersect with other identities (Goodley, Lawthom, Liddiard, & Runswick-Cole, 2019; Hall & Wilton, 2017). With this understanding, PLWD are not predetermined to live a certain life post-diagnosis, and their lives are influenced by an incredible array of other personal identities, relationships, where they live, circumstances, personal history, etc. (Power et al., 2019). The power of relational narratives to illustrate the relational connections between self, neighbourhood, friends, family and the global world have been used in gerontological research (Andrews et al., 2013) and to understand life space of PLWD (Lloyd & Stirling, 2014).

Chapter 3 employed this call by investigating socio-spatial relationalities at all scales, highlighting the experiences of dementia as fluid, complex, and as providing a powerful counternarrative to dependency through examining the innovative practices that they employ to live well in their suburban landscapes. Chapter 3 shows how this socio-spatial relational care lens can reveal a lot about human flourishing in space, as well as challenging the in/dependent dichotomy by emphasizing that we are all interdependent and simultaneously vulnerable, requiring us to care for each other in community (Rosa, 2019). As planners – it is our duty to learn about these practices and think critically about how we can better enable this flourishing together in community. Further, in Chapters 4-5, this socio-spatial relational lens allowed this research to question why able bodies move with "apparent ease" (Hall & Wilton, 2017) compared to PLWD both in their familiar suburban neighbourhoods, and in the typical spaces used for planning engagement sessions, revealing structural (in)equities. This kind of relational inquiry is not only appropriate in the planning discipline, but it also demonstrates a way to do this that is operational for planning scholarship and practice (which was a critique of the original Graham & Healy, 1999 article). Further, a socio-spatial relational understanding of everyday life allows planning scholarship and practitioners to understand the complexities of what a just, accessible city looks like, by understanding disability and impairment in tandem. Without this perspective, it would be difficult to assess what is just/unjust for disabled people especially.

It is vital that insights from critical disability studies be considered in planning. Experiences not fitting the 'normate' body need to be considered in order to plan cities that are usable and livable for the most marginalized. Given the rising importance of centering disabled access to the city, I argue that disability studies be considered a part of planning, not a separate topic to be referenced. It is only by deeply understanding the experiences of disabled people, and working with them that planning scholarship and practice can investigate and design built environments and processes to create truly accessible and just cities.

6.2.4.2 Citizenship for PLWD

How PLWD have been thought of in academia and popular culture has advanced greatly in the past three decades, and has been heavily influenced by activists living with dementia demanding equality and justice (Bartlett, 2014). The conceptualization of PLWD has progressed from being seen as suffers of a deadly disease, then as persons (Kitwood, 1990; 1997), and now through the lens of citizenship, a lens through which scholars claim is necessary to achieve social justice (Bartlett, 2016).

I believe that relational citizenship is a unifying conceptualization of citizenship for PLWD. My understanding follows other scholars by combining a human rights/justice approach with an understanding of agency and embodied selfhood, as well as a focus on interdependence (Keyes et al., 2019; Kontos et al., 2017; Shakespeare et al., 2019). It recognizes the messy nature of bodies, the difficulty separating impairment from disablism, while maintaining a rights-based contextual orientation. I have demonstrated below how the three individual manuscripts in this dissertation support my argument for a relational citizenship conceptualization at the neighbourhood scale within planning practice and in terms of the right to the city.

Citizenship occurs in everyday places (Bartlett, 2016), and can be seen as practice, the act of movement in place and taking up space, in addition to being a source of identity and belonging, a way in which people relate to their communities (Bartlett & O'Connor, 2007; Brannelly, 2016). In terms of existing literature on experiences of PLWD in outdoor spaces, studies have examined the experiences of PLWD in organized walking groups, concluding that they are expressing citizenship as practice by walking in the neighbourhood (Phinney, Kelson, Baumbusch, O'Connor, & Purves, 2016) and interacting with public art (Kelson, Phinney, & Lowry, 2017), in addition to uncovering everyday instances and encounters of belonging (called citizenship within the paper) that promote PLWD's social health (Ward et al., 2018).

Chapter 3 emphasizes interdependent relationships as key for realizing the participation of PLWD in society, realizing their citizenship as taking up space, and feeling like they belong in their neighbourhood. Chapter 3 shows the importance of understanding citizenship of PLWD as being interdependent, relying on a combination of socio-spatial relationalities with the built environment, family/friends, human and more-than-human others, as well as their past/present/future selves to be able to practice citizenship in the neighbourhood. Chapter 3 also highlighted the negative impact of socio-cultural discourse about dementia (in terms of stigma, perceived capacity, etc.) on the movement of PLWD in their neighbourhoods. This emphasizes the need to focus on relationalities at all scales when thinking about citizenship for PLWD, including the socio-cultural-political, as this is a powerful discourse that profoundly impacts PLWD's lives.

Chapter 4 adds to this discussion of citizenship as practice and belonging by going beyond describing walking practices as citizenship, and investigating the socio-spatial embodied reactions of PLWD to their familiar neighbourhoods, and built environment features. By investigating embodied reactions with the built environment, Chapter 4 was able to discern socio-spatial relational barriers and facilitators to this everyday practice of citizenship in context. Chapter 4 makes evident that broader socio-cultural discourse (re)produces ideas about 'who belongs' in a spatialized way in suburban neighbourhoods, in that there are a number of built environment features that are barriers for PLWD. Chapter 4 can also be conceived of as research upon which to base demands for equity and justice as citizens, highlighting the right-based part of the relational citizenship understanding (Bartlett, 2016). Both of these chapters make an argument for the utility of the relational citizenship for understanding how movement and a sense of inclusion in familiar neighbourhoods can be supported in a relational way for PLWD.

Lastly, a relational citizenship conceptualization must engage with PLWD's relationship with the state. This form of citizenship for PLWD has been discussed in terms of representative democracy, and voting in democratic elections (Sonnicksen, 2016). Chapter 5 expands this notion of citizenship and relationship with the state to having a voice in the city-building process, going beyond voting for a representative. While PLWD have been consulted before on social policy concerning their care, they have not been truly consulted about the places they live in (Lin & Lewis, 2015). They deserve, just like any other citizen, to have a voice in this process, to (re)shape the places they live in, which could also be seen as an opportunity for growth post-diagnosis, and an alternative to what activist Swaffer (2014) calls "prescribed disengagement™" (p.713). The relationship with the state is integral, as it is the state (at the municipal level) that is most likely to make decisions that can differentially impact their experiences in their familiar neighbourhoods − for better or worse (Fainstein, 2010). In examining of accessibility of the open house, Chapter 5 also centered embodied experiences and reactions to all aspects of the open house meetings (a key component of a relational citizenship approach). The three manuscripts in this thesis responded to the three challenges to citizenship as outlined by Brannely (2016): citizenship as practice, as identity and belonging and the relationship between PLWD and the state.

PLWD are, and always will be, citizens of the cities, communities and neighbourhoods that they live in. They have a right to comment on and be consulted about how those places enable or disable them in a way that is relational and recognizes their agency, embodied selfhood, and interdependencies in context. There is a need for specialized rights for PLWD in planning scholarship and practice. Young (1989)'s influential work on specialized rights builds from the assumption that group difference exists and in order to build a participatory democracy, we have to work harder to include the voices of these groups. A similar approach is advocated by Fainstein (2010) and Bartlett

& O’Connor (2010). I argue that the voices of PLWD are necessary if planning as a discipline seeks to build truly inclusive neighbourhoods. Mobilizing for citizenship for PLWD is emerging (Bartlett, 2014), and this dissertation demonstrates the potential synergies between it and the quest for the just city by planning scholarship and practice. Together, they could change misconceptions about living with dementia and build truly inclusive places.

6.3 Limitations

The greatest limitation of this thesis was the sample size and the location, preventing the study from making claims beyond the experiences of participants who were Caucasian, as well as born, raised and living in similar Canadian suburban neighbourhoods. Further, this research was exploratory, adding to an evidence base of work and indicating potential areas of future research, as well as methods and analysis to expand upon. Finally, while this dissertation sought to understand the everyday practices of PLWD, it only captured their everyday practices in spring, summer and autumn Ontario weather, which left out experiences in winter months. The participants recruited in this study were already pre-disposed to participating in support groups/ other research, as they were all part of the former, and the majority was part of the latter. As a result, this research gained perspective from folks who are perceived to be ‘doing something’ about living with dementia by getting involved, which necessarily missed PLWD who are not. Lastly, one of the prerequisites for this study was being able to walk outdoors by oneself. This means that the research did not investigate the experiences of those who perceived it to be too dangerous to go outside alone.

6.4 Future Research + Practice

Further to the key findings and limitations as outlined above, future research and practice should focus on a few areas:

Wayfinding for PLWD in Familiar Environments: Nearly all studies (e.g. from psychology, architecture) have focused on wayfinding experiments (i.e. challenging participants to get to a certain location on their own) in unfamiliar environments or measuring responses to certain built environment features on a predetermined route (where level of familiarity is unknown). This thesis examined how PLWD wayfind in familiar suburban landscapes, answering a call put forward by O’Malley, Innes, & Wiener (2017), and this research should be continued, as cognitive research tells us that wayfinding in familiar versus unfamiliar settings involve different processes in the brain. Further, more work connecting personal histories/lifecourse approaches to how people wayfind will be integral in future, as these processes do not happen in a vacuum, and we need to more deeply understand how and why people place meaning on certain features that help them find their way.

Sense-scapes of PLWD: Evidence from this dissertation and elsewhere have indicated that PLWD can feel overwhelmed or disoriented by certain noises, moving objects (like cars), and certain lighting situations. Future research should focus explicitly on sensory experiences – perhaps using a mobile decibel meter during a go-along interview that collects decibel data every few meters, and then correlating that with the image-quote connecting method as used in Chapter 4. This could also be combined with a mobile device to measure galvanic skin response (i.e. arousal level). These diverse data sources, when combined with perceptions of PLWD could provide more deeply relational understanding of place.

Accessing the Planning Process and Knowledge Translation with Professional Planners: This thesis assessed the accessibility of one type of planning engagement tool – the open house. This work was exploratory, and provides indication as to the kinds of aspects to pay attention to when conducting public engagement (selection of the room, communication style, and presentation of information). Future studies should evaluate other commonly used planning engagement tools (e.g. design charettes) and test certain types of visuals in terms of ease of understanding for PLWD (e.g. using virtual reality, 3D versus 2D models, certain communication styles etc.). Another potential avenue for research would be to use a similar model to the Blue Umbrella program, in which Regional/City Planning Staff in Waterloo Region would be trained using the findings from Chapter 5, and then have PLWD be 'secret' participants who evaluate the engagement event for its accessibility according to that tool. Further, one could conduct a pre- and post- survey of Regional/City Planning Staff to understand if their perceptions of PLWD were changed by the workshop, and how.

Care as a lens for understanding everyday life: Through Chapter 3, it became evident that a care lens was an effective way to understand everyday life in public spaces for PLWD. The lens brought to light a multitude of practices that highlight the complexity of one's route choices and activity space, and how that is influenced by personal history, and relationships with others through time. A care lens can be an effective way to understand structural inequities, as well as the lived experiences of impairment. It can help paint a fuller picture of one's everyday life. This kind of lens also fits well with recent writings in planning theory calling for compassionate and restorative planning (Lyles & Swearingen White, 2019; Schweitzer, 2016). Future research might consider how this care lens can fit with these writings on compassionate processes in planning. Perhaps designing a course or workshop around using care and compassion as a lens in planning with pre- and post- studies of students or practitioners would be a good way to start.

Planning dementia-inclusive suburban spaces with/for new Canadians in Toronto's inner suburbs: This project included participants who were all Caucasian, born and raised in similar Canadian suburban neighbourhoods, following most research on this topic - with white people in the UK, Australia, and Sweden) who were born in the country they reside in. Based on this thesis and proceeding literature, the impact of racialization (further stigmatization), time since immigration, and gender are under-researched topics in this area of study. That is why my future SSHRC Post-Doctoral Fellowship research, with Dr. Roger Keil at York University, will address these gaps in the literature.

References

American Institute of Certified Planners (AICP). (2016). Code of Ethics. Retrieved from: https://www.planning.org/ethics/ethicscode.htm

Alzheimer Society of Canada. (2010). *Rising Tide: The Impact of Dementia on Canadian Society*. Toronto, ON. Retrieved from http://www.alzheimer.ca/~/media/Files/national/Advocacy/ASC_Rising_Tide_Full_Report_e.pdf

Alzheimer Society of Canada. (2018). *10 Warning Signs.* Retrieved from http://alzheimer.ca/en/Home/About-dementia/Alzheimers-disease/10-warning-signs

Alzheimer Society of Canada. (2019). *Early Onset Dementia.* Retrieved from https://alzheimer.ca/en/Home/About-dementia/Dementias/young-onset-dementia

Amin, A. (2002). Ethnicity and the multicultural city: living with diversity. *Environment and Planning A*, *34*, 959–980.

Andrews, G. J., Evans, J., & Wiles, J. L. (2013). Re-spacing and re-placing gerontology: Relationality and affect. *Ageing and Society*, *33*(8), 1339–1373.

Arnstein, S. R. (1969). A Ladder of Citizen Participation. *Journal of the American Institute of planners*, *35*(4), 216-224.

Bailey, A., Dening, T., & Harvey, K. (2019). Battles and breakthroughs: Representations of dementia in the British press. *Ageing & Society*, 1–15.

Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, *21*(2), 107–118.

Bartlett, R., & O'Connor, D. (2010). *Broadening the dementia debate: Towards social citizenship*. Bristol, UK: Policy Press.

Bartlett, R. (2014). Citizenship in action: the lived experiences of citizens with dementia who campaign for social change. *Disability and Society*, *29*(8), 1291–1304.

Bartlett, R. (2016). Scanning the conceptual horizons of citizenship. *Dementia*, *15*(3), 453–461.

Bartlett, R., & Brannelly, T. (2019). On being outdoors: How people with dementia experience and deal with vulnerabilities. *Social Science & Medicine*, *235*.

Barnes, M., Knops, A., Newman, J., & Sullivan, H. (2004). Recent research: The micro-politics of deliberation: Case studies in public participation. *Contemporary Politics, 10*(2), 93–110.

Baxter, J., & Eyles, J. (1997). Evaluating qualitative research in social geography: establishing "rigour" in interview analysis. *Transactions of the Institute of British Geographers*, *22*(4), 505–525.

Berbary, L. A., & Boles, J. C. (2014). Eight Points for Reflection: Revisiting Scaffolding for Improvisational Humanist Qualitative Inquiry. *Leisure Sciences*, *36*(5), 401–419.

Bevan, M., & Croucher, K. (2011). Lifetime Neighbourhoods. London, UK: Department of Communities and Local Government, Government of the United Kingdom.

Biglieri, S. (2015). Building a Dementia-Friendly Neighbourhood: An Examination of the Economic Costs of Implementing 'Dementia-Friendly' Urban Design and Land Use Strategies in Whitby, Ontario (Major Research Paper). Ryerson University, Toronto, ON.

Biglieri, S. (2018). Implementing Dementia-Friendly Land Use Planning: An Evaluation of Current Literature and Financial Implications for Greenfield Development in Suburban Canada. *Planning Practice and Research*, *33*(3), 264–290.

Binette, J., & Vasold, K. (2018). *2018 Home and Community Preferences: A National Survey of Adults Age 18-Plus*. *AARP Research*. Washington, DC. Retrieved from https://www.aarp.org/research/topics/community/info-2018/2018-home-community-preference.html

Blackman, T., Mitchell, L., Burton, E., Jenks, M., Parsons, M., Raman, S., & Williams, K. (2003). The accessibility of public spaces for people with dementia: A new priority for the "open city." *Disability and Society*, *18*(3), 357–371.

Blackman, T., Van Schaik, P., & Martyr, A. (2007). Outdoor environments for people with dementia: An exploratory study using virtual reality. *Ageing and Society*, *27*(6), 811–825.

Blue, G., Rosol, M., & Fast, V. (2019). Justice as Parity of Participation. *Journal of the American Planning Association*, *85*(3), 363–376.

Bowlby, S. (2012). Recognising the Time—Space Dimensions of Care: Caringscapes and Carescapes. *Environment and Planning A: Economy and Space*, *44*(9), 2101–2118.

Brannelly, T. (2016). Citizenship and people living with dementia: A case for the ethics of care. *Dementia*, *15*(3), 304–314.

Brittain, K.R., Corner, L., Robinson, L., & Bond, J. (2010). Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments. *Sociology of Health and Illness, 32*(2), 272–287.

Brorsson, A., Öhman, A., Lundberg, S., & Nygård, L. (2011). Accessibility in public space as perceived by people with Alzheimer's disease. *Dementia*, *10*, 587–602.

Brorsson, A., Öhman, A., Cutchin, M., & Nygård, L. (2013). Managing critical incidents in grocery shopping by community-living people with Alzheimer's disease. *Scandinavian Journal of Occupational Therapy*, *20*(4), 292–301.

Brorsson, A., Öhman, A., Lundberg, S., & Nygård, L. (2014). Being a pedestrian with dementia: A qualitative study using photo documentation and focus group interviews. *Dementia*.

Brown, K. M., Elliott, S. J., Leatherdale, S. T., & Robertson-Wilson, J. (2015). Searching for rigour in the reporting of mixed methods population health research: a methodological review. *Health Education Research* , *30*(6), 811–839.

Bryden, C. (2005). *Dancing with dementia: My story of living positively with dementia*. London, UK: Jessica Kingsley Publishers.

Bryson, J. M., Moynihan, D. P., Quick, K. S., Slotterback, C. S., & Crosby, B. C. (2012). Designing Public Participation Processes. *Public Administration Review*, *73*(1), 23–34.

Burton, E., & Mitchell, L. (2006). *Inclusive urban design: Streets for life*. New York, NY: Elsevier.

Cannuscio, C. C., Weiss, E. E., Fruchtman, H., Schroeder, J., Weiner, J., & Asch, D. A. (2009). Visual epidemiology: Photographs as tools for probing street-level etiologies. *Social Science and Medicine*, *69*(4), 553–564.

Campbell, S., Clark, A., Keady, J., Kullberg, A., Manji, K., Rummery, K., & Ward, R. (2019). Participatory social network map making with family carers of people living with dementia. *Methodological Innovations*, *12*(1), 205979911984444.

Carpiano, R. M. (2009). Come take a walk with me: The “Go-Along” interview as a novel method for studying the implications of place for health and well-being. *Health & Place*, *15*(1), 263–272.

Carr, K., Weir, P. L., Azar, D., & Azar, N. R. (2013). Universal design: a step toward successful aging. *Journal of Aging Research*, 1-8.

Cassarino, M., & Setti, A. (2016). Complexity As Key to Designing Cognitive-Friendly Environments for Older People. *Frontiers in Psychology, 7*, 1-12.

Cedervall, Y., Åberg, A. C., Cristina, A., & Berg, A. ˚. (2010). Physical activity and implications on well-being in mild Alzheimer’s disease: A qualitative case study on two men with dementia and their spouses. *Physiotherapy Theory and Practice*, *26*(4), 226–239.

Cerin, E., Nathan, A., Van Cauwenberg, J., Barnett, D. W., & Barnett, A. (2017). The neighbourhood physical environment and active travel in older adults: a systematic review and meta-analysis. *International Journal of Behavioral Nutrition and Physical Activity*, *14*(15), 1–23.

Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). Thousand Oaks, CA: SAGE Publications Inc.

Charmaz, K. (2016). The Power of Constructivist Grounded Theory for Critical Inquiry. *Qualitative Inquiry*, *23*(1), 34–45.

Charmaz, K., & Keller, R. (2016). A Personal Journey with Grounded Theory Methodology: Kathy Charmaz in Conversation With Reiner Keller. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, *17*(1), 27.

Chaudhury, H., & Cooke, H. (2014). Design matters in dementia care: The role of the physical environment in dementia care settings. *Excellence in dementia care*, *2*, 144-158.

Chaudhury, H., Cooke, H. A., Cowie, H., & Razaghi, L. (2017). The Influence of the Physical Environment on Residents With Dementia in Long-Term Care Settings: A Review of the Empirical Literature. *The Gerontologist*.

Chaudhury, H., Mahmood, A., Michael, Y. L., Campo, M., & Hay, K. (2012). The influence of neighborhood residential density, physical and social environments on older adults' physical activity: An exploratory study in two metropolitan areas. *Journal of Aging Studies*, *26*(1), 35–43.

Clarke, P. J., Ailshire, J. A., House, J. S., Morenoff, J. D., King, K., Melendez, R., & Langa, K. M. (2012). Cognitive function in the community setting: the neighbourhood as a source of 'cognitive reserve'?. *Journal of Epidemiology and Community Health, 66*(8), 730-736.

Clarke, P., Weuve, J., Barnes, L., Evans, D., & Mendes de Leon, C. (2015). Cognitive decline and the neighbourhood environment. *Annals of Epidemiology, 25*, 849-854.

Corburn, J. (2009). *Toward the healthy city: people, places, and the politics of urban planning*. Cambridge, MA: MIT Press.

Corburn, J. (2017). Urban place and health equity: Critical issues and practices. *International Journal of Environmental Research and Public Health*, *14*(2), 1–10.

Cummins, S., Curtis, S., Diez-Roux, A. V., & Macintyre, S. (2007). Understanding and representing "place" in health research: A relational approach. *Social Science and Medicine*, *65*(9), 1825–1838.

de Souza Briggs, X. (1998). Doing Democracy Up-Close: Culture, Power, and Communication in Community Building. *Journal of Planning Education and Research*, *18*(1), 1–13.

Dear, M., Wilton, R., Gaber, S. L., & Takahashi, L. (1997). Seeing people differently: The sociospatial construction of disability. *Environment and Planning D: Society and Space*, *15*(4), 455–480.

Dementia Alliance Interational. (2018). *Inclusive Communities*. Retrieved from: https://www.dementiaallianceinternational.org/dementia-friendly-communities/

Dewing, J. (2009). Caring for people with dementia: noise and light. *Nursing Older Adults, 21*(5), 34-38.

Doherty, S. T., Lemieux, C. J., & Canally, C. (2014). Tracking human activity and well-being in natural environments using wearable sensors and experience sampling. *Social Science and Medicine*, *106*, 83–92.

Downs, M., & Collins, L. (2015). Person-centred communication in dementia care. *Nursing Standard, 30*(11), 37–41.

Duggan, S., Blackman, T., Martyr, A., & Van Schaik, P. (2008). The impact of early dementia on outdoor life: A shrinking world'?. *Dementia*, *7*(2), 191-204.

Dunlop, I. N., Casello, J. M., & Doherty, S. T. (2015). Tracking the Transit Rider Experience: Using Smartphones to Measure Comfort and Well-Being Throughout the Trip. In *Transportation Research Board 94th Annual Meeting* (p. 15). Washington, DC.

Dupuis, S. L., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L., & Sadler, L. (2012). Moving beyond patient and client approaches: Mobilizing "authentic partnerships" in dementia care, support and services. *Dementia*, *11*(4), 427–452.

Dupuis, S. L., Whyte, C., Carson, J., Genoe, R., Meshino, L., & Sadler, L. (2012). Just dance with me: An authentic partnership approach to understanding leisure in the dementia context. *World Leisure Journal*, *54*(3), 240–254.

Dupuis, S. L., Wiersma, E., & Loiselle, L. (2012). Pathologizing behavior: Meanings of behaviors in dementia care. *Journal of Aging Studies*, *26*(2), 162–173.

Edick, C., Holland, N., Ashbourne, J., Elliott, J., & Stolee, P. (2017). A review of Canadian and international dementia strategies. *Healthcare Management Forum*, *30*(1), 32–39.

Eggenberger, E., Heimerl, K., & Bennett, M. I. (2013). Communication skills training in dementia care: a systematic review of effectiveness, training content, and didactic methods in different care settings. *International Psychogeriatrics, 25*(3), 345–358.

Fainstein, S. S. (2010). *The Just City*. Ithaca, NY: Cornell University Press.

Fainstein, S. S. (2014). The Just City. *International Journal of Urban Sciences*, *18*(1), 1–18.

Fainstein, S. S., & Campbell, S. (Eds.). (2012). *Readings in Planning Theory*. *Planning Theory & Practice* (3rd ed., Vol. 13). Wiley-Blackwell.

Faith, V., Rooney, C., Hadjri, K., McAllister, K., & Craig, C. (2015). Finding a way : long-term care homes to support dementia. *Urban Design and Planning*, *168*(4), 204–217.

Farmer, T., Robinson, K., Elliott, S. J., & Eyles, J. (2006). Developing and Implementing a Triangulation Protocol for Qualitative Health Research. *Qualitative Health Research, 16*(3), 377–394.

Farthing, S. (2016). *Research Design in Urban Planning: A Student's Guide* (1st ed.). London, UK: SAGE Publications Ltd.

Filion, P. (2018). The Morphology of Dispersed Suburbanism: The Land-use Patterns of the Dominant North American Urban Form. In U. Lehrer & R. Harris (Eds.), *The Suburban Land Question: A Global Survey* (1st ed., pp. 122–144). Toronto, ON: University of Toronto Press.

Finlay, J. M., & Bowman, J. A. (2017). Geographies on the Move: A Practical and Theoretical Approach to the Mobile Interview. *The Professional Geographer*, *69*(2), 263–274.

Fisher, B., & Tronto, J. (1990). Toward a feminist theory of caring. *Circles of care: Work and identity in women's lives*, 35-62.

Fleet, C. (2019, October). Digital Frictions in Nonvisual Accessibility and the Built Environment. *#a11yIRL.* Talk presented at 2019 Accessibility in Real Life Conference, Toronto, Canada.

Fleming, R., Bennett, K., Preece, T., & Phillipson, L. (2016). The development and testing of the dementia friendly communities environment assessment tool (DFC EAT). *International psychogeriatrics, 29*(2), 303-311.

Flyvbjerg, B., & Richardson, T. (2002). Planning and Foucault: in search of the dark side of planning theory. In P. Allmendinger, & M. Twedr-Jones (Eds.), *Planning Futures: New Directions for Planning Theory* (pp.44-62). London, UK: Routledge.

Flyvbjerg, B. (1998). *Rationality and power: Democracy in practice*. Chicago, IL: University of Chicago Press.

Flyvbjerg, B. (2006). Five Misunderstandings About Case-Study Research. *Qualitative Inquiry*, *12*(2), 219–245. https://doi.org/10.1177/1077800405284363

Forester, J. (1999). *The deliberative practitioner: Encouraging participatory planning processes*. Boston, MA: MIT Press.

Franke, T., Sims-Gould, J., Chaudhury, H., Winters, M., & Mckay, H. (2019). Re-framing mobility in older adults: an adapted comprehensive conceptual framework. *Qualitative Research in Sport, Exercise and Health*, *0*(0), 1–14. https://doi.org/10.1080/2159676X.2019.1575269

Friedmann, J. 1987. *Planning in the Public Domain: From Knowledge to Action.* Princeton, NJ: Princeton University Press.

Fusco, C., Moola, F., Faulkner, G., Buliung, R., & Richichi, V. (2012). Toward an understanding of children's perceptions of their transport geographies: (non)active school travel and visual representations of the built environment. *Journal of Transport Geography*, *20*(1), 62–70.

Gaber, S. N., Nygård, L., Brorsson, A., Kottorp, A., & Malinowsky, C. (2019). Everyday technologies and public space participation among people with and without dementia. *Canadian Journal of Occupational Therapy*, 1–12.

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, *13*(117), 1–8.

Gärling, T., Böök, A., & Lindberg, E. (2013). Adults' memory representations of the spatial properties of their everyday physical environment. In R. Cohen (Ed.), *The Development of Spatial Cognition* (pp. 141-184). Hillsdale, NJ: Lawrence Erlbaum Associates, Inc.

Gehl, J. (2010). *Cities for People* (1st ed.). Washington, DC: Island Press.

Genoe, M. R., & Dupuis, S. L. (2013). Picturing Leisure: Using Photovoice to Understand the Experience of Leisure and Dementia. *Qualitative Report*, *18*(11), 1–21.

Ghani, F., Rachele, J. N., Loh, H. Y., Washington, S., & Turrell, G. (2018). Do differences in built environments explain age differences in transport walking across neighbourhoods? *Journal of Transport & Health*, *9*, 83–95.

Gleeson, B. (2013). Lost and Found in Space: The Geographical Imagination and Disability. In M. Wappett & K. Arndt (Eds.), *Foundations of Disability Studies* (pp. 69–81). New York, NY: Palgrave Macmillan.

Golant, S. M. (2019). Stop bashing the suburbs: Mobility limitations of older residents are less relevant as connectivity options expand. *Journal of Aging Studies*.

Goodley, D. (2011). *Disability Studies: An Interdisciplinary Introduction.* London, UK: SAGE Publications Ltd.

Goodley, D., Lawthom, R., Liddiard, K., & Runswick-Cole, K. (2019). Provocations for Critical Disability Studies. *Disability and Society*, *34*(6), 972–997.

Google Earth. (2019). [Google Earth View of the Regional Municipality of Waterloo, Ontario, Canada]. Retrieved September, 20, 2018, from https://earth.google.com/web/@43.47824855,-80.52831995,-28.38714569a,134950.8927465d,35y,0h,0t,0r/data=CmYaZBJeCiUweDg4MmM3NGQyYWZiZTU1Y2Q6MHg4M2FhNDdkNmNkZWYwZjNiGYR8dfrmvEVAIfVFQlvOIlTAKiNNdW5pY2lwYWxpdMOgIFJlZ2lvbmFsZSBkaSBXYXRlcmxvbxgCIAE

Google Maps. (2019). [Google Maps View of the Regional Municipality of Waterloo, Ontario, Canada]. Retrieved August 15, 2018, from https://www.google.com/maps/place/Waterloo+Regional+Municipality,+ON/@43.4699251,-80.7633074,10.25z/data=!4m5!3m4!1s0x882c74d2afbe55cd:0x83aa47d6cdef0f3b!8m2!3d43.4757989!4d-80.543845

Gordon, E., Schirra, S., & Hollander, J. (2011). Immersive planning: a conceptual model for designing public participation with new technologies. *Environment and Planning B: Planning and Design, 38*(3), 505–519.

Gordon, D. (2019). Kitchener-Waterloo-Cambridge: Transportation T9 Method. Retrieved from: http://canadiansuburbs.ca/files/Kitchener_T9_2016.pdf

Graham, S., & Healey, P. (1999). Relational concepts of space and place: Issues for planning theory and practice. *European Planning Studies*, *7*(5), 623–646.

Graham, J. (2017, March 10). Don't write us off: People with dementia press for more rights — and respect. *StatNews*. Retrieved from: https://www.statnews.com/2017/03/10/dementia-human-rights/

Gresham, M., Taylor, L., Keyes, S., Wilkinson, H., McIntosh, D., & Cunningham, C. (2019). Developing evaluation of signage for people with dementia. *Housing, Care and Support*, *22*(3), 153–161. https://doi.org/10.1108/HCS-12-2018-0035

Guba, E. G., & Lincoln, Y. S. (1989). *Fourth Generation Evaluation*. Newbury Park, CA: SAGE.

Gunder, M. (2010). Fake it until you make it, and then…. *Planning Theory*, *10*(3), 201–212.

Hall, E., & Wilton, R. (2017). Towards a relational geography of disability. *Progress in Human Geography*, *41*(6), 727–744.

Hamraie, A. (2013). Designing Collective Access: A Feminist Disability Theory of Universal Design. *Disability Studies Quarterly*, *33*(4). Retrieved from http://dsq-sds.org/article/view/3871/3411

Hamraie, A. (2017). *Building Access: Universal Design and the Politics of Disability* (1st ed.). Minneapolis, MN: University of Minnesota Press.

Hand, C., Huot, S., Rudman, D. L., & Wijekoon, S. (2017). Qualitative-Geospatial Methods of Exploring Person-Place Transactions in Aging Adults: A Scoping Review. *Gerontologist*, *57*(3), 47–61.

Hand, C. L., Laliberte Rudman, D., Huot, S., Gilliland, J. A., & Pack, R. (2018). Toward Understanding Person–Place Transactions in Neighborhoods: A Qualitative-Participatory Geospatial Approach. *The Gerontologist*, *58*(1), 89–100.

Harris, J. C. (2017). Vulnerable Youth's Perspectives and Priorities for Informal Settlements: Photovoice Evidence from Lusaka, Zambia. *Journal of Planning Education & Research*, 1–15.

Hastings, S. L. (2012). Triangulation. In N. J. Salkind (Ed.), *Encyclopedia of Research Design* (pp. 1538–1540). Thousand Oaks, CA: SAGE Publications Inc.

Healey, P. (1996). The communicative turn in planning theory and its implications for spatial strategy formation. *Environment and Planning B: Planning and design*, *23*(2), 217-234.

Hershberg, R. M. (2014). Constructivism. In D. Coghlan & M. Brydon-Miller (Eds.), *The SAGE Encyclopedia of Action Research* (pp. 183–186). London, UK: SAGE Publications Ltd.

Higgs, P., & Gilleard, C. (2017). Ageing, dementia and the social mind: past, present and future perspectives. *Sociology of Health and Illness*, *39*(2), 175–181.

Hodge, G. (2008). The Geography of Aging: Preparing Communities for the Surge in Seniors. McGill-Queen's University Press.

Hodge, G., & Gordon, D. (2014). *Planning Canadian Communities* (6th ed.). Toronto, ON: Nelson Education.

Hosking, D. L. (2008). Critical Disability Theory. In *4th Biennial Disability Studies Conference* (pp. 1–17). Retrieved from http://www.lancaster.ac.uk/fass/events/disabilityconference_archive/2008/papers/hosking2008.doc

Hughes, B., & Paterson, K. (1997). The Social Model of Disability and the Disappearing Body : Towards a sociology of impairment The Social M odel of Disability and the Disappearing Body : towards a sociology of impairment. *Disability & Soiciety*, *12*(3), 325–340.

Hung, L., Phinney, A., Chaudhury, H., Rodney, P., Tabamo, J., & Bohl, D. (2017). "Little things matter!" Exploring the perspectives of patients with dementia about the hospital environment. *International Journal of Older People Nursing*, *12*(3), 1–11.

Imrie, R. (2003). Architects' conceptions of the human body. *Environment and Planning D: Society and Space*, 21(1), 47-65.

Imrie, R, & Hall, P. (2001). *Inclusive Design: Designing and Developing Accessible Environments*. London, UK: Taylor and Francis Group Ltd.

Imrie, Rob, & Kullman, K. (2017). Designing with Care and Caring with Design. In C. Bates, R. Imrie, & K. Kullman (Eds.), *Care and Design: Bodies, Buildings, Cities* (1st ed., pp. 1–15). West Sussex, United Kingdom: John Wiley & Sons, Ltd.

Innes, J. (1995). Planning Theory's Emerging Paradigm: Communicative Action and Interactive Practice. *Journal of Planning Education and Research, 14*(3), 183–189.

Jeffries, K., & Agrawal, N. (2009). Early Onset Dementia. *Advances in Psychiatric Impairment, 15*(5), 380-388.

Jones, R. (2019). Really shit work? Bodily becoming and the capacity to care for the urban forest. *Social & Cultural Geography*, *20*(5), 630–648.

Keady, J., Hydén, L. C., Johnson, A., & Swarbrick, C. (Eds.). (2017). *Social research methods in dementia studies: Inclusion and innovation*. New York, NY: Routledge.

Keady, J., Campbell, S., Barnes, H., Ward, R., Li, X., Swarbrick, C., … Elvish, R. (2012). Neighbourhoods and dementia in the health and social care context: A realist review of the literature and implications for UK policy development. *Reviews in Clinical Gerontology*, *22*(2), 150–163.

Keating, N., & Gaudet, N. (2012). Quality of life of persons with dementia. *The Journal of Nutrition, Health & Aging*, 16(5), 454–456.

Keil, R. (2018). *Suburban Planet: making the world urban from the outside in*. Cambridge, UK: Polity Press.

Keller, H. H. (2007). Promoting food intake in older adults living in the community: a review. *Applied Physiology, Nutrition, and Metabolism*, *32*(6), 991-1000.

Kelson, E., Phinney, A., & Lowry, G. (2017). Social citizenship, public art and dementia: Walking the urban waterfront with Paul's Club. *Cogent Arts & Humanities*, *4*(1).

Kerr, J., Rosenberg, D., & Frank, L. (2012). The Role of the Built Environment in Healthy Aging: Community Design, Physical Activity, and Health among Older Adults. *Journal of Planning Literature*, *27*(1), 43–60.

Keyes, S. E., Clarke, C. L., & Gibb, C. E. (2019). Living with dementia, interdependence and citizenship: narratives of everyday decision-making. *Disability & Society* , *34*(2), 296–319.

Keyes, S. E., Webber, S. H., & Beveridge, K. (2015). Empowerment through care: Using dialogue between the social model of disability and an ethic of care to redraw boundaries of independence and partnership between disabled people and services. *Alter*, *9*(3), 236–248.

Kitwood, T. (1990). The dialectics of dementia: with particular reference to Alzheimer's disease. *Ageing & Society*, *10*(2), 177-196.

Kitwood, T. (1997). The experience of dementia. *Aging & Mental Health*,*1*(1), 13-22.

Kontos, P., Grigorovich, A., Dupuis, S., Jonas-Simpson, C., Mitchell, G., & Gray, J. (2018). Raising the curtain on stigma associated with dementia: fostering a new cultural imaginary for a more inclusive society. *Critical Public Health*, 1–13.

Kontos, P., Grigorovich, A., Kontos, A. P., & Miller, K.-L. (2016). Citizenship, human rights, and dementia: Towards a new embodied relational ethic of sexuality. *Dementia*, *15*(3), 315–329.

Kontos, P., Miller, K., & Kontos, A. P. (2017). Relational citizenship : supporting embodied selfhood and relationality in dementia care. *Sociology of Health and Illness*, *39*(2), 182–198.

Lacey-Avon, S. (2016). Examining the Livability of a Day Program for Individuals with Alzheimer's Disease and Other Memory-related Disorders: A Case Study of The Dotsa Bitove Wellness Academy (Master's Thesis). University of Waterloo, Waterloo, ON.

Lawson, V. (2007). Presidential Address: Geographies of Care and Responsibility. *Annals of the Association of American Geographers*, *97*(1), 1–11.

Lawson, V. (2008). Geographies of Care and Responsibility. *Annals of the Association of American Geographers*, *97*(1), 1–11.

Lee, E., & Dean, J. (2018). Perceptions of walkability and determinants of walking behaviour among urban seniors in Toronto, Canada. *Journal of Transport & Health*, *9*, 309–320.

Lefebvre, H. (1996). *Writings on Cities* (E. Koffman & E. Lebas, Trans.). Oxford, UK: Blackwell.

Levasseur, M., Généreux, M., Bruneau, J.-F., Vanasse, A., Chabot, É., Beaulac, C., & Bédard, M.-M. (2015). Importance of proximity to resources, social support, transportation and neighborhood security for mobility and social participation in older adults: results from a scoping study. *BMC Public Health*, *15*(1), 503.

Lewis, J. L. (2011). Student attitudes toward impairment: An assessment of passive and active learning methods in urban planning education. *Teaching in Higher Education*, 16(2), 237-249.

Lincoln, Y. S., & Guba, E. A. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Lin, S. Y., & Lewis, F. M. (2015). Dementia friendly, dementia capable, and dementia positive: Concepts to prepare for the future. *Gerontologist*, *55*(2), 237–244.

Link, B. G., & Phelen, J. C. (2006). Stigma and its public health implications. *The Lancet, 367*, 528-529.

Liu, L., Cruz, A. M., Ruptash, T., Barnard, S., & Juzwishin, D. (2017). Acceptance of Global Positioning System (GPS) Technology Among Dementia Clients and Family Caregivers. *Journal of Technology in Human Services*, *35*(2), 99–119.

Livingston, G., Kelly, L., Lewis-Holmes, E., Baio, G., Morris, S., Patel, N., … Cooper, C. (2014). Non-pharmacological interventions for agitation in dementia: Systematic review of randomised controlled trials. *British Journal of Psychiatry, 205*(6), 436–442.

Lloyd, B. T., & Stirling, C. (2015). The will to mobility: Life-space satisfaction and distress in people with dementia who live alone. *Ageing and Society*, *35*(9), 1801–1820.

Lord, A., Mair, M., Sturzaker, J., & Jones, P. (2017). 'The planners' dream goes wrong?' Questioning citizen-centred planning. *Local Government Studies*, *43*(3), 344–363.

Loukaitou-Sideris, A., Wachs, M., & Pinski, M. (2019). Toward a Richer Picture of the Mobility Needs of Older Americans. *Journal of the American Planning Association*, *0*(0), 1–19.

Lui, C. W., Everingham, J. A., Warburton, J., Cuthill, M., & Bartlett, H. (2009). What makes a community age-friendly: A review of international literature. *Australasian Journal on Ageing*, 28(3), 116-121.

Lyles, W., & Swearingen White, S. (2019). Who Cares?: Arnstein's Ladder, the Emotional Paradox of Public Engagement, and (Re)imagining Planning as Caring. *Journal of the American Planning Association*.

Lynch, K. (1960). The Image of the City. Boston, MA: MIT Press.

Manthorpe, J., & Iliffe, S. (2018). Muddling along in the city: Framing the cityscape of dementia. *Dementia*, *0*(0), 1–15.

Marquardt, G. (2011). Wayfinding for People with Dementia: A Review of the Role of Architectural Design. *Health Environments Research & Design Journal*, *4*(2), 75–90.

Mathers, A. R. (2008). Hidden voices: the participation of people with learning disabilities in the experience of public open space. *Local Environment*, *13*(6), 515–529.

Mathers, A. R., Thwaites, K., Simkins, I. M., & Mallett, R. (2010). Beyond participation_the practical application of an empowerment process to bring about environmental and social change. *Journal of Human Development, Disability and Social Change*, *19*(3), 37–57.

McClimens, A., Partridge, N., & Sexton, E. (2014). How do people with learning disability experience the city centre? A Sheffield case study. *Health & Place*, *28*, 14–21.

McCunn, L. J., & Gifford, R. (2018). Spatial navigation and place imageability in sense of place. *Cities*, *74*(June 2017), 208–218.

McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing, 19*(13–14), 1935–1943.

Meekosha, H., & Shuttleworth, R. (2009). What's so 'critical' about critical disability studies? *Australian Journal of Human Rights*, *15*(1), 47–75.

Meléndez, J. W. (2018). Studying Learning in Neighborhood Level Democratic Activities - Participatory Budgeting in Chicago's 49th Ward. In R. Allen Hayes (Ed.), *Neighborhood Change and Neighborhood Action: The struggle to create neighborhoods that serve human needs* (pp. 91–122). Lanham, Maryland: Lexington Books.

Mills, J., Bonner, A., & Francis, K. (2006). The Development of Constructivist Grounded Theory. *International Journal of Qualitative Methods*, *5*(1), 25–35.

Mitchell, G., Dupuis, S., & Kontos, P. (2013). Dementia Discourse: From Imposed Suffering to Knowing Other-Wise. *Journal of Applied Hermeneutics*, *0*(2).

Mitchell, L., & Burton, E. J. (2010). Designing Dementia-Friendly Neighbourhoods: Helping People with Dementia to Get Out and About. *Journal of Integrated Care*, *18*(6), 11–19. https://doi.org/10.5042/jic.2010.0647

Mitchell, L., Burton, E., & Raman, S. (2004). Dementia-friendly cities: Designing intelligible neighbourhoods for life. *Journal of Urban Design*, *9*(1), 89–101.

Mitchell, L., Burton, E., Raman, S., Blackman, T., Jenks, M., & Williams, K. (2003). Making the outside world dementia-friendly: Design issues and considerations. *Environment and Planning B: Planning and Design*, *30*(4), 605–632.

Mitchell, L., & Elizabeth, B. (2006). Neighbourhoods for life: designing dementia-friendly outdoor environments. *Quality in Ageing*, *7*, 26–33.

Mohammad, R. (2001). “Insiders” and/or “outsiders”: positionality, theory and praxis. In M. Limb & C. Dwyer (Eds.), *qualitative Methodologies for Geographers* (pp. 101–120). New York, NY: Oxford University Press.

Mondschein, A., & Moga, S. T. (2018). New Directions in Cognitive-Environmental Research: Applications to Urban Planning and Design. *Journal of the American Planning Association*, *84*(3–4), 263–275.

Mueller, J., Lu, H., Chirkin, A., Klein, B., & Schmitt, G. (2018). Citizen Design Science: A strategy for crowd-creative urban design. *Cities*, *72*, 181–188.

Nathan, A., Villanueva, K., Rozek, J., Davern, M., Gunn, L., Trapp, G., … Christian, H. (2019). The Role of the Built Environment on Health Across the Life Course: A Call for CollaborACTION. *American Journal of Health Promotion*, *32*(6), 1460–1468.

Nedlund, A. C., & Nordh, J. (2015). Crafting citizen(ship) for people with dementia: How policy narratives at national level in Sweden informed politics of time from 1975 to 2013. *Journal of Aging Studies*, *34*(34), 123–133.

Neubauer, N. A., Lapierre, N., Ríos-Rincón, A., Miguel-Cruz, A., Rousseau, J., & Liu, L. (2018). What do we know about technologies for dementia-related wandering? A scoping review. *Canadian Journal of Occupational Therapy*, *85*(3), 196–208.

O’Brien, R., Goldberg, S. E., Pilnick, A., Beeke, S., Schneider, J., Sartain, K., … Harwood, R. H. (2018). The VOICE study – A before and after study of a dementia communication skills training course. *PLoS ONE, 13*(6), 1–16.

O’Connor, D., & Nedlund, A.C. (2016). Editorial introduction: Special issue on Citizenship and Dementia. *Dementia*, *15*(3), 285–288.

O’Connor, D., Phinney, A., & Hulko, W. (2009). Dementia at the Intersections: A unique case study exploring social location. *Journal of Aging Studies*, *24*, 30–39.

O’Connor, D., Phinney, A., Smith, A., Small, J., Purves, B., Perry, J., … Beattie, L. (2007). Personhood in dementia care: Developing a research agenda for broadening the vision. *Dementia*, *6*(1), 121–142. https://doi.org/10.1177/1471301207075648

O’Malley, M., Innes, A., & Wiener, J. M. (2017). Decreasing spatial disorientation in care-home settings: How psychology can guide the development of dementia friendly design guidelines. *Dementia*, *16*(3), 315–328.

O’Malley, M., Innes, A., & Wiener, J. M. (2018). How do we get there? Effects of cognitive aging on route memory. *Memory & Cognition*, *46*(2), 274–284.

Ontario Professional Planners Institute (2019). *OPPI By-Law*. Retrieved from https://ontarioplanners.ca/become-an-rpp/oppi-membership/oppi-by-law-update/oppi-by-law

Odzakovic, E., Hellstrom, I., Ward, R., & Kullberg, A. (2018). “Overjoyed that I can go outside”: Using walking interviews to learn about the lived experience and meaning of neighbourhood for people living with dementia. *Dementia*, *0*(0), 1–21.

Park, D. C., Radford, J. P., & Vickers, M. H. (1998). Disability studies in human geography. *Progress in Human Geography, 22*(2), 208-233.

Passini, R., Rainville, C., Marchand, N., & Joanette, Y. (1998). Wayfinding and Dementia: Some Research Findings and a New Look at Design. *Journal of Architectural and Planning Research*, *15*(2), 133–151.

Phillipson, L., & Hammond, A. (2018). More than talking: A scoping review of innovative approaches to qualitative research involving people with dementia. *International Journal of Qualitative Methods*, *17*(1), 1609406918782784.

Phinney, A., Chaudhury, H., & O’Connor, D. L. (2007). Doing as much as I can do: The meaning of activity for people with dementia. *Aging and Mental Health*, *11*(4), 384-393.

Phinney, A., Kelson, E., Baumbusch, J., O’Connor, D., & Purves, B. (2016). Walking in the neighbourhood: Performing social citizenship in dementia. *Dementia*, *15*(3), 381–394.

Plouffe, L. & Kalache, A. (2010). Towards Global Age-Friendly Cities: Determining Urban Features that Promote Active Aging. *Journal of Urban Health, 87*(5), 733-739.

Pot, A. M., Willemse, B. M., & Horjus, S. (2012). A pilot study on the use of tracking technology: Feasibility, acceptability, and benefits for people in early stages of dementia and their informal caregivers. *Aging & Mental Health*, *16*(1), 127–134.

Power, A., Bell, S. L., Kyle, R. G., & Andrews, G. J. (2019). ‘Hopeful adaptation’ in health geographies: Seeking health and wellbeing in times of adversity. *Social Science and Medicine*, *231*(May 2018), 1–5.

Public Health Agency of Canada. (2018). *Dementia in Canada, including Alzheimer’s Disease*. Ottawa, ON. Retrieved from https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/diseases-conditions/dementia-highlights-canadian-chronic-disease-surveillance/dementia-highlights-canadian-chronic-disease-surveillance.pdf

QGIS Development Team (2019). QGIS Geographic Information System. Open Source Geospatial Foundation Project. http://qgis.osgeo.org.

Quinlan Cutler, S., Doherty, S., & Carmichael, B. (2018). The experience sampling method: examining its use and potential in tourist experience research. *Current Issues in Tourism*, *21*(9), 1052–1074. https://doi.org/10.1080/13683500.2015.1131670

Radinsky, J., Milz, D., Zellner, M., Pudlock, K., Witek, C., Hoch, C., & Lyons, L. (2017). How planners and stakeholders learn with visualization tools: using learning sciences methods to examine planning processes. *Journal of Environmental Planning and Management*, *60*(7), 1296–1323.

Rahman, S., & Swaffer, K. (2018). Assets-based approaches and dementia-friendly communities: *Dementia*, *17*(2), 131–137.

Rainville, C., Passini, R., & Marchand, N. (2001). A Multiple Case Study of Wayfinding in Dementia of the Alzheimer Type: Decision Making. *Aging, Neuropsychology, and Cognition (Neuropsychology, Development and Cognition: Section B)*, *8*(1), 54–71.

Region of Waterloo (2019). *Year-End 2018 Population and Household Estimates for Waterloo Region* (Planning, Development and Legislative Services - Report No. PDL-CPL-19-14). Waterloo, Ontario. Retrieved from: https://www.regionofwaterloo.ca/en/regional-government/resources/Census/2018_Population_and_Household_Estimates_for_Waterloo_Region_.pdf

Rempel, L. (2015). Caring for those who once cared for us: dementia-friendly planning for a Winnipeg, Manitoba winter (Master's Thesis). University of Manitoba, Winnipeg, MB.

Richardson, T. (1996). Foucauldian discourse: power and truth in urban and regional policy making. *European Planning Studies, 4*(3), 279-292.

Risser, R., Lexell, E. M., Bell, D., Iwarsson, S., & Ståhl, A. (2015). Use of local public transport among people with cognitive impairments–a literature review. *Transportation Research Part F: Traffic Psychology and Behaviour, 29,* 83-97.

Rosa, E. (2019). Why self-care matters for Roma people and beyond. Vulnerability and the (un)making of water and sanitation infrastructure at the margins of the city. *Geoforum*, *101*, 192–201.

Rosenbaum, R. S., Winocur, G., Binns, M. a, & Moscovitch, M. (2012). Remote spatial memory in aging: all is not lost. *Frontiers in Aging Neuroscience*, *4*(September), 25.

Rosenberg, F. (2009). The MoMA Alzheimer's Project: Programming and resources for making art accessible to people with Alzheimer's disease and their caregivers. *Arts & Health, 1*(1), 93–97.

Ross, T., & Buliung, R. (2018). A systematic review of disability's treatment in the active school travel and children's independent mobility literatures. *Transport Reviews*, *38*(3), 349–371.

Royal Town Planning Institute (2017). *RPTI Practice Advice: Dementia and Town Planning*. London, UK. Retrieved from https://www.rtpi.org.uk/media/2213533/dementia_and_town_planning_final.compressed.pdf

Sandercock, L. (2003). *Cosmopolis II: Mongrel Cities in the 21st Century*. London, UK: Continuum.

Satariano, W. A., Guralnik, J. M., Jackson, R. J., Marottoli, R. A., Phelan, E. A., & Prohaska, T. R. (2012). Mobility and Aging: New Directions for Public Health Action. *American Journal of Public Health*, *102*(8), 1508–1515.

Scheidt, R. J., & Windley, P. G. (2006). Environmental gerontology: Progress in the post-Lawton era. In J. E. Birren, K. W. Schaie, R. P. Abeles, M. Gatz, & T. A. Salthouse (Eds.), *Handbook of Psychology of Aging* (pp. 105–125). Boston, MA: Elsevier Academic Press.

Schroth, O., Pond, E., & Sheppard, S. R. J. (2015). Evaluating presentation formats of local climate change in community planning with regard to process and outcomes. *Landscape and Urban Planning, 142,* 147–158.

Schweitzer, L. (2016). Restorative planning ethics: The therapeutic imagination and planning in public institutions. *Planning Theory*, *15*(2), 130–144.

Seetharaman, K. (2018). *Neighborhood Landmarks as Perceived by Persons Living with Dementia*. Cornell University. Retrieved from https://ecommons.cornell.edu/handle/1813/59474

Shakespeare, T., Zeilig, H., & Mittler, P. (2019). Rights in Mind: Thinking Differently About Dementia and Disability. *Dementia*, *18*(3), 1075–1088.

Shoval, N., Wahl, H.-W., Auslander, G., Isaacson, M., Oswald, F., Edry, T., … Heinik, J. (2011). Use of the global positioning system to measure the out-of-home mobility of older adults with differing cognitive functioning. *Ageing and Society*, *31*, 849–869.

Silva, E. A., Healy, P., Harris, N., & Van den Broeck, P. (2015). Introduction: The craft of ‘doing research’ in spatial and regional planning. In *The Routledge Handbook of Planning Research Methods* (pp. xxiv–xlii). New York, NY: Routledge.

Skinner, M. W., Cloutier, D., & Andrews, G. J. (2015). Geographies of ageing: Progress and possibilities after two decades of change. *Progress in Human Geography*, *39*(6), 776–799.

Slotterback, C. S., & Lauria, M. (2019). Building a Foundation for Public Engagement in Planning. *Journal of the American Planning Association*, *85*(3), 183–187.

Sonnicksen, J. (2016). Dementia and representative democracy: Exploring challenges and implications for democratic citizenship. *Dementia*, *15*(3), 330–342.

Stafford, L., & Baldwin, C. (2018). Planning Walkable Neighborhoods: Are We Overlooking Diversity in Abilities and Ages? *Journal of Planning Literature*, *33*(1), 17–30.

Swaffer, K. (2014). Dementia: Stigma, Language, and Dementia-friendly. *Dementia*, *13*(6), 709–716.

Swaffer, K. (2015). Dementia and Prescribed Disengagement(TM). *Dementia*, *14*(1), 6.

Swaffer, K. (2016). *What the hell happened to my brain?: Living beyond dementia.* London, UK: Jessica Kingsley Publishers.

Swerhun, N., & AvRuskin, V. (2012). *Discuss, Decide, Do: The Value of Engagement as a Decision-Support Tool.* Toronto, ON: Swerhun Inc. Retrieved from https://www.swerhun.com/discussdecidedo1/

Su, J. (2013). Built for Dementia: Urban Design Analysis for Dementia-Friendly Communities (Master's Thesis). San Jose State University, San Jose, CA.

Tellez, J., Krishnakumar, J., Bungener, M., & Le Galès, C. (2016). Capability deprivation of people with Alzheimer's disease: An empirical analysis using a national survey. *Social Science and Medicine*, *151*, 56–68.

Thomas, C. (2004a). Disability and impairment. In J. Swain, S. French, C. Barnes & C. Thomas. (Eds.), *Disabling Barriers, Enabling Environments* (pp.21-27). London, UK: Sage Publications Ltd.

Thomas, C. (2004b). How is disability understood? An examination of sociological approaches. *Disability and Society*, *19*(6), 569–583.

Thomas, B. W. H., & Blanchard, J. M. (2009). Moving Beyond Place: Aging in Community. *Journal of the American Society on Aging*, *33*(2), 12–17.

Thomas, G. (2011). A typology for the case study in social science following a review of definition, discourse, and structure. *Qualitative Inquiry*, *17*(6), 511–521.

Tornaghi, C. (2015). The relational ontology of public space and action-oriented pedagogy in action - Dilemmas of professional ethics and social justice. In C. Tornaghi & S. Knierbein (Eds.), *Public Space and Relational Perspectives: New Challenges for Architecture and Planning* (1st ed., pp. 17–42). Oxfordshire, UK: Routledge.

Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethic of care*. Psychology Press.

Van Holle, V., Van Cauwenberg, J., Simons, D., Clarys, P., Goubert, L., Nasar, J., … Deforche, B. (2012). Using walk-along interviews to explore the environmental factors related to older adults, walking for transportation. *Journal of Science and Medicine in Sport*, *9*(85), 1–11.

Van Schaik, P., Martyr, A., Blackman, T., & Robinson, J. (2008). Involving persons with dementia in the evaluation of outdoor environments. *CyberPsychology & Behavior*, *11*(4), 415–24.

Wahl, H-W., & Gitlin, L. (2007). Environmental Gerontology. In J. Birren (Ed.), Encyclopedia of Gerontology: Age, Aging and the Aged (pp. 494-501). Oxford, UK: Elsevier.

Wahl, H-W., & Oswald, F. (2010). Environmental perspectives on aging. In D. Dannefer & C. Phillipson (Eds.), *International Handbook of Social Gerontology* (pp. 111-124). London, UK: Sage.

Wang, C. C. (1999). Photovoice: A Participatory Action Research Strategy Applied to Women's Health. *Journal of Womens Health the Official Publication of the Society for the Advancement of Womens Health Research*. https://doi.org/10.1089/jwh.1999.8.185

Ward, R., Clark, A., Campbell, S., Graham, B., Kullberg, A., Manji, K., … Keady, J. (2018). The lived neighborhood: understanding how people with dementia engage with their local environment. *International Psychogeriatrics*, *30*(6), 867–880.

Webber, S. C., Porter, M. M., & Menec, V. H. (2010). Mobility in older adults: A comprehensive framework. *Gerontologist*, *50*(4), 443–450.

Wettstein, M., Wahl, H. W., Shoval, N., Oswald, F., Voss, E., Seidl, U., ... & Landau, R. (2015). Out-of-home behavior and cognitive impairment in older adults: findings of the SenTra project. *Journal of Applied Gerontology*, *34*(1), 3-25.

Whitman, L. (2015). *People with Dementia Speak Out: Creative Ways to Achieve Focus and Attention by Building on AD/HD Traits*. London, UK: Jessica Kingsley Publishers.

Williams, M. J. (2017). Care-full Justice in the City. *Antipode*, *49*(3), 821–839.

Williams-Roberts, H., Jeffery, B., Johnson, S., & Muhajarine, N. (2015). The Effectiveness of Healthy Community Approaches on Positive Health Outcomes in Canada and the United States. *Social Sciences*, *5*(1), 3.

Wilson, R., Rochon, E., Leonard, C., & Mihailidis, A. (2012). Formal Caregivers' Perceptions of Effective Communication Strategies while Assisting Residents with Alzheimer's Disease During Activities of Daily Living. *Canadian Journal of Speech-Language Pathology and Audiology, 36*(4), 314–331.

Winters, M., Voss, C., Ashe, M. C., Gutteridge, K., Mckay, H., & Sims-Gould, J. (2015). Where do they go and how do they get there? Older adults' travel behaviour in a highly walkable environment. *Social Science & Medicine*, *133*, 304–312.

Worth, N. (2008). The significance of the personal within disability geography. *Area, 40*(3), 306-314.

Worth, N. (2013). Visual impairment in the city: Young people's social strategies for independent mobility. *Urban Studies*, *50*(3), 574-586.

Wong, S. (2018). The limitations of using activity space measurements for representing the mobilities of individuals with visual impairment: A mixed methods case study in the San Francisco Bay Area. *Journal of Transport Geography*, *66*, 300–308.

World Health Organization. (2012). *Dementia – A Public Health Priority* (*Report)*. London, UK: World Health Organization. Retrieved from http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf

World Health Organization. (2017). *Global action plan on the public health response to dementia 2017-2025*. Geneva, Switzerland. Retrieved from http://apps.who.int/bookorders.

Yiftachel, O. (1998). Planning and Social Control: Exploring the Dark Side. *Journal of Planning Literature*, *12*(4), 395–406. https://doi.org/10.1177/088541229801200401

Yin, R. K. (2009). *Case Study Research: Design and Methods*. (L. Bickman & D. J. Rog, Eds.), *Essential guide to qualitative methods in organizational research* (Vol. 5). Sage Publications.

Yin, R. K. (2013). Validity and generalization in future case study evaluations. *Evaluation, 19*(3), 321–332. https://doi.org/10.1177/1356389013497081

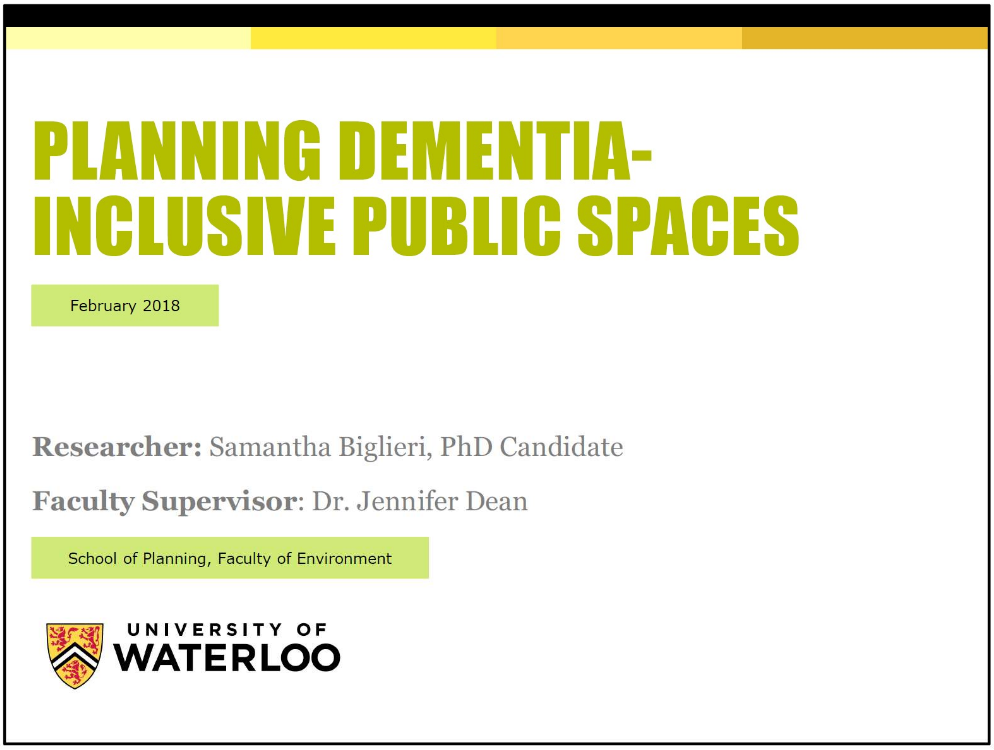
Young, I. M. (1989). Polity and group difference: A critique of the ideal of universal citizenship. *Ethics*, *99*(2), 250-274.

Young, R., Camic, P. M., & Tischler, V. (2016). The impact of community-based arts and health interventions on cognition in people with dementia: A systematic literature review. *Aging and Mental Health, 20*(4), 337–351.

Zenk, S. N., Matthews, S. A., Kraft, A. N., & Jones, K. K. (2018). How many days of global positioning system (GPS) monitoring do you need to measure activity space environments in health research? *Health and Place*, *51*(January), 52–60.

Appendices

Appendix A – PowerPoint Presentation to Support group



PLANNING DEMENTIA-INCLUSIVE PUBLIC SPACES

February 2018

Researcher: Samantha Biglieri, PhD Candidate

Faculty Supervisor: Dr. Jennifer Dean

School of Planning, Faculty of Environment

UNIVERSITY OF WATERLOO

- Good morning and thank you so much for being here today and for allowing me to do this quick presentation during your meeting time.
- My name is Samantha Biglieri, but you can call me Sam. I wanted to start off my telling you a bit about myself, so you can understand where I am coming from and where this research comes from.
- I am currently a PhD student at UW, but I am also a practising urban planner.
- I’ve worked as an urban planner in a private consulting firm, and still do part time.
- Every day, planners make decisions about how to build sidewalks, where to put stores, where to put different types of homes (like apartments or bungalows) and public transit lines, as well as what features a park or plaza should have (like benches or play structures for children).
- I also know from my research and work as an urban planner, that where we live has an impact on our health and wellbeing. Today, research about how we have built communities shows us that there are inequities in the places we live in. Some people can walk to work, others end up in their cars for 4 hours a day. The decisions made about cities impact not only health outcomes, like the prevalence of diabetes and heart disease in sprawling suburban cities, but they also impact the quality of lives and our relationships with other people.
- The kinds of places we live in also affect how well we can get around our neighbourhoods. Let me give you an example, but before I get to that, I would like you to know that (go to next slide)

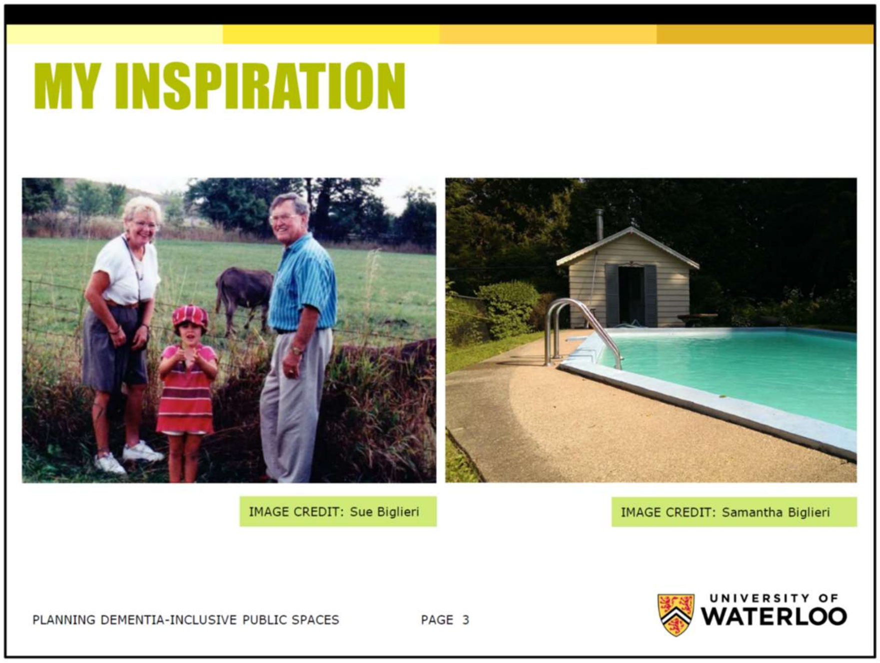
ETHICS APPROVAL

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #22795). If you have questions for the Committee contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

PLANNING DEMENTIA-INCLUSIVE PUBLIC SPACES PAGE 2

UNIVERSITY OF WATERLOO

- …this study been approved by the University of Waterloo Research Ethics Committee



MY INSPIRATION

IMAGE CREDIT: Sue Biglieri

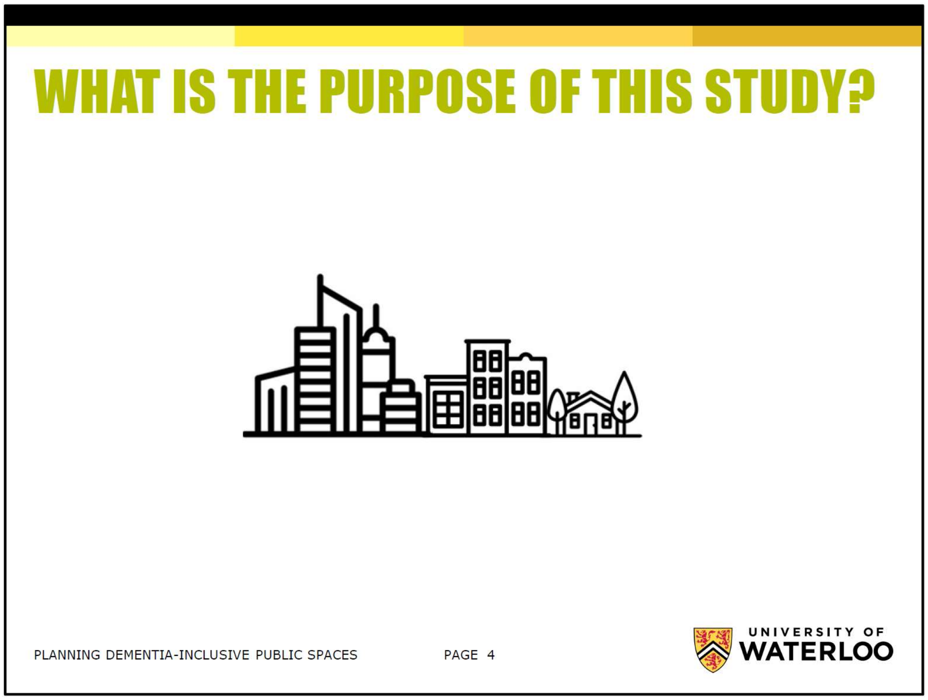
IMAGE CREDIT: Samantha Biglieri

PLANNING DEMENTIA-INCLUSIVE PUBLIC SPACES PAGE 3

UNIVERSITY OF WATERLOO

- My example also happens to be the reason that I am doing this PhD.
- So here is my story. I grew up very close to downtown Toronto, in a neighbourhood called the Beaches. I could walk to everything – the grocery store, school, Shopper’s, the park, and the beach – all within a quarter mile. I could also take transit anywhere in the city and when I learned to drive, I could get to even more places.
- My grandma, my nanny, however, lived in a place called Oakville, which is a suburban city southeast of Waterloo.
- As you can see, this is my nanny, and my poppa, and me – and a donkey’s bum.

- The place on the left was my nanny and poppa’s pool. When I was a kid, we spent every single weekend there. Picking raspberries, digging in the garden, playing baseball, making sandwiches, reading stories and for me, swimming and diving in the pool.
- It truly was the most magical place. It was at the end of a cul-de-sac.
- After my poppa died just before Christmas when I was 13, my nanny was diagnosed with dementia.
- I watched the place that was so magical become isolating for my nanny.
- She stopped driving, taking the transit was inaccessible, and she would have had to walk over 2km to get anywhere.
- And I kept thinking – if she had lived in my neighbourhood, in the Beaches, would it have been easier for her? Was their something about how we build places that affect accessibility for people living with dementia?
- So, I’ve set out in my phd to try to figure out – how can we make cities and neighbourhoods that are accessible to PLWD?
- As someone with a wheelchair needs a ramp, I want to find out, what are those ‘cognitive ramps’ for PLWD? And that is why I am here to ask you!

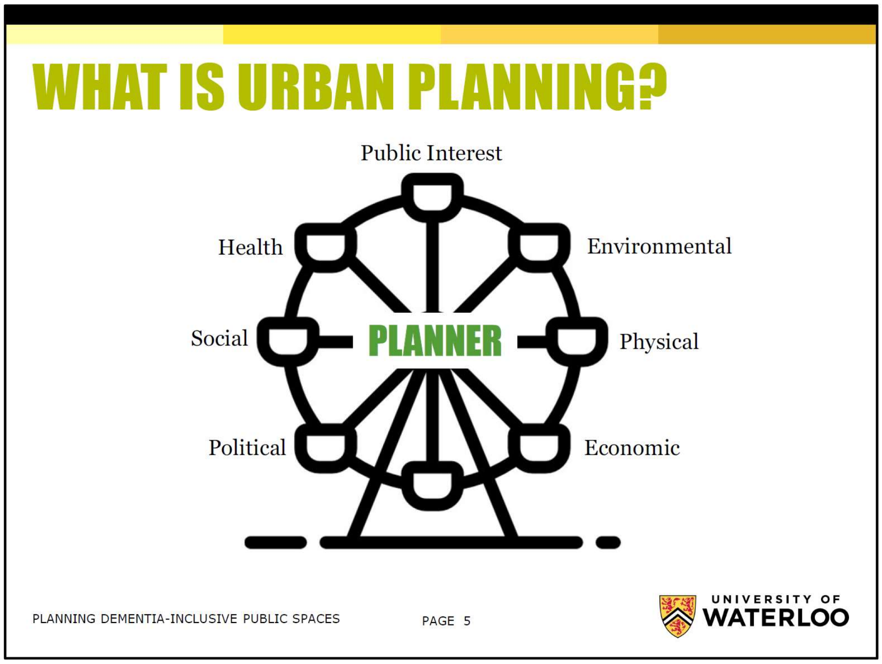


WHAT IS THE PURPOSE OF THIS STUDY?

PLANNING DEMENTIA-INCLUSIVE PUBLIC SPACES

UNIVERSITY OF WATERLOO

- So, as part of my PhD research, you are invited to participate in a research study about your experiences in your neighbourhood as someone living with dementia.
- The purpose of the study is understand what built environment elements of your neighbourhood are a support or a barrier to you in terms of getting around, and what things in your neighbourhood make you feel safe or comfortable, or even anxious or afraid.
- The built environment can mean any public space outside your home, like streets and sidewalks, public plazas, parks and recreation trails.
- The goal of this research is to help urban planners and municipalities understand how to build neighbourhoods that make you feel more comfortable, independent and safe.
- So what is urban Planning you ask?

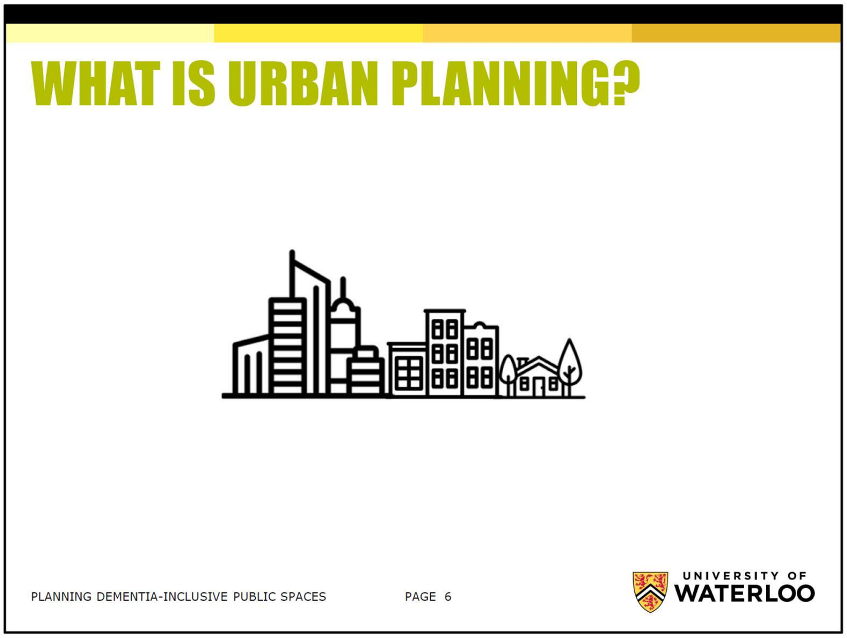


WHAT IS URBAN PLANNING?

PLANNING DEMENTIA-INCLUSIVE PUBLIC SPACES PAGE 5

UNIVERSITY OF WATERLOO

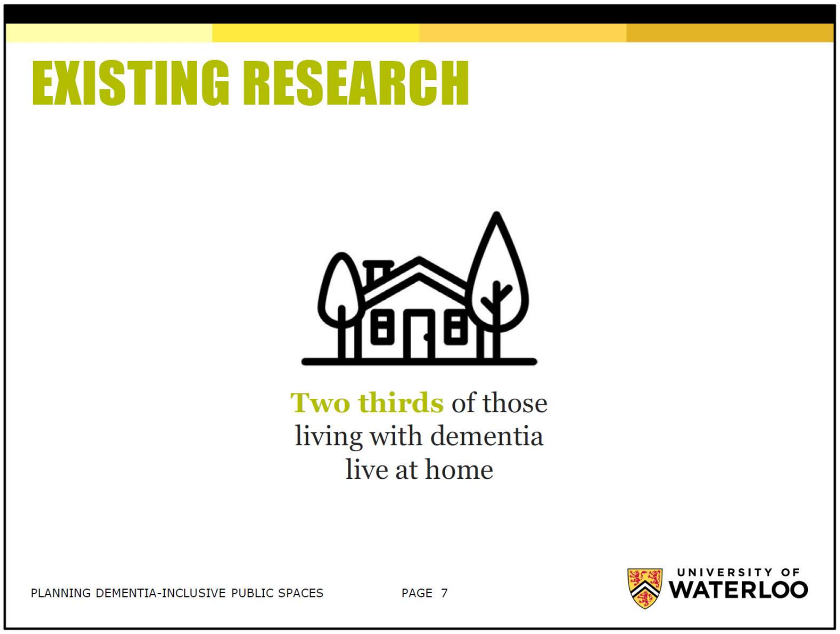
- ❖ An urban planner works in the public and private sectors, shaping the content and direction of city building processes and outcomes.
- ❖ Urban planning is a profession, in which we evaluate research, policies and best practices about where to put certain things in a community – like land uses, roads, and public facilities. Planners have to take into account a large amount of information and knowledge about other domains in order to address complex, often wicked problems associated with cities. When I teach, I tell my first year planners that they are like the hub of a wheel – bringing together several disciplines to think about how to address wicked problems.
- ❖ Urban issues are often called wicked by virtue of their complexity, lack of definitive formulation, and the fact that they can never be truly 'solved' definitively.
- ❖ This is because the places we live in are messy – there are many interrelated issues and forces, and there is no 'one solution', no perfect controlled experiment.
- ❖ But what we can do as planners is bring citizens into the planning process in a meaningful way and consider our actions that shape the built environment as part of a process, for which there will constantly be new actions, with better evidence.
- ❖ Above all, is the duty of that a professional planner has – and that is to the public interest – to create healthy, complete communities for people and the environment to thrive in.
- ❖ However, ultimately the professional planner is an advisor. Their power rests in their ability advise and influence decision makers about policy and implementation.



WHAT IS URBAN PLANNING?

UNIVERSITY OF WATERLOO

- Planners deal fundamentally with two things: processes and outcomes
- Process- the planning process involves public consultation, which makes it also a fantastic way to get involved in government. process refers to act of citizenship in which people are enabled or face barriers to commenting on the places they live in.
- Outcomes refer to how cities get built in the end – for example, whether or not a ramp was constructed. it's about building an evidence base of the types of 'cognitive ramps' that PWD may need in different places
- Often, in terms of accessibility, planners tend to think of those with sensory/ mobility impairments, but not those with cognitive impairments.



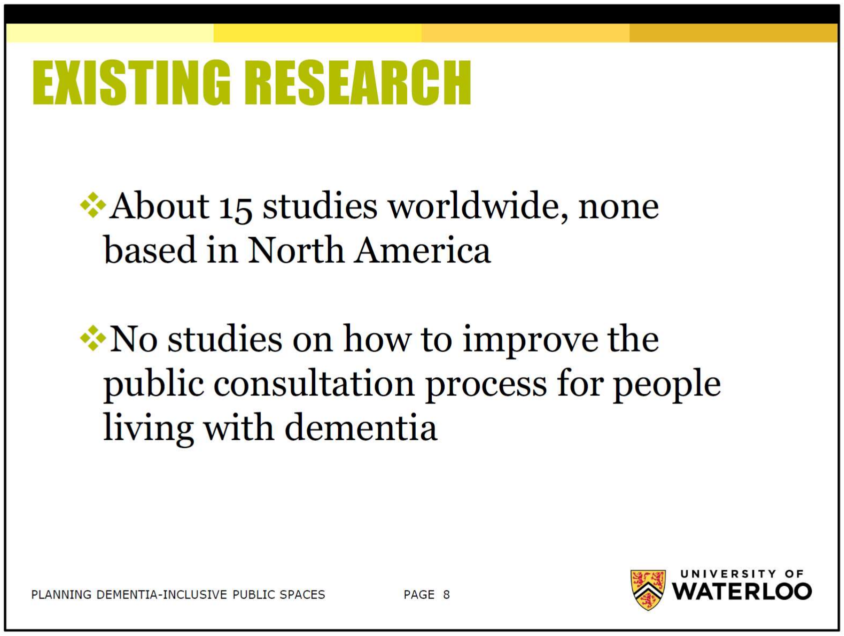
EXISTING RESEARCH

Two thirds of those
living with dementia
live at home

UNIVERSITY OF WATERLOO

- What does the existing research tell us?

- Many people assume that PWD live in care homes. This is not the case. Canadian estimates believe up to two thirds of PWD live in the community, and UK estimates put this number at 80%.
- Thus, this begs the question – how can neighbourhoods enable or disable PWD?
- PWD deserve to access their neighbourhood as much as an other able bodied person.
- Planners are poised to be able to answer this question, due to its ability to influence city building processes. The planner is supposed to be concerned with the public interest, and fundamentally plays an influential role in local decisions.

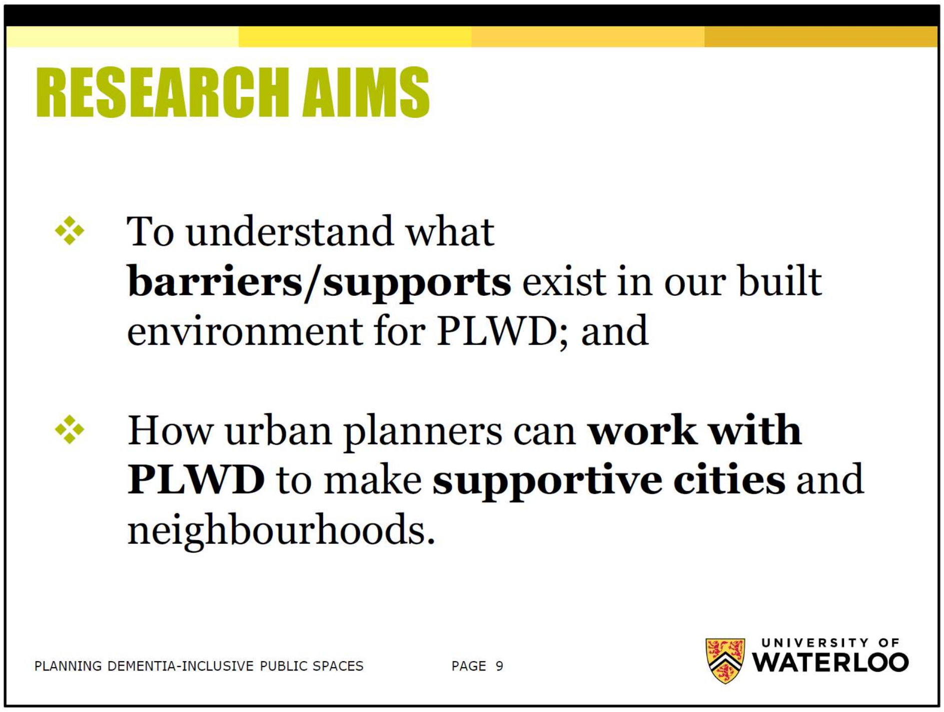


EXISTING RESEARCH

- About 15 studies worldwide, none based in North America
- No studies on how to improve the public consultation process for people living with dementia

UNIVERSITY OF WATERLOO

- There are a few flaws with the existing research –
    - 1) It is very limited – only 15 or so studies worldwide, and mostly from disciplines outside of urban planning. I want to be able to do this research as an urban planner, because it is urban planners who end up making the decisions that affect everyday lives. In addition – the studies are based mostly in the UK and Sweden. These places are very different from North America and Canada in terms of our neighbourhoods.
    - 2) there are no studies on how to improve the public planning consultation process for people living with dementia.



RESEARCH AIMS

- To understand what **barriers/supports** exist in our built environment for PLWD; and
- How urban planners can **work with PLWD** to make **supportive cities** and neighbourhoods.

PLANNING DEMENTIA-INCLUSIVE PUBLIC SPACES PAGE 9

UNIVERSITY OF WATERLOO

- Here are the research aims:
- (Read the slide)

PROPOSED RESEARCH PLAN

1. Introduction interview with researcher
(One 1-hour session)

2. Smartphone App Use (on own or with researcher
(Two weeks)

3. Focus group session to sort photos/videos
(One 2-hour session)

PLANNING DEMENTIA-INCLUSIVE PUBLIC SPACES PAGE 10

UNIVERSITY OF WATERLOO

Participating in this study would be done OUTSIDE of your scheduled time together here at [redacted]. It will involve a few steps, including:

1. A 1 hour one-on-one interview about your neighbourhood and where you go most often;

2. Using your own smartphone (or using one with the researcher's help) to take approximately 20-40 photographs/videos (over a time period of two weeks) of built environment features in your neighbourhood that you see as a support or as a barrier to getting around. For example, you might take a picture of an intersection that you find confusing, or take a picture of the landmark that helps you find the street your house is on. For each photograph, you will also be asked to answer a few questions to give the photo context like, "What was the weather like? Were you walking or driving? Where were you headed?" This will involve the researcher helping the you install a mobile application on your personal smart phone, in addition to providing training on how to use the mobile application. If you do not have a personal smartphone, the researcher will provide a smartphone and accompany you on a walk around your neighbourhood to take photos/videos.
Note* Owning a smartphone is not required to participate in this research;
3. Participating in a 1-2 hour long focus group session with their peers where their photos/videos will be printed by the researcher, and you will work with peers to sort the photographs/videos into categories that make the most sense to you;"

PROPOSED RESEARCH PLAN

4. Field Trip to an Open House planning meeting somewhere in the Region of Waterloo
(One 1-hour session)

5. Debrief interview with researcher after Open House planning meeting
(One 1-hour session)

PLANNING DEMENTIA-INCLUSIVE PUBLIC SPACES PAGE 11

UNIVERSITY OF WATERLOO

- 4. Together, you and I will attend a public planning open house in the local municipality in which you reside. They happen every week in the Region somewhere!
- 5. We would have a brief one-on-one interview afterwards about your experiences, in the hopes of understanding what could have been changed about the open house that would have made it better for you.

YOUR RIGHTS AS A PARTICIPANT

❖ Participation is completely voluntary

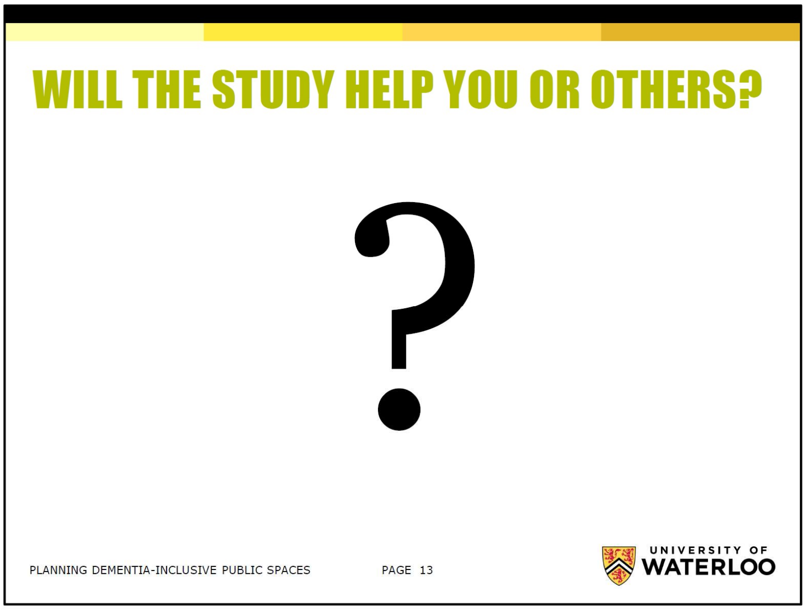
❖ Risks are considered minimal

❖ The link between your personal information and the data will be kept confidential

PLANNING DEMENTIA-INCLUSIVE PUBLIC SPACES PAGE 12

UNIVERSITY OF WATERLOO

❖ Participation is completely voluntary and you can withdraw from a portion of the study or from a question at any time
❖ Risks are considered minimal. The study requires you to take photographs/videos of your neighbourhood with a smartphone. If you are already comfortable taking photographs, we don't expect this to bother you. We would however, like to remind you to only take photographs/videos when at a safe vantage point (for example, not from the middle of a street). If you are uncomfortable taking photographs, the researcher is happy to help you get comfortable by working with you and providing you with a step by step guide.
❖ All information given during the study will be held in confidence. The information will be kept in a locked filing cabinet at the University of Waterloo, School of Planning and will be accessed only by members of the research team. The link between your identity and the research data will be kept confidential, and your name will not appear on any published data. Instead, with your permission, anonymous quotations may be presentations at conferences, journal articles and workshop guides.



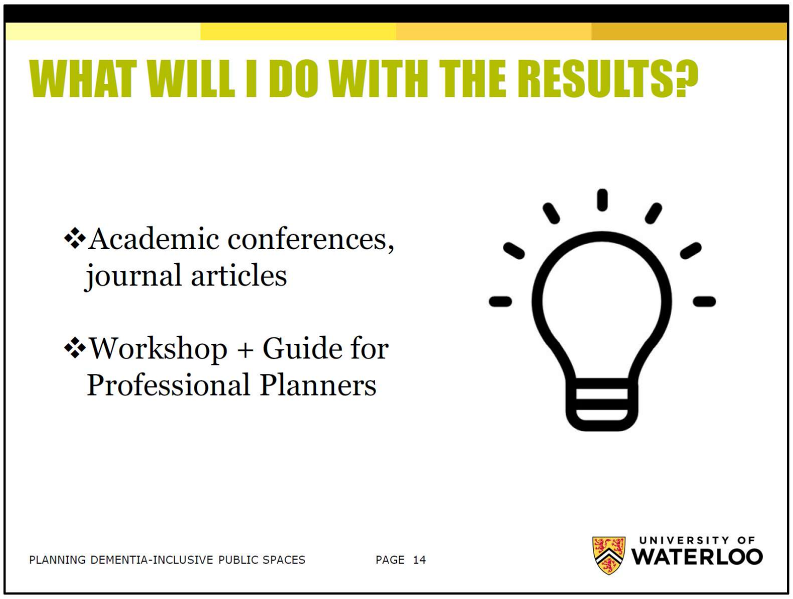
WILL THE STUDY HELP YOU OR OTHERS?

?

PLANNING DEMENTIA-INCLUSIVE PUBLIC SPACES PAGE 13

UNIVERSITY OF WATERLOO

- ❖ With this study, I hope to understand from your perspective, what urban planners could do to make you feel more independent and comfortable in your neighbourhood, and how we can improve public forums to be accessible to you.
- ❖ Every day, planners make decisions about how to build sidewalks, where to put stores, where to put different types of homes (like apartments or bungalows) and public transit lines, as well as what features a park or plaza should have (like benches or play structures for children).
- ❖ Through this study, I hope to understand what could be changed about your neighbourhood to make it more accessible to you, as a person living with dementia, and hopefully influence urban planning in the future.
- ❖ And if you would like to participate, and when the study is over, help me in teaching other planners about how to create dementia-inclusive cities – I would love that. But, it is not a requirement for this study.



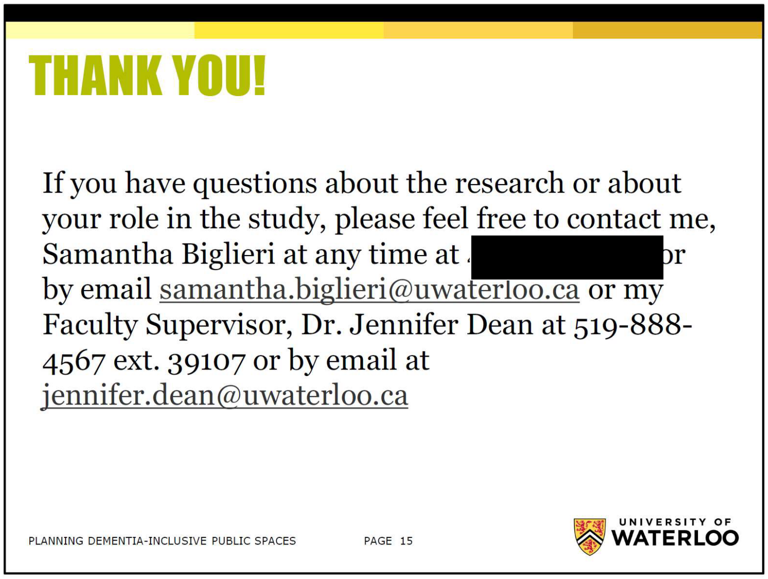
WHAT WILL I DO WITH THE RESULTS?

- ❖Academic conferences, journal articles
- ❖Workshop + Guide for Professional Planners

PLANNING DEMENTIA-INCLUSIVE PUBLIC SPACES PAGE 14

UNIVERSITY OF WATERLOO

- As an academic, I will be doing the typical things, like presenting at conferences and publishing the results in academic journals.
- However, most importantly for me, I want to be able to create a summary of these findings, present them back to you, and then create a guide for professional planners on how they could do their job better in order to be able to meet your needs in the community.
- I plan on hosting a workshop for professional planners, both public and private in the Region of Waterloo on how to physically build and alter public spaces to be dementia-inclusive, but also how they should adapt their public consultation practices to make it easier for you to have your say in the future of your city.



THANK YOU!

If you have questions about the research or about your role in the study, please feel free to contact me, Samantha Biglieri at any time at [redacted] or by email samantha.biglieri@uwaterloo.ca or my Faculty Supervisor, Dr. Jennifer Dean at 519-888-4567 ext. 39107 or by email at jennifer.dean@uwaterloo.ca

PLANNING DEMENTIA-INCLUSIVE PUBLIC SPACES PAGE 15

UNIVERSITY OF WATERLOO

- Thank you so much for listening. I would be happy to take any questions from the audience.
- (DO Q&A)
- Now, you have in front of you a sheet of paper that asks you if you would like to be contacted about this study further. IF you would like to hear more, please circle yes, record your name and contact info – like a phone number or email address. If not, no worries – just select no!
- Please also keep in mind that if you say yes right now, it does not commit you to the study. This is just to hear more information, and you can withdraw at any time.

Appendix B – Information Letter (addressed to participant)

Study Name: Planning Dementia-Supportive Public Spaces

Researcher:
Samantha Biglieri, PhD Candidate
School of Planning, Faculty of Environment, University of Waterloo
Phone: [redacted]
Email: samantha.biglieri@uwaterloo.ca

Faculty Supervisor:
Dr. Jennifer Dean, Associate Professor
School of Planning, Faculty of Environment, University of Waterloo
Phone: 519-888-4567 ext. 39107
Email: jennifer.dean@uwaterloo.ca

What is this letter about?
This letter is to help you make an informed decision regarding your participation in the study, *Planning Dementia-Supportive Public Spaces*, conducted by Samantha Biglieri, PhD Candidate in the School of Planning at the University of Waterloo. The faculty supervisor for this research is Dr. Jennifer Dean, also in the School of Planning. This letter will explain what the study is about, the possible risks and benefits, and your rights as a research participant. If you do not understand something in the letter or have any concerns, please ask the researcher before consenting to participate in the study. You will be provided with a copy of the consent form and this Information Letter if you choose to participate in the study.

What is this study about?
You are invited to participate in a research study about your experiences in your neighbourhood as someone living with dementia. The purpose of the study is understand what built environment elements of your neighbourhood are a support or a barrier to you in terms of getting around, and what things in your neighbourhood make you feel safe or comfortable, or even anxious or afraid. The built environment can mean any public space outside your home, like streets and sidewalks, public plazas, parks and recreation trails. The goal of this research is to help urban planners and municipalities understand how to build neighbourhoods that make you feel more comfortable, independent and safe. Previous research has found that certain types of neighbourhood features make getting around easier for people living with dementia, making them feel more independent. This previous research however, has only been done in the United Kingdom and Sweden. This study hopes to understand our Canadian neighbourhoods from your perspective. The second part of the research has never been conducted before. It involves you attending a public planning open house and being observed by a researcher, and then discussing the events afterwards. This part of the study wants to understand if/how planners should change public open houses so that they are accessible to you.

1. Your Responsibilities as a Participant

What does participation involve?
Your participation in this study would involve a few steps including:

- A 1 hour one-on-one interview about your neighbourhood and where you go most often;

- A go-along interview with you, in which you will be requested to take the researcher on a walk you feel comfortable doing on your own. You will be asked questions like, "Can you describe the route we are taking? What do you like/dislike about this route? What are important landmarks for you?, etc. You and the researcher will be accompanied by research assistant who will plot your route on a map as you walk;

- Using your own smartphone (or using one with the researcher's help) to take approximately 20-40 photographs/videos (over a time period of two weeks) of built environment features in your neighbourhood that you see as a support or as a barrier to getting around. For example, you might take a picture of an intersection that you find confusing, or take a picture of the landmark that helps you find the street your house is on. For each photograph, you will also be asked to answer a few questions to give the photo context like, "What was the weather like? Were you walking or driving? Where were you headed?" This will involve the researcher helping the you install a mobile application on your personal smart phone, in addition to providing training on how to use the mobile application. If you do not have a personal smartphone, the researcher will provide a smartphone and accompany you on a walk around your neighbourhood to take photos/videos.
  Note* Owning a smartphone is not required to participate in this research;

- Carrying a small GPS tracker (about half the size of a deck of cards) for a period of 10 days. The tracker's data is stored on the device (it will be transferred manually to the researcher's secure computer once the 10 days are over). All you have to do is to charge the unit using a wall charger every evening, and carry it around during the day. You can wear the GPS tracker by placing it in your sweater, shirt or pants' pocket or even in your purse;

- Participating in a 1-2 hour long focus group session with their peers where their photos/videos will be printed by the researcher, and you will work with peers to sort the photographs/videos into categories that make the most sense to you;"

- Attending 1 public planning open house in the local municipality in which you reside, and participating in a brief one-on-one interview with the researcher afterwards about your experiences.

These steps will be audio-recorded to help the researcher with transcription only. By talking about your experiences, you will help urban planners understand how to make neighbourhoods more accessible for people living with dementia and their families.

Who can participate in the study?
This study will involve up to 20 participants, and in order to participate you must self-identify as living with dementia, and you must be living at home, as opposed to a congregate living setting (like a retirement home).

Where will the study take place?
The interviews will take place at your home, or a location that is most convenient for you. The part of the study where the go-along interview will be and where you will be taking photographs in your neighbourhood will take place in the neighbourhood near your home. For the GPS tracker portion, you are encouraged to move around as you normally do. When you are collectively sorting your photographs with peers, that will take place on site at [redacted]. And finally, the attendance at a public planning open house will depend on the council's schedule at that time, and you can select a time that is convenient for you.

2. Your Rights as a Participant

Is your participation voluntary?
Your participation in the study is completely voluntary and you may choose to withdraw from participating at any time. You can decline to participate in the study without penalty. If you agree to participate, you will be able to talk about whatever you are comfortable with answering any questions. If there is a question you do not want to answer, you may say, "I don't want to answer that question."

Can you change your mind or decide not to answer a question?
You can change your mind and stop being part of the study at any time. Your decision to stop, or to refuse to answer particular questions, has no effect on your participation in the programs run by [redacted] now or in the future. If you decide to leave the study, all of the data collected from you will be immediately destroyed.

Will the study help you or others?
We do not know if being in the study will help you directly. However, with this study, I hope to understand from your perspective, what urban planners could do to make you feel more independent and comfortable in your neighbourhood, and how we can improve public forums to be accessible to you. Every day, planners make decisions about how to build sidewalks, where to put stores, where to put different types of homes (like apartments or bungalows) and public transit lines, as well as what features a park or plaza should have (like benches or play structures for children). Through this study, I hope to understand what could be changed about your neighbourhood to make it more accessible to you, as a person living with dementia, and hopefully influence urban planning in the future.

What are the risks associated with the study?
The study requires you to take the researcher on a walk in your neighbourhood that you are already comfortable taking, and we do not expect this to bother you. The study also requires you to take photographs/videos of your neighbourhood with a smartphone. If you are already comfortable taking photographs, we don't expect this to bother you. We would however, like to remind you to only take photographs/videos when at a safe vantage point (for example, not from the middle of a street). If you are uncomfortable taking photographs, the researcher is happy to help you get comfortable by working with you and providing you with a step by step guide.

The phase involving a group discussion about the photos/videos that you took, and a collective sorting of these photos into themes will take approximately 1-2 hours, and we don't expect these to bother you. However, if the conversations are upsetting to you, we will stop the conversation and can make sure you have someone to talk with to get help.

Will my identity be known?
The phase involving the group discussion will be a 1-2 hour interactive group discussion, where you will sort your photos with your peers into themes. Given the group format of this session and sharing of the photos with your peers, we will ask that you keep in confidence the information that identifies or could potentially identify a participant and/or his/her comments. The researcher and the other participants in the focus group will know what you said, and view your photographs. Outside of the focus group (in research papers, conferences, etc.), you will only be identified by a number of pseudonym.

Will my information be kept confidential?

All information given during the study will be held in confidence. The information will be kept in a locked filing cabinet at the University of Waterloo, School of Planning and will be accessed only by members of the research team. The link between your identity and the research data will be kept confidential, and your name will not appear on any published data. Instead, with your permission, anonymous quotations may be used in the following way(s):

- in teaching and demonstration materials
- in scholarly papers, articles and other publications, and
- in presentations at academic, health care conferences

Electronic files containing study data will be password-protected and will be kept for at least 5 years in a locked filing cabinet in the Researcher's office on the University of Waterloo campus. Audiotapes, transcriptions, questionnaires and data files will remain anonymous such that no names will be associated with the data. Each participant will be assigned an identification number, which will be used to organize the data.

What will happen after the study is over?

The researchers will ask if you would like to be contacted in the future to go over the findings and give your opinions on the results. If you do not want to be contacted in the future, you may indicate this preference without penalty and without any consequences to your health care or your relationship to [redacted]

Has the study received ethics clearance?

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #22795). If you have questions for the Committee contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

Who can I contact if I have any questions?

If you have questions about the research or about your role in the study, please feel free to contact researcher Samantha Biglieri at any time at [redacted] or by email samantha.biglieri@uwaterloo.ca or her Faculty Supervisor, Dr. Jennifer Dean at 519-888-4567 ext. 39107 or by email at jennifer.dean@uwaterloo.ca

Appendix C – Consent Form (addressed to participant)

Study Name: Planning Dementia-Supportive Public Spaces

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Samantha Biglieri, PhD Candidate under the Faculty supervision of Dr. Jennifer Dean, both in the School of Planning at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I was informed that participation in the study is voluntary and that I can withdraw this consent by informing the researcher.

I am aware that I have the option of allowing my interviews and participation in the focus group session to be audio recorded to ensure an accurate recording of my responses.

I am aware that I have the option of participation in the GPS tracking portion of this study.

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#22795). If you have questions for the Committee contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or oreceo@uwaterloo.ca. For all other questions, please contact the Faculty Supervisor, Dr. Jennifer Dean at 519-888-4567 ext. 39107 or by email at jennifer.dean@waterloo.ca.

I agree, of my own free will to participate in this study.
☐ YES
☐ NO

I agree, of my own free will to participate in the GPS tracking portion of this study.
☐ YES
☐ NO

I agree to be audio recorded during this study.
☐ YES
☐ NO

I agree to the use of anonymous quotations from me in any thesis, presentation or publication that comes of this research.
☐ YES
☐ NO

Participant's Name:

Participant's Signature: Date:

Participant's Contact Information:

Witness Signature: Date:

When this study is completed, we will write a summary of the results. Would you be interested in receiving a copy?
☐ YES, please e-mail me a summary of the results. My e-mail address is:
☐ YES, please mail me a summary of the results. My mailing address is:
☐ NO, I do not wish to receive a summary of results

Appendix D – Information Letter (addressed to care partner)

Study Name: Planning Dementia-Supportive Public Spaces: Examining experiences of the neighbourhood and its influence on people living with dementia

Researcher:
Samantha Biglieri, PhD Candidate
School of Planning, Faculty of Environment, University of Waterloo
Phone: [redacted]
Email: samantha.biglieri@uwaterloo.ca

Faculty Supervisor:
Dr. Jennifer Dean, Associate Professor
School of Planning, Faculty of Environment, University of Waterloo
Phone: 519-888-4567 ext. 39107
Email: jennifer.dean@uwaterloo.ca

What is this letter about?

We are asking for your consent to have the person you care for participate in our study. The person you care for is being invited to participate, in the study **Planning Dementia-Supportive Public Spaces,** conducted by Samantha Biglieri, PhD Candidate in the School of Planning at the University of Waterloo. The faculty supervisor for this research is Dr. Jennifer Dean, also in the School of Planning.

The participation of the person you care for is entirely voluntary. Before you decide to provide consent, it is important for you to understand what the research study involves. This letter will explain what the study is about, the possible risks and benefits, and the rights of the person you care for as a research participant. If you do not understand something in the letter or have any concerns, please ask the researcher before providing consent for the person you care for to participate in the study. You will be provided with a copy of the information and consent form if you choose to have the person you care for participate in the study.

What is this study about?

The person you care for is being invited to participate in a research study about their experiences in their neighbourhood as someone living with dementia. The purpose of the study is understand what built environment elements of their neighbourhood are a support or a barrier in terms of getting around, and what things in the neighbourhood make them feel safe or comfortable, or even anxious or afraid. The built environment can mean any public space outside their home, like streets and sidewalks, public plazas, parks and recreation trails. The goal of this research is to help urban planners and municipalities understand how to build neighbourhoods that make people living with dementia feel more comfortable, independent and safe. Previous research has found that certain types of neighbourhood features make getting around easier for people living with dementia, making them feel more independent. This previous research however, has only been done in the United Kingdom and Sweden. This study hopes to understand our Canadian neighbourhoods from the person you care for's perspective.

The second part of the research has never been conducted before. It involves the person you care for attending a public planning open house and being observed by a researcher, and then discussing the events afterwards. This part of the study wants to understand if/how planners should change public open houses so that they are accessible to the person you care for.

1. Responsibilities as a Participant

What does participation involve?
The person you care for's participation in this study would involve a few steps including:

- A 1 hour one-on-one interview about the person you care for's neighbourhood and where they go most often;

- A go-along interview with the person you care for, in which the person you care for will be directed to take the researcher on a walk they feel comfortable doing on their own;

- Using their own smartphone (or using one with the researcher's help) to take approximately 20-40 photographs/videos (over a time period of two weeks) of built environment features in their neighbourhood that they see as a support or as a barrier to getting around. For example, they might take a photo/video of an intersection that they find confusing or take a picture of the landmark that helps them find the street their house is on. For each photograph/video, they will also be asked to answer a few questions to give the photo context like, "Were you walking or driving? Where were you headed?" This will involve the researcher helping the person you care for install a mobile application on their personal smart phone, in addition to providing training on how to use the mobile application. If the participant does not have a personal smartphone, the researcher will provide a smartphone and accompany the participant on a walk around their neighbourhood to take photos/videos.
  Note* Owning a smartphone is not required to participate in this research;

- Carrying a small GPS tracker (about half the size of a deck of cards) for a period of 10 days. The tracker's data is stored on the device (it will be transferred manually to the researcher's secure computer once the 10 days are over). All the person you care for has to do is to charge the unit using a wall charger every evening, and carry it around during the day. To supplement the use of the GPS Tracker, the person you care for will be asked to fill out a 'Travel Diary' for every trip outside your home. They will be asked to answer questions like: listing the date, time left and returned, where they went, who they were with and what form of transportation they used;

- Participating in a 1-2 hour long focus group session with their peers where their photos/videos will be printed by the researcher, and they will work with peers to sort the photographs/videos into categories that make the most sense to them; and

- Attending 1 public planning open house in the local municipality in which they reside and participating in a brief one-on-one interview with the researcher afterwards about their experiences.

These steps will be audio-recorded to help the researcher with transcription only. By talking about their experiences, they will help urban planners understand how to make neighbourhoods more accessible for people living with dementia and their families.

Who can participate in the study?
This study will involve up to 20 participants, and in order to participate they must self-identify as living with dementia, and be living at home, as opposed to a congregate living setting (like a retirement home).

Where will the study take place?
The interviews will take place at their home, or a location that is most convenient for them. The part of the study where the go-along interview will be and where they will be taking photographs in their neighbourhood will take place in the neighbourhood near their home. For the GPS tracker portion, the person you care for is encouraged to move around as they normally do. When they are collectively sorting their photographs with peers, that will take place on site at [redacted]. And finally, the attendance at a public planning open house will depend on the council's schedule at that time, and they can select a time that is convenient for them.

2. Rights as a Participant

Is participation voluntary?
The participation of the person you care for is completely voluntary and they may choose to withdraw from participating at any time. The person you care for can decline to participate in the study without penalty. If the person you care for agrees to participate, they will be able to talk about whatever they are comfortable with answering any questions. If there is a question the person you care for does not want to answer, they may say, "I don't want to answer that question."

Can they change their mind or decide not to answer a question?
The person you care for can change their mind and stop being part of the study at any time. The decision to stop, or to refuse to answer particular questions, has no effect on their participation in the programs run by [redacted]s now or in the future. If the person you care for decides to leave the study, all of the data collected from them will be immediately destroyed.

Will the study help them or others?
We do not know if being in the study will help the person you care for directly. However, with this study, I hope to understand from their perspective, what urban planners could do to make people living with dementia feel more independent and comfortable in their neighbourhood, and how we can improve public forums to be accessible to them. Every day, planners make decisions about how to build sidewalks, where to put stores, where to put different types of homes (like apartments or bungalows) and public transit lines, as well as what features a park or plaza should have (like benches or play structures for children). Through this study, I hope to understand what could be changed about neighbourhoods to make it more accessible to people living with dementia, and hopefully influence urban planning in the future.

What are the risks associated with the study?
The study requires the person you care for to take the researcher on a walk in their neighbourhood that they are already comfortable taking, and we do not expect this to bother them. The study also requires the person you care for to take photographs/videos of their neighbourhood with a smartphone. If they are already comfortable taking photographs, we don't expect this to bother them. We would however, like to remind them to only take photographs/videos when at a safe vantage point (for example, not from the middle of a street). If they are uncomfortable taking photographs, the researcher is happy to help them get comfortable by working with them and providing them with a step by step guide.

The phase involving a group discussion about the photos/videos that they took, and a collective sorting of these photos into themes - these groups discussions will take approximately 1-2 hours, and we don't expect these to bother them. However, if the conversations are upsetting to the person you care for, we will stop the conversation and can make sure they have someone to talk with to get help.

Will their identity be known?
The collective sorting will be a one-hour interactive group discussion, where the person you care for will sort their photos with their peers into themes. Given the group format of this session and sharing of the photos with their peers, we will ask that the person you care for keep in confidence the information that identifies or could potentially identify a participant and/or his/her comments. The researcher and the other participants in the focus group will know what they said and view their photographs. although the researchers will keep the identity of participants and what they said confidential, there is no guarantee that the other participants will do so. Outside of the focus group (in research papers, conferences, etc.), they will only be identified by a number or pseudonym.

Will their information be kept confidential?
All information given during conversations with the person you care for will be held in confidence. The information will be kept in a locked filing cabinet at the University of Waterloo, School of Planning and will be accessed only by members of the research team. The link between the person you care for's identity and the research data will be kept confidential, and their name will not appear on any published data. Instead, with permission from you and the person you care for, anonymous quotations may be used in the following way(s):

- in teaching and demonstration materials
- in scholarly papers, articles and other publications, and
- in presentations at academic, health care conferences

Electronic files containing study data will be password-protected and will be kept for at least 5 years in a locked filing cabinet in the Researcher's office on the University of Waterloo campus. Audiotapes, transcriptions, questionnaires and data files will remain anonymous such that no names will be associated with the data. Each participant will be assigned an identification number, which will be used to organize the data.

What will happen after the study is over?
The researchers will ask if the person you care for would like to be contacted in the future to go over the findings and give their opinions on the results. If the person you care for does not want to be contacted in the future, they may indicate this preference without penalty and without any consequences to your health care or your relationship to [redacted]

Has the study received ethics clearance?
This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #22795). If you have questions for the Committee contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

Who can I contact if I have any questions?
If you have questions about the research or about the role of the person you care for in the study, please feel free to contact Samantha Biglieri at any time at [redacted] or by email samantha.biglieri@uwaterloo.ca or her Faculty Supervisor, Dr. Jennifer Dean at 519-888-4567 ext. 39107 or by email at jennifer.dean@uwaterloo.ca

Appendix E – Consent Form (with care partner)

Study Name: Planning Dementia-Supportive Public Spaces

By signing this consent form, you are not waiving your legal rights, the legal rights of the person you care for, or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Samantha Biglieri, PhD Candidate under the Faculty supervision of Dr. Jennifer Dean, both in the School of Planning at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I was informed that participation in the study is voluntary and that I can withdraw this consent by informing the researcher.

I am aware that the person I care for has the option of allowing their participation to be audio recorded to ensure an accurate recording of their responses.

I am aware that the person I care for has the option of participation in the GPS tracking portion of this study.

I am also aware that excerpts from the interview with the person I care for may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#22795). If you have questions for the Committee contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or oreceo@uwaterloo.ca. For all other questions, please contact the Faculty Supervisor, Dr. Jennifer Dean at 519-888-4567 ext. 39107 or by email at jennifer.dean@waterloo.ca.

With full knowledge of all foregoing, I agree to provide consent for the person I care for to participate in this study

☐ YES
☐ NO

I agree for the person I care for to participate in the GPS tracking portion of this study.

☐ YES
☐ NO

I agree for the person I care for to be audio recorded during this study.

☐ YES
☐ NO

I agree to the use of anonymous quotations from the person I care for in any thesis, presentation or publication that comes of this research.

☐ YES
☐ NO

Caregiver’s Name:

Caregiver’s Signature: Date:

Caregiver’s Contact Information:

Witness Name:

Witness Signature: Date:

When this study is completed, we will write a summary of the results. Would you be interested in receiving a copy?

☐ YES, please e-mail me a summary of the results. My e-mail address is:
☐ YES, please mail me a summary of the results. My mailing address is:
☐ NO, I do not wish to receive a summary of results

Appendix F – Sample Form for participants to fill out post-presentation

Name: ____

Phone Number: ____

Email: ____

☐ Yes, I would like to be contacted further about participating in this study

☐ No, please do not contact me about participating in this study

Appendix G – Poster for Recruitment through email

Are you or someone you love living with dementia in the community?

Every day, urban planners make decisions about where to put stores and houses, how to build sidewalks, roads, and public transit – even what kinds of features to put in parks. However, there is limited research on how to make cities accessible to people living with dementia. This study aims to change that - to make cities better now & for future generations.

WE ARE LOOKING FOR VOLUNTEERS LIVING WITH DEMENTIA IN THE COMMUNITY

The study involves a walking interview, taking photos in your neighbourhood, GPS tracking + going to a public meeting. You can choose to participate in any or all of these activities. Participation in all activities will take about 2 weeks.

Interested in learning more?

Contact PhD Candidate Samantha Biglieri at samantha.biglieri@uwaterloo.ca or call Dr. Jennifer Dean at 519-888-4567 ext. 39107

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #22795). If you have questions for the Committee contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

UNIVERSITY OF WATERLOO
FACULTY OF ENVIRONMENT
School of Planning

Appendix H – Consent Form (addressed to participant) for focus groups only

Study Name: Planning Dementia-Supportive Public Spaces: Examining experiences of the neighbourhood and its influence on people living with dementia

Researcher:
Samantha Biglieri, PhD Candidate
School of Planning, Faculty of Environment, University of Waterloo
Phone: [redacted]
Email: samantha.biglieri@uwaterloo.ca

Faculty Supervisor:
Dr. Jennifer Dean, Associate Professor
School of Planning, Faculty of Environment, University of Waterloo
Phone: 519-888-4567 ext. 39107
Email: jennifer.dean@uwaterloo.ca

What is this letter about?
This letter is to help you make an informed decision regarding your participation in the study, *Planning Dementia-Supportive Public Spaces*, conducted by Samantha Biglieri, PhD Candidate in the School of Planning at the University of Waterloo. The faculty supervisor for this research is Dr. Jennifer Dean, also in the School of Planning. This letter will explain what the study is about, the possible risks and benefits, and your rights as a research participant. If you do not understand something in the letter or have any concerns, please ask the researcher before consenting to participate in the study. You will be provided with a copy of the information and consent form if you choose to participate in the study.

What is this study about?
You are invited to participate in a research study about your experiences in your neighbourhood as someone living with dementia. The purpose of the study is understand your perceptions of how the built environment affects you in terms of getting around, and what things in your neighbourhood make you feel safe or comfortable, or even anxious or afraid. The built environment can mean any public space outside your home, like streets and sidewalks, public plazas, parks and recreation trails. The goal of this research is to help urban planners and municipalities understand how to build neighbourhoods that make you feel more comfortable, independent and safe. Previous research has found that certain types of neighbourhood features make getting around easier for people living with dementia, making them feel more independent. This previous research however, has only been done in the United Kingdom and Sweden. This study hopes to understand our Canadian neighbourhoods from your perspective.

1. Your Responsibilities as a Participant

What does participation involve?
Your participation in this study would involve:

- Participating in a 1-2 hour long focus group session with your peers at [redacted] to discuss photographs taken by your peers of neighbourhood features.

This will be audio-recorded to help the researcher with transcription only. By talking about your experiences, you will help urban planners understand how to make neighbourhoods more accessible for people living with dementia and their families.

Who can participate in the study?
This study will involve up to 20 participants. In order to participate you must self-identify as living with dementia.

Where will the study take place?
This will take place on site at [redacted], during [redacted] programming.

2. Your Rights as a Participant

Is your participation voluntary?
Your participation in the study is completely voluntary and you may choose to withdraw from participating at any time. You can decline to participate in the study without penalty. If you agree to participate, you will be able to talk about whatever you are comfortable with answering any questions. If there is a question you do not want to answer, you may say, "I don't want to answer that question."

Can you change your mind or decide not to answer a question?
You can change your mind and stop being part of the study at any time. Your decision to stop, or to refuse to answer particular questions, has no effect on your participation in the programs run by [redacted] now or in the future. If you decide to leave the study, all of the data collected from you will be immediately destroyed.

Will the study help you or others?
We do not know if being in the study will help you directly. However, with this study, I hope to understand from your perspective, what urban planners could do to make you feel more independent and comfortable in your neighbourhood. Every day, planners make decisions about how to build sidewalks, where to put stores, where to put different types of homes (like apartments or bungalows) and public transit lines, as well as what features a park or plaza should have (like benches or play structures for children). Through this study, I hope to understand what could be changed about your neighbourhood to make it more accessible to you, as a person living with dementia, and hopefully influence urban planning in the future.

What are the risks associated with the study?
This group discussions will take approximately 1-2 hours, and we don't expect these to bother you. However, if the conversations are upsetting to you, we will stop the conversation and can make sure you have someone to talk with to get help.

Will my identity be known?
Given the group format of this session and sharing of photos, we will ask that you keep in confidence the information that identifies or could potentially identify a participant and/or his/her comments. The researcher and the other participants in the focus group will know what you said. Outside of the focus group (in research papers, conferences, etc.), you will only be identified by a number or pseudonym.

Will my information be kept confidential?
All information given during the study will be held in confidence. The information will be kept in a locked filing cabinet at the University of Waterloo, School of Planning and will be accessed only by members of the research team. The link between your identity and the research data will be kept

confidential, and your name will not appear on any published data. Instead, with your permission, anonymous quotations may be used in the following way(s):

- in teaching and demonstration materials
- in scholarly papers, articles and other publications, and
- in presentations at academic, health care conferences

Electronic files containing study data will be password-protected and will be kept for at least 5 years in a locked filing cabinet in the Researcher's office on the University of Waterloo campus. Audiotapes, transcriptions, questionnaires and data files will remain anonymous such that no names will be associated with the data. Each participant will be assigned an identification number, which will be used to organize the data.

What will happen after the study is over?
The researchers will ask if you would like to be contacted in the future to go over the findings and give your opinions on the results. If you do not want to be contacted in the future, you may indicate this preference without penalty and without any consequences to your health care or your relationship to [redacted].

Has the study received ethics clearance?
This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #31658). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca

Who can I contact if I have any questions?
If you have questions about the research or about your role in the study, please feel free to contact researcher Samantha Biglieri at any time at [redacted] or by email samantha.biglieri@uwaterloo.ca or her Faculty Supervisor, Dr. Jennifer Dean at 519-888-4567 ext. 39107 or by email at jennifer.dean@uwaterloo.ca

Appendix I – Consent Form (addressed to participant) for focus groups only

Study Name: Planning Dementia-Supportive Public Spaces: Examining experiences of the neighbourhood and its influence on people living with dementia

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Samantha Biglieri, PhD Candidate under the Faculty supervision of Dr. Jennifer Dean, both in the School of Planning at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I was informed that participation in the study is voluntary and that I can withdraw this consent by informing the researcher.

I am aware that I have the option of allowing my participation in the focus group session to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the focus group may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #31658). I was informed that if I have any comments or concerns resulting from the participation of the person I care for in this study, I may contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca. For all other questions, please contact the Faculty Supervisor, Dr. Jennifer Dean at 519-888-4567 ext. 39107 or by email at jennifer.dean@waterloo.ca.

I agree, of my own free will to participate in this study.
☐ YES
☐ NO

I agree to be audio recorded during this study.
☐ YES
☐ NO

I agree to the use of anonymous quotations from me in any thesis, presentation or publication that comes of this research.
☐ YES
☐ NO

Participant's Name: Date:

Participant's Signature: ____ Date:

Witness Signature: Date:

Witness Name: Date:

When this study is completed, we will write a summary of the results. Would you be interested in receiving a copy?

☐ YES, please e-mail me a summary of the results. My e-mail address is:

____

☐ YES, please mail me a summary of the results. My mailing address is:

____

____

☐ NO, I do not wish to receive a summary of results

Appendix J – Introductory Interview Questions

Good morning, and thank you for taking the time to meet with me today. For the next hour or so, we will be chatting about your neighbourhood, and where you go on a typical day or week. This interview is being recorded so that I can write down our conversation later, and will not be shared with anyone else. You may ask to stop the interview at any time or skip any question at any time. IN addition, I would like to reaffirm the consent you have already given in writing to conduct this interview.

Participant: YES or NO.

Researcher: (if yes) Let's get started. (if no) Thank you so much for your time.

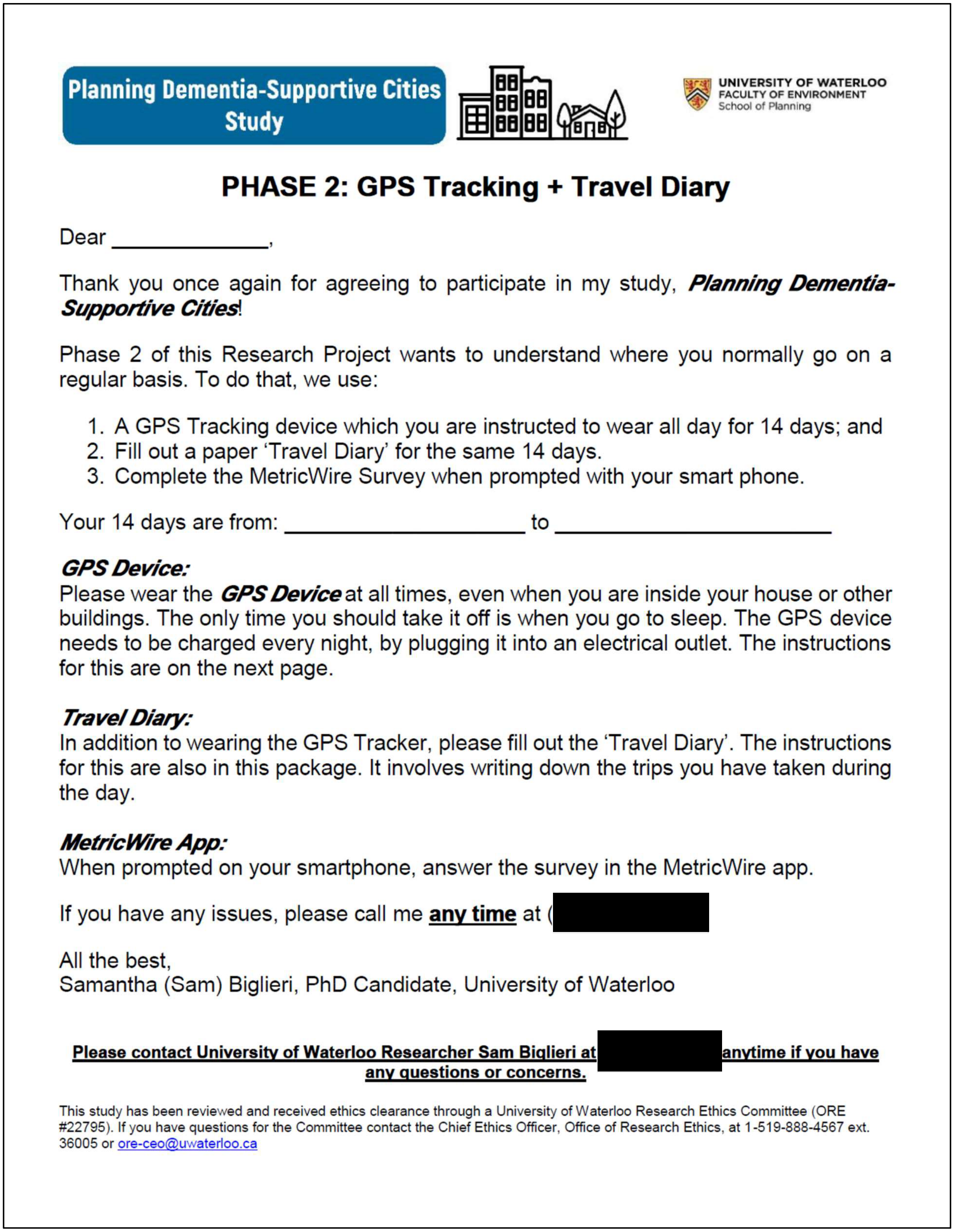
Questions:

EVERY TIME WE VISIT, WE REMIND THEM ABOUT THE project PURPOSE, AND GET PROCESS CONSENT – ORALLY. What we want to do today is _______ is it okay if we continue?

1. About how long would you say you have lived in _____ ?
2. Have you lived here your whole life, or did you grow up somewhere else?
3. Do you like your neighbourhood? Why or why not?
4. Do you find it easy to get around your neighbourhood? Why or why not?
5. If you were diagnosed, when they were diagnosed? What the diagnosis was?
6. How dementia has impacted their life in terms of how they get around. Are you still able to go to the places you want to go? What are some things you are concerned about as things change?
7. Where do you go when you leave the house? (Could consider drawing this on a piece of paper)
8. How do you get there?

Researcher: Thank you so much for your time for this interview. If you would like to continue being part of this research study, I would like to introduce you to the second part, which involves going on a walk together that you feel comfortable taking. Would you like to continue to participate?

Appendix K – Instructions for participants on how to use GPS tracker



Planning Dementia-Supportive Cities Study

UNIVERSITY OF WATERLOO
FACULTY OF ENVIRONMENT
School of Planning

PHASE 2: GPS Tracking + Travel Diary

Dear _____________,

Thank you once again for agreeing to participate in my study, ***Planning Dementia-Supportive Cities***!

Phase 2 of this Research Project wants to understand where you normally go on a regular basis. To do that, we use:

1. A GPS Tracking device which you are instructed to wear all day for 14 days; and
2. Fill out a paper 'Travel Diary' for the same 14 days.
3. Complete the MetricWire Survey when prompted with your smart phone.

Your 14 days are from: ____________________ to ______________________

GPS Device:
Please wear the ***GPS Device*** at all times, even when you are inside your house or other buildings. The only time you should take it off is when you go to sleep. The GPS device needs to be charged every night, by plugging it into an electrical outlet. The instructions for this are on the next page.

Travel Diary:
In addition to wearing the GPS Tracker, please fill out the 'Travel Diary'. The instructions for this are also in this package. It involves writing down the trips you have taken during the day.

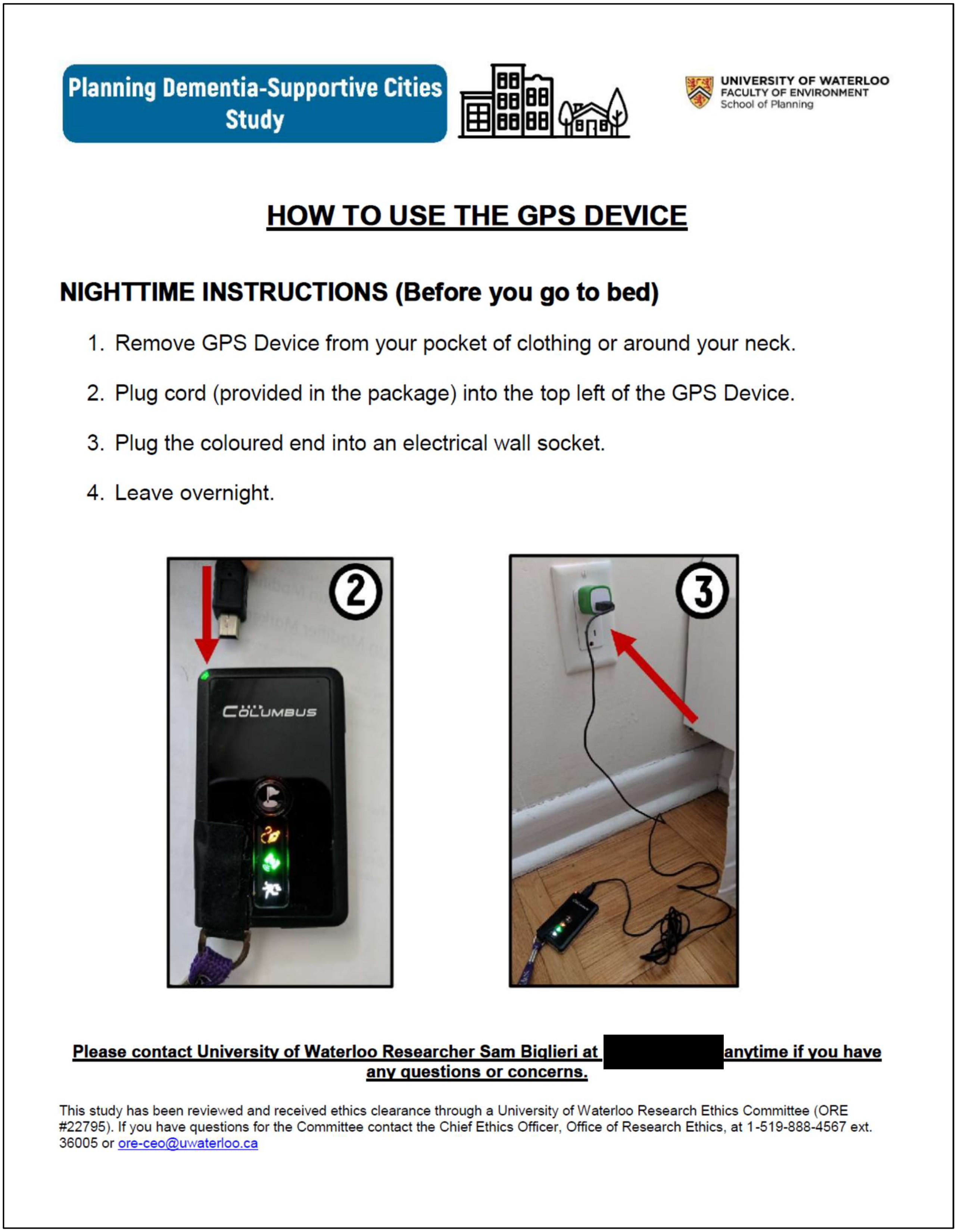
MetricWire App:
When prompted on your smartphone, answer the survey in the MetricWire app.

If you have any issues, please call me **any time** at ([redacted]

All the best,
Samantha (Sam) Biglieri, PhD Candidate, University of Waterloo

Please contact University of Waterloo Researcher Sam Biglieri at [redacted] anytime if you have any questions or concerns.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #22795). If you have questions for the Committee contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca



Planning Dementia-Supportive Cities Study

UNIVERSITY OF WATERLOO
FACULTY OF ENVIRONMENT
School of Planning

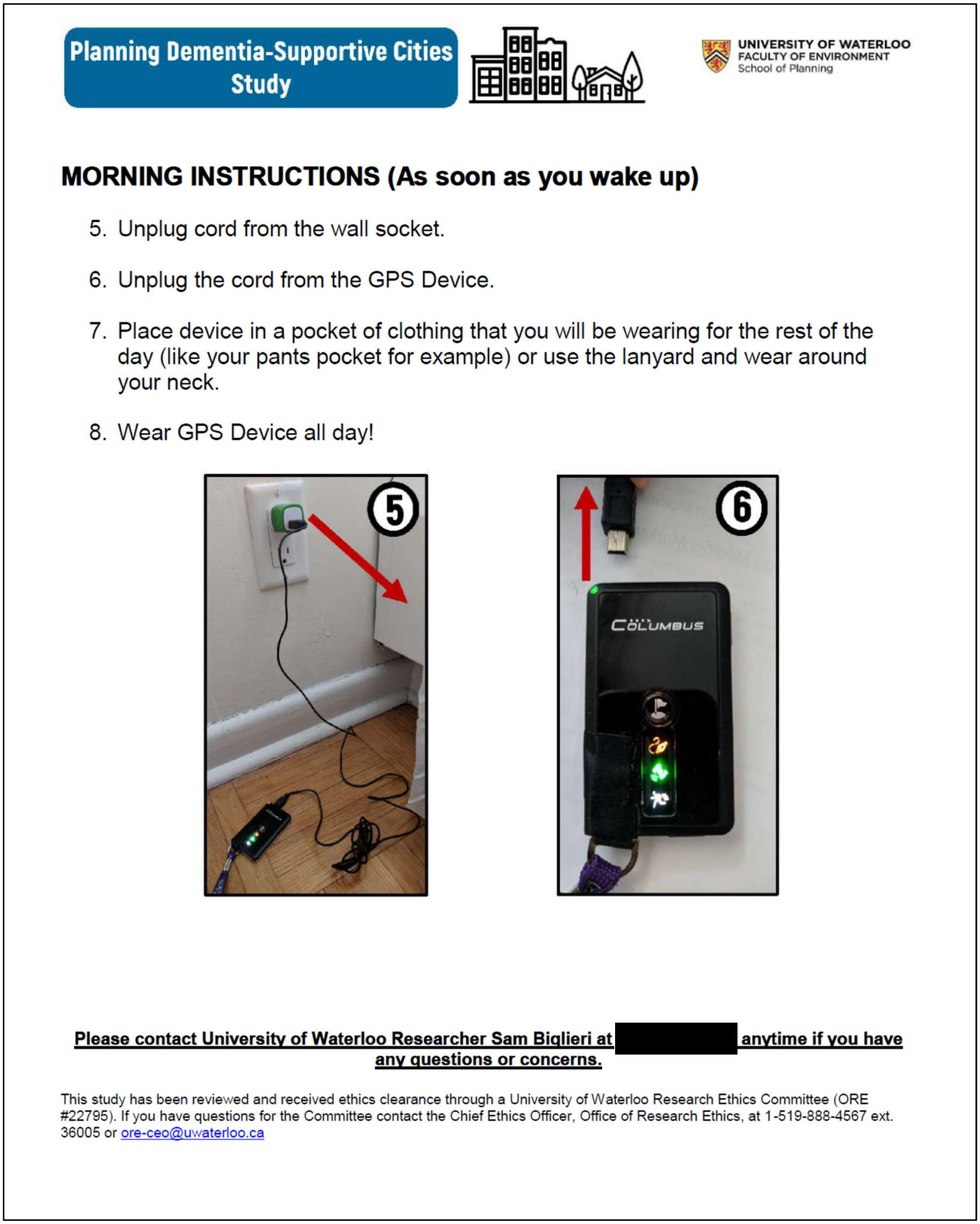
HOW TO USE THE GPS DEVICE

NIGHTTIME INSTRUCTIONS (Before you go to bed)

1. Remove GPS Device from your pocket of clothing or around your neck.
2. Plug cord (provided in the package) into the top left of the GPS Device.
3. Plug the coloured end into an electrical wall socket.
4. Leave overnight.

Please contact University of Waterloo Researcher Sam Biglieri at [redacted] anytime if you have any questions or concerns.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #22795). If you have questions for the Committee contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca



Planning Dementia-Supportive Cities Study

UNIVERSITY OF WATERLOO
FACULTY OF ENVIRONMENT
School of Planning

MORNING INSTRUCTIONS (As soon as you wake up)

5. Unplug cord from the wall socket.

6. Unplug the cord from the GPS Device.

7. Place device in a pocket of clothing that you will be wearing for the rest of the day (like your pants pocket for example) or use the lanyard and wear around your neck.

8. Wear GPS Device all day!

<u>Please contact University of Waterloo Researcher Sam Biglieri at [redacted] anytime if you have any questions or concerns.</u>

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #22795). If you have questions for the Committee contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca

Planning Dementia-Supportive Cities Study

UNIVERSITY OF WATERLOO
FACULTY OF ENVIRONMENT
School of Planning

IMPORTANT NOTES ABOUT THE GPS DEVICE

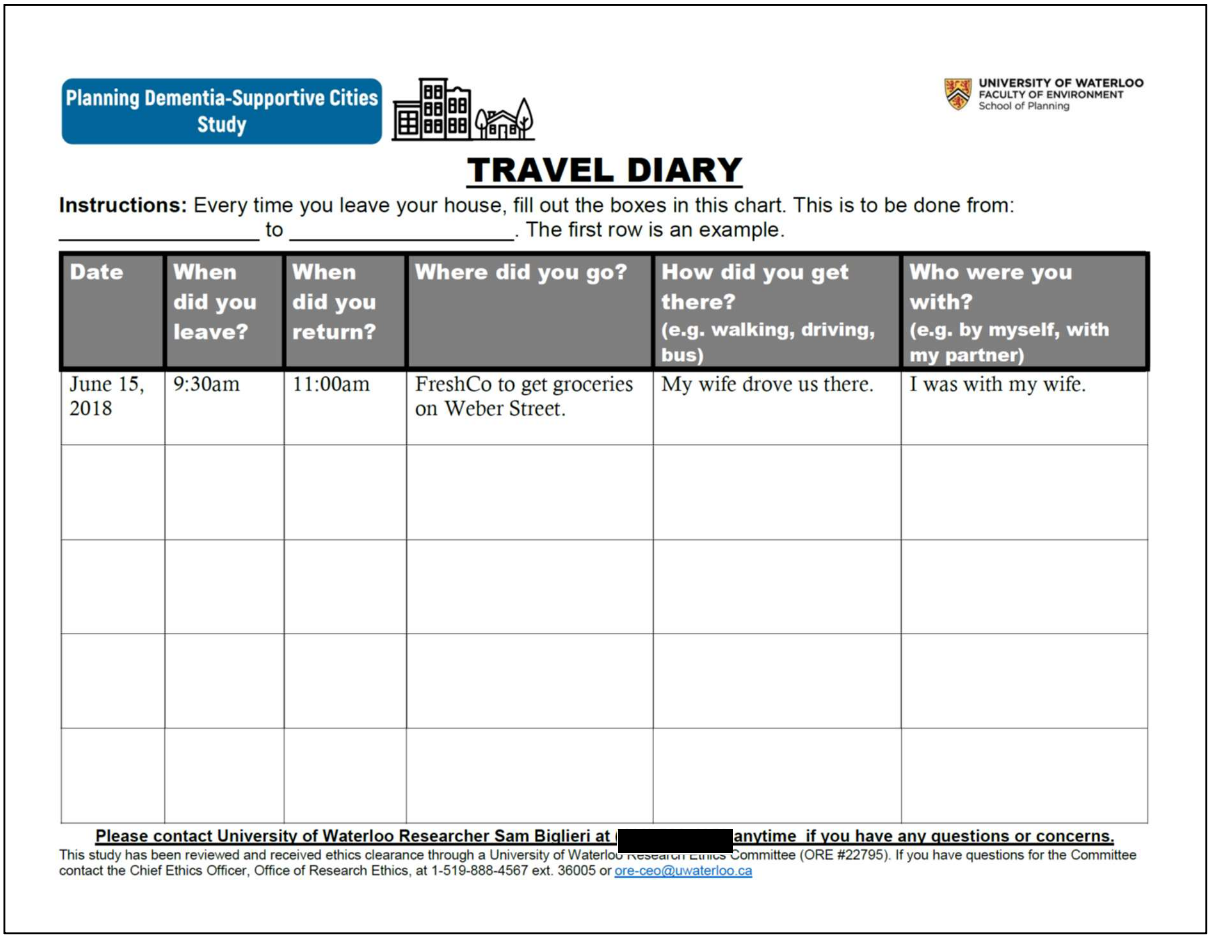
- Do **not** push any buttons on the GPS Device
- The three buttons on the GPS Device should be lit up at all times (see photo below)

All three buttons should be "on" at all times. If one button is not on, please call Sam right away.

Please contact University of Waterloo Researcher Sam Biglieri at [redacted] anytime if you have any questions or concerns.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #22795). If you have questions for the Committee contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca

Appendix L – Travel Diary Form



Planning Dementia-Supportive Cities Study

UNIVERSITY OF WATERLOO
FACULTY OF ENVIRONMENT
School of Planning

TRAVEL DIARY

Instructions: Every time you leave your house, fill out the boxes in this chart. This is to be done from: __________________ to ____________________. The first row is an example.

Date	When did you leave?	When did you return?	Where did you go?	How did you get there? (e.g. walking, driving, bus)	Who were you with? (e.g. by myself, with my partner)
June 15, 2018	9:30am	11:00am	FreshCo to get groceries on Weber Street.	My wife drove us there.	I was with my wife.

Please contact University of Waterloo Researcher Sam Biglieri at [redacted] anytime if you have any questions or concerns.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #22795). If you have questions for the Committee contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca

Appendix M – Post Open House Interview Questions

Do you have any initial thoughts about your experience?

Room Set-Up

1. Did you like how the room was set-up? What could have been changed to make it better?
2. How was the noise level?
3. How was the lighting?

Concentration

4. Did you feel like you could concentrate easily? Why or why not?

Visual/Auditory Presentation

5. Were the materials being presented easy to understand?
    a. Hand outs
    b. Presentation by Planners
    c. Visual Boards
6. Was it too much, too little, or just enough information?
7. What do you think could have been changed to make it easier for you to understand?

Communication with Staff

8. Where the City staff people helpful? Why or why not?
9. What could they have done better?
10. Were they respectful?

OTHER

1. I noticed you looked a bit confused when (observed XYZ), can you tell me a bit more about what was happening?
2. Is there anything that could be changed to make it easier for you?

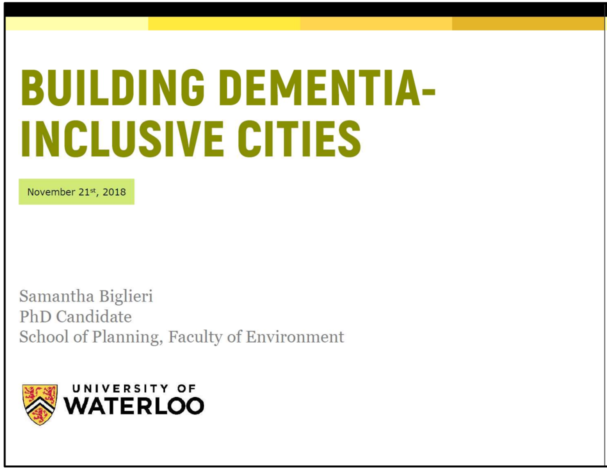
Appendix N – Focus Group Facilitator's Supplemental Question Sheet

(use only if there is a lull in conversation)

- Imagine you are in the place in the photograph. Would you feel safe there? Why or why not?
- What do you think of the [insert feature here – e.g. the sidewalk, the path, the trees, the houses]?
- What do you like/don't like about [insert feature here]?
- Would you feel safe crossing the road by yourself? With someone?
- Would you like to walk here?
- What do you think of the road? Is it too big, too small or just right?
- What about the noise level?
- Would you go here in the dark?

Appendix O – Focus Group Photo Package for each participant

Each image here was printed by itself on 8.5x11 paper, in colour.

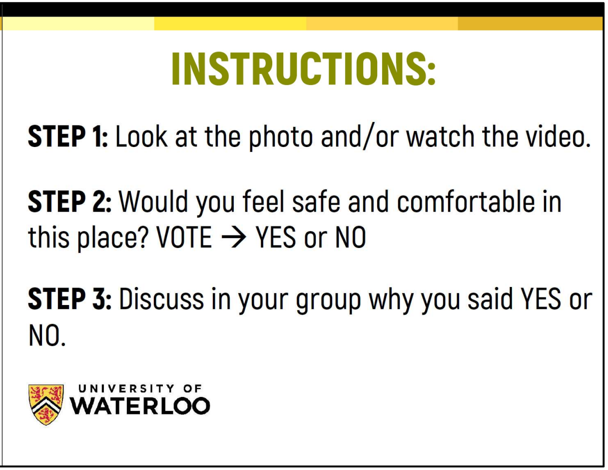


BUILDING DEMENTIA-INCLUSIVE CITIES

November 21st, 2018

Samantha Biglieri
PhD Candidate
School of Planning, Faculty of Environment

UNIVERSITY OF WATERLOO



INSTRUCTIONS:

STEP 1: Look at the photo and/or watch the video.

STEP 2: Would you feel safe and comfortable in this place? VOTE → YES or NO

STEP 3: Discuss in your group why you said YES or NO.

UNIVERSITY OF WATERLOO

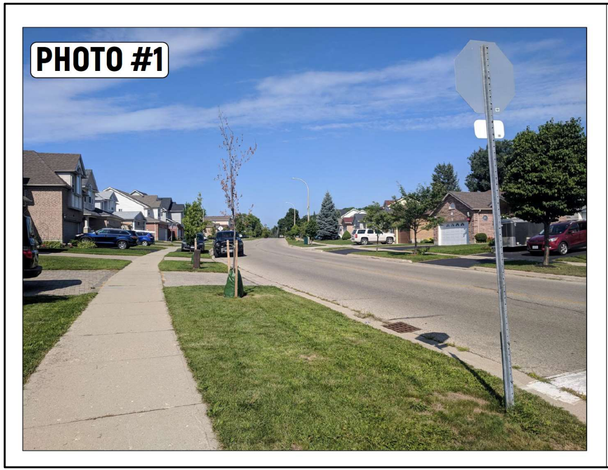
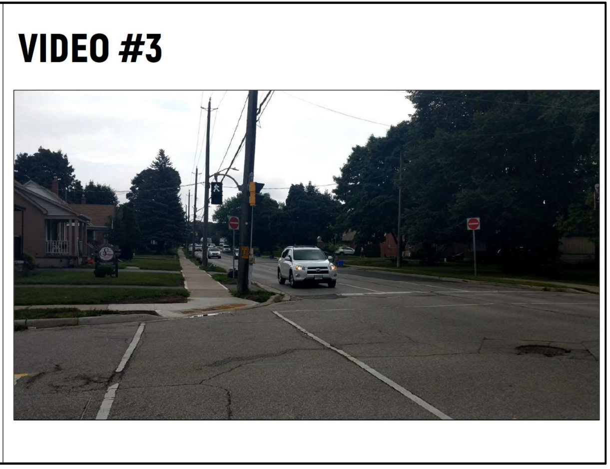


PHOTO #1

PHOTO #2

PHOTO #3



VIDEO #3

PHOTO #4

PHOTO #5

PHOTO #6

PHOTO #7

VIDEO #7

VIDEO #8


PHOTO #9

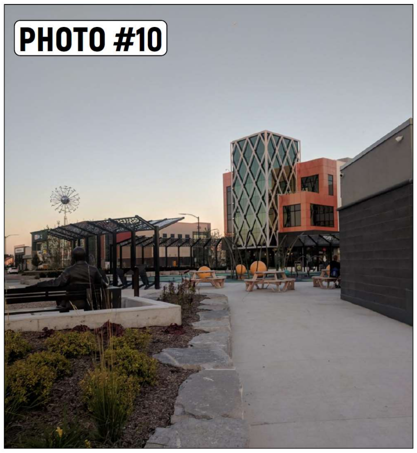


PHOTO #10

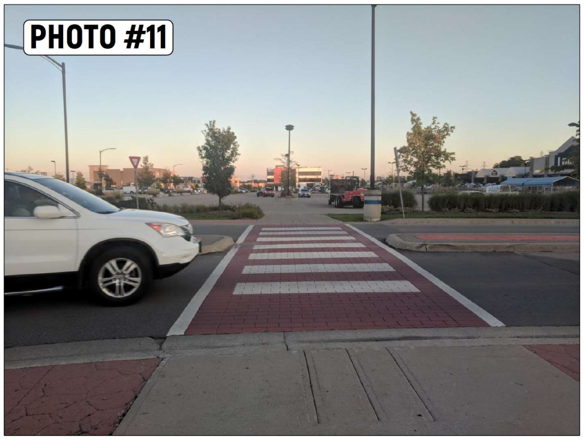


PHOTO #11

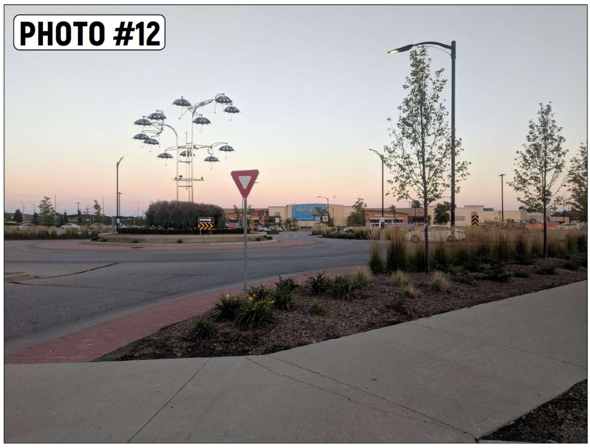


PHOTO #12

Appendix P: Criteria for Evaluating Qualitative Research (Lincoln & Guba, 1985)

Criteria	Definition	Assumptions	Strategies Used in Thesis to Satisfy Criteria
Credibility	Authentic representations of experience	-Multiple Realities -Causes not distinguishable from effects -Empathetic Researcher -Researcher as instrument -Emphasis of the research endeavor	-purposeful sampling was undertaken to ensure multiple understandings of lived experiences in suburban settings -persistent observation (15+ hours with each participant), with multiple methods was employed -debriefed consistently with supervisor during data generation phases, and analysis (peer debriefing)
Transferability	Fit within contexts outside of the study situation	-Time and context-bound experiences -Not responsibility of 'sending' researcher - Provision of information for 'receiving' researcher	-purposeful sampling (see above) -thick description through multiple methods to understand the realities of the participants -suburban landscape context is transferable to many similar places in Canada
Dependability	Minimization of idiosyncrasies in interpretation, variability tracked to identifiable sources	-Researcher as instrument -Consistency in interpretation (same phenomena always matched with the same constructs) -Multiple realities -Idiosyncrasy of behaviour and context	-peer examination during each coding stage of analysis (Chapters 3-5) -multiple researchers doing analysis (Chapter 5) -ongoing review during analysis – exploring other possible explanations
Confirmability	Extent to which biases, motivations, interests or perspectives of the inquirer influence interpretations	-Biases, motivations, interests or perspectives of the inquirer can influence interpretation -Focus on investigator and interpretations	-kept a journal of observations after data generation activities, to reflect on what had just happened and the researcher's response to it based on personal experience -positionality reflection (Section 2.3.3) -final retrospective audit of steps taken

Checklist for evaluating qualitative research (Baxter & Eyles, 1997, p.518)

Question	Examples	Thesis
What was the natural history of the research?	Original purpose(s) of the research	Section 1.1 – Research Questions + Objectives
	Rationale for methodology	Section 2.1 – Case Study Methodology Section 2.2 – Defining the Case Study
	How research developed over time	Section 2.2.3.1 - Methods
	Fieldwork relations	Section 2.2.2.2 – Case Descriptions – Participants Section 2.4 – Reflection on Research Design
What data were collected and by what methods?	Method of note-keeping; Method of tape-recording	Section 2.2.3.1 - Methods
How was the sampling done?	Explicit delineation of sample frame (working universe)	Section 2.2.2 – Cases
How was the data analysis done?	Random or purposeful? Rationale for type of sampling used Procedures for summarizing and presenting data	Section 2.3.2 – Analysis of Empirical Data
What results are presented? Description of researcher's objective for results presentation (e.g. theory-building or description)	Differentiation of data-derived as opposed to pre-existing constructs Differentiation of participant concepts as opposed to theoretical (researcher-derived) constructs	Section 1.1 – Research Questions + Objectives Chapters 3,4,5
How credible is the theory/hypothesis?	Specification of the relationship between constructs/concepts and theory/hypotheses	Chapters 3,4,5
How transferable are the findings?	Recognition of the limits imposed by the sampling	Chapters 3,4,5 Section 6.2 – Limitations

Appendix Q - Reflections on skills developed during PhD

In October 2017, I submitted the proposal for my PhD research. That proposal included skills that I wanted to learn, and supervisory experience that I wanted to gain. Upon reflection, I had the opportunity to develop each of the skills I set out to, including:

- *Enhance my ability to supervise and teach a RA or Co-op student new skills* – I did this by working with a co-op student who I trained to code/ analyze data for Chapter 5. I also trained them to help me with a participant observation and with facilitating the focus group done with the 15-member support group. I hope that this student found these techniques to advance their own skill set as a future professional planner;
- *Enhance my knowledge and ability to facilitate the use of photo and video voice as a methodological tool* – I used a modified version of photo and video-voice, both of which informed the focus group;
- *Enhance my ability to use coding programs like Atlas.ti or NVivo* – I learned how to use Atlas.ti for coding images, videos, as well as constructivist grounded theory approaches (with the use of renaming quotations, and comment sections). I also learned how to use networking functions in the program;
- *Enhance my ability to learn how use co-creation with participants as a way to learn what accommodations PLWD might need* - I learned so much about how to work with PLWD with different communication needs and preferences. I learned how to adapt on the go, and co-create solutions;
- *Enhance my understanding of relational theory as a guide for understanding socio-spatial phenomena* – I did this through all my papers, but most notably through Chapter 3; and
- *Enhance my ability to create easy to follow guides and instructions for PLWD using graphics and other strategies* – I did this by creating photograph guides on how to use the equipment, which participants really appreciated.