Does Living with Parkinson's Disease Affect Life-Space Mobility? A Multiple-Methods Study

by

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Abstract

BACKGROUND: Parkinson's disease (PD) is a progressive, neurodegenerative disorder characterized by resting tremors, instability, slowness of movement and rigidity, generally accompanied by non-motor symptoms such as mood disturbance, fatigue, constipation, incontinence and sleep disorders. Any one of these symptoms can affect an individual's capacity for home and community mobility but does not independently determine mobility performance. The objectives of this multiple-methods study were to identify a diverse set of explanatory factors that contributed to a model life-space mobility in people with PD and determine facilitators and barriers to mobility in a sample of this population.

METHODS: We recruited 227 individuals with (n = 113) and without (n = 114) PD, who were comparable in age, from the community to complete a cross-sectional survey regarding mobility. The primary outcome was the life-space mobility composite score (LSA-C), which ranges from 0-120 (University of Alabama Birmingham Life-Space Assessment). Higher LSA-C represents more mobility in the home and community based on the frequency, distance, and independence of trips. Explanatory variables included demographics, lifestyle behaviours, driving status, self-reported health status, social participation and characteristics of the built environment. Descriptive statistics were used to describe and compare patterns of life-space mobility between participants with and without PD. Multivariable linear regression was used to identify factors that explained life-space mobility. Ten participants with PD participated in a semi-structured interview about facilitators and barriers to mobility. Guided by a comprehensive framework for mobility in older adults, transcripts were content analyzed.

RESULTS: Mean LSA-C was reduced for people with PD (life-space mobility composite score 64.2, SD = 25.8) in comparison to people without PD (70.3, SD=23.1; mean difference = 6 points, 95% CI: -0.4, 12.5). Participants with PD employed assistive mobility devices in higher proportions than participants without PD to reach the same life-space levels. Among people with PD, not driving, receiving caregiving and not having extra money in the house were associated with reduced life-space mobility. Social participation was the only factor associated with increased life-space mobility in the multivariable model. Data from qualitative interviews supported quantitative findings regarding the facilitating influence of driving, having social support and participating in the community. Interviewees identified additional barriers to mobility, which included PD-related anxiety and certain characteristics of the built environment such as being in crowded and confined spaces.

CONCLUSIONS: People with PD reach similar levels of life-space compared to their counterparts without PD, but more commonly use an assistive mobility device to do so. We provide evidence that a diverse set of factors related to the individual, and social and built environments are associated with life-space mobility among people with PD.

IMPLICATIONS: Clinicians and policy-makers should consider personal, social and environmental factors when developing interventions to improve the life-space mobility of the PD population.

Preface

This thesis is original work by Charlotte Ryder-Burbidge. No part of this thesis has been previously published. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Does living with Parkinson’s disease affect life-space mobility? A multiple-methods study”, Pro00086390.

Dedication

This work is dedicated to 114 citizens of Edmonton and 113 members of the Alberta Parkinson's disease community who graciously shared their time and stories with me in hopes of, in some small way, improving the lives of Albertans who have been touched by Parkinson's disease.

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There are some people and organizations I'd like to thank for their contributions to this thesis.

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Finally, I am supremely thankful to my loved ones near and far for joining me on this journey called grad school. It turns out I took us on the scenic route. It's a good thing that you all like nature.

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List of Abbreviations

ADL	Activities of daily living
GPS	Global positioning system
HRQL	Health-related quality of life
IADL	Instrumental activities of daily living
IQR	Interquartile range
LSA	Life-Space Assessment
LSA-A	Life-Space Assessment-Assisted
LSA-C	Life-Space Assessment-Composite
LSA-I	Life-Space Assessment-Independent
LSA-M	Life-Space Assessment-Maximal
MCI	Mild cognitive impairment
PD	Parkinson’s disease
PDQ-8	Parkinson’s disease questionnaire-8
SD	Standard deviation
SE	Standard error
WHO	World Health Organization
WHOQOL-BREF	World Health Organization Quality of Life-BREF

Chapter 1: Statement of the problem & organization of the dissertation

Introduction

Mobility is fundamental to optimal ageing as it allows individuals to complete daily tasks, meet the challenges of the environment, and satisfy psychosocial needs. Broadly defined as the movement within and between environments, mobility can take form as unassisted ambulation, ambulation assisted by mobility aids, or other forms of transportation including a bicycle or a city bus (Prohaska et al., 2011). When and how someone chooses to be mobile is influenced by a complex set of circumstances including ability, preferences, resources, and motivation. For older adults, the changes in physical and cognitive functioning that often accompany ageing further complicate the matter.

An important consideration in the discussion of mobility is the distinction between capacity and performance. Capacity represents what an individual is capable of doing and is generally defined by the physical and cognitive abilities of the individual. Performance represents what an individual actually does, and is affected by capacity as well as a plethora of other internal and external factors at multiple levels (World Health Organization, 2002). Understanding the theoretical gap between capacity and performance can help us understand the role of the social, political, and physical environment in an individual's mobility. Generally, for older adults or people with mobility limitations, capacity is higher than performance indicating that some aspects of these environments could be altered to lower the barrier to mobility (World Health Organization, 2002).

Parkinson's disease (PD) is a chronic neurodegenerative disorder affecting approximately

120,000 Canadians, 85% of whom are aged 65 or older (Dorsey et al., 2007; Guttman et al., 2003). It is characterized by a set of cardinal motor features - bradykinesia, rigidity, and resting tremor - resulting primarily from a loss of dopaminergic neurons in the basal ganglia, a midbrain structure associated with the activation and inhibition of movement (Davie, 2008; Lanciego et al., 2012), and non-motor features including mood disorders, fatigue, constipation, sleep disturbance, orthostatic hypotension and cognitive changes (Pfeiffer, 2016). The presence of any of these features is likely to affect ambulation but does not necessarily restrict mobility. As the number of older adults in Canada increases, so will the prevalence of PD. PD poses a serious challenge to persons wishing to age-in-place, that is, to remain in their home and community as long as possible. Symptom progression can severely limit independence, in large part by affecting the ability to be mobile.

The features associated with the disease impact movement. Ambulation is one type of movement that is affected. Additionally, difficulty with activities of daily living (ADLs) such as grooming, dressing, and eating; and instrumental activities of daily living (IADLs) such as cooking, doing housework, and driving are affected by the features of PD. IADLs also include participation in social and recreational activities which can become more difficult to partake in when one experiences difficulty with movement. Previous research has observed that the psychosocial needs of people with PD may have a more significant impact on their health-related quality of life (HRQL) than their functional needs, underscoring the importance of participation and strong interpersonal relationships for people of this population (Kwok et al., 2018).

In PD, the loss of the neurotransmitter dopamine within the basal ganglia is associated with mood and cognitive disturbances which impact HRQL and challenge mobility-related independence (Jones et al., 2009). Reports in the literature vary but it is suggested that up to 50%

of people with PD have some form of depression, while 24-31% of people with PD are estimated to have PD dementia impairing memory and mental processing (Aarsland et al., 2005; Reijnders et al., 2008). As is explained in Webber, Porter, and Menec's Comprehensive Framework for Mobility in Older Adults, increasing social and cognitive demands are required as an individual ventures further away from their home (2010). Therefore, the overall space in which a person with PD lives their life is likely to shrink as the disease progresses due to physical and cognitive changes.

Although there is a growing body of literature that measures the mobility of older adults in terms of performance, almost none has focused on the specific needs of people with PD (Ireland et al., 2013; Liddle et al., 2014; Rantakokko et al., 2019). Mobility research that *is* specific to PD tends to measure mobility by testing functional outcomes such as the motor examination of the Unified Parkinson's Disease Rating Scale (UPDRS III) (Goetz et al., 2008), the Timed Up and Go test (Vance et al., 2015)or the Berg Balance Scale (Berg et al., 1992). While functional capacity is an important piece of the mobility picture, it does not comprise the whole. It is necessary to consider factors beyond the level of the individual, such as the built, interpersonal (social), and policy environment when designing interventions to improve the mobility of people with PD. By promoting performance, in addition to capacity, interventions are more likely to facilitate meaningful improvements for individuals with mobility challenges.

Life-space mobility is one concept of mobility that bridges capacity and performance to holistically define mobility in the home and community (Baker et al., 2003). Data for life-space mobility is most commonly collected with a self-report survey called the University of Alabama Birmingham Life-Space Assessment (LSA) and transformed into a composite score (0-120) where lower scores indicate more restricted mobility (Peel et al., 2005). The LSA has been extensively validated and is widely used to measure the comprehensive mobility of older adults due to its observed associations with executive functioning, motor performance, sense of autonomy, health literacy, and accessibility of the built environment (Matsuda et al., 2018; Poranen-Clark et al., 2018; Portegijs, Rantakokko, et al., 2014; Ullrich et al., 2019). When measured longitudinally, the LSA has been shown to predict health-care utilization, frailty, cognitive decline, quality of life, and mortality in older adults, suggesting it may be a suitable and inexpensive tool for monitoring PD progression in addition to evaluating cross-sectional mobility (Crowe et al., 2008; Kennedy et al., 2017; Rantakokko et al., 2016; Xue et al., 2008).

Problem Statement

PD is a prevalent condition among older adults which affects mobility; movement within and between environments. Mobility is fundamental for optimal ageing and ageing-in-place as it allows individuals to complete daily tasks and meet the demands necessary to remain in their homes. Additionally, mobility is an important determinant for participation in activities outside of the home which is fundamental for sustaining HRQL. By 2030, the number of Canadian adults aged 65 and over is expected to make up close to 25% of the national population, a large number of whom will be diagnosed with PD (Government of Canada, 2016).

People living with PD face unique mobility-related challenges resulting from a loss of dopamine in brain areas responsible for coordinating motor planning, decision-making, and motivation (Emamzadeh & Surguchov, 2018; Lanciego et al., 2012). Both motor (i.e. walking difficulties and postural instability) and non-motor symptoms (i.e. depression and executive functioning) can affect the mobility of persons with PD. However, little is known about the patterns by which people with PD move throughout their homes and communities, or what environmental, social, or personal factors facilitate or restrict the desire and ability of persons in this population to be mobile.

The purpose of our research is to address this gap in knowledge by understanding the impact of living with PD on life-space mobility; that is, how the condition may alter the frequency or distance of travel within an individual's community. More specifically, we examine the differences in life-space mobility between a population of people with and without PD in terms of overall and individual attributes of life-space mobility (e.g. frequency and distance of trips, use of assistive mobility devices)

The information generated from this study is some of the first to examine the life-space mobility of people with PD and, to our knowledge, the first research of its kind to examine the influencing effect of the social and built environment and employ a healthy control group for comparison. Understanding how the life-space mobility of persons with PD differs from that of the general population is an initial step in developing accessible social and physical spaces that facilitate the mobility of people living with PD.

Research overview

Research questions and objectives

The overall purpose of this multiple-methods research is to understand the impact of living with PD on life-space mobility. We will achieve this aim by sequentially conducting two complementary components, each with its own main research question and a unique set of objectives. Then, we will synthesize the findings of the two studies.

Component 1 (quantitative):

Primary objective:

- To identify explanatory factors that contribute to a model of life-space mobility in people with PD.

Secondary objective:

- To compare the life-space mobility patterns of people with PD to healthy peers of a similar age.

Component 2 (qualitative):

Primary objective:

- To explore barriers and facilitators to life-space mobility that can be targeted by interventions and policies to promote community mobility in this population.

Organization of the dissertation

This dissertation follows the paper-based thesis guidelines for thesis-based Master's students set out by the University of Alberta, School of Public Health. It consists of five chapters in total including one stand-alone study intended for publication in a relevant journal at a later time. Chapter 1, this opening chapter, has provided an overview of the context pertinent to the research and outlined a problem statement. As well, a research overview lists the purpose, questions, and objectives of the research. Chapter 2 provides a more comprehensive background into three themes related to this study: PD, mobility in general, and the concept of life-space mobility. In Chapter 3, original research titled, *Does living with Parkinson's disease affect life-*

space mobility: A multiple-methods study, is introduced. The study reports on findings from quantitative and qualitative methods used to explore questions relevant to the life-space mobility of people with PD. It is comprised of an abstract, introduction, methods, results, discussion, and conclusions section. Chapter 4 offers an expanded discussion of the results of the quantitative and qualitative components of the study. Chapter 5 offers an expanded conclusion in the form of a summary of the research, important findings, and future directions.

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Chapter 2: Literature review

Introduction

Within this chapter, Parkinson's disease (PD) is introduced as a chronic, progressive, neurodegenerative disorder affecting mobility, as well as other aspects of health. The pathology of the disease occurring in the brain is briefly described, as well as a summary of hypothesized etiologies. PD epidemiology is discussed from a Canadian perspective, with insights from the international prevalence and incidence rates. The diagnosis of PD, common motor and non-motor symptoms manifest in PD, and current strategies for treating those symptoms, including pharmaceutical and non-pharmaceutical interventions are outlined. Mobility is then discussed using definitions and conceptual frameworks that guide and inform modern understandings of health and health-related issues. Then the relationships between mobility and ageing-in-place, health-related quality of life, the built environment, and social participation are elucidated with evidence from previous research. Lastly, the concept of life-space mobility is explored through its history and commonly used iterations.

Parkinson's disease

Parkinson's disease: pathology and etiology

Parkinson's disease was originally described by James Parkinson in his "Essay of the Shaking Palsy in 1817" (Parkinson, 1969). Pathologically, PD features result primarily from a loss of dopaminergic cells of the pars compacta in the substantia nigra leading to a loss of dopamine in the striatum (Wirdefeldt et al., 2011). Dopamine plays an important role in motor planning, movement initiation, motor learning, decision-making, and motivation (Yager et al., 2015). It is not until about 50-70% of the nigral neurons have degenerated and about 80-85% of the striatal dopamine content is lost that parkinsonian symptoms start to emerge (Cheng et al., 2010)

Although the cause of this loss of dopaminergic neurons is still unknown, it is hypothesized to be some combination of genetic and environmental factors. A 2018 review of the genetic forms of PD provided evidence that 23 loci and 19 disease-causing genes may be associated with the development of PD, and that many more may be linked to sporadic cases of the disease (Deng et al., 2018). However, it is estimated that these genetic variations explain only between 5-10% of monogenic forms (de Lau & Breteler, 2006; Deng et al., 2018). In some of these monogenetic cases, such as that of familial PD, the condition may not be properly diagnosed as the clinical characteristics presented are often atypical of PD. For example, young-onset, dystonia, and early onset of dementia are common in familial cases of PD but are not typically expected in cases of idiopathic PD. This is leading to a new conceptual understanding of PD and related disorders as a group of neurodegenerative diseases with clinical and pathological overlap (de Lau & Breteler, 2006; Schiesling et al., 2008). The remaining 90% of cases are still considered to be sporadic (idiopathic) but are potentially induced by interactions between susceptible genes and cellular processes such as oxidative stress, mitochondrial dysfunction, and protein mishandling (Greenamyre & Hastings, 2004). These processes result in variations in the gene that can modify susceptibility to PD. Studies testing the relationship of PD to proposed susceptible genes are often limited by, among other concerns, small sample sizes and low statistical reproducibility (Borrageiro et al., 2018).

In 2003, Braak and colleagues formed a novel hypothesis that sporadic PD begins when pathogens enter the neurons of the nasal cavity and / or the neurons in the gut triggering the aggregation of ɑ-Synuclein, a constituent protein in Lewy bodies (Braak et al., 2003; Rietdijk et al., 2017). According to the hypothesis, ɑ-Synuclein then travels towards the central nervous system via the olfactory bulb and vagus nerve, ultimately arriving at the substantia nigra. Braak Staging divides PD progression into six phases determined by the abnormal migration of ɑ-Synuclein through the lower brainstem to the neocortex (Braak et al., 2003). Early stages are considered to be presymptomatic but potentially explain some non-motor (olfactory and autonomic) symptoms early in the disease course (Braak et al., 2003; Jellinger, 2019). Later stages are associated with mild and then severe motor symptoms, which are hallmarks of the disease.

Braak's staging and pathological theory have been met with criticisms, among which is the observation that many people with PD do not present with the features proposed by the staging system (Rietdijk et al., 2017). However, disease progression in people of young-onset with long disease duration is well predicted by Braak Staging and research theorizing that changes to gut microbiome may be related to PD onset continue to gain traction (Halliday et al., 2008). A body of research is forming showing that people with PD lack bacterial diversity and richness in comparison to healthy controls (Scheperjans et al., 2015; Tetz et al., 2018). Work in this area of PD research provides a promising avenue for future diagnostic tools and interventions.

In literature examining possible associations between PD and occupational, environmental, and lifestyle factors, reliable findings are limited. A systematic review examining these relationships identified only two factors with sufficient epidemiologic evidence to suggest a protective association: smoking, and to a lesser degree, coffee consumption (Wirdefeldt et al., 2011). The same review identified 4 other factors with limited epidemiological evidence to suggest an association. Pesticides and consumption of dairy products may be positively associated with PD, while physical activity and dietary intake of antioxidants may be inversely associated with PD.

Prevalence and incidence of Parkinson's disease

A 2014 systematic review and meta-analysis of the prevalence of PD by geographic region, sex, and age reported that in Europe, North America, and Australia, the prevalence of PD in the 50-59 age group was 113 per 100,000; in Asia, 88 per 100,000; and South America, 228 per 100,000 (Pringsheim et al., 2014). For each subsequent decade, the prevalence per 100,000 in Europe, North America, and Australia increased to 540 for those 60-69; 1,601 for those 70-79; and 2,953 for those 80+. For each subsequent decade, the prevalence per 100,000 in Asia increased to 376 for those 60-69; 646 for those 70-79; and 1,418 for those 80+. For each subsequent decade, the prevalence per 100,000 in South America increased to 637 for those 60-69; 2,180 for those 70-79; and 6,095 for those 80+. The review found that across all regions, the prevalence of PD was slightly higher in males than in females, but the difference was only found to be statistically significant ($p<0.05$) in the 50-59 age group.

A 2016 systematic review and meta-analysis of the incidence of PD by age and gender reported that the overall incidence rate of PD in females 40+ was 38 per 100,000 person-years and in males 40+ was 61 per 100,000 person-years (Hirsch et al., 2016). For both females and males, the incidence rate of PD increased with age. For females, the incidence rate increased from 3 per 100,000 person-years between the ages of 40-49 to 103 per 100,000 person-years at and above age 80. For males, the incidence rate increased from 4 per 100,000 person-years between ages 40-49 to 258 per 100,000 person-years at and above age 80. The gender-specific analysis also revealed that in all age groups, incidence rates were higher for men than women, but this finding was only statistically significant in the 60-69 and 70-79 age groups. Of 27 studies included in the review, 16 were performed in Europe, 5 in Asia, 4 in North America, and 1 in Australia.

In Canada, PD affects approximately 120,000 Canadians, 85% of whom are aged 65 or older (Dorsey et al., 2007; Guttman et al., 2003). Only a small number of peer-reviewed articles have measured the prevalence of PD by province yielding estimates from 74 to 359 per 100,000 (Guttman et al., 2003; Lai et al., 2003; Snow et al., 1989; Svenson et al., 1993). For Alberta specifically, overall crude prevalence rates were estimated to be 248.9 and 239.8 per 100,000 for men and women, respectively, during a 1983-1989 time period (Svenson et al., 1993).

One study of incidence rates in Alberta using physician billing for case ascertainment observed 11.5 per 100,000 new cases of PD per year during the decade of 1995-2005 (Martin et al., 2010). In British Columbia, using a cohort created from five provincial databases, the crude annual incidence rate was found to be 252 per 100,000 person-years in persons 65 and older (Jones et al., 2012). Over nine years, persons of advanced age and males were more likely to develop PD than persons who were younger or female. In Ontario, using linked population-based health administrative databases, the crude annual incidence was 45.9 per 100,000 person-years for the years 2013-2014 (Wong et al., 2019).

Diagnosis of Parkinson's disease

Making an accurate diagnosis of PD can be complicated as there is no specific test or assessment that is definitive. Instead, it is a diagnosis of exclusion where clinicians rely on a careful examination of medical history and clinical criteria to rule out other possible explanations of symptoms suggestive of PD (Jankovic, 2008). A definitive diagnosis of PD can only be confirmed postmortem (Dickson et al., 2009).

Bradykinesia (slowness of initiation of voluntary movement with a progressive reduction in speed and amplitude of repetitive actions), rigidity, resting tremor, and postural instability are motor symptoms characteristic to PD or a parkinsonian syndrome (National Institute for Health and Clinical Excellence, 2006). According to the Parkinson's Foundation, the 1988 UK Parkinson's Disease Society Brain Bank Clinical Diagnostic Criteria is still the most widely employed set of diagnostic criteria. Inclusion criteria for the diagnosis of PD according to these criteria include bradykinesia and at least one of muscular rigidity, resting tremor, or postural instability. The diagnostic criteria also include a list of other symptoms that can be used as evidence for or against a diagnosis. Newer criteria such as those published by the International Parkinson and Movement Disorder Society (MDS) task force are believed by some to be more relevant given advancements made in the last 30 years (Marsili et al., 2018; Postuma et al., 2015). The MDS-PD criteria are bradykinesia and rigidity, resting tremor, or both. The task force excluded the criteria of postural instability suggesting that its presence in the early stages of PD is indicative of an alternative diagnosis (Postuma et al., 2015).

Because there is no definitive diagnostic test for PD, diagnostic accuracy is one of exclusion. In the early stages of the disease when symptoms are more subtle, rates of misdiagnoses are as high as 20-30% (Poewe & Wenning, 2002). Non-experts, specifically, only properly diagnose PD in about 74% of cases and accuracy has not improved significantly in the last 25 years (Rizzo et al., 2016). An accurate diagnosis is more likely to be made by a specialist such as a neurologist who is an expert in movement disorders, but in clinical practice, overdiagnosis is common (Hughes et al., 2002; Litvan et al., 1998).

A diagnosis of PD is more likely if there is a sustained improvement in response to dopaminergic medications such as levodopa (Poewe & Wenning, 2002). A poor response to levodopa, possibly with additional symptoms uncharacteristic of idiopathic PD, points to a different parkinsonian diagnosis. Typical differential diagnoses include the Parkinson-Plus Syndromes, also known as atypical parkinsonian syndromes or atypical parkinsonism. These syndromes have been characterized into two distinct groups, based on the type of protein that accumulates in the brain. Synucleinopathies are characterized by an aggregation of alpha-synuclein proteins in neurons, nerve fibres, or glial cells and form a group comprised of PD, dementia with Lewy bodies, and multiple system atrophy (McCann et al., 2014). Tauopathies are characterized by an accumulation of tau protein in cells in the subcortical and cortical areas and form a group comprised of progressive supranuclear palsy and corticobasal degeneration (Poewe & Wenning, 2002). In a clinicopathologic study comparing the diagnostic accuracy of PD, dementia with Lewy bodies, and Lewy body disease, the authors found that PD was overdiagnosed (median sensitivity= 73.3% and 80% for first and last visit, respectively), while dementia with Lewy bodies was underdiagnosed (median sensitivity=17.8% and 28.6% for first and last visit) (Litvan et al., 1998).

Symptoms

Motor symptoms

Based on the MDS-PD diagnostic criteria, the cardinal symptoms of PD are bradykinesia plus rigidity, resting tremor, or both. Bradykinesia is defined as slowness of movement with decreased amplitude or speed as the movement continues (Postuma et al., 2015). It is the only criteria that must be present for a clinical diagnosis of PD and it must be measured in a limb, specifically, even though it can occur in other parts of the body including the face. Rigidity is judged to be present when resistance is encountered by an examiner passively moving the neck or a major joint of the limbs while the client is relaxed. Resting tremor is defined as a 4 to 6 Hz tremor in a limb fully at rest. When movement is initiated, the tremor is suppressed or attenuated. People with PD can experience several motor symptoms in addition to these classic criteria, including instability, gait disorders, loss of postural reflexes, dystonia, reduced facial expression, micrographia, and bulbar symptoms such as dysphagia, sialorrhea, hypophonia, and dysarthria (Garcia Ruiz et al., 2011).

Non-motor symptoms

Virtually all people with PD report experiencing associated non-motor symptoms. Non-motor symptoms tend to correlate with age and disease severity, and many are suggested to be preclinical markers of the condition (Chaudhuri et al., 2006). Common non-motor symptoms of PD include depression, sleep disruption, constipation, incontinence, cognitive impairment, and pain - all of which have been shown to affect levels of mobility (Buchman et al., 2017; Finlayson & van Denend, 2003; Kong et al., 2019; O'Connor et al., 2010; Stenholm et al., 2010). Other non-motor symptoms that can affect HRQL include fatigue, anxiety, apathy, psychosis, orthostatic hypotension, decreased olfaction, and restless leg syndrome (Park & Stacy, 2009).

Non-motor symptoms present in the vast majority of PD cases and contribute substantially to health-related quality of life, cost of care and the likelihood of institutionalization (Pfeiffer, 2016). Although the recognition of non-motor symptoms by physicians has improved recently, these symptoms are under-recognized and undertreated due to the gap inadequately powered research focusing on their prevalence, effect and treatment efficacy (Chaudhuri et al., 2006). Underreporting of non-motor symptoms by patients themselves may also contribute to a lag in the diagnosis and treatment of these symptoms (Pfeiffer, 2016).

Monitoring symptom progression

The Hoehn and Yahr Scale (HY) is widely used to represent the severity of overall PD dysfunction related to motor symptoms. Developed in 1967, the scale charts PD progression across five stages: unilateral disease (1), bilateral disease without balance difficulties (2), and then bilateral disease in addition to postural instability (3), loss of physical independence (4), and wheelchair- or bed-bound (5) (Hoehn & Yahr, 1967). More than 20 years later, the development of a modified HY Scale for use in some clinical trials added two additional stages at 0.5 increments: unilateral disease and axial involvement (1.5) and mild bilateral disease with recovery on pull test (2.5) (Jankovic et al., 1990).

In addition to monitoring the progression of motor symptoms, the Movement Disorder Society's Unified Parkinson's Disease Rating Scale (MDS-UPDRS) comprehensively assesses non-motor symptoms associated with PD (Goetz et al., 2008). The MDS-UPDRS is comprised of four parts including the non-motor experiences of daily living, motor experiences of daily living, and motor complications.

Dual-tasking

In PD, dopamine loss in the basal ganglia disrupts motor and cognitive performance. Historically treatment has focused on treating the motor symptoms. Increasing awareness and knowledge of complex neurocircuitry in the basal ganglia highlights the close relationship between movement and cognition. Studies of gait performance in people with PD provide evidence for their intimate relationship (Horak, 2006; Penko et al., 2018; Rochester et al., 2014; Yogev-Seligmann et al., 2008). Dual-tasking is the performance of a motor-cognitive activity such as walking at the same time as holding a conversation. This is especially challenging for people with PD because cognitive and motor processes compete for the same compromised resources of the basal ganglia to coordinate and complete tasks (Galvan et al., 2015; Peterson & Horak, 2016). In the example of walking, the addition of a cognitive demand results in decreased gait velocity and increased gait variability, which both increase the risk of falling (Penko et al., 2018; Pieruccini-Faria et al., 2020). Evidence shows that, for people with PD, changes in gait, and consequently fall risk, are further exacerbated on irregular terrain (Xu et al., 2018).

Management of Parkinson's disease

Pharmacological interventions

Alone, and in combination, PD medications aim to manage functional impairment, thus also helping to avoid social embarrassment resulting from the disease (Connolly & Lang, 2014). Each medication has its own set of risks and possible adverse side effects which may be compounded with each addition to an individual's pharmaceutical regime. Motor symptoms are managed by the gold standard treatment of levodopa in combination with a peripheral decarboxylase inhibitor (carbidopa or benserazide). The combination helps reduce side effects such as vomiting, nausea, arrhythmia, and postural hypotension resulting from the conversion of levodopa into dopamine in the peripheral nervous system (Cheong et al., 2019). While most people experience treatment-related symptom improvement with levodopa, the risk of long-term motor and non-motor side effects is substantial (Davie, 2008).

Marsden and Parkers were the first to describe motor fluctuations seen in people with PD with chronic use of levodopa and advancing disease (Marsden & Parkes, 1976). They termed these disturbances, "on-off" effects, and identified "off" as the "change from mobility to disability". Today the term "motor fluctuations" is used to describe the range of motor experiences stemming from the decreased benefit from levodopa between doses (whether it be gradual or abrupt), as well as Marsden's "on-off" effect (Chou et al., 2018). Motor fluctuations are part of a larger group of "motor complications", which also contain "offs" and dyskinesias. The latter are involuntary muscle movements which can be the result of PD medication or the disease itself. Studies report that between 25-50% of people with PD taking levodopa will experience some sort of wearing-off within two years of starting treatment (Fahn et al., 2004; Parkinson Study Group, 2000). Trials investigating the relationship between levodopa and wearing-off showed motor complications are more prevalent in people who are younger age, female, have higher disease severity and dosage of levodopa (Chou et al., 2018). Non-motor fluctuations are also likely and tend to arise in people who experience motor fluctuations.

Several other pharmacological therapies may be used as monotherapy early in the course of the disease to disease to delay treatment with dopamine, and therefore the onset of dyskinesia or motor fluctuations, or in combination with dopamine replacement therapies to achieve optimal symptom control (Connolly & Lang, 2014). Pharmacological alternatives to dopamine include dopamine agonists, monoamine oxidase B inhibitors, catechol-o-methyltransferase inhibitors, anticholinergics, and amantadine. Dopamine agonists directly activate dopamine receptors, while the other drugs work with existing dopamine to slow its breakdown or improve its uptake (Borovac, 2016; Robottom, 2011; Sharma et al., 2018)

There is a separate set of pharmaceuticals used to treat non-motor symptoms associated with PD. These commonly include rivastigmine, for improving symptoms of dementia; clozapine, an antipsychotic agent; and macrogol for constipation (Cheong et al., 2019). The effective management of non-motor symptoms is limited by the scarcity of large, high-quality studies (Connolly & Lang, 2014).

Deep brain stimulation

Deep brain stimulation is a therapeutic intervention that uses electrical impulses from an implant inside the brain to offer lasting relief of some motor symptoms of PD, with relatively few side effects. A number of anatomical target areas have been identified for this surgery over the years based on beneficial effects in motor regulation, but the most common regions are the subthalamic nucleus and the globus pallidus interna (Dallapiazza et al., 2018). Since its clinical establishment in 1997, it has become the most common surgical intervention for PD and research is continuously underway to improve the range of symptoms it addresses and the number of PD patients it can help (Lozano et al., 2019). The therapy aims to treat the debilitating motor symptoms of the disease, such as rigidity, bradykinesia, and resting tremor. Currently, DBS is most effective for people with long "wearing-off" periods, disabling tremors, and medication-related adverse effects such as dyskinesias. In a cohort of 400 patients with PD, DBS was found to offer the stability of motor functioning and ADLs over 10 years of follow-up (Hitti et al., 2019). Although it can provide long-lasting relief from some symptoms, DBS does not slow the underlying disease process the disease.

Physical activity

Since it was first suggested in 1992 by Sasco et al., a considerable amount of research has been conducted to test the hypothesis that physical activity is one avenue for treating symptoms of PD (Sasco et al., 1992). A 2018 review of systematic reviews outlined the clinical studies that have been conducted for specific types of exercise as well as exercise in general (Bhalsing et al., 2018). Aerobic exercise, treadmill training, dance therapy, Tai Chi, and Qigong were all found to be suitable types of physical activity to provide relief of motor symptoms while improving mobility and balance. A systematic review of randomized trials studying non-motor symptoms showed that physical activity improved the overall burden of non-motor symptoms including depression, apathy, fatigue, daytime sleepiness, sleep problems, and cognition, although the risk of bias in the studies was variable and they could not be pooled due to methodological heterogeneity (Cusso et al., 2016). A Cochrane review investigating the effectiveness of physiotherapy (including exercise generally, but also cueing, treadmill training, physiotherapy, dance, and martial arts) in PD, concluded that there is evidence for the short-term benefits of physiotherapy for the treatment of PD motor symptoms (Tomlinson et al., 2013). However, due to an unclear or high risk of bias in many of the included studies, the authors cautioned against over-interpretation of the observed effect.

The mechanism by which physical activity enhances functioning is poorly understood, but there is evidence to suggest that structural changes in the brain, including the proliferation of grey matter or striatal dopamine receptor density and dopamine levels, might be involved (Fisher et al., 2013; Hou et al., 2017; Sehm et al., 2014). Animal models continue to be used to better understand these exercise-induced improvements at a cellular level and, while interesting results in the areas of neuroprotection, neurogenesis, and anti-inflammation have been seen, researchers work continuously to translate these findings to humans. One group successfully translated findings in mouse models to humans, showing that treadmill exercise increased dopamine D2 receptor binding potential in people with early-stage PD, resulting in improved postural control (Fisher et al., 2013). D2 receptors are implicated in indirect pathways in the basal ganglia which help to control movement. In the PD model, dopamine depletion leads to inappropriate inhibition of neural pathways and induce motor impairments (DeLong & Wichmann, 2010).

Presently, physical activity is recommended for people with PD. Although there is disagreement regarding how the disease may affect the functional characteristics of exercise such as oxygen uptake, the health benefits of physical activity experienced by the general population are still relevant to those with PD (Haas et al., 2004; Protas et al., 1996). Some motor and non-motor symptoms of PD might make participation in regular physical activity difficult. For example, fatigue is a common symptom among individuals with PD and one study found that more than 20% of people with PD considered to be “low-exercisers” reported fatigue as a barrier to physical activity (Afshari et al., 2017). Nevertheless, with regular physical activity, muscle strength and aerobic fitness improve, while the risk of physical disability, sleep problems, dementia, and depression decrease (Candow et al., 2006; Eldar & Marincek, 2000; Hamer & Chida, 2009; Kredlow et al., 2015; Van Den Brink et al., 2005; Warburton et al., 2006). Many authors agree that future research should focus on identifying the frequency and intensity of physical activity that is most beneficial to people with PD.

Mobility

Definitions of mobility

The World Health Organization’s International Classification of Functioning, Disability and Health (ICF) has a broad definition of mobility, which recognizes indoor and outdoor movement, as well as the use of assistive devices and/or transportation (World Health Organization, 2002). However, scientific research aiming to quantify mobility still commonly use narrow definitions that insufficiently capture all the possible approaches to achieving it.

Definitions of mobility can influence conversations about *mobility disability*, defined as a case in which functional mobility is reduced to a point where individuals have difficulty carrying out tasks essential to everyday life and consequently mobility itself becomes the disability (Patla & Shumway-Cook, 1999). If we discuss mobility as a product of an individual, we may see mobility disability using the *medical model* of disability. This model describes disability as a feature of an individual, directly caused by a health condition, and requiring medical interventions to ‘correct’ the problem (World Health Organization, 2002). In contrast, if we discuss mobility as a product of the environment or society, we may see mobility disability using the *social model* of disability. This model describes disability as a socially-created problem independent of the characteristics of an individual and requiring political response leading to changes in attitudes and the environment in an attempt to accommodate individuals with limitations (World Health Organization, 2002). Alone, neither model is complete, which is why the ICF uses the *biopsychosocial model*, reflecting the role of the biological, individual and social factors contributing to disability. Despite the evolution of conversations surrounding disability, in most research mobility is still viewed as a feature of an individual and therefore interventions to improve or maintain it are designed to treat physical limitations experienced by the individual. This approach disadvantages older adults in particular, as they face additional social, financial, cognitive and environmental barriers to mobility in comparison to younger adults or children.

A transdisciplinary approach: the ecological model

The ecological approach to problem-solving examines the interplay within and between factors at the intrapersonal, interpersonal, institutional, community, and policy levels to understand the various influences affecting one issue (McLeroy et al., 1988). Sallis and colleagues (2006) employed an ecological approach to suggest that a multilevel intervention is best suited to create active living communities. In their 2006 paper, they proposed a model - informed by contributions from research in public health and behavioural science; urban planning and transportation; leisure and recreation studies; and public policy, economics, and political science - illustrating the array of factors requiring consideration before attempting to define an intervention. These factors, broadly grouped into categories such as the information environment, natural environment, perceived environment, and behaviour, can be easily applied to discussions about mobility as many of the factors influencing physical activity and mobility are the same.

An ecological model is an applicable model for representing real-world challenges within the context of mobility in daily lives. Most research discussing strategies to improve mobility problem-solve at the level of the individual: an exercise regime, a home modification, a walking aid. What is lacking is a body of comprehensive research that can be used to inform multi-level strategies for sustainably improving the mobility of any given community or population. Without consideration of the broader social, political, and environmental context, interventions designed for the individual are likely to fail. To build on the examples given above related to improving mobility: an exercise regime might not be completed if the individual does not have transportation to a recreation facility; a home modification might not be made if the individual lacks the funds to pay for it, and a walking aid might not be employed if its use is stigmatized by an individual's peer group. Conceptualizing mobility and strategies to improve and maintain mobility using a social-ecological model can help to close the gap between capacity and performance.

A framework for mobility in older adults

To address mobility in older adults the need for a conceptual model of the environmental impact on mobility, Patla and Shumway-Cook developed a framework to help quantify the relationship between the environment and an individual's mobility (Patla & Shumway-Cook, 1999). As someone moves along the mobility continuum, from non-functional ambulator to independent community ambulator, they face more and greater challenges in navigating the environment (Figure 2.1).

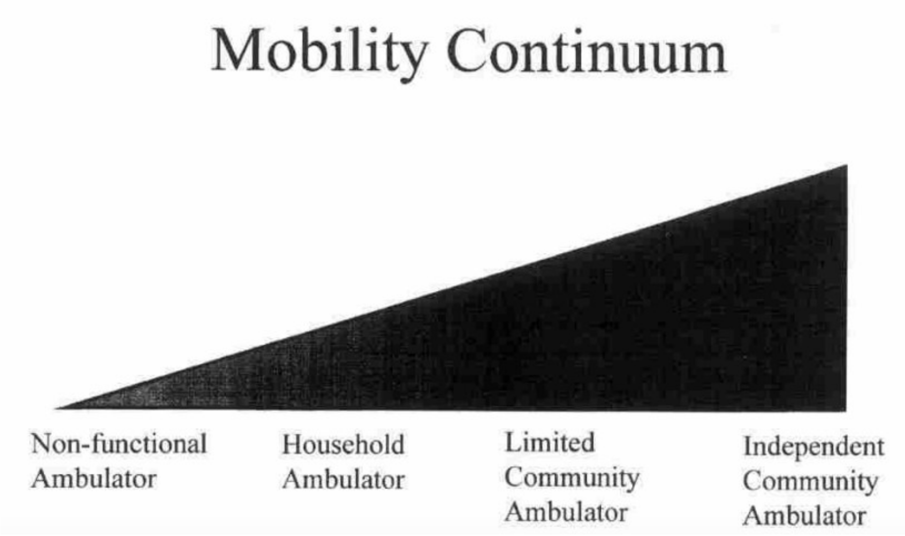

Figure 2.1. Patla and Shumway-Cook's mobility continuum (1999) representing the number of skills required by an older adult to be mobile in increasingly complex environments.[1]

Eight environmental dimensions were outlined to capture the physical demands that must be met for an individual to be mobile in the community: minimum walking distance, time constraints, ambient conditions, terrain characteristics, external physical load, attentional demands, postural transitions and traffic level. These dimensions were conceptualized as spokes on a wheel with optimal performance on all eight dimensions represented as the perimeter of the wheel (Figure 2.2). An individual's operating range can be mapped onto the wheel in an

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[1] Patla, A. E., & Shumway-Cook, A. (1999). Dimensions of Mobility: Defining the Complexity and Difficulty Associated with Community Mobility. *Journal of Aging and Physical Activity*, *7*(1), 7–19. https://doi.org/10.1123/japa.7.1.7

environmental context to elucidate mobility restrictions that may not be apparent through clinical tests in an ideal setting. With this model, the authors also showed that mobility within the home requires a different set of capabilities than mobility in the community.

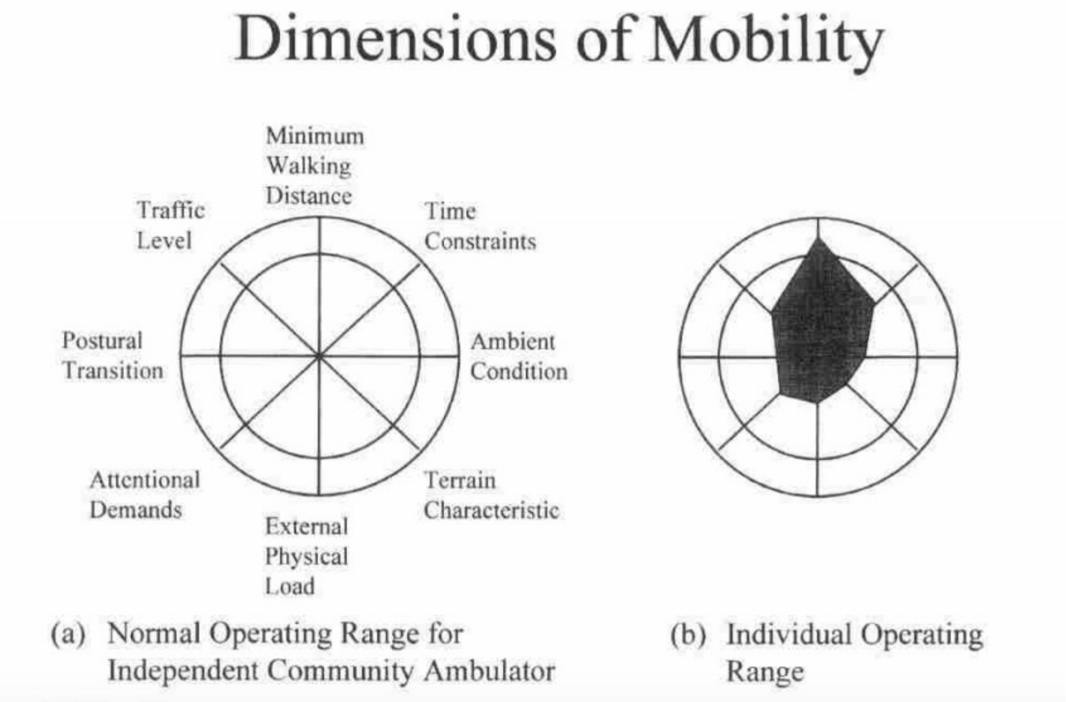

Figure 2.2. Patla and Shumway-Cook's Wheel Model of environmental dimensions affecting mobility in older adults (1999) a) Each dimension is characterized as a spoke on the wheel with optimal performance on all eight dimensions represented as the perimeter of the wheel. b) The operating range of a hypothetical individual in each of the eight environmental dimensions is mapped onto the wheel to reflect a holistic measure of mobility.[1]

Webber, Porter and Menec (2010) built upon the Wheel Model and published the Comprehensive Framework for Mobility in Older Adults. This framework is more comprehensive than the Wheel Model by including psycho-social, environmental, physical, cognitive, and IADL factors. This model has been used by others to shape recent research related to mobility in older adults (Levasseur et al., 2004; Rosso, Taylor, et al., 2013). By understanding that older adults use means other than walking to achieve community mobility, the authors considered additional contextual factors that can impact mobility. In the conical model of this framework, mobility is determined by cognitive, psychosocial, physical, environmental and financial factors, which are all shaped by gender, culture and biographical influences (Figure 2.3). A conical shape is used to represent the idea that as one moves further away from their bedroom, an increasing number of contextual factors contribute to each determinant life-space area.

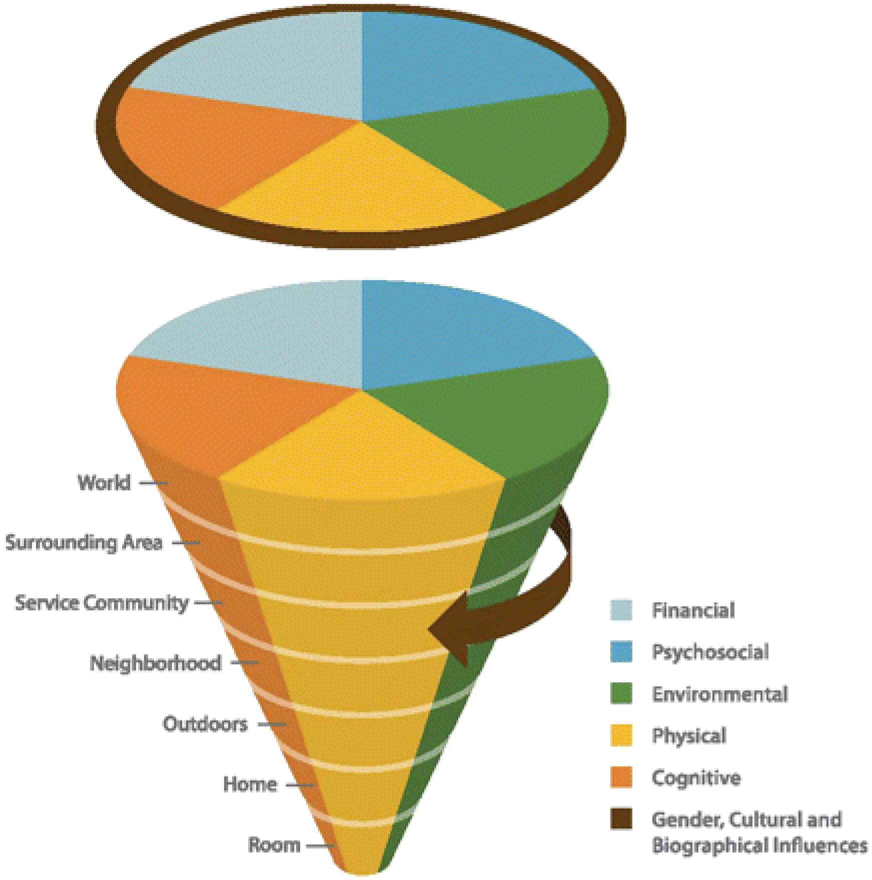

Figure 2.3. Webber, Porter & Menec's conical model (2010) for a comprehensive framework of mobility in older adults in which an increasing number of financial, psychosocial, environmental, physical, and cognitive factors are at play with each level of life-space and these factors are influenced by gender, culture and biographical contexts.[2]

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[2] Webber, S. C., Porter, M. M., & Menec, V. H. (2010). Mobility in older adults: a comprehensive framework. *The gerontologist*, *50*(4), 443-450.

Mobility and ageing-in-place

One of the motivating factors for maintaining mobility as we age is the prospect of ageing-in-place, or “remaining in the community, with some level of independence, rather than in residential care” (Davey et al., 2004, pg. 113). This concept is a priority of many older adults who associate the community or area in which they live with a sense of security, social connection, and autonomy (Wiles et al., 2012). Socially, ageing-in-place allows people to reap the health and personal benefits of living in an area that is familiar to them. It is important to note that the majority of research related to ageing-in-place – and indeed, the research that is described in the following sections - reflects North American and Western European culture. Thus, this research may not be representative of individuals belonging to other races/ethnicities, for whom the experience of ageing may manifest differently (Fung, 2013).

Due to improved medical technologies and public health interventions, older adults are living longer while managing more chronic diseases and physical limitations. In Canada, more than one-third of the older adult population (65+) lives with a mobility disability which affects the ability to complete ADLs, engage socially with others, and generally maintain a good quality of life (Government of Canada, 2011). For this reason, this group is more likely to have to leave their home for a nursing home, senior’s residence, or some other kind of long-term care.

While some older adults may welcome the transition into assisted living, the overwhelming majority (93%) choose to remain in private households (Statistics Canada, 2011). Policy-makers also value ageing in place because delaying or preventing an individual’s progression into long term care makes economic and social sense (World Health Organization, 2007). In Canada, long term care is offered through a mix of public, private-for-profit and private-not-for-profit institutions, depending on the policies of individual provinces (Hirdes, 2002). According to evidence from a prospective study of older adults living in Melbourne, Australia, people who age-in-place tended to like their neighbourhood or have made recent modifications to their homes. These are considered to be “push” factors for remaining at home (Kendig et al., 2017). In contrast, “pull” factors centred around deteriorating health or the need for care, and included being over age 75 at baseline, female, without a partner, depressed, non-home owning, and dependent in daily living. This evidence is in agreement with research about older adults in the United Kingdom, who were found to be less likely to stay in their home and age-in-place if they were dissatisfied with their personal dwelling, specifically if they had concerns about the amount of property maintenance required (Hillcoat-Nallétamby & Ogg, 2014). Furthermore, having at least one chronic condition and lack of interaction with the community and neighbours both significantly increased the odds of wanting to move out of the home.

Sometimes ageing-in-place does not result from preference, but rather a need. Research in Detroit, USA found that low-income older adults were more likely to expect to age-in-place than their high-income counterparts (Lehning et al., 2015). Although the authors acknowledge that the reasoning was unclear, they speculated that this was a result of having nowhere else to go. The same study found that those with more neighbourhood and housing problems and fewer feelings of safety were less likely to expect to age-in-place.

In anticipation of the needs of this growing population, researchers studying ageing and mobility have turned their attention to the care and support of older adults choosing to age-in-place. The ability to move around in the home and community is essential to remaining in the home. Strategies for improving mobility can be focused on remediation or adaptation. Remediation is centred on the restoration of function or ability that has been lost, while adaptation refers to an evolution of habits, compensatory strategies, and skills to suit a changing context (Radomski & Trombly, 2008). Some argue that an adaptive approach should be implemented first because it can have immediate effects and make a change at the individual and community level (Chippendale & Bear-Lehman, 2010). For example, adding a ramp up to the front door of a house yields immediate benefit to the occupants who no longer have to navigate stairs and can more easily maneuver in and out of the home with mobility aids, such as a walker. This small change removes a barrier to independence and improves the ability to age-in-place. Similarly, losing the ability to drive can disrupt someone's independence, especially if they have become overly reliant on their car over the years as many have. In this case, remediation is not a plausible solution: for the safety of the driver and others around them, the driver may never regain their ability to drive. However, an adaptation such as offering free public transit to those without a driver's license may help older adults improve their community mobility.

The ability to age-in-place is dependent on a complex and dynamic set of factors including those of the built and social environment. Previous literature, primarily from the fields of occupational therapy and environmental gerontology, has suggested physical changes that can be made inside the home to promote well-being and deter adverse events such as falls (Gillespie et al., 2012). Outside the home, frameworks for age-friendly communities can direct policy-makers and local governments towards the development of communities that encourage optimal ageing and discourage withdrawal from social life (Lui et al., 2009). Originally conceptualized by the World Health Organization (WHO) in 1986 through the *Healthy Cities Project,* the intention to build communities that maximize the health of residents by leveraging the natural, social, and built environment has gained traction in countries experiencing a major shift in the average age including Canada, the United States, and the United Kingdom (World Health

Organization, 2020). Although models in each country emphasize change at different points along the social-physical spectrum, each of them includes key dimensions of the social environment and physical infrastructure (Lui et al., 2009).

Mobility and health-related quality of life

When discussing mobility, it is necessary to consider how changes in mobility may impact an individual's life. Mobility is generally of concern because it is a reflection of health and chronic conditions. The WHO’s commonly cited definition of health defines it to be “a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity” (World Health Organization, 1958, pg. 459). This definition of health can be used to provide a degree of specificity when talking about happiness or satisfaction, and conversely unhappiness or dissatisfaction, in our lives as a direct or indirect result of our health status. Health-related quality of life (HQRL) is often used in health research to describe “the value assigned to the duration of life as modified by the impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy” (Patrick & Erickson, 1993, pg. 22).

It is well-established that mobility is an important determinant of HRQL and therefore should be targeted to improve health (Chang et al., 2010; La Grow et al., 2013; Shafrin et al., 2017). This is especially true for older adults, for whom functional decline may accompany advanced age. When one is mobile, household chores, ADLs, and IADLs are undertaken without, or with less of, a reliance on others - allowing control over one’s life. Preserving this independence, a domain that older adults emphasize as one of the most important factors contributing to the quality of life improves well-being and prolongs the ability to age-in-place (Gabriel & Bowling, 2004).

Mobility and the built environment

To be functionally independent requires the ability to move within one's environment. Both the natural (e.g. a river) and the built (e.g. a bridge) environment can change the way we move around and the ease at which we travel from A to B. These are important considerations when working to help people maintain or regain mobility.

Places with green space, open space, and structures such as restaurants, cafes, libraries and parks help to facilitate social interaction and engagement (Baum, 2002; Richard et al., 2009). Safe and well-maintained pedestrian walkways encourage people to travel on foot or by bicycle and are an important feature for people with strollers, walkers, wheelchairs, or other assistive devices (e.g. scooters, walkers and crutches). In contrast, a negatively perceived environment can discourage trips outside the home for social participation, physical activity, or IADLs.

Older adults, especially those with mobility limitations, perceive the natural and built environment differently than those who do not face the same challenges. Glass and Balfour (2003) outlined three reasons why older adults are more vulnerable to the effects of the environment in their homes and neighbourhoods: 1) a longer duration of exposure to potentially hazardous neighbourhood environments, 2) changes in cognitive capacity resulting in a decreased capacity to cope with environmental change, and 3) an increase in the relative amount of time spent in the home and immediate community. The person-environment interaction described by Lawton and Nahemow (1973) over five decades ago concerning the ageing process is a surprisingly contemporary idea. They argued that it is important to consider the unintended consequences of every change we make to the natural and man-made environment, such as building roads instead of improving public transport, especially in regard to how decisions affect older adults. A recent study identified neighbourhood-level characteristics promote participation of older adults in activities such as sports, social, or other clubs; organizational meetings; and volunteering (Hand & Howrey, 2019). They found that having a high proportion of older adults in the neighbourhood was the only variable associated with participation in all of these activities. High population density, neighbourhood social cohesion, ability to drive, and the ability to walk several blocks were also significantly associated with participation in some of these activities. These features are important when addressing the impact of the built environment on the mobility and social participation of older adults.

The built environment can also influence the likelihood of older adults to walk in the community - a facilitator to physical activity, independence, and social interaction. According to a systematic review examining the health implications of outdoor walking groups in 41 studies, walking is associated with a significant reduction in blood pressure, resting heart rate, weight, and depression scores; and significant improvement in physical functioning including 6-minute walk time (Hanson & Jones, 2015). Very few adverse events, such as falls, were reported across 74,000 participant hours, indicating that outdoor walking is a safe and healthy activity for older adults.

While previous work tends to confirm that various characteristics of the built environment can facilitate or restrict walking, the associations can become muddled when comparing characteristics associated with mobility for different purposes. For example, environmental factors may affect walking for recreation differently than walking for transportation (Saelens & Handy, 2008). Proximity to commercial and public spaces, population density, and mixed land tend to promote walking for transportation. However, these attributes are not necessarily needed to promote recreational walking. Some evidence suggests that pedestrian infrastructure and perceptions of safety are particularly important to promote walking for older adults (Li et al., 2005). Other evidence exists to suggest that these factors are not associated with the likelihood of walking, but rather the level of walking activity among those who already walk (Nagel et al., 2008). These uncertainties may be a result of the complexity of the person-environment relationship or a shortcoming of research, such as inconsistent use of valid and objective measurements for walking or cross-sectional studies of specific sites or sub-populations.

Mobility and social participation

The ability to move independently within the community contributes to HRQL because it creates better access to social participation (Sundar et al., 2016). Although there is some debate about the meaning of social participation (Piškur et al., 2014), it can be simply defined as involvement in life situations such as work, religious practice, civil engagement and play (World Health Organization, 2001, pg. 10.). Approximately 20% of trips that older adults make outside of the home are related to this purpose and include activities such as unpaid community work, visiting with friends and family, and involvement with recreational organizations (Mollenkopf et al., 1997). These activities are important to the creation of a strong social network that relates to health and life satisfaction (Nakagawa & Hülür, 2019). However, adults tend to experience shrinking social networks as they age due to changes in their stage of life (i.e. retiring from the workforce, fewer family responsibilities), declining health, and increasing mobility limitations (Kemperman et al., 2019). The result of this can be a transition into loneliness, social isolation, or other unwelcome feelings related to lack of companionship (National Seniors Council, 2014). Mobility is directly or indirectly related to most risk factors for social isolation including loss of social networks, older age, poor functional status, poverty, female gender, and a number of chronic illnesses (Cohen-Mansfield et al., 2016; Havens et al., 2004).

Human connectedness is a fundamental human need. This is clear from the evidence that social participation is associated with, among other things, a better quality of life, improved cognition, lower rates of depression and less premature mortality (Glass et al., 1999, 2006; Levasseur et al., 2004; Zunzunegui et al., 2003). Protecting older adults from a loss of mobility with age is one approach to encourage social participation and reduce social isolation with this population. This aim is especially important among individuals with PD who's motor and non-motor symptoms can affect the ability to participate meaningfully with friends, family, and their community.

Life-space mobility

History

In their 1985 study, May, Nayak and Isaacs introduced the concept of "life-space" as, "the area which [a] subject move[s] through in each 24 hour period" (pg. 182) and divided that area into 5 concentric zones: 1) the bedroom, 2) the rest of the dwelling, 3) the garden, courtyard, or grounds surrounding the dwelling, 4) the block on which the dwelling was located, and 5) the area across a traffic bearing street (May et al., 1985). Subjects were to report their movements in relation to each of the zones every day for one month. This was considered by the authors to be of value, as life-space measured what subjects were actually doing, instead of measuring what they were capable of, a distinction that is known as the difference between capacity and performance (World Health Organization, 2002).

Measures of Life Space Mobility

Over the years, the concept of life-space has evolved and, in some cases, has been developed into assessments to suit certain populations, such as the Nursing Home Life-Space Diameter (Tinetti & Ginter, 1990). The University of Alabama Birmingham Study of Aging Life-Space Assessment (LSA) was introduced by Baker et al. in 2003 and aimed to capture the original intention of life-space by using a one-time interview or survey (Figure 2.4) (Baker et al., 2003). Since then it has become a commonly used measure of life-space, because of its validity and ease of use.

The assessment consists of 15 items and asks subjects to recall their activity in an average week in the month prior to the assessment. There are five levels of life-space: 1) outside the bedroom, 2) outside the house, 3) outside the community, 4) outside the city, 5) beyond the city. Respondents are asked to recall how many times in a typical week during the last month they travelled to each of these levels on a scale of 1-4: 1) less than once a week, 2) 2-3 times a week, 3) 4-6 times a week, 4) daily. They are also asked to recall what type of assistive device or personal assistance they required to reach each level: 1) personal assistance required, 1.5) equipment required, 2) no assistance required from person or equipment. A life-space composite score (LSA-C) reflecting the distance, frequency and level of independence is calculated by multiplying the three characteristics for each life-space level and summing the five levels (∑ [level score*frequency score*assistance score]). The scores range from 0 (totally bed-bound) to 120 (travelling outside the city, every day, without assistance).

The life-space assessment composite score has been shown to reflect physical function and performance, sociodemographic factors, and to a lesser extent, cognitive function and depressive symptoms, while simultaneously showing unshared variance with these factors (Peel et al., 2005). This indicates that the LSA and traditional performance-based measures are not redundant but instead may capture performance and capacity, respectively. The goal of the LSA is to measure mobility comprehensively, exploring why it might be limited and tracking changes over time. So far, little research focuses on mobility as measured by the LSA so it is not well-understood how it impacts the HRQL of older adults, independent of disability (Rosso et al., 2013).

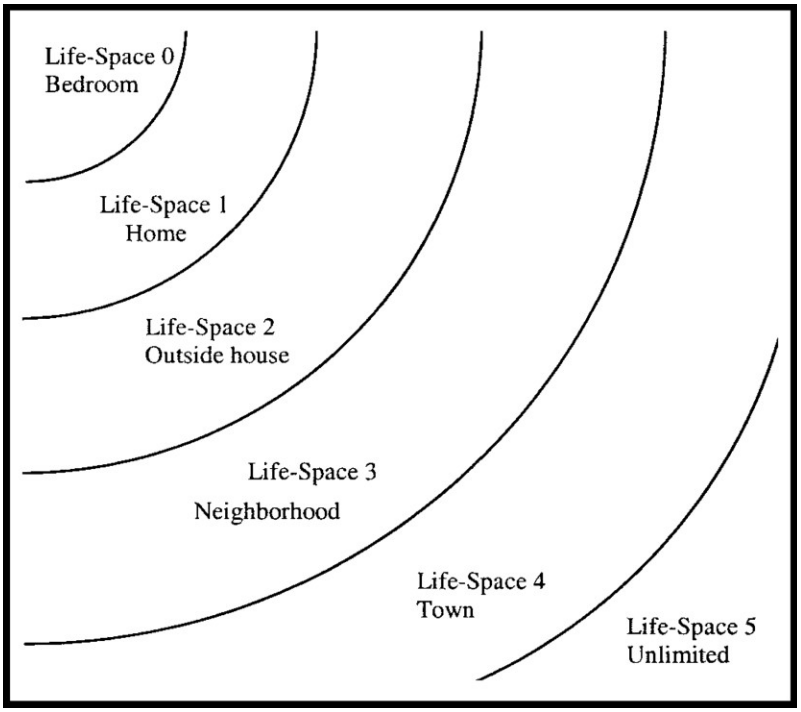

Figure 2.4. A conceptual model of concentric life-space zones as depicted in Peel et al., 2005.[3]

Psychometric properties of the University of Alabama Birmingham Life-Space Assessment

The validity and reliability of the LSA were tested by its original authors in 2003 (Baker et al., 2003). Study participants in the longitudinal study were a random sample of 306 Medicare

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[3] Peel, C., Baker, P. S., Roth, D. L., Brown, C. J., Bodner, E. V., & Allman, R. M. (2005). Assessing Mobility in Older Adults: The UAB Study of Aging Life-Space Assessment. *Physical Therapy*, *85*(10), 1008–1019.

beneficiaries aged 65 and older in Alabama, USA. The sample was stratified by county, race, sex, and urban or rural residence. The life-space composite score was most highly correlated with physical performance, IADLs, comorbid conditions, depressive symptoms, and self-reported health, demonstrating its validity for holistically representing these aspects of health and well-being. Test-retest reliability was evaluated by intraclass correlation coefficients of life-space mobility over a two-week period. Between baseline and 2-week follow-up assessments, the correlation was 0.96 (95% confidence interval: 0.95-0.97) for the LSA-C score (Baker et al., 2003). Over this period of time, 97% of participants reported a consistent definition of the distance to the perimeter of their neighbourhood and town.

The construct validity of the LSA was tested using Spearman correlations between life-space and measures of physical function and mental health. LSA-C was most highly correlated with a composite measure of physical function involving scores from tests of standing balance, walking speed, and the ability to rise from a chair (0.603); ADLs (0.309); IADLs (0.392); depressive symptoms (0.411), and self-reported health (0.421) (Baker et al., 2003). Peel and colleagues (2005) also demonstrated construct validity amongst the same population of Medicare beneficiaries studied by Baker et al.

Baker et al. (2003) also demonstrated that LSA-C is sensitive to change. This is in contrast to life-space maximal (LSA-M) scores and life-space independence (LSA-I) scores which experience more serious ceiling effects. LSA-M represents the farthest distance from home that the participant travelled without considering the frequency of travel. Sixty-six percent of the population experienced a ceiling effect and their scores would not be sensitive to an improvement in mobility. LSA-I represents the farthest distance from home that the participant travelled without assistance. Forty-seven percent of the population would not be sensitive to an improvement in mobility. Floor effects are less of a concern, with 1% of LSA-M scores and 15% of LSA-I scores being unable to decline.

The LSA has been found to have acceptable validity and reliability in other populations such as older adults in South America (Curcio et al., 2013), Sweden (Kammerlind et al., 2014), and China (Ji et al., 2015). Creation of a French-Canadian LSA for power mobility device users with neurological, orthopedic, or medically complex conditions showed a high test-retest reliability for LSA-C of 0.87 over a two-week period (Auger et al., 2009). When investigating content validity by comparing the French LSA with the original meaning, the authors expressed some concerns with the ambiguity of certain questions about what is defined as a "neighbourhood" but generally deemed the questions to have equivalent meanings to most participants. Floor or ceiling effects, defined in this case as clustering of 20% and over of the highest or lowest possible responses, were observed for LSA-I and LSA-M, respectively. LSA-C was normally distributed (Auger et al., 2009).

Weather can also impact life-space mobility. In a sample of community-dwelling older adults aged 75 and older in Finland, LSA-C scores were found to be higher in people assessed in spring versus winter indicating worse mobility in the winter (Portegijs, Iwarsson, et al., 2014). One of the original LSA studies by Baker et al. (2003) found no significant difference in the LSA-C of older adults over 6 months, but the study was conducted in Alabama where there is not as much variation in seasons as in Finland. Two-week intra-class correlation of LSA-C was 0.72, but it was marginally higher for the spring population versus the winter population (Portegijs, Iwarsson, et al., 2014). Together, these findings suggest that the environment location and timing should be consistent especially when seasonal variation exists.

A minimal important change is defined as “the smallest difference in score in the domain of interest which patients perceive as beneficial” (Jaeschke et al., 1989). The minimal important change has been ascertained to be five for the LSA based on associated changes in walking ability over a period of time in a population of African American and non-Hispanic White adults aged 75 years and older (Kennedy, Almutairi, et al., 2019; Suijker et al., 2017). No minimal important change for the LSA has been defined with older adults of persons with PD.

Predictive value of the Life-Space Assessment

Healthcare utilization

The life-space assessment could be implemented in a healthcare setting to quickly identify individuals who are at an increased risk of care. For example, in individuals with heart failure and in a population of older adults more generally, life-space mobility was shown to predict healthcare utilization such as emergency department visits and hospital admissions in intervals as short as 1 month (Kennedy, Williams, et al., 2019a; Lo et al., 2015). Similarly, restricted life-space was associated with hospital readmission within 90 days of discharge in older adults with congenital heart failure and chronic obstructive pulmonary disorder (Fathi et al., 2017). The LSA has also been suggested as a useful tool for predicting nursing home admission in older adults as far as 6 years in advance (Sheppard et al., 2013).

Mortality

Constricted life-space is associated with greater mortality in older adults (Kennedy et al., 2017; Xue et al., 2008). In one study, this relationship (HR 1.18, 95% CI 1.09-1.27) was found to be independent of potential confounders such as physical activity, performance-based physical function, and the number of chronic medical conditions (Boyle et al., 2010). Another found that a life-space score of 40 or below predicted mortality in older men independent of age and gait speed (Mackey et al., 2014).

Cognitive decline

The relationship between life-space mobility and cognitive status is one of the more frequently studied associations in the domain of the life-space of older adults. In a population of African American and White older adults, life-space mobility has been shown to predict cognitive decline over 4 years regardless of age, race, or gender (Crowe et al., 2008). These findings were mirrored in older Mexican Americans over 5 years (Silberschmidt et al., 2017). However, the cross-sectional relationship between cognition and life-space mobility is more inconclusive with one study finding that older adults with better cognition have a bigger life-space, but another found the association to be poorly defined while noting the moderating effect of depressive symptoms (Béland et al., 2018; Sartori et al., 2012). In individuals with mild cognitive impairment (MCI), self-reported exhaustion has been shown to affect life-space mobility, while individuals with amnestic MCI have been shown to experience limited life-space with fear-of-falling, slower processing speed, and restricted independent activities of daily living (Uemura et al., 2013). Life-space assessments may be useful for predicting the risk of MCI, in addition to global cognition and risk of Alzheimer's disease (James et al., 2011). Because life-space mobility assessments typically rely on recall of activity, this type of mobility captured by the concept of life-space may be better evaluated with technology such as global positioning system (GPS) and personal activity monitors to avoid recall in persons with MCI.

Frailty

Studies investigating the relationship between life-space mobility and frailty in older adults have suggested that constricted life-space predicts frailty, but also that frailty predicts constricted life-space (Portegijs et al., 2016; Xue et al., 2008). Although limited research has evaluated frailty with life-space mobility, life-space mobility may serve to be a useful screening tool for frailty.

Quality of life

Over two years of follow-up, life-space mobility has been shown to predict the quality of life as measured using the World Health Organization Quality of Life (WHOQOL)-BREF in a sample of 761 older adults (Rantakokko et al., 2016). In comparison to those who maintained their life-space mobility score over the 24 month follow-up period, those who experienced any sort of decline - late, early, or constant - of >10 points showed a greater decrease in WHOQOL-BREF.

The LSA is a valid and reliable self-reported tool to measure mobility in many populations of older adults. Although it is self-report tools are commonly used in epidemiologic and medical research, they are prone to biases such as recall bias and social desirability bias. The psychometric properties of this test have not been assessed in populations with Parkinson's disease, but its performance in older populations with cognitive, memory, and physical difficulties implies that it would be appropriate to study PD.

Life-space mobility of people with Parkinson's disease

To our knowledge, only one published article has studied associations with life-space mobility in people with PD. Rantakokko et al. observed 164 community-dwelling people with PD in Sweden to collect data on the associations of motor symptoms and non-motor symptoms with life-space mobility (Rantakokko et al., 2019). Motor symptoms were quantified using the self-report Unified Parkinson's Disease Rating Scale III. Non-motor symptoms were quantified using self-report questionnaires about depressive symptoms (Geriatric Depression Scale-15)

(Sheikh & Yesavage, 1986), fatigue (Nottingham Health Profile) (Hunt et al., 1980), pain ("Are you bothered by pain?" Yes/No), and global cognition (Montreal Cognitive Assessment) (Nasreddine et al., 2005). After controlling for confounders, only perceived walking difficulty was significantly associated with life-space mobility suggesting this is an important symptom to target with interventions. Furthermore, this cross-sectional study highlighted the importance of mobility aids and assistance for this population, as almost all (90%) of participants reached the highest level of life-space with the use of an assistive aid, but less than half (47.5%) reached this level without (Rantakokko et al., 2019)

Although the study by Rantakokko et al. (2019) provided an initial glimpse into the life-space mobility of people with PD, more studies are needed to further explore factors that contribute to life-space mobility among individuals with PD. Specifically, the authors noted that the role of environmental and personal factors on life-space mobility in this population has not been properly elucidated. No evaluation of life-space mobility with PD has compared the life-space mobility with a healthy cohort that has employed a control group to make direct comparisons and better discern if PD affects life-space mobility among a population living in a similar area.

Conclusion

The complexity of mobility, particularly in older adults with chronic conditions, makes it a challenge to evaluate interventions aiming to improve mobility. Life-space mobility is one conceptualization of mobility that has been used to understand how older adults function within their community and environment. Little evidence exists which examines PD, a chronic condition known for poverty of movement, using the concept of life-space mobility. Thus far, the single study investigating factors related to life-space mobility among people with PD did not consider the role of personal and environmental factors or made comparisons to a control group.

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Chapter 3: Original Study

Does living with Parkinson's disease affect life-space mobility? A multiple-methods study

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Abstract

BACKGROUND: Motor and non-motor symptoms of Parkinson's disease (PD) can affect an individual's capacity for movement, but are likely not the only factors to determine mobility in the home and community. Using multiple-methods, we explored associations of internal and external factors with life-space mobility in PD.

METHODS: 227 individuals with (n = 113) and without (n = 114) PD were recruited from the community to complete a cross-sectional survey of mobility. The primary outcome was the life-space mobility composite score, which ranges from 0-120, for which a higher value indicates more trips that are more frequent, distant and independent (University of Alabama Birmingham Life-Space Assessment). Explanatory variables included demographics, lifestyle behaviours, self-reported health status, social participation and the built environment. Multivariable linear regression was used to identify factors that explained life-space mobility. Ten participants with PD participated in a semi-structured interview about facilitators and barriers to mobility; data were content analyzed.

RESULTS: Mean life-space mobility was reduced for people with PD (64.2, SD = 25.8) in comparison to people without PD (70.3, SD=23.1; mean difference = 6 points, 95% CI: -0.4, 12.5). Among people with PD, not driving, receiving caregiving and not having extra money in the house were associated with reduced life-space mobility. Higher social participation was associated with increased life-space mobility. Data from qualitative interviews supported quantitative findings and offered additional insights into the features of the built environment that facilitate and restrict mobility.

CONCLCUSION: Both internal and external factors are associated with the life-space mobility among people with PD. Clinicians and policy-makers should include both individual and community-based factors when developing interventions to encourage the life-space mobility of the PD population.

KEYWORDS: Parkinson's disease, life-space mobility, social participation, built environment

Introduction

Parkinson's disease (PD) is a chronic neurodegenerative disease affecting approximately 120,000 Canadians, most of whom are age 65 or older (Dorsey et al., 2007; Guttman et al., 2003). The disease manifests as a variable set of motor (i.e. slowness of movement, rigidity, instability) and non-motor (i.e. depression, incontinence, cognitive impairment, fatigue) symptoms which are managed to varying degrees of success by medications and surgical interventions (Armstrong & Okun, 2020). Alone, and in combination, the symptoms of PD can make excursions out of the home challenging. Disease progression may further hamper functional independence, have deleterious effects on social participation and generally undermine the ability to age-in-place (Benharoch & Wiseman, 2004; Kennedy-Behr & Hatchett, 2017). It is important for people with PD to maintain mobility, the ability to move between environments, throughout the disease course to facilitate these ageing-related goals (Gardner, 2014).

Life-space mobility is a concept of movement and participation in and out of the home (Baker et al., 2003). It is designed to reflect what an individual actually does, instead of what they have the ability to do, and recognizes that mobility can be achieved by means other than unassisted ambulation. Generally, life-space mobility is structured as concentric life-space "levels" or "zones", which are centred around a single point; commonly the bedroom. The frequency and approach by which an individual enters each specific level of life-space in a given time period determines their life-space mobility. In older adults, measures of life-space mobility have been strongly associated with personal (internal) factors such as executive functioning and motor performance, as well as external factors such as the accessibility of the built environment (Poranen-Clark et al., 2018; Portegijs, Rantakokko, et al., 2014; Rantakokko et al., 2015; Ullrich et al., 2019). When measured over time in older adults, reduced life-space mobility has been shown to predict the health-care utilization, cognitive decline, mortality and lower health status making it an indicator of overall health and resilience in later life (Crowe et al., 2008; Kennedy, Williams, et al., 2019b; Rantakokko et al., 2016).

To our knowledge, only one cross-sectional study has examined associations with life-space mobility in people with PD (Rantakokko et al., 2019). Focusing on the impact of motor and non-motor PD symptoms, the authors found that depressive symptoms, pain and perceived walking difficulties were negatively associated with life-space mobility. However, they did not evaluate the relationship between environmental and social factors with life-space mobility. Thus, there is a dearth of knowledge regarding environmental and social factors relevant to community mobility in this population.

Using a multiple-methods approach, we explored the life-space mobility of people with PD residing primarily in an urban setting. The primary objective of the quantitative component was to identify demographic (e.g. family finances, education), health-related (e.g. walking limitations, chronic conditions), social (e.g. level of social participation), or environmental factors (e.g. neighbourhood cleanliness) that explained life-space mobility in PD. The secondary objective was to compare the life-space mobility patterns of people with PD to community-dwelling older adults without PD residing in the community. The primary objective of the qualitative component was to explore “patient”-identified barriers and facilitators to life-space mobility that can be targeted by interventions and policies to promote community mobility in this population

Methods

Participants

We conducted a staged multiple-methods study using a cross-sectional survey and a concurrent qualitative narrative inquiry. Participants with PD (n=113) were recruited from the community via private neurology clinics (Edmonton, AB, Canada), a PD-specific research participant registry (Calgary Parkinson Research Initiative [CaPRI]), a PD-specific fitness class (Camrose, AB, Canada) and the Parkinson's Association of Alberta (PAA); a non-profit organization. Participants with PD were eligible for inclusion if they had a diagnosis of PD for at least 6 months. Specific recruitment strategies varied by site. Recruitment strategies included practitioners (neurologists and fitness instructors) asking interested participants, on behalf of the researchers, to review the information sheet and fill out the survey (Appendix 1 and 2). Alternatively, the researcher made in-person or over-the-phone contact with potential participants identified through the PAA or CaPRI. To provide a comparison, a group of age-matched adults without PD (n=114) was recruited in-person from senior's associations in Edmonton, Alberta. Edmonton and Calgary are both large, metropolitan centers with comparable population sizes and public services including transit systems. Camrose is a much smaller city relative to Edmonton and Calgary, but a minority of the PD participants were recruited from this site. Participants in the PD and without PD groups met the following inclusion criteria: 1) residing in the community, 2) able to speak and understand English, and 3) willing to participate. Surveys were completed in-person at PAA events (PD group) and senior's centers (without PD group) or taken home and returned by mail. Participants from CaPRI completed the survey over the phone. Participants in both groups were permitted to have a proxy, such as a caregiver, to help them complete the survey (Cavanaugh & Crawford, 2014).

In addition to measuring life-space mobility, the survey captured demographics, lifestyle behaviours (smoking and alcohol), finances, caregiving, medical conditions (comorbidities and self-rated health status), and mobility (walking distance and limitations, and transportation). Physical activity was measured by asking participants if they engaged in more or less than 150 minutes per week of exercise. A series of eight questions concerning the participants' perceptions of the neighbourhood where they lived was included to measure physical disorder (i.e. cleanliness and perceived safety) and cohesion (i.e. feeling part of the area) in the built environment (Canadian Longitudinal Study on Aging, Raina et al., 2008).

Participants with PD additionally reported disease duration and medications and completed the Parkinson's Disease Questionnaire (PDQ)-8 (Jenkinson et al., 1997). Moreover, if they were recruited from the greater Edmonton area, they were asked if they could be contacted for an interview about their experience navigating their homes and community with PD. To capture a variety of experiences, we considered life-space mobility, gender, and age when determining which participants were contacted first. Specifically, we contacted individuals with the highest and lowest life-space mobility first, alternating male and female participants, while also attempting to include people of various ages and thus various stages of life. Ten participants agreed to participate and were interviewed before data saturation was achieved. Data were collected between January and November 2019. Participants who only completed the survey reviewed an information sheet and implied consent was given upon submission. Interview participants reviewed a separate information sheet and gave informed consent (Appendix 3). Ethics approval was obtained from the Health Research Ethics Board at the University of Alberta (Pro00086390) (Appendix 4).

Measures

Life-Space Assessment

The University of Alabama Birmingham Life-Space Assessment (LSA) is a self-report measure that includes 15 items concerning mobility in five distinct life-space areas: bedroom, home, outside the home, neighbourhood, outside of town. For each life-space area, participants report how frequently they travelled to these areas (1x per week, 2-3x per week, 4-6x per week, daily) and whether they required a mobility device or the help of another person to get there (Peel et al., 2005). The recall period is a “typical week in the last month”. A composite score (LSA-C), ranging from 0-120 where higher values indicate increased mobility, was calculated to represent overall life-space mobility. Some studies have defined an LSA-C score of <60 as “restricted” (Allman et al., 2006; Portegijs, Iwarsson, et al., 2014) and longitudinal studies have found a five-point change in LSA-C to be clinically meaningful (Kennedy, Almutairi, et al., 2019). Three other life-space mobility indicators are also generated from the LSA. These indicators represent the frequencies in which participants reach each level of life-space given certain criteria: 1) independent life-space (LSA-I), the maximum level achieved without help from an assistive device or another person; 2) life-space with equipment (LSA-A), the maximum level achieved using equipment but without the help of another person; and 3) maximum life-space (LSA-M), the maximum level achieved with help from a mobility device or another person. The LSA is reported to be valid and reliable in populations of community-dwelling older adults (Baker et al., 2003).

Social Participation

An eight-item questionnaire from the Canadian Longitudinal Study on Aging captured different activities participants engage in, and how frequently they participate in a typical week (Raina et al., 2008). A social participation index (range 0-32) was created to indicate an individual's level of social participation based on the activities they were a part of in the last year (Harasemiw et al., 2018). Participants responded to how frequently they engaged in eight different types of activities with other people in the last 12 months (never, at least once a year, at least once a month, at least once a week, at least once a day). Responses were reverse coded and summed across the eight activities to determine the social participation score.

Parkinson's disease questionnaire-8

The Parkinson's Disease Questionnaire-8 (PDQ-8) will be administered as part of the survey to collect information related to quality of life and experiences living with PD (Jenkinson et al., 1997). The PDQ-8 ranges from 0 (normal) to 100 (worst disability) based on a scaled response to eight questions related to mobility, ADLs, emotional well-being, stigma, social support, cognition, communication and bodily discomfort.

Quantitative analysis

Quantitative measures were scored according to their standardized algorithms. Descriptive statistics including means and standard deviations (SD) or frequencies and percentages were calculated for all variables including the three life-space mobility indicators: LSA-I, LSA-A and LSA-M. Students' t-tests were used to compare the life-space mobility composite score between groups with and without PD. Other covariates were compared descriptively. For missing items on the LSA, we used the nearest neighbour approach to impute one or more missing items (13 with PD and 15 without PD).

A univariate analysis was performed using simple linear regression to determine the individual contribution of each potential factor on life-space mobility in the overall cohort, the PD subset and the group without PD. Multivariable linear regression models were generated to identify personal, environmental and social factors associated to explain the primary outcome, life-space mobility. To identify whether the covariates that explained life-space mobility differed by PD status, separate multivariable models were examined for PD only and without-PD only participants. Variables were initially collected on their clinical relevance within the literature and were guided by a mobility framework for older adults for inclusion of the regression models (Webber et al., 2010).

Forwards and backwards stepwise elimination was applied, wherein important variables and those with *p*-values ≤ 0.2 at the univariate level were included in the first model as covariates. Those variables that were clinically meaningful (age, gender, and where applicable, PD status) were forced into the model. In subsequent models, the variables with the highest *p*-values were eliminated sequentially until the final model was fitted. Confounding, set at a threshold of ≥15% change in the regression coefficient, was investigated in each re-estimated model. Whenever a confounding relationship occurred between any two variables, both were retained in the model, and the variable with the next highest statistically non-significant *p*-value was considered for elimination. This iterative process of variable elimination and retention persisted until the best fitted model was obtained. In the final model, interactions between covariates were investigated, but no interaction terms for any two of the covariates were found to be statistically significant. For each fitted regression model, assumptions of linearity, independence, normality, and homoscedasticity were tested and confirmed using residual plots and residual histograms (Appendix 5). All assumptions were satisfied in each domain model. Analyses were conducted using Stata Version 16 (StataCorp, 2019).

Qualitative study

Interviews took place in-person, so only local (Edmonton and area) participants were invited to be interviewed. Participants chose the setting for the interview, which included a quiet room at the University of Alberta, at the participant's home, or a cafe. At each interview, a masters-level student with basic qualitative training (CRB) asked participants four main open-ended questions related to their understanding of mobility and their lived-mobility experiences with PD (Appendix 6). Probes were used when necessary, but an effort was made to encourage natural discussion. The interviews were 20-30 minutes in duration, at the end of which the researcher summarized the key points from the discussion and asked the participant to confirm their accuracy. Field notes were generated by the researcher commenting on the body language, emotions and responses of the participant, and reflected on her thoughts about the interview as well as her position within it. These data sources informed the interpretation of transcripts and the subsequent generation of codes. The participants were aware that the research was being conducted as a master's thesis project.

Qualitative analysis

All interviews were audio-recorded and transcribed verbatim using pseudonyms to replace names. Content analysis was conducted on the transcript data using the phases of preparation, organizing and reporting to objectively and systematically derive a description of mobility determinants affecting life-space mobility (Elo & Kyngäs, 2008). Content analysis was chosen to provide new insights and knowledge that can act as a practical guide for interventions (Krippendorff, 2004). Our analysis was guided by Webber and colleagues' comprehensive framework for mobility in older adults, which outlines five broad, interrelated categories that determine mobility: financial, psychosocial, environmental, physical, and cognitive, each of which is influenced by gender, culture and biography (Webber et al., 2010). One author (CRB) selected a subset of the transcripts to review to create an initial codebook and later consulted with the other authors (CN, MW, AJ) to determine if the codebook was representative of the substance of the transcripts and emerging themes. The coding scheme was then applied to all transcripts and iteratively updated to reflect new topics captured by the remaining transcripts. The code tree is available in Appendix 7.

Results

Life-space mobility survey

Participants with PD (n = 113) were younger (mean 71, SD 9.0 vs. 75, SD 7.6) and more frequently male (60% vs. 37%), married (83% vs. 51%) and with less post-secondary education (62% vs. 70%) than participants without PD (n = 114). Participants with and without PD were comparable in their family finances and employment status (>

85% retired) (Table 3.1). The vast majority of participants in both groups lived in an urban setting (PD 91%; without-PD 99%). Eighty-five percent of participants without PD did not use an assistive mobility device, in comparison to 56% of PD participants. Groups were similar in their health behaviours: smoking, alcohol use and physical activity ($p > 0.05$). The mean number of comorbidities was similar for both groups (PD, mean 2.1, SD 1.6; without PD, mean 2.3, SD 1.5) with musculoskeletal conditions (49%), cardiovascular conditions (35%) and depression (34%) being the most prevalent chronic condition listed for participants with PD. Participants with PD had been diagnosed for a mean of 8.3 years (SD 6.3, range 0.5-25.4) and had an average PDQ-8 score of 27.4 (SD 18.5, range 0-78.1) suggesting that most participants had mild (Stage I) to moderate (Stage II) PD (Jenkinson et al., 1997; Katsarou et al., 2004).

PD participants were less socially active than participants without PD (mean social participation index 12.8, SD 5.7 vs. 16.8, SD 6.1), and engagement in volunteer/charity, club/organizational, neighbourhood-related or other types of recreational activities outside of the home contributed less to their overall participation in comparison to participants without PD (Figure 3.1). Both groups generally perceived their communities to be safe and cleanly, and felt a sense of social cohesion.

LSA-C was normally distributed for both groups (Appendix 8). The mean overall LSA-C score was 64.2 (SD 25.8) for the group with PD and 70.3 (SD 23.1) for the group without PD. Although no statistical difference was seen between the two groups (mean difference 6, 95% CI: -0.36, 12.45), a higher proportion of PD participants reported requiring assistance with mobility within both the home and community than participants without PD. Specifically, 77% (n=87) of participants with PD and 95% (n=108) without-

PD reported that they moved independently throughout the home, that is, without the help of an assistive device or another person (LSA-I). The majority of participants required the use of assistive mobility devices (LSA-A) (PD, n = 90, 80%; without-PD, n = 104, 91%) to navigate within their neighbourhoods. A smaller proportion reported being able to travel beyond their 'towns' without assistance (PD, n = 56, 50%; without-PD, n = 62, 54%). Lastly, when considering aid from assistive devices or other people (LSA-M), participants reached each life-space level in almost equal proportions, with nearly all participants reporting that they can leave their bedroom and their home. A higher proportion of the PD cohort reported travel outside of their communities (65%, n = 73) than the cohort without PD (55%, n = 63) despite a larger proportion of the PD group reporting not having a drivers' license (21.8% vs. 12.4%).

Using a univariate regression, several environmental and social variables were statistically significant with the LSA-C. Not having a driver's license, receiving caregiving, and having no extra money in the house were associated with a lower LSA-C score (Table 3.3). Having a higher level of social participation and not feeling lonely in the neighbourhood were associated with high LSA-C scores. Other mobility factors, such as walking distance, physical activity, or reporting issues with balance, freezing or gait were significant at the univariate level but were not statistically significant in the multivariate model (Appendix 9).

When controlled for gender, age and PD status in the overall multivariable linear regression model, environmental and social factors explained life-space mobility both. y (Table 3.4). Specifically, not having a driver's license was reflected in nearly 19 points lower LSA-C score than having a driver's license. Receiving formal or informal caregiving and having no extra money had lower LSA-C scores, 15.1 points for receiving caregiving and 8.8 points for having no extra money in the house. Having greater levels of social participation and not feeling lonely in the neighbourhood explained greater life-space mobility. For instance, a decrease in 10 points in the social participation index was associated with a 12-point increase in life-space mobility. Activities with family and friends were the most commonly reported activity for both groups (PD 22%; without-PD 18%). Overall, 39.8% of the variation in life-space mobility was explained by the model.

The factors explaining life-space mobility specifically among people with PD were similar to those of the overall multivariable linear regression model developed for participants with and without PD. Of all the factors included in the final model, not having a driver's license (β = -0.40) and having greater levels of social participation (β = 0.36) contributed most to the model. The variables in this model explained 56.6% of the variation seen with LSA-C. The variables in the multivariable model for the group without PD had a lower R squared (17%) which may be in part to the inclusion of other variables such as respiratory condition and the exclusion of driver license status.

Semi-structured interviews

Of 113 participants with PD surveyed, 32 (28%) indicated they were interested in participating in an interview, 24 were contacted for an interview, of whom 14 refused and 10 agreed to participate. We purposely included an equal number of women and men so that a variety of experiences could be captured. In comparison to survey participants with PD, interviewees were slightly younger (68.9 years, SD = 6.0). Interviewees tended to be similar to survey participants in levels of education, family finances, and employment and marital status (Appendix 10). A larger percentage of interviewees used an assistive device (60%) and had a driver's license (70%), but the mean life-space score of the interview participants was the same as survey participants (64.6, SD = 21.6). Interviewees had been diagnosed with PD for an average of 10.9 years (SD = 8.0) and two had undergone deep brain stimulation surgery.

Mobility determinant: Physical Health

Four themes related to physical health emerged from our transcripts: Non-motor and motor symptoms, Experiences with medication, Managing symptoms, and the Ability to participate. For most participants, difficulties with stability, gait, freezing of gait, incontinence and/or anxiety impacted their ability to be mobile and were often somewhat unpredictable. PD-specific medications, assistive devices and physical activity featured prominently in interviews as approaches that were used to successfully manage symptoms. However, each of these coping strategies came with drawbacks that could further inhibit mobility, including the on-off effects of levodopa-based medications, environmental challenges when using assistive devices or risk of injury during exercise (Appendix 11).

> *"Movement is slower, balance is much worse, freezing is an issue; going off medication is something that I have to deal with now. These aren't things that were problems before...but now I seem to be getting more difficulty all the time." (P78, female).*

Physical symptoms affected the ability to participate directly, by limiting the activities that an individual could comfortably partake in, or indirectly, by making getting to the activity a challenge. For example, in response to PD symptoms, many participants ceased driving entirely or in certain circumstances. Thus, participants needed to arrange alternate transportation to and from activities outside the home, which most commonly involved asking family or friends to drive them. However, if family or friends were unavailable to drive, or if participants felt they were being a burden by asking for a ride, it was possible that they would forgo the activity entirely.

Mobility determinant: Cognition

Only one unique theme emerged from the interviews relating to cognition as a mobility determinant, which was “Navigation and dual-tasking”. Participants noticed that cognitive symptoms such as memory loss and slower processing speed sometimes affected their ability to navigate to new or familiar destinations. Moreover, participants described changes to their concentration which, in turn, affected their ability to dual-task. In particular, participants who required focus for ambulation sometimes struggled in situations that required them to split their attention, such as walking and talking at the same time.

Mobility determinant: Environment

Barriers to mobility in the built environment were represented by the themes of “Challenging spaces”, which was specific to PD, and “Accessibility of public spaces”, which was relevant for anyone with mobility limitations. For participants with PD, having to move through crowded or confined spaces resulted in instability and episodes of freezing.

> *"If there's too many people around - like the hockey game - sometimes the concourse is really quite crowded… I can't take big steps so take micro-steps all over the place and then it's hard to keep your balance when you're doing that. It's just difficult to move around when, when the crowd is that bad." (P71, male)*

Descriptions of difficult experiences related to the accessibility of public washrooms arose frequently throughout the interviews, with participants reporting that they avoided locations or events without sufficient facilities. Washrooms with ample space (i.e. family units) and a suitable solution for temporarily storing assistive devices were the most desirable. For participants with incontinence, proximity was also an essential criterion. Generally speaking, mobility was additionally hampered in spaces that had poor lighting, stairs, or are otherwise inappropriate for the use of assistive devices.

Mobility determinant: Psychosocial

Five psychosocial themes emerged from our interviews: Activity avoidance, Receiving help from others, Planning excursions, Setting expectations and Navigating the social environment. Participants avoided activities for which they doubted their own self-confidence (e.g. driving), feared falling or risked feeling embarrassed. Conversely, there were several ways that having a social network - namely family, friends, healthcare professionals and other people with PD - helped them to meet their participation and mobility goals. Notably, participation in PD support groups was crucial to many participants for knowledge sharing, encouragement and emotional comfort.

Taking the time to plan excursions facilitated successful trips into the community. Participants with PD worked with their spouses to coordinate schedules, helped choose accessible destinations for socializing with friends and planned out safe routes for driving. Psychosocial factors also influence self-expectation, thereby shaping participants' understanding of what activities could and could not be done safely.

> *"My anxiety level was so high that I couldn't drive. I did recognize that and it's been that way a couple of times." (P71, male)*

Lastly, some participants found self-advocacy to be a valuable tool when navigating a social environment. Those who openly talked about their health succeeded in having their financial, physical and psychosocial needs met, thus facilitating mobility and participation in the community. However, not all participants were able to successfully advocate for themselves in their personal relationships and consequently had fewer opportunities for participation outside the home.

> *"I used to be able to run and jog; and kick a football and soccer ball with my grandsons. I don't see them very much. They live ten minutes from here, but they want to play, and I can't – so I don't. And so we're drifting apart." (P41, male)*

Mobility determinant: Finance

Only one participant directly talked about how financial constraints affected her mobility, especially in situations when her symptoms prevented her from otherwise driving. Although this finding was not sufficient to constitute a theme, it captures the importance of considering finances as a determinant of mobility.

> *"I don't want to take the taxi to the [Parkinson's Association]. It depends on [which driver] you get. You either get someone who goes really slow and it costs you $40 each way, or you can get somebody who's pretty fast and it takes, its $20 each way and that can be expensive for something you want to do every day." (P97, female)*

Influence of gender, culture, and biography

The theme of "Identity" was present in many interviews. Mobility was discussed as an essential aspect of independence, for which participants closely associated with their identity: the person that they are, and wish to continue to be.

> *Interviewer: "And why is mobility important to you?"*
>
> *Participant: "Independence. I don't want somebody having to walk with me. I like to walk by myself." (P78, female)*

Discussion

While we did not find that the life-space mobility of people with PD was statistically significantly different from people without PD, the factors explaining life-space mobility differed between the two groups. Life space mobility for persons with PD was associated with personal and social factors, such as not having a driver's license, level of social participation, receiving caregiving and family finances. Qualitative interviews offered insights into internal and external mobility determinants, which both supported and broadened the findings from the quantitative findings. In particular, physical themes, related to driving; psychosocial themes, related to participation in the community; and environmental themes, related to the accessibility of public spaces, emerged as important mobility factors for people with PD. Collectively, findings from our multiple-methods research suggest that the impact of PD on life-space mobility is multidimensional and support the application of the mobility framework developed by Webber et al. (2010) to populations with PD. Moreover, factors influencing life-space differ among people with and without PD.

We found that that a large proportion of participants with PD used assistive mobility devices to reach similar levels of life-space as their counterparts without PD. The life-space mobility of PD participants in our study was lower in relation to another cross-sectional study examining life-space mobility in 164 community-dwelling people with all severities of PD living in Sweden (Rantakokko et al., 2019). Participants in the two studies were comparable in their independent (LSA-I) and assisted (LSA-A) life-space, but 25% fewer participants reached the highest life-space level with maximal assistance (LSA-M) within this study. Although age and gender/sex were similar in both studies, the sample population in our study was overwhelmingly based in an urban area, whereas most (57%) of participants in the previous study lived in rural or semi-urban areas. Participants living rurally may be more likely to have to leave their community to access shops, services, healthcare or social gathering places, resulting in additional trips into higher levels of life-space.

Possession of a valid driver's license emerged as a meaningful facilitator of life-space mobility. Driving is intimately linked with autonomy and mobility in North American society and is the preferred means of transportation by Canadians (Dickerson et al., 2007; Turcotte, 2012). Older adults who do not drive, or who drive but avoid certain situations, have reduced life-space mobility, and this association appears to be exacerbated in people with walking difficulties (Kuspinar et al., 2020; Viljanen et al., 2016). Other studies of older adults have shown that driving cessation leads to progressive life-space restriction, although the most substantial decline (28 points) occurred at the time of driving cessation (Shah et al., 2012; Huisingh et al., 2017). The authors noted that this pattern may be expected because an individual who is a passenger in a car requires the help of another person (the driver) to reach their destination. Requiring assistance is a criterion on which life-space mobility is scored; therefore, that individual would reflect a lower score, even if their level and frequency of travel stayed the same (Huisingh et al., 2017). Participants who drove often adapted their driving behaviours in response to PD; learning to carefully plan excursions around medication schedules, symptoms and driving conditions. Modifying driving behaviours (i.e. avoiding driving in the dark or in traffic) was also a theme of a previous qualitative study exploring experiences of driving in people with PD (Holmes et al., 2019). Participants who did not drive conceded that they worried about burdening their loved ones by asking for rides, and thus were not as participatory as they may like to be (Holmes et al., 2019). In the PD group, fewer participants had driver's licenses, but more had spouses who were likely able to drive them to where they needed to go.

Social participation was significantly associated with life-space mobility; however, the directional relationship between social participation and life-space mobility is undetermined within this cohort. PD participants in the present and previous studies discussed activity avoidance, including social participation, due concerns about self-efficacy, feeling embarrassed and falling (Jonasson et al., 2018; Sjödahl Hammarlund et al., 2018). Quantitative evidence has also emerged to support a relationship between fear of falling and decreased life-space mobility in older adults (Auais et al., 2017). In an international cohort of 1,985 older adults, the frequency and severity of injurious falls were increasingly associated with reductions in life-space mobility over 4 years (Ahmed et al., 2020). People who experienced recurrent or non-injurious falls were able to improve their life-space mobility over time with the use of assistive devices, underscoring the importance of these devices for individuals at risk of falling. Aside from intentional activity avoidance, interviewees in our study described missing out on social activities for reasons beyond their control. The unpredictable nature of symptoms (i.e. freezing, tremors) and medications (i.e. on-off effects) affected the ability of some interviewees to engage with friends and family. An earlier qualitative study conducted among people with all stages of PD also found that unpredictable symptoms influence social participation, but restrictions were most profound in participants with severe PD (Thordardottir et al., 2014).

Although aspects of the community cleanliness, cohesion and perceived safety were not associated with life-space mobility among people with PD in this study, interviewees did reveal other aspects of the environment that could facilitate or restrict their mobility in the community. Crowded and confined spaces were problematic because frequent stopping, starting and changing direction exacerbated motor symptoms and anxiety. Interviewees discussed either avoiding activities involving large crowds (such as outdoor festivals) or requiring help from another person to manage these environments. Lamont and colleagues (2012) also found crowded environments to be overwhelmingly disliked by people with PD, additionally noting that these circumstances lead to more frequent episodes of freezing of gait. The inability to manage walking difficulties such as these can negatively impact an individual's self-concept and ability to socially participate (Hammarlund et al., 2014). Walking outdoors is, in and of itself, an activity used for leisure, socializing, and transportation, but not all outdoor spaces provide a safe and enjoyable physical environment for walking. In recent quantitative studies, features of the built environment, such as slope and sidewalk conditions, were associated with changes in gait speed, while perceived neighbourhood usability was found to be a determinant of mobility, more generally speaking (Twardzik et al., 2019; Raggi et al., 2018). Furthermore, high neighbourhood walkability facilitates active transportation among older adults living in low-income (Chudyk et al., 2017). This relationship highlights the interplay between individual-level factors, such as socioeconomic status and health, and the physical condition of communities, which are shaped by local politics and economics.

At a clinical level, individual mobility issues need to be addressed so that persons with PD can maintain their quality of life. This research has highlighted that a multitude of factors may contribute to the life-space mobility of people with PD. Each of these factors should garner the attention of a healthcare professional who can ensure that individuals are properly supported in every aspect of their life to facilitate independence and social engagement. Specifically, applying a social-ecological approach to the examination of each of the mobility determinants comprising the framework for mobility in older adults would serve as a comprehensive assessment of their quality of life and ability to age-in-place (Sallis et al., 2006; Webber et al., 2010). There is a dearth of research directly studying what impacts the ability of people with PD to remain in their homes. However, evidence from research on dementia, a related neurodegenerative disease, suggest that lost skills (i.e. activities of daily living), safety-related concerns, decreased self-reliance and high caregiver burden are modifiable factors which commonly lead to institutionalization and can be improved to facilitate ageing-in-place (Ciro, 2014; Thoma-Lürken et al., 2018). Additionally, after considering individual health and sociodemographic risk factors, older adults living in communities with accessible sidewalks and public transit stops facilitate outdoor mobility and ageing-in-place (Clarke & Gallagher, 2013).

At a community level, municipal policy-makers, such as city councils, should consider strategies for improving life-space mobility for people with PD are centred on providing safe, convenient and cost-effective alternatives to driving a personal car. For example, spacious, conveniently located washrooms in restaurants and other public spaces are one feature that may support the usage of these spaces by people with PD, as well as older adults and others who may have mobility limitations. Given the current shift in age demographics in Canada, alterations such as these could grow the customer base for businesses, aiding in the recovery of costs associated with retrofits or modernizations. At large events, options should be available for people with PD to circumvent or distance themselves from crowds thereby preventing avoidance of the activity entirely. In a space such as a sports arena or music venue, these interventions could present as separate entrances and elevators, "mobility escorts" employed by the venue to help individuals maneuver more easily and with more space through crowds or more accessible seating reserved for individuals with mobility challenges. It would be important for these options to be available at little or no cost to the individual requiring special accommodation.

The strengths of this study lie in its novel, multiple-methods design: a cross-sectional survey complemented by qualitative interviews that added depth and context to the quantitative findings. Furthermore, we employed the use of a healthy, age-matched comparison group to observe differences in the life-space mobility patterns between PD and without-PD participants living in a similar geographical area.

In light of these strengths, several limitations should be noted. Although life-space mobility has been validated in several older adult populations and adults with chronic health conditions, psychometric properties of the LSA in a PD population have not been established (Auger et al., 2009; Curcio et al., 2013; Ji et al., 2015; Kammerlind et al., 2014). A recent comparison of methods for community mobility reported poor convergent validity between LSA and a wireless inertial measurement unit with GPS which suggested the LSA has poor discrimination of which may be related to poor recall (Zhu et al., 2020). Because of the survey format, the disease severity of participants with PD and cognition of participants with and without PD could not be measured.

Conclusion

Relative to their counterparts without the disease, individuals with PD do not experience statistically significant lower life-space mobility of people with PD, but individuals with PD appear to rely more heavily on assistive devices to maintain these comparable levels of mobility. Clinicians and policy-makers should consider factors beyond the capacity of the individual, such as social and environmental factors, when designing interventions to support the community mobility of people with PD.

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Table 3.1. Characteristics of the sample population by participants with and without Parkinson’s disease.

Covariate	Parkinson's disease (n = 113)	Without Parkinson's disease (n = 114)
Socio-demographics		
Age, mean (SD)	71.2 (9.0)	75.2 (7.6)
Gender (male), n (%)	68 (60.2)	42 (36.8)
Education, n (%)		
Less than postsecondary	18 (15.9)	5 (4.4)
At least some postsecondary	70 (62.0)	80 (70.8)
Completed postsecondary	25 (22.1)	28 (24.6)
Employment status, n (%)		
Working or volunteer	7 (6.2)	6 (6.2)
Retired	97 (85.8)	104 (91.2)
On disability or unemployed	9 (8.0)	4 (3.5)
Marital status, n (%)		
Married/ Common law	94 (83.2)	58 (50.1)
Widowed	8 (7.1)	30 (26.3)
Single	4 (3.5)	10 (8.8)
Divorced/ Separated	7 (6.2)	16 (14.0)
Living situation, n (%)		
Living alone	46 (40.4)	14 (12.4)
Living with spouse	57 (50.0)	94 (83.2)
Living with others	11 (9.6)	5 (4.4)
Receiving formal caregiving, n (%)	12 (10.7)	8 (7.1)
Receiving informal caregiving, n (%)	43 (38.4)	12 (10.7)
Urban living, n (%)	103 (91.2)	113 (99.1)
Family finances, n (%)		
Some money left over	68 (60.7)	64 (56.6)
No extra money in the house	23 (20.5)	26 (23.0)
Mobility		
Assistive devices		
None	63 (55.8)	94 (84.7)
Cane/ Walking poles	32 (28.1)	12 (11.4)
Walker	16 (14.2)	3 (2.7)
Wheelchair	2 (1.8)	1 (0.9)
Walking ability, n (%)		
Unlimited	40 (35.4)	60 (54.1)
6-10 blocks	23 (20.4)	10 (9.0)
1-5 blocks	32 (28.3)	26 (23.4)
< 1 block/ Indoor only	18 (15.9)	15 (13.5)
Walking limitations, n (%)		
No limitations	18 (16.2)	46 (42.2)
Pain and/or discomfort	44 (39.6)	34 (31.2)
Fatigue	39 (35.1)	12 (11.0)
Issues with balance,freezing or gait	10 (9.0)	17 (15.6)
No driver's license, n (%)	24 (21.8)	14 (12.4)
Lifestyle behaviours		
Ever smoked, n (%)	56 (50.0)	49 (43.4)
Use of alcohol, n (%)		
≥1x/month	56 (50.9)	65 (57.5)
2-4x/month	27 (24.5)	23 (20.4)
2-7x/week	22 (20.0)	24 (21.2)
Social participation index	12.8 (5.7)	16.8 (6.1)
Health status		
Self-rated overall physical health, n (%)		
Excellent or very good	43 (38.4)	28 (24.8)
Good	51 (45.5)	44 (38.9)
Fair or poor	18 (16.1)	41 (36.3)

Table 3.1. Continued.

Covariate	Parkinson's disease (n = 113)	Without Parkinson's disease (n = 114)
Self-rated overall mental health, n (%)		
Excellent or very good	68 (60.2)	36 (31.9)
Good	36 (31.9)	47 (41.6)
Fair or poor	9 (8.0)	30 (26.5)
Self-rated overall health, n (%)		
Excellent or very good	47 (42.0)	31 (27.4)
Good	50 (44.6)	45 (39.8)
Fair or poor	15 (13.4)	37 (32.7)
Chronic conditions, n (%)		
Musculoskeletal	49 (45.4)	54 (48.2)
Cardiovascular	35 (32.1)	39 (34.8)
Depression	34 (32.1)	16 (14.5)
Hearing loss	33 (30.3)	45 (40.5)
Vision impairment	32 (29.6)	43 (38.7)
Other	18 (16.8)	11 (10.0)
Diabetes	13 (12.0)	23 (21.1)
Neurological	11 (10.2)	5 (4.5)
Respiratory	7 (6.4)	14 (12.7)
Total, mean (SD)	2.1 (1.6)	2.3 (1.5)
Built environment		
I really feel a part of this area, n (%)		
Agree	86 (78.2)	92 (85.2)
Neither agree nor disagree	17 (15.5)	13 (12.0)
Disagree	7 (6.4)	3 (2.8)
Vandalism or graffiti are a big problem in this area, n (%)		
Agree	11 (10.0)	27 (25.7)
Neither agree nor disagree	17 (15.5)	16 (15.2)
Disagree	82 (74.5)	62 (59.0)
I often feel lonely living in this area, n (%)		
Agree	18 (16.5)	19 (17.8)
Neither agree nor disagree	20 (18.3)	14 (13.1)
Disagree	71 (65.1)	74 (69.2)
Most people in this area can be trusted, n (%)		
Agree	95 (86.4)	81 (74.3)
Neither agree nor disagree	8 (7.3)	20 (18.3)
Disagree	7 (6.4)	8 (7.3)
People in this area will take advantage of you, n (%)		
Agree	5 (4.5)	10 (9.3)
Neither agree nor disagree	15 (13.5)	17 (15.9)
Disagree	91 (82.0)	80 (74.8)
This area is kept very clean, n (%)		
Agree	88 (79.3)	78 (71.6)
Neither agree nor disagree	9 (8.1)	19 (17.4)
Disagree	14 (12.6)	12 (11.0)
If you were in trouble, there are lots of people in this area who would help you, n (%)		
Agree	89 (80.2)	84 (77.8)
Neither agree nor disagree	15 (13.5)	14 (13.0)
Disagree	7 (6.3)	10 (9.3)
People in this area are unfriendly, n (%)		
Agree	6 (5.4)	12 (11.1)
Neither agree nor disagree	15 (13.5)	27 (25.0)
Disagree	90 (81.1)	69 (63.9)

Table 3.2. Life-space mobility composite score and life-space levels reached among participants with and without Parkinson’s disease.

	Parkinson's disease (n=113)			Without-Parkinson's disease (n=114)		
Life-space composite score, mean (SD)	64.2 (25.8)			70.3 (23.1)		
Life-space level reached	Independent*	Assisted†	Maximal‡	Independent*	Assisted†	Maximal‡
Bedroom, n (%)	113 (100.0)	113 (100.0)	113 (100.0)	114 (100.0)	114 (100.0)	114 (100.0)
Home, n (%)	87 (77.0)	101 (89.4)	113 (100.0)	108 (94.7)	112 (98.2)	114 (100.0)
Outside home, n (%)	82 (72.6)	98 (86.7)	110 (97.3)	101 (88.6)	109 (95.6)	111 (97.4)
Neighbourhood, n (%)	70 (61.9)	90 (79.6)	103 (91.2)	92 (80.7)	104 (91.2)	107 (93.9)
Within town, n (%)	73 (64.6)	95 (84.1)	109 (96.5)	97 (85.1)	108 (94.7)	110 (96.5)
Beyond town, n (%)	47 (41.6)	56 (49.6)	73 (64.6)	58 (50.9)	62 (54.4)	63 (55.3)

SD: standard deviation.

*Independent life-space (LSA-I) is mobility achieved without the help of an assistive mobility device or another person.

†Assisted life-space (LSA-A) is mobility achieved with or without the help of an assistive mobility device.

‡Maximal life-space (LSA-M) is mobility achieved by any means, whether that be with or without help from an assistive mobility device or another person.

Table 3.3. Univariate regression of variables with life-space mobility composite score among the overall group, PD group and without-PD group.

	Overall			Parkinson's disease			Without Parkinson's disease		
Covariate (reference)	Coefficient *(SE)*	Stan. Beta	95% CI	Coefficient *(SE)*	Stan. Beta	95% CI	Coefficient *(SE)*	Stan. Beta	95% CI
Parkinson's disease status (No)	-6.0 (3.3)	-0.12	-12.4, 0.4						
Gender (Male)	1.3 (3.3)	0.03	-5.2, 7.7	1.4 (5.0)	0.03	-8.5, 11.2	-1.7 (4.5)	-0.03	-10.6, 7.3
Age	-0.4 (0.2)	-0.15	-0.8, 0	**-0.8 (0.3)**	**-0.27**	**-1.3, -0.3**	**-0.2 (0.3)**	**-0.07**	**-0.8, 0.4**
Individual									
Walking distance	**-8.9 (1.3)**	**-0.40**	**-11.6, -6.3**	**-10.8 (2.0)**	**-0.50**	**-14.6, -6.9**	**-6.9 (1.8)**	**-0.30**	**-10.5, -3.2**
Walking limitations (No limitations)									
Pain and/or discomfort	**-11.7 (3.7)**	**-0.24**	**-19.1, -4.3**	**-22.1 (6.3)**	**-0.34**	**-34.6, -9.7**	-7.4 (4.8)	-0.16	-16.9, 2.1
Fatigue	**-17.2 (4.3)**	**-0.30**	**-26.0, -8.7**	**-27.3 (6.4)**	**-0.51**	**-40.1, -14.6**	-11.9 (7.5)	-0.16	-26.8, 2.9
Issues with balance, freezing or gait	**-32.7 (7.6)**	**-0.29**	**-47.6, -17.8**	**-50.5 (9.2)**	**-0.54**	**-68.7, -32.3**	7.6 (16.8)	0.04	-25.7, 40.8
Chronic conditions									
Cardiovascular	-4.0 (3.5)	-0.08	-10.9, 2.9	**-12.7 (5.2)**	**-0.23**	**-23.0, -2.4**	3.8 (4.6)	0.08	-5.3, 12.8
Respiratory	-8.9 (5.5)	-0.11	-19.9, 2.0	-0.5 (10.2)	-0.01	-20.7, 19.7	**-15.3 (6.3)**	**-0.23**	**-27.8, -2.8**
Depression	-4.6 (4.0)	-0.08	-12.5, 3.3	-3.4 (5.5)	-0.06	-14.2, 7.4	-3.1 (6.3)	-0.05	-15.6, 9.4
Diabetes	-6.2 (4.5)	-0.09	-15.0, 2.7	1.9 (7.7)	0.02	-13.4, 17.2	**-13.2 (5.2)**	**-0.24**	**-23.5, -2.8**
Musculoskeletal	-2.6 (3.3)	-0.05	-9.2, 4.0	-9.6 (5.0)	-0.19	-19.4, 0.2	3.8 (4.4)	0.08	-4.9, 12.4
Neurological	**-13.5 (6.2)**	**-0.15**	**-25.7, -1.3**	**-17.3 (7.8)**	**-0.21**	**-32.7, -1.8**	-0.8 (10.6)	-0.01	-21.8, 20.3
Hearing loss	-4.7 (3.5)	-0.09	-11.5, 2.2	-9.3 (5.4)	-0.17	-19.9, 1.3	-2.2 (4.5)	-0.05	-11.0, 6.8
Vision impairment	**-7.1 (3.5)**	**-0.14**	**-14.0, -0.2**	-10.5 (5.4)	-0.19	-21.3, 0.2	-5.5 (4.5)	-0.12	-14.4, 3.4
Other	-5.6 (4.9)	-0.08	-15.3, 4.1	-10.7 (6.7)	-0.15	-24.0, 2.6	4.4 (7.3)	0.06	-10.0, 18.8
Total number of chronic conditions	-3.5 (1.1)	-0.22	-5.6, 1.4	**-5.3 (1.5)**	**-0.32**	**-8.3, -2.3**	-1.8 (1.4)	-0.12	-4.7, 1.0
Social									
Receiving caregiving	**-20.7 (3.4)**	**-0.35**	**-27.4, -14.0**	**-21.0 (4.6)**	**-0.40**	**-30.3, -11.9**	**-19.0 (5.8)**	**-0.30**	**-29.0, -1.6**
Social participation index	**1.9 (0.3)**	**0.42**	**1.4, 2.5**	**2.2 (0.4)**	**0.48**	**1.4, 2.9**	**1.2 (0.4)**	**0.32**	**0.5, 1.9**
No extra money in the house (Some money left over)	**-15.5 (4.0)**	**-0.26**	**-23.4, -7.7**	**-12.5 (5.9)**	**-0.21**	**-24.2, -0.8**	**-18.3 (5.3)**	**-0.32**	**-28.8, -7.8**
Environmental									
No driver's license	**-25.1 (4.0)**	**0.39**	**-33.1, -17.2**	**-34.4 (4.9)**	**-0.56**	**-44.2, -24.7**	-9.5 (6.6)	-0.14	-22.6, 3.59
I often feel lonely living in this area (Agree)									
Neither agree nor disagree	9.3 (5.8)	0.1	-2.2, 20.8	0.8 (8.4)	0.0	-15.8, 17.4	20.5 (8.0)	0.30	4.6, 36.5
Disagree	**14.1 (4.5)**	**0.20**	**5.2, 23.0**	9.4 (6.8)	0.2	-4.0, 23.0	18.5 (5.9)	0.40	6.9, 30.2

Table 3.4. Multivariable model explaining life-space mobility composite score among the overall group, PD group and without-PD group.

Covariate (reference)	Overall Coefficient (SE)	Stan. Beta	95% CI	Parkinson's disease Coefficient (SE)	Stan. Beta	95% CI	Without Parkinson's disease Coefficient (SE)	Stan. Beta	95% CI
Parkinson's disease status (No)	1.2 (3.1)	0.02	-4.9, 7.4						
Gender (Male)	-5.5 (2.8)	-0.11	-11.1, 0.1	-3.8 (3.5)	-0.1	-10.7, 3.0	-6.4 (4.4)	-0.14	-15.0, 2.3
Age	-0.5 (2.8)	-0.17	-0.8, -0.2	-0.5 (0.2)	-0.17	-0.9, -0.1	-0.3 (0.3)	-0.11	-0.9, 0.2
No driver's license	-18.8 (4.1)	-0.27	-27.0, -10.6	-25.3 (4.5)	-0.40	-34.6, -16.4			
Receiving caregiving	-15.1 (3.3)	-0.28	-21.7, -8.6	-12.7 (3.5)	-0.24	-19.7, -5.4	-16.8 (5.6)	-0.27	-28.0, -5.6
Social participation index	1.2 (0.2)	0.30	0.7, 1.6	1.6 (0.3)	0.36	1.0, 2.2			
No extra money in the house	-8.8 (3.5)	-0.15	-15.8, -1.9	-13.4 (4.2)	-0.22	-21.8, -5.1	-13.2 (5.5)	-0.23	-24.2, -2.2
Chronic conditions									
Respiratory							-15.1 (6.2)	-0.23	-27.4, -2.8
I often feel lonely living in this area (Agree)									
Neither agree nor disagree									
Disagree	10.0 (4.8)	0.13	0.7, 1.6						
Y-intercept		89.3			95.6			106.9	
R-squared (%)		39.8			56.6			17.0	

SE: Standard error.

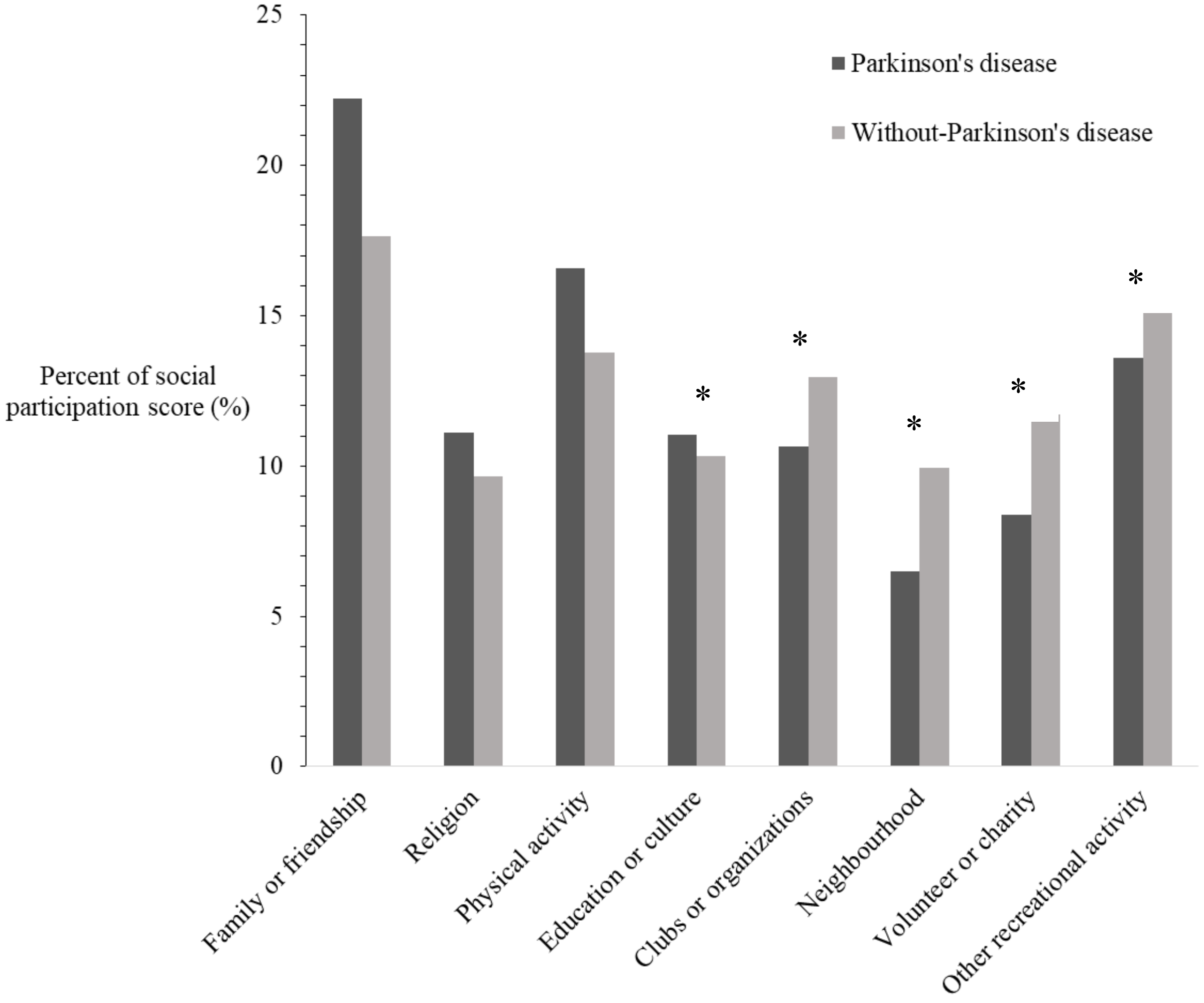

Figure 3.1. Percentage of each domain of social activity (activities done with other people) contributing to overall social participation among participants with (PD) and without Parkinson's disease (without-PD). *p <0.05.

Chapter 4: Discussion

Introduction

Studies examining mobility in older adults typically use performance-based measures of ambulation or lower extremity function to represent an individual's ability to move around independently (Chung et al., 2015). However, these measures do not broadly capture the physical, functional, cognitive, environmental and social parameters that affect the mobility patterns of older adults and influence their daily activities. The concept of life-space represents movement in the community and participation in activities, both in and out of the home, that are required to support daily living. Thus, life-space mobility relates to independence and the ability to age-in-place. For people with PD, mobility limitations arise from a decline in physical and cognitive functioning. Given that individuals with PD typically live seven to 14 years post-diagnosis, life-space mobility can be used to inform interventions aiming to delay or prevent unsought institutionalization in this population (Macleod et al., 2014).

Several factors impact life-space mobility including personal ability and preferences, and the social and physical environment (Taylor et al., 2019). Compared to a controlled environment in which tests of functional mobility generally take place, the outside world is full of distractions, hazards and inconveniences that can make moving from A to B a challenge. How these inhibiting and facilitating forces contend in the outside world can contribute a little, or a lot, to the mobility of an individual. The ability to find and use transportation (driving or organizing another form of transportation) is one example of a task that requires complex thinking and skills. This IADL, despite being essential to independent living, is difficult to measure outside of the context where the activity typically takes place. Assessing life-space mobility can help practitioners understand if their clients successfully navigate moving through their homes and community.

Summary of findings

We used a multiple-methods study design to examine the life-space mobility of people with PD and built a model explaining life-space mobility informed by rich descriptions of barriers and facilitators affecting community mobility from interviews with participants. Given that physical competence is a primary concern of persons with PD (Caap-Ahlgren & Lannerheim, 2002; Soleimani et al., 2016), an interesting finding is that the life-space of people with PD in this study is slightly reduced compared to their age-matched community counterparts, but this result was not statistically significant. This finding may be explained by the fact that 44% of participants with PD in our study used a variety of assistive devices to navigate in the surroundings, particularly while outdoors. Other studies have reported similar levels of assistive device use by PD populations (Haak et al., 2013; Kader et al., 2018). Another finding that was seen both in the survey and qualitative findings was that having a driver’s license was important for managing mobility, but questions about the safety of driving with PD remain. While studies have shown that motor vehicle crashes are higher among people with PD and that drivers demonstrate impaired driving behaviours during simulations as well during on-road assessments, it is unclear how disease status and various medications or medication-states (on vs. off) affect driving performance (Classen et al., 2014). Additionally, no PD-specific assessment tools currently exist to determine fitness for driving, leaving clinicians without validated resources to determine their patients' risk on the road (Classen et al., 2014).

Quantitative analyses suggested that for people with PD not having a driver's license, requiring caregiving and not having extra money in the house were negatively associated with life-space mobility, while the level of social participation is positively associated with the outcome. Relative to 10% of participants without PD, nearly 40% of participants with PD reported receiving informal caregiving and many interviewees commented that their spouse was the person who most helped them manage their PD. People with PD tend to require greater assistance with ADLs and IADLs compared to other individuals with activity limitations (Terriff et al., 2012). Additionally, the PD sample in our study was predominantly (60%) men, who have an informal caregiver more often than women, because women fulfill caregiving duties as a social role and women with PD are more likely to outlive their male spouses (Dahodwala et al., 2018). Informal caregivers providing good-quality care offer psychological, physical and social benefits to people with PD (Tod et al., 2016). While some benefits, like improved safety and social contact, have an immediate effect on the person with PD, others, like saving money and avoiding institutional living, continue to provide benefits over time. Informal caregivers serve individuals with PD and provide economic benefit to society by helping to delay physical and cognitive decline, as well as premature institutionalization, but caregiver burnout poses a risk to these gains (Mosley et al., 2017). Caregiver burnout, broadly captured as "the extent to which caregivers perceive caregiving has had an adverse effect on their emotional, social, financial, physical and spiritual functioning", can threaten high-quality caregiving (Zarit et al., 1986, pg.261). About half of caregivers of individuals with PD report feeling stressed about caregiving and feel that there is a need for services to help them with symptom management, coping with changes in lifestyle, future planning, relationships, cognition and wellness strategies (Lageman et al., 2015). Women who care for men with PD report higher levels of burden than men who care for women with PD and women with PD are more likely to be institutionalized (Dahodwala et al., 2018).

In Western society, physicians and nurses have long been recognized for their role in managing disability by treating the symptoms of impairment which inhibit task completion, thus improving functional capacity. However, additional steps are required to maximize functional performance. Social planners, service agencies and governments have an important role to play in reducing the incidence and severity of disability by modifying features of the social and physical environment (World Health Organization, 2002). In models of health and disability, the individual, or the individual's health condition, only represents one node in the framework. In the ICF biopsychosocial model of disability, environmental and personal factors crucially influence the execution of a task by an individual (World Health Organization, 2002). In the context of a socio-ecological model, the individual is the smallest of four or five overlapping rings of which the largest capture broad societal factors that directly or indirectly impact individual-level health (Sallis et al., 2006). The broad scope of the socio-ecological model gives it some advantage over the comprehensive framework for mobility in older adults by Webber et al. (2010), which focuses on determinants of mobility (physical, environmental, financial, psychosocial, and cognitive) that directly impact the individual. However, this model possesses several important strengths, including its recognition that individuals can be mobile by many modes (e.g. riding transit or using a wheelchair), that a larger number of determinants affect mobility as an individual moves further away from home, and that mobility is inherently multidimensional, particularly in the sense that it is influenced by gender, culture and other biographical traits. The comprehensive nature of this conceptual model makes it appropriate to be applied to people with PD whose experiences with the disease can be highly varied.

Indeed, by addressing barriers both intrinsic and extrinsic to the individual, mobility limitations caused by conditions like PD need not restrict people from being mobile and thus performing the IADLs that facilitate independence, social participation and ageing-in-place (Giannouli et al., 2016). People with PD are more likely to move to assisted living facilities earlier in life, which comes at a cost to society and those affected (Vossius et al., 2009). Even with the addition of this research study to the body of literature, we have a limited understanding of the interactions of PD with perceived and objective aspects of ageing at home.

The study findings presented in Chapter 3 have highlighted that several real-life personal, social and environmental barriers restrict the mobility of people with PD, but also that this population takes initiative to close the gap between functional capacity and performance. The following sections will review some of the contextual factors related to life-space mobility or community mobility among older adults and compare and contrast findings from previous research studies with our own.

Demographics

We controlled for age and gender in our multivariable analyses of life-space mobility, because both characteristics are not modifiable, but are known to be associated with life-space mobility. Older age and female gender both typically correspond with lower life-space mobility (Choi et al., 2016; Suzuki et al., 2014). Our participants with PD were predominantly married men, just over a third of whom received informal caregiving, likely from their spouse. In comparison, the group without PD were predominantly women, of whom about half were married and a quarter were widowed. Older men in heterosexual marriages are less likely to be widowers than older women are to be widows because men are typically slightly older than their spouses and women have longer life expectancies. Therefore, the majority of participants in the PD group had a spouse who may assist with daily tasks including transportation, whereas the group without PD may not have had the same benefit. Because our groups were not perfectly matched on age and gender, it is possible that the older, majority-female without PD group had a lower mean life-space score and the younger, majority male PD group had a higher mean life-space score compared to samples that had a more equal proportion of men and women. The models were adjusted for age and gender, but residual confounding may remain.

Monthly family finances (more than enough or enough/not enough to make ends meet) was the only variable found to be statistically significant in the overall, PD and without-PD models of life-space mobility. One study, using level of education and occupation as a proxy for SES found that compared to people of moderate to high SES, people with low SES had lower life-space mobility (Eronen et al., 2016). Finances are considered to be one of the mobility determinants in Webber's framework for mobility in older adults and income is a social determinant of health, because socioeconomic status is consistently associated with the likelihood of having mobility disability (Satariano et al., 2012; Webber et al., 2010). In the context of mobility, higher income can facilitate capacity and access, such as to transportation in various forms, physiotherapists and exercise classes, renovations to the home and hired help.

Social support and participation

The need for social engagement is a strong motivator for activity and mobility outside of the home and is known to promote functional ability and well-being (Gardner, 2014). The association between mobility and social participation and support has been well-documented in the context of life-space mobility including in the present study, which demonstrated that social participation and life-space mobility are positively associated (Gardner, 2014; Kuspinar et al., 2020; Murata et al., 2006). Social participation has been shown to be lower among people with poor mobility, particularly if they have a mobility limitation (Rosso, Taylor, et al., 2013). There was some evidence of this relationship in our study which showed that participants with PD had lower social participation scores than their counterparts without PD. Data from previous interviews with people with PD revealed that progressive physical disability, mood disturbances, shrinking of social activities and self-seclusion disrupted social connectedness (Soleimani et al., 2014). As discussed in interviews with PD participants and in agreement with previous research, mobility challenges may reduce the number of opportunities for engagement outside of the home (Rosso, Taylor, et al., 2013). For example, older adults who are frequent drivers or have consistent access to a ride are more likely to engage in social activities outside of the home in comparison to those who ceased driving or never drove (Pristavec, 2018). Additionally, lost opportunities for participation are also a lost opportunity to reinforce social relationships which could lead to further engagement.

Physical environment

The physical environment is an important factor when considering life-space mobility (Webber et al., 2010). The survey contained a series of questions regarding the perceived safety, cleanliness and safety of their neighbourhoods to capture a sense of the built environment and how it might have contributed to life-space mobility. We expected that through semi-structured interviews, participants with PD would describe myriad additional features of the built environment that would facilitate or restrict their mobility, but only a few barriers related to indoor accessibility were mentioned: crowded or confined spaces and access to the washroom being the most commonly described. In previous qualitative research, crowded environments were a mobility barrier for people with PD who experienced excess freezing of gait in these settings (Lamont 2012). Although no research appears to contradict these findings, older adults in earlier quantitative studies identified additional features, such as sidewalk conditions and neighbourhood walkability, to be associated with more difficult mobility (Chudyk et al., 2017; Raggi et al., 2018).

A number of researchers have recently turned their attention to how the built environment affects the community mobility of older adults (Cerin et al., 2017; Rosso et al., 2011; Tuckett et al., 2018). Neighbourhood characteristics, including features related to transportation, real and perceived safety, sense of community, aesthetics, physical structure and certain weather conditions (i.e. snow and ice) appear to be associated with lower life-space or community mobility in cross-sectional studies (C. Hand, 2016; Hinrichs et al., 2019; Rantakokko et al., 2015; Rosso, Grubesic, et al., 2013). Facilitators to outdoor community mobility include appealing scenery and familiar surroundings (Rantakokko et al., 2015). Interviews involving middle- to older-aged adults with mobility disabilities added that sidewalk availability and condition, aesthetics and lighting contribute to neighbourhood-based activity (Rosenberg et al., 2013). Finally, Portegjis et al. (2017) found that perceived environmental barriers at the entrance to the home (i.e. narrow door openings, insufficient maneuvering space at doors, heavy doors) decreased the odds of daily out-of-home mobility for community-dwelling older adults. Interestingly, few of these features were brought up in interviews with PD participants, possibly because the interviews were conducted in the fall when there was no snow on the ground to pose challenges. The majority of the presented research has involved older adults, so significant questions remain as to how the built environment affects the community mobility of people with PD, specifically.

Methodological limitations

There are limitations and possible information and selection biases that may have impacted the results. First, this study may lack generalizability to persons with PD living rurally, or who are racial/ethnic minorities. The majority of participants in our study lived in urban settings, preventing generalizability of the results of our study to rural populations who may experience different environmental factors contributing to life-space mobility. For example, most rural communities have no public transportation, which unsurprisingly, has been shown to be associated with smaller life-space mobility in older adults living rurally (Murata et al., 2006). In Alberta, more than 80% of residents live in urban areas, but the distribution of urban versus rural living among residents with PD is unknown (Government of Alberta, 2017a).

This study did not capture the race/ethnicity of the participants, so we were unable to observe if this biographical factor was associated with life-space mobility. Previous research involving African Americans suggests that racial/ethnic minorities typically experience lower life-space mobility resulting from disadvantages related to income, education and transportation availability (Allman et al., 2004; Choi et al., 2016). An 18-month prospective cohort study examining predictors of life-space mobility by race in 900 community-dwelling older adults found that having PD statistically significantly reduced LSA score in Black participants, but not White participants (Choi et al., 2016). However, only 7% of Albertans older than 65 identified themselves as a visible minority on the 2016 census (Government of Alberta, 2017b). This statistic implies two consequences for our study: 1) it is likely that only a small number of participants in our study identified as a racial/ethnic minority and therefore it is unlikely that this unmeasured variable had a significant impact on the findings, and 2) the findings lack generalizability to racial/ethnic minorities with PD.

Recruitment strategies utilized in this study may have targeted may have attracted a select group of people with PD who chose to attend support groups offered by the

Parkinson Association of Alberta and exclude as compared to those who, for various reasons, do not. They could be in more need of social support, or they could be less need because they are using resources to help them cope with the changes in their lives brought on by PD. Attending support groups is suggestive of a certain degree of life-space mobility. It is unknown whether those who attended were more or less mobile than this cohort.

Similarly, participants without PD were recruited from fewer and more homogenous sites than the PD group. The group without PD was recruited from five seniors activity centers in Edmonton, whereas the PD were recruited from three different urban areas (Edmonton, Calgary and Camrose) and multiple sources: seniors centers, the Parkinson Association of Alberta, two neurology offices, a PD-specific exercise class and a PD research participant registry. This diverse set of sources was required to recruit a larger sample size and improve the power of the study.

It could be argued that life-space mobility is dependent upon the locale setting. The characteristics of the Edmonton, Calgary and Camrose populations were descriptively compared for differences in demographics and health status. Although some descriptive differences were noted in age and sex distribution, we found that the mean life-space mobility of participants across the three centers was very similar.

Responses between participants with and without PD may have differed because of the time of year that the survey was administered. Participants without PD were all surveyed between January and April 2019, while PD participants were surveyed between October 2018 and October 2019, as we worked to increase sample size in this population. The PD group, therefore, was surveyed throughout four seasons in Alberta. Seasonal weather conditions (i.e. very high or low temperatures, shorter daylight time, and snow and ice) can affect the level of physical activity and walking, particularly among older adults (Klenk et al., 2012; Y. Li et al., 2013). It has also been shown that the life-space mobility of Finnish older adults, as measured by the LSA, is slightly higher in the spring when participants faced fewer climatologic challenges compared to the winter (Portegijs, Iwarsson, et al., 2014). Given that life-space mobility of the group without PD was predominantly measured in the winter months, the mean life-space score of the group may be presenting as artificially low in comparison to the PD group.

About 12% of PD and without-PD participants were missing one or more items on the LSA. Missing data reduces the sample size, and therefore power, in statistical analyses, so these missing data were imputed using the nearest neighbour approach. To combat this limitation, we conducted a sensitivity analysis and found that imputation did not have a statistically significant effect on the mean life-space scores in the PD or without-PD groups (data not shown).

Qualitative research comes with its own set of limitations, as well as researcher and participant biases that can affect the results of a study. To promote rigour in our research, steps were taken to improve the credibility, transferability, dependability and confirmability of the qualitative component of our study (Lincoln & Guba, 1985). Among the PD participants who agreed to be contacted about participating in an interview, we employed purposeful sampling in an attempt to collect information-rich perspectives from men and women at the lowest and highest ends of the age range and life-space mobility scores to increase transferability. This is a limitation of qualitative research, but it does not diminish the importance of sharing individual stories to better understand the impact of PD. The credibility of the research was established by ensuring that the primary researcher had training in basic qualitative methods and was familiar with the subject areas of PD and mobility. Several techniques were used to improve the rigour of the study during data collection. First, we used an interview guide with open-ended questions to create consistency across the interviews, while encouraging participants to direct the conversation. We recorded conversations on two tape recorders, took field notes and reflected in a journal entry as soon as possible after each interview. These techniques helped to create credibility, dependability and confirmability within the study. Furthermore, member checking was used to confirm the researcher's primary takeaways from each interview, which fostered credibility and confirmability. Confirmability was also established during data analysis when the primary researcher (CRB) discussed early findings with other team members to mitigate the influence of her own biases within the project.

Epidemiological value of life-space mobility in Parkinson's disease

Using evidence from studies of older adults and people with PD, we have discussed a variety of wide-ranging, yet interconnected, contextual factors that impact life-space mobility and are relevant to general well-being. From an epidemiological perspective, surveys of life-space mobility offer a simple and quick way to gauge resilience to physical decline and social isolation in populations with PD. If used to measure life-space mobility in a large, nationally-representative cohort of people with PD, the characteristics and circumstances of people who require extra support could be quickly identified. For individuals with PD undergoing a new intervention, such as a change in medication or physiotherapy, life-space mobility offers another metric to holistically assess that intervention. The LSA is already being used as a measure of functional mobility in community-based physical therapy practices (McCrone et al., 2019). Furthermore, the concept of life-space is sensitive to the influences of the built environment, mental health and social support – modifiable factors that are relevant to current public health objectives. For these reasons, research interest in the concept and measurement of life-space mobility continues to grow (Britto et al., 2018; Edgren et al., 2019; Münch et al., 2019; Taylor et al., 2019). Our study contributes to this growing body of literature, and particularly aligns with the work of Rantakokko et al. (2019), by identifying internal and external factors that are associated with the life-space mobility of people with PD.

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Chapter 5: Conclusion

Guided by a comprehensive framework for mobility in older adults (Webber et al., 2010), life-space mobility in persons with PD was found to be comparable with that of persons without PD in this study. Using a multiple-methods design, social and environmental factors influence life-space mobility in this patient population. Although some factors were similar to those identified with a comparison group of older adults without PD, differences were seen with factors such as having a valid driver's license and being more socially active being associated with life-space mobility in people with PD, but not without. While most of these individual factors are modifiable, the findings of this study stress that interventions should take a holistic approach to mobility in recognition of the multidimensional relationships affecting an individuals' ability and desire to be mobile when living with PD. The findings of this study are most applicable to community-dwelling persons with mild to moderate PD who live in an urban setting.

Clinical recommendations

- Practitioners should encourage people with PD to retain physical and cognitive functioning to specific to driving to delay driving cessation. Meanwhile, practitioners should help people with PD plan for driving cessation and prepare to adapt to using other forms of transportation (e.g. public transportation).

- With their clients with PD, practitioners should reinforce the importance of engaging in social activities outside the home. More social participation is associated with higher life-space mobility and trips outside the home to interact with other people require individuals to practice complex physical and cognitive tasks necessary for independent living.

- Practitioners should assess the life-space mobility of people with PD as an indicator of functional mobility, quality of life, participation in the community and risk of falling. Assessments should focus on barriers such as not having a driver’s license, family finances, access to caregiving/social support and level of social participation to determine how life-space mobility might be sustained or improved.

- Individuals newly diagnosed with PD should be referred to local PD support groups to receive immediate social support and build connections that will continue to encourage participation outside of the home.

Recommendations for the built and social environment

- Public washrooms, movie theatres, hockey arenas, and other spaces with stairs, poor lighting or uneven terrain should be designed or altered to better accommodate persons wanting or needing to use a mobility device.

- People with PD describe having anxiety, instability and difficulty moving in spaces that were crowded with people or felt confining in other ways. Public spaces where these populations could reasonably be expected to attend should be designed to improve the flow of person-traffic and prevent crowded environments.

- Safe and viable alternatives to driving a personal car are needed for people with PD. To improve the community mobility and participation of people with PD who do not or cannot drive, municipal governments should develop programs to transport individuals at low cost and ensure that public transportation routes are designed to reach neighbourhoods that are not located centrally.

- To reduce the reliance the reliance on using cars for mobility, communities and governments should encourage the development of more walkable neighbourhoods and incorporate design features that evidence has shown to promote walking for leisure and purpose. These changes would additionally promote physical activity and spontaneous social interactions among community members.

Future research

In addition to basic PD research investigating causes and treatments, future research should focus on elucidating the relationships between independence, participation, and mobility. As this study was cross-sectional, we could not determine directionality for any of the associations that we observed with mobility among people with PD and longitudinal studies are warranted. Further investigations into aspects of the social and built environment that affect the life-space of people with PD would also be beneficial for a more comprehensive understanding of the interplay between person and environment. Linking GPS-tracked life-space mobility with satellite imagery may be an interesting strategy to reduce recall bias and improve the accuracy of life-space measurements, as well as descriptions of the built environment. One small proof-of-concept study demonstrated that GPS data collected via smartphones are a viable option for measuring the life-space of people with PD (Liddle et al., 2014). Having a driver's license emerged as the most significant factor associated with life-space mobility in people with PD and research indicates that drivers with mild to moderate PD are at a higher risk of failing on-road driving tests compared to older adults without the condition (Devos et al., 2015). Yet, little evidence exists to support the creation of contextual (i.e. on-road practice or driving simulator) or non-contextual (i.e. off-road skills) programs to improve on-road skills as well as cognitive and motor impairments to delay driving cessation (Devos et al., 2015). Studies are needed to identify the best modalities to deliver this training and determine the optimal duration, frequency and intensity of training programs.

Finally, there appears to be a paucity of research pertaining to effective knowledge translation strategies specifically among populations with PD. Based on interviews with participants with PD in this study, it seems that much of this population is highly motivated to learn about their disease and make changes in their lives to improve symptoms, yet we do not know what is the most effective way for researchers and clinicians to share information with people with PD. It is also important that we understand how to support both individual decision-making and the creation of supportive learning environments for people who may lack the motivation, time, or resources to engage in meaningful PD education.

Knowledge translation strategy

Although the objectives of this research were exploratory in nature, it is still important to disseminate the results to interested parties, particularly those living with PD in Alberta. A traditional KT approach will be taken in that a one-page infographic of this research and its findings will be made available to the Parkinson’s Association of Alberta (PAA) to be distributed to interested members, including those who shared their data and experiences for the purpose of this study (Appendix 12). We hope that the findings will be a catalyst for conversations between stakeholders about barriers and facilitators to community mobility for people with PD. Additionally, this research will be circulated through various academic forums. Findings will be disseminated locally at the University of Alberta through oral presentations or poster presentations at the School of Public Health, and a Master’s Thesis based on this research will be submitted to the Faculty of Graduate Studies. A manuscript of the original research presented in Chapter 3 will be submitted for publication to relevant peer-reviewed academic journals so that results and recommendations can be more widely accessed by the academic community and add to the body of existing literature working to understand the impact of PD.

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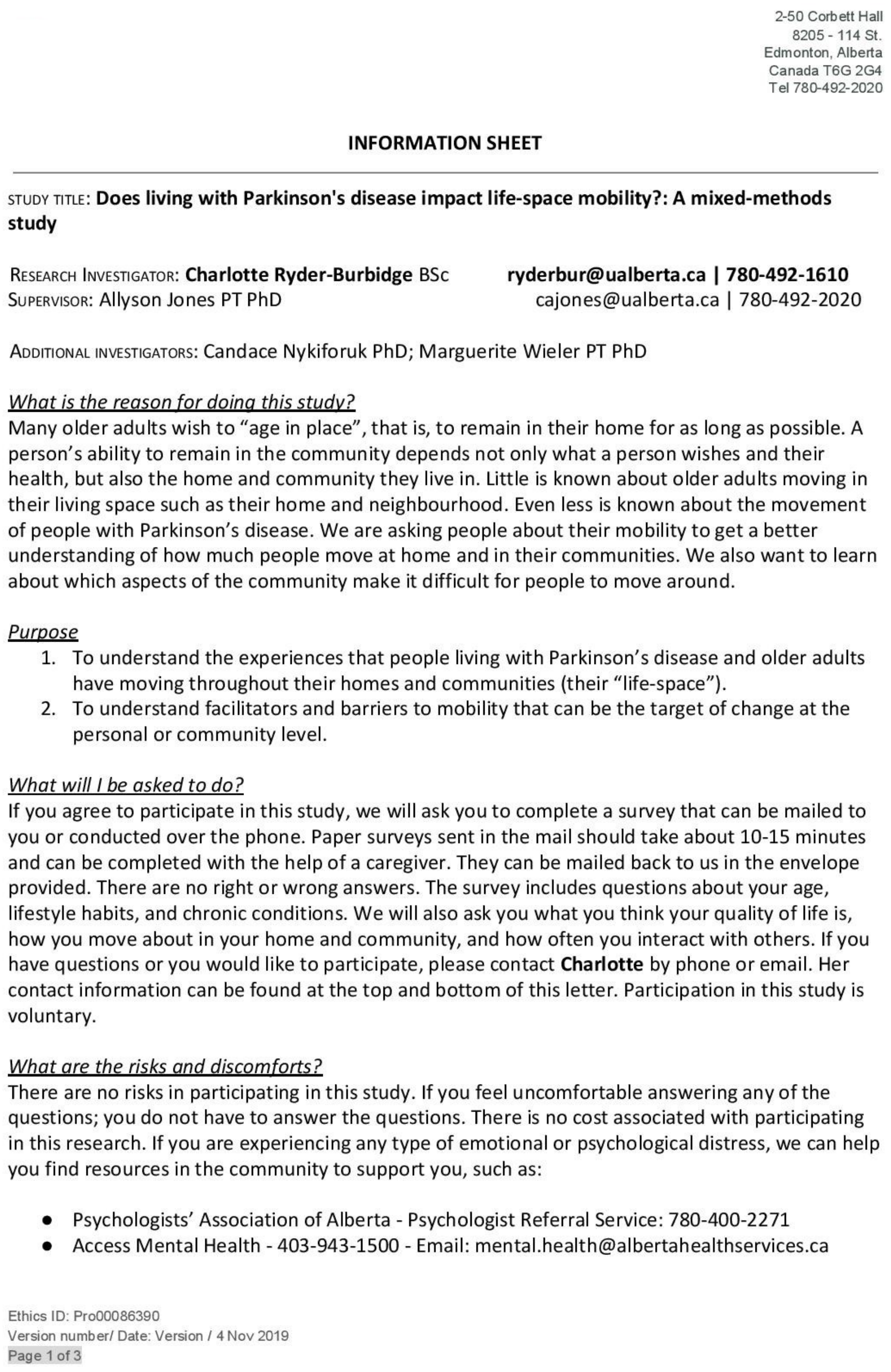
Appendices

Appendix 1. Information sheet for survey participants with Parkinson's disease recruited from the Calgary Parkinson Research Initiative (CaPRI).



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INFORMATION SHEET

STUDY TITLE: **Does living with Parkinson's disease impact life-space mobility?: A mixed-methods study**

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ADDITIONAL INVESTIGATORS: Candace Nykiforuk PhD; Marguerite Wieler PT PhD

What is the reason for doing this study?

Many older adults wish to "age in place", that is, to remain in their home for as long as possible. A person's ability to remain in the community depends not only what a person wishes and their health, but also the home and community they live in. Little is known about older adults moving in their living space such as their home and neighbourhood. Even less is known about the movement of people with Parkinson's disease. We are asking people about their mobility to get a better understanding of how much people move at home and in their communities. We also want to learn about which aspects of the community make it difficult for people to move around.

Purpose

1. To understand the experiences that people living with Parkinson's disease and older adults have moving throughout their homes and communities (their "life-space").
2. To understand facilitators and barriers to mobility that can be the target of change at the personal or community level.

What will I be asked to do?

If you agree to participate in this study, we will ask you to complete a survey that can be mailed to you or conducted over the phone. Paper surveys sent in the mail should take about 10-15 minutes and can be completed with the help of a caregiver. They can be mailed back to us in the envelope provided. There are no right or wrong answers. The survey includes questions about your age, lifestyle habits, and chronic conditions. We will also ask you what you think your quality of life is, how you move about in your home and community, and how often you interact with others. If you have questions or you would like to participate, please contact **Charlotte** by phone or email. Her contact information can be found at the top and bottom of this letter. Participation in this study is voluntary.

What are the risks and discomforts?

There are no risks in participating in this study. If you feel uncomfortable answering any of the questions; you do not have to answer the questions. There is no cost associated with participating in this research. If you are experiencing any type of emotional or psychological distress, we can help you find resources in the community to support you, such as:

- Psychologists' Association of Alberta - Psychologist Referral Service: 780-400-2271
- Access Mental Health - 403-943-1500 - Email: mental.health@albertahealthservices.ca

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- Woods Homes Eastside Family Centre - 403-299-9696
- South Calgary Health Centre - 403-943-9300
- Calgary Counselling Centre - 403-691-5991
- Distress Centre Calgary - 403-266-4357

What are the benefits to me?

There are no direct benefits to you for taking part in this study. Your participation will give us valuable information on what makes a community easy to move about or what makes it especially difficult to move. We hope that the information from this study will help us better understand the experience of living with Parkinson's disease. Information is important in letting the community know what makes it easy or hard to move for older adults and for people with Parkinson's Disease.

Voluntary Participation

Completing the survey over the phone or mailing it back to the researchers means that you agree to participate. You are free to withdraw from the study at any time without consequence.

Confidentiality & Anonymity

Any personal information that you provide for this study will be kept confidential. The program staff will not know your responses. Anything that is published from this study will not contain your name. Data will be kept in written, hard-copy and password-protected electronic formats.

The information will be stored for a minimum of five years after the study is completed. It will be stored in Dr. Allyson Jones' locked office and electronic data on the Department of Physical Therapy secure server at the University of Alberta. After that time, all paper and electronic formats will be destroyed in a way that ensures privacy and confidentiality. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed; your personal information may be disclosed if required by law. The information from this study may be used to plan future research, but if we do this it will have to be approved by a Research Ethics Board. You may request a report of the research findings and your own results at any time by contacting one of the study investigators. Information gathered from this study may be published or presented in public forums; however, we will never use or reveal your name or any other personally-identifying information.

Further Information

The plan for this study has been reviewed for its adherence to ethical guidelines by a Health Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at 780-492-2615. This office has no direct involvement with this project. Please contact the following investigators if you have any questions or concerns.

Charlotte Ryder-Burbidge BSc, MSc Student ryderbur@ualberta.ca | 780-492-1610
Allyson Jones PT PhD cajones@ualberta.ca | 780-492-2020

2-50 Corbett Hall
8205 - 114 St.
Edmonton, Alberta
Canada T6G 2G4
Tel 780-492-2020

If you are interested in receiving a report about the research findings, please leave us your email address or a phone number at which we can contact you; findings can be sent by email or by mail.

Appendix 2. Life-space mobility survey given to study participants with Parkinson's disease.

Participant ID: ___________ Date: ___________ Time: ___________

Life-space mobility survey

*Please select **only one** answer unless otherwise specified.*

1. We would like to know if you are responding to this survey as yourself or on behalf of another person.

☐ I am responding to this survey as myself.
☐ I am filling out this survey on behalf of another person.
Their relationship to me is: ______________________.

2. Which of the following best describes you?

☐ Female
☐ Male
☐ Other (Specify_________________________)

3. What is your date of birth? ___ ___ / ___ ___ ___ / ___ ___ ___ ___
D D M M M Y Y Y Y

4. What is the highest level of education you have completed?

☐ Less than secondary
☐ Completed high school (grade 12)
☐ Some postsecondary (college or university)
☐ Completed postsecondary (college or university)

5. Which of the following categories best describes your usual **daily** activity?

☐ Full or part-time paid work
☐ Volunteer work
☐ Student
☐ Retired
☐ On disability or sick leave
☐ Unemployed

Participant ID: __________

6. Are you currently?

☐ Single
☐ Married/ common-law
☐ Widowed
☐ Divorced/ separated

7. Which of the following best describes your current living situation?

☐ Living alone
☐ Living with children
☐ Living with spouse
☐ Living with spouse and children
☐ Living with others

8. What are the first 3 digits of your postal code? ___ ___ ___

9. How would you describe your use of cigarettes?

☐ Current smoker
☐ Ex-smoker
☐ Never smoked

10. During the **past 12 months**, how often did you drink alcoholic beverages?

☐ Less than once a month
☐ Once a month
☐ 2 to 3 times a month
☐ Once a week
☐ 2 to 3 times a week
☐ 4 to 6 times a week
☐ Every day
☐ Don’t know

11. Approximately how many **minutes per week** do you spend doing moderate- (i.e. brisk walking) to vigorous-intensity (i.e. cross country skiing) physical activity?

☐ Less than 150 minutes
☐ 150 minutes or more

Participant ID: __________

12. How far can you walk before you must stop to rest?

☐ Unlimited (10 blocks or longer) ☐ Less than one block

☐ 6-10 blocks ☐ Indoors only

☐ 1-5 blocks

13. What limits you from walking further?

☐ No limitations ☐ Fatigue

☐ Pain and/ or discomfort ☐ Other (Specify_______________________)

14. What types of supports do you use when walking? (Check the one you use most often.)

☐ None ☐ Wheelchair

☐ Cane ☐ Other (Specify_______________________)

☐ Walker

15. In general, how do your family finances work out at the end of the month? Do you usually have?

☐ Some money left over ☐ Not enough to make ends meet

☐ Just enough to make ends meet ☐ Prefer not to say

16. During the **past 12 months**, did you receive short-term or long-term professional assistance at home, because of a health condition or limitation that affects your daily life?

☐ Yes ☐ No

17. During the **past 12 months**, did you receive short-term or long-term assistance from family, friends, or neighbours because of a health condition or limitation that affects your daily life?

☐ Yes ☐ No

Participant ID: ___________

18. How would you rate your **overall physical health**?

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

19. How would you rate your **overall mental health**?

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

20. How would you rate your **overall health**?

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

Participant ID: __________

Parkinson's disease

We are interested in long-term conditions which have lasted, or are expected to last, ***6 or more months*** *and have been diagnosed by a health professional.*

1. Do you have **Parkinson's disease**? ☐ Yes (proceed to questions 2-4) ☐ No

2. When were you diagnosed with Parkinson's disease? ___ ___ ___ / ___ ___ ___ ___
M M M Y Y Y Y

3. If you are taking medications to treat the symptoms of your Parkinson's disease, please list your medications below:

____

____

____

____

4. Are you currently experiencing an "On" or "Off" period with your medication?

- ☐ On
- ☐ Off
- ☐ Don't know/ Not applicable

Participant ID: __________

Chronic conditions

Do you have any chronic health conditions? We are interested in long-term conditions which have lasted, or are expected to last, **6 or more months** and have been diagnosed by a health professional. Check all that apply:

		A. Has your doctor prescribed you medication for this condition?	B. Have you had to make changes to your daily routine because of this condition?
1. Cardiovascular disease *(heart failure, hypertension, ischemic heart disease, stroke, etc.)*	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
2. Chronic respiratory illness *(asthma, chronic obstructive pulmonary disease, etc.)*	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
3. Mental illness *(depression, anxiety, schizophrenia, etc.)*	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
4. Diabetes	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
5. Musculoskeletal disorder *(osteoporosis, gout, rheumatoid arthritis, fibromyalgia, etc.)*	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
6. Neurological condition OTHER than Parkinson's disease *(dementia, epilepsy, multiple sclerosis, etc.)*	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
7. Hearing loss	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
8. Vision loss OTHER than impairments corrected by prescription lenses	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
9. Other (Specify__________)	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

Participant ID: __________

Life-space assessment

These questions refer to your activities in a **typical week in the last month**:

During the last four weeks have you been to...	A. How frequently have you been to these places?	B. Did you use any auxiliary device? Did you need the help of another person?
1...other rooms in your house besides the room where you sleep? ☐ Yes → ☐ No (proceed to 2)	☐ 1x / week ☐ 2-3x / week ☐ 4-6x / week ☐ Daily	☐ Personal assistance ☐ Only equipment ☐ No equipment nor personal assistance
2...an area outside your house such as your building hallway, playground, garage or your own garden? ☐ Yes → ☐ No (proceed to 3)	☐ 1x / week ☐ 2-3x / week ☐ 4-6x / week ☐ Daily	☐ Personal assistance ☐ Only equipment ☐ No equipment nor personal assistance
3... places in your neighbourhood, other than your own yard or apartment building? ☐ Yes → ☐ No (proceed to 4)	☐ 1x / week ☐ 2-3x / week ☐ 4-6x / week ☐ Daily	☐ Personal assistance ☐ Only equipment ☐ No equipment nor personal assistance
4...places outside your neighbourhood but within your city? ☐ Yes → ☐ No (proceed to 5)	☐ 1x / week ☐ 2-3x / week ☐ 4-6x / week ☐ Daily	☐ Personal assistance ☐ Only equipment ☐ No equipment nor personal assistance
5...places outside your city? ☐ Yes → ☐ No (end)	☐ 1x / week ☐ 2-3x / week ☐ 4-6x / week ☐ Daily	☐ Personal assistance ☐ Only equipment ☐ No equipment nor personal assistance

Participant ID: __________

Parkinson's disease questionnaire – 8 (PDQ-8)

Many people with Parkinson's disease report problems from time to time. We are interested in how you have been in your general health over the **last four weeks**.

1. Over the past four weeks, have you, because of your Parkinson's disease...	Never	Occasionally	Sometimes	Often	Always, or cannot do at all
A... had difficulty getting around in public?	☐	☐	☐	☐	☐
B... had difficulty dressing yourself?	☐	☐	☐	☐	☐
C... felt depressed?	☐	☐	☐	☐	☐
D... had problems with close relationships?	☐	☐	☐	☐	☐
E... had problems with concentration?	☐	☐	☐	☐	☐
F... felt unable to communicate properly?	☐	☐	☐	☐	☐
G... had painful muscle cramps and pain?	☐	☐	☐	☐	☐
H... felt embarrassed from having Parkinson's disease?	☐	☐	☐	☐	☐

Participant ID: ___________

Community mobility

1. Which of the following best describes your driving status?

- ☐ Never had a driver's license
- ☐ Had a driver's license at one point in your life, but currently do not have it
- ☐ Have a driver's license with restrictions (except eyeglasses)
- ☐ Have a driver's license without restrictions

2. In the past month, which of the following forms of transportation have you used? **(Check all that apply.)**

- ☐ Driver in a motor vehicle
- ☐ Passenger in a motor vehicle
- ☐ Taxi
- ☐ Public transit such as bus, rapid transit, subway/ metro or train
- ☐ Accessible transit
- ☐ Cycling
- ☐ Walking
- ☐ Wheelchair or motorized cart/ scooter

3. In the past year, which was your most common form of transportation? **(Select one answer only.)**

- ☐ Driver in a motor vehicle
- ☐ Passenger in a motor vehicle
- ☐ Taxi
- ☐ Public transit such as bus, rapid transit, subway/ metro or train
- ☐ Accessible transit
- ☐ Cycling
- ☐ Walking
- ☐ Wheelchair or motorized cart/ scooter

5. What kind of trip(s) do you usually make in a week, whether by car, public transit, walking or other means? **(Check all that apply.)**

- ☐ Commute to/ from work
- ☐ Banking and other business appointments
- ☐ Medical appointments
- ☐ Grocery shopping
- ☐ Leisure shopping, restaurants
- ☐ Leisure trips to park, other outdoor spaces
- ☐ Church/ worship service
- ☐ Visiting friends and family
- ☐ Social activities
- ☐ Other (Specify_________________________)

Participant ID: ___________

6. How do you feel about the community which you live in, that is, everywhere within a 20 minute walk or about a kilometer from your home?

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
A. I really feel a part of this area.	☐	☐	☐	☐	☐
B. Vandalism or graffiti are a big problem in this area.	☐	☐	☐	☐	☐
C. I often feel lonely living in this area.	☐	☐	☐	☐	☐
D. Most people in this area can be trusted.	☐	☐	☐	☐	☐
E. People in this area will take advantage of you.	☐	☐	☐	☐	☐
F. This area is kept very clean.	☐	☐	☐	☐	☐
G. If you were in trouble, there are lots of people in this area who would help you.	☐	☐	☐	☐	☐
H. People in this area are unfriendly.	☐	☐	☐	☐	☐

Participant ID: __________

Social participation

The next questions are about community-related activities that you may have participated in during the **past 12 months**. Please place an "X" in the appropriate response.

1. In the **past 12 months**, how often did you participate in:	At least once a day	At least once a week	At least once a month	At least once a year	Never	Don't know
A… family or friendship activities outside the household?	☐	☐	☐	☐	☐	☐
B… church or religious activities such as services, committees or choirs?	☐	☐	☐	☐	☐	☐
C… sports or physical activities that you do with other people?	☐	☐	☐	☐	☐	☐
D... educational and cultural activities involving other people such as attending courses, concerts or visiting museums?	☐	☐	☐	☐	☐	☐
E… clubs or organization activities?	☐	☐	☐	☐	☐	☐
F… neighbourhood, community or professional association activities?	☐	☐	☐	☐	☐	☐
G… volunteer or charity work?	☐	☐	☐	☐	☐	☐
H… any other recreational activities involving other people, including hobbies, gardening, cards, and other games?	☐	☐	☐	☐	☐	☐

2. In the **past 12 months**, have you felt like you wanted to participate in more social, recreational or group activities?

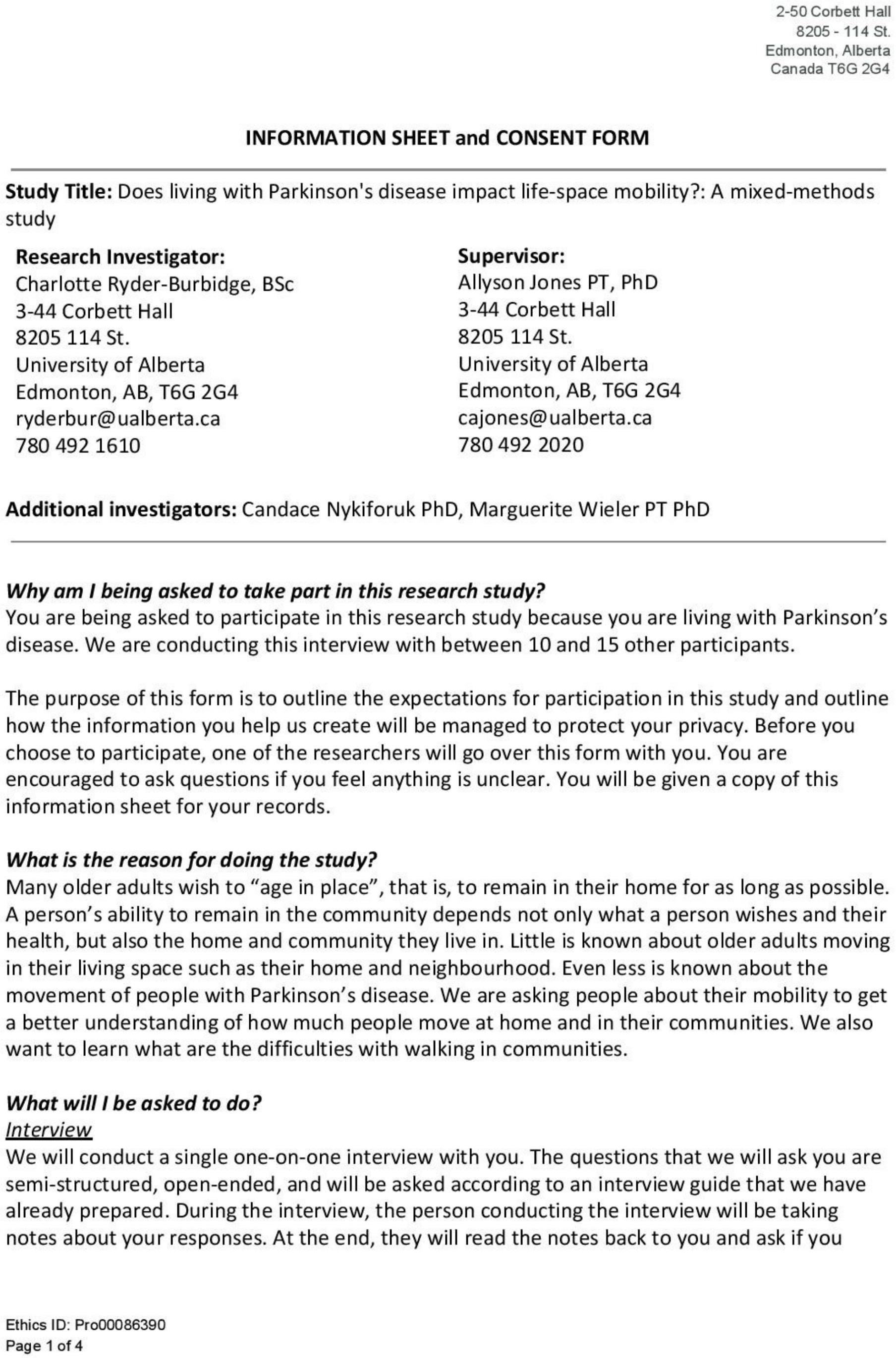
☐ No ☐ Yes

3. What prevented/ would prevent you from participating in these activities? **(Check all that apply.)**

☐ Cost
☐ Transportation problems
☐ Activities not available in the area
☐ Location not physically accessible
☐ Location is too far
☐ Health condition limitation
☐ Time of the activities not suitable
☐ Don't want to go alone
☐ Personal or family responsibilities
☐ Language related reasons
☐ Too busy
☐ Afraid or concerns about safety
☐ Other (Specify________________________)
☐ Not applicable

Thank you for responding to this survey!

Appendix 3. Information sheet and consent form reviewed and signed by interview participants.



2-50 Corbett Hall
8205 - 114 St.
Edmonton, Alberta
Canada T6G 2G4

INFORMATION SHEET and CONSENT FORM

Study Title: Does living with Parkinson's disease impact life-space mobility?: A mixed-methods study

Research Investigator: Charlotte Ryder-Burbidge, BSc 3-44 Corbett Hall 8205 114 St. University of Alberta Edmonton, AB, T6G 2G4 ryderbur@ualberta.ca 780 492 1610	**Supervisor:** Allyson Jones PT, PhD 3-44 Corbett Hall 8205 114 St. University of Alberta Edmonton, AB, T6G 2G4 cajones@ualberta.ca 780 492 2020

Additional investigators: Candace Nykiforuk PhD, Marguerite Wieler PT PhD

Why am I being asked to take part in this research study?
You are being asked to participate in this research study because you are living with Parkinson's disease. We are conducting this interview with between 10 and 15 other participants.

The purpose of this form is to outline the expectations for participation in this study and outline how the information you help us create will be managed to protect your privacy. Before you choose to participate, one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything is unclear. You will be given a copy of this information sheet for your records.

What is the reason for doing the study?
Many older adults wish to "age in place", that is, to remain in their home for as long as possible. A person's ability to remain in the community depends not only what a person wishes and their health, but also the home and community they live in. Little is known about older adults moving in their living space such as their home and neighbourhood. Even less is known about the movement of people with Parkinson's disease. We are asking people about their mobility to get a better understanding of how much people move at home and in their communities. We also want to learn what are the difficulties with walking in communities.

What will I be asked to do?
Interview
We will conduct a single one-on-one interview with you. The questions that we will ask you are semi-structured, open-ended, and will be asked according to an interview guide that we have already prepared. During the interview, the person conducting the interview will be taking notes about your responses. At the end, they will read the notes back to you and ask if you

Ethics ID: Pro00086390
Page 1 of 4

think the notes match what was discussed during the interview.

Time commitment
The interviews will last between 20-30 minutes, depending on the length of your responses.

Location
Interviews will take place at Corbett Hall at the University of Alberta, at your home, or somewhere else that you are comfortable meeting.

What are the risks and discomforts?
There are no risks involved in participating in this study. You may feel uncomfortable answering questions about feelings or experiences; you do not have to answer all of the questions. There is no cost associated with participating in this research. If you are experiencing any type of emotional distress we can help you find resources in the community to support you, such as:

- Psychologists' Association Alberta - Psychologist Referral Service: 780-400-2271
- Catholic Social Services – Mercy Counselling: 780-391-3233
- Canadian Mental Health Association – Edmonton Region: 780-414-6300
- Sage Seniors Association – Social Worker: 780-423-5510 ext. 323
- Emotions Anonymous: 780-436-2951
- Momentum Walk – In-Counselling – Drop-in Support Groups: 780-757-0900
- University of Alberta – Faculty of Education: Clinical Services (September – April): 780-492-3746

It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me?
There are no direct personal benefits to taking part in this study. However, your participation will give us valuable information on what are the features of a community that is easy to move about or what are the features that make it especially difficult to move. We hope that the information we get from doing this study will help us better understand the experience of living with Parkinson's disease. Information is important in letting the community know what makes it easy or hard to move for older adults and for people with Parkinson's disease.

Do I have to take part in the study?
Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect the care or support that you are entitled to. You do not have to answer any interview question that you are not comfortable with and you can end the interview at any time.

Will my information be kept private?
Your interview will be audio-recorded and later transcribed by a research assistant. Personally identifying information, such as your name or names of other, will be replaced by acronyms and

the original audio-recordings will be deleted. You may ask that the audio-recorder be turned off at any time. You may ask that your information be withdrawn from the study up to the point that your interview is transcribed. By signing this consent form you are saying it is okay for the study team to collect, use and disclose information about you from your personal health records as described above. If you leave the study, we will not collect new health information about you, but we may need to keep the data that we have already collected.

Any personal information that you provide for this study will be kept confidential. Data will be kept in paper copy and encrypted electronic formats. Paper copies will be stored in Dr. Allyson Jones' locked office and electronic data on the Department of Physical Therapy server at the University of Alberta, which is only accessible to the research investigators by a password-protected login. We are required by University of Alberta policy to keep research documents for a minimum of five years after the study is completed. After that time, all paper and electronic formats will be destroyed in a way that ensures privacy and confidentiality.

During the study we will be collecting data about you. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

The information from this study may be used to plan future research, but if we do this it will have to be approved by a Research Ethics Board. You may request a report of the research findings and your own results at any time by contacting one of the study investigators. Information gathered from this study may be published or presented in public forums; however, we will never use or reveal your name or any other personally identifying information.

What if I have questions?
If you have any questions about the research now or later, please contact:

Charlotte Ryder-Burbidge (Research Investigator)
ryderbur@ualberta.ca
780-492-1610

Dr. Allyson Jones (Supervisor)
cajones@ualberta.ca
780-492-2020

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

2-50 Corbett Hall
8205 - 114 St.
Edmonton, Alberta
Canada T6G 2G4

CONSENT FORM

Title of Study: Does living with Parkinson's disease impact life-space mobility?: A mixed-methods study
Principal Investigator(s): Charlotte Ryder-Burbidge - ryderbur@ualberta.ca - 780-492-1610
Dr. Allyson Jones - cajones@ualberta.ca - 780-492-2020

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your future care and support without penalty.	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your study records?	☐	☐
Do you agree to be contacted for follow-up or to facilitate future research?	☐	☐

Who explained this research to you? ____

I agree to take part in this study:
Signature of Research Participant: ____

(Printed name): ____

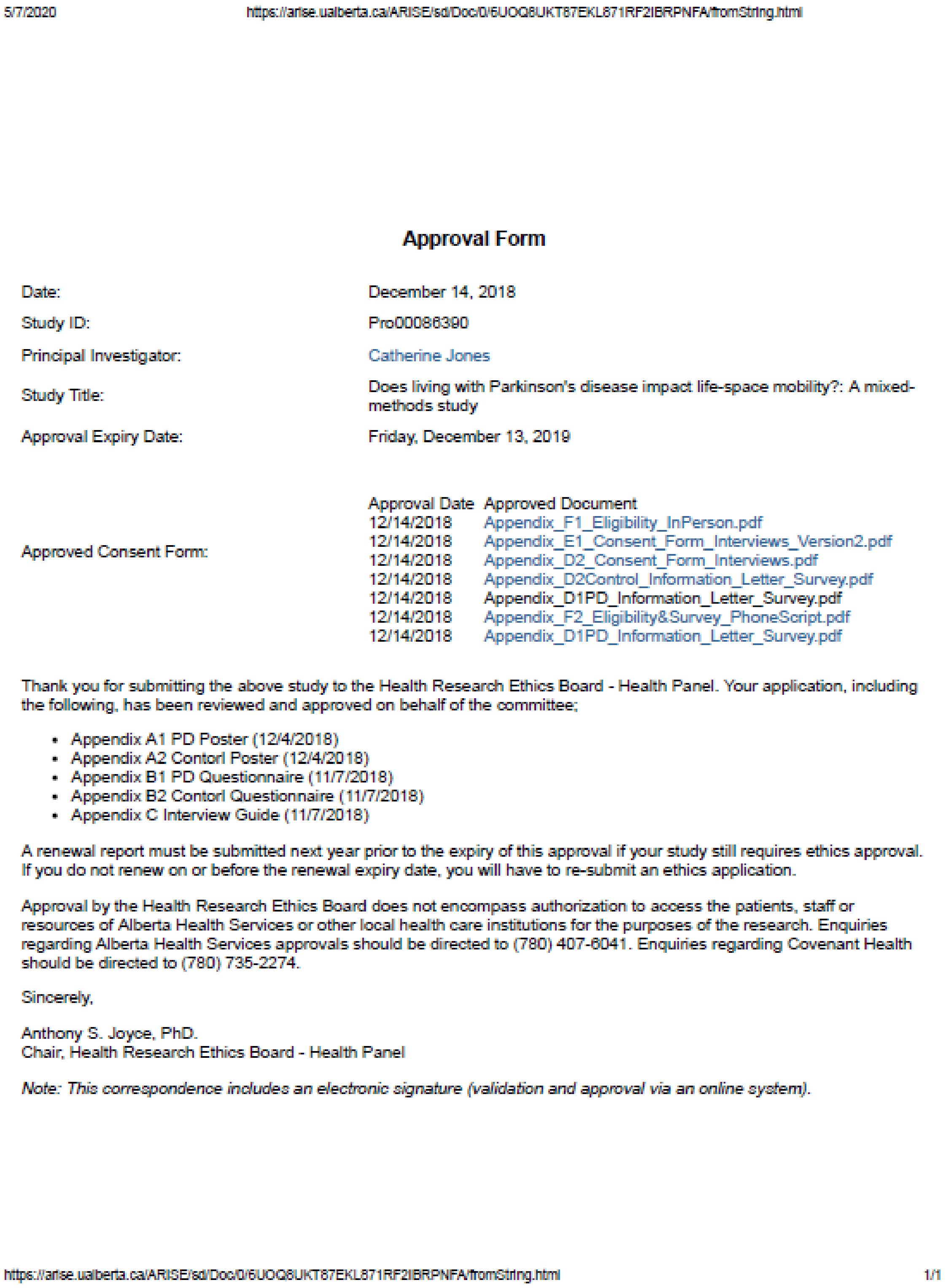
Date: ____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee: _______________________ Date: _________________

Ethics ID: Pro00086390

Appendix 4. Letter of ethics approval from the University of Alberta Health Research Ethics Board.



5/7/2020 https://arise.ualberta.ca/ARISE/sd/Doc/0/6UOQ8UKT87EKL871RF2IBRPNFA/fromString.html

Approval Form

Date: December 14, 2018

Study ID: Pro00086390

Principal Investigator: Catherine Jones

Study Title: Does living with Parkinson's disease impact life-space mobility?: A mixed-methods study

Approval Expiry Date: Friday, December 13, 2019

Approved Consent Form:

Approval Date	Approved Document
12/14/2018	Appendix_F1_Eligibility_InPerson.pdf
12/14/2018	Appendix_E1_Consent_Form_Interviews_Version2.pdf
12/14/2018	Appendix_D2_Consent_Form_Interviews.pdf
12/14/2018	Appendix_D2Control_Information_Letter_Survey.pdf
12/14/2018	Appendix_D1PD_Information_Letter_Survey.pdf
12/14/2018	Appendix_F2_Eligibility&Survey_PhoneScript.pdf
12/14/2018	Appendix_D1PD_Information_Letter_Survey.pdf

Thank you for submitting the above study to the Health Research Ethics Board - Health Panel. Your application, including the following, has been reviewed and approved on behalf of the committee;

- Appendix A1 PD Poster (12/4/2018)
- Appendix A2 Contorl Poster (12/4/2018)
- Appendix B1 PD Questionnaire (11/7/2018)
- Appendix B2 Contorl Questionnaire (11/7/2018)
- Appendix C Interview Guide (11/7/2018)

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Alberta Health Services or other local health care institutions for the purposes of the research. Enquiries regarding Alberta Health Services approvals should be directed to (780) 407-6041. Enquiries regarding Covenant Health should be directed to (780) 735-2274.

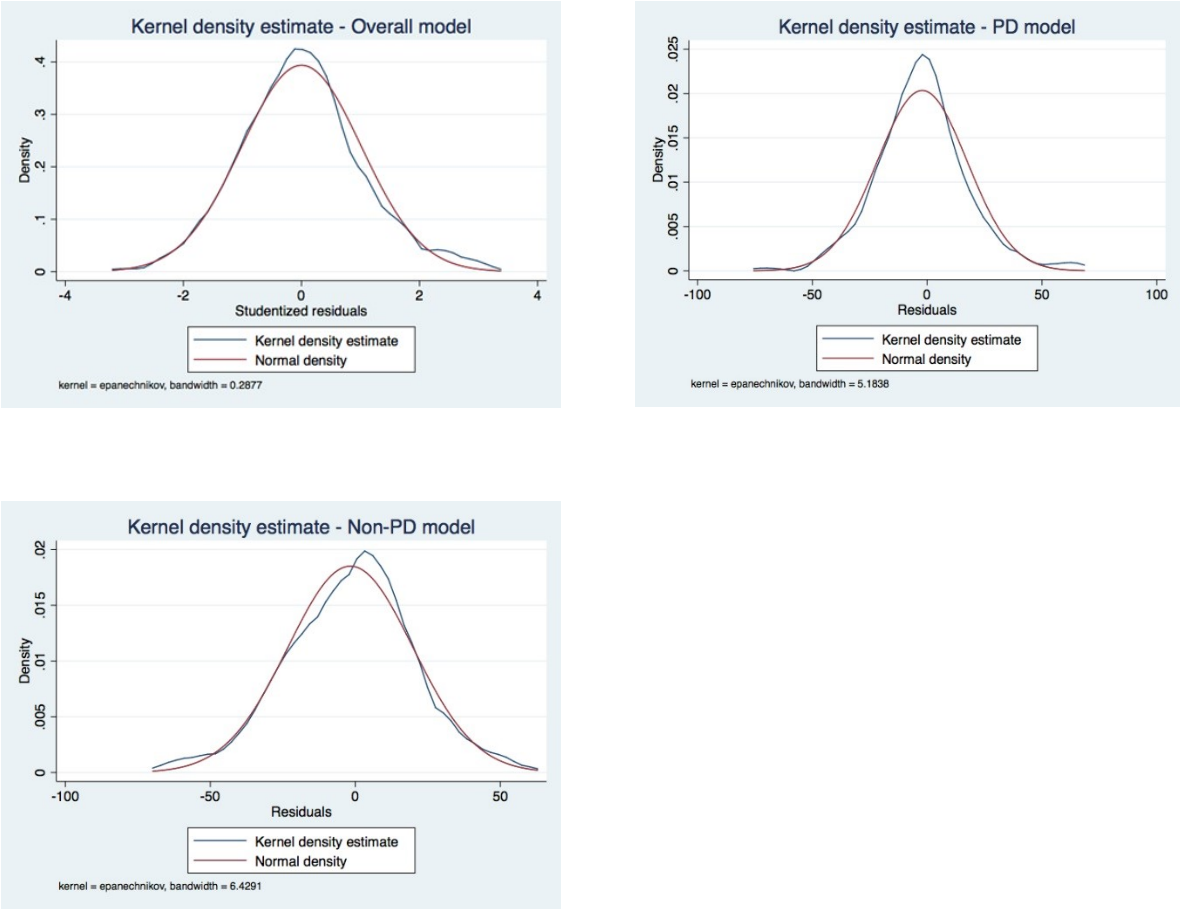
Sincerely,

Anthony S. Joyce, PhD.
Chair, Health Research Ethics Board - Health Panel

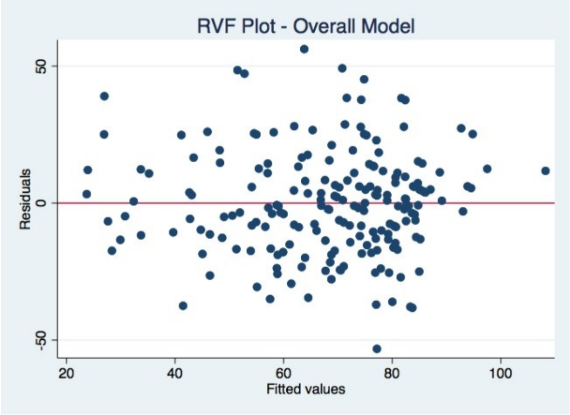
Note: This correspondence includes an electronic signature (validation and approval via an online system).

https://arise.ualberta.ca/ARISE/sd/Doc/0/6UOQ8UKT87EKL871RF2IBRPNFA/fromString.html 1/1

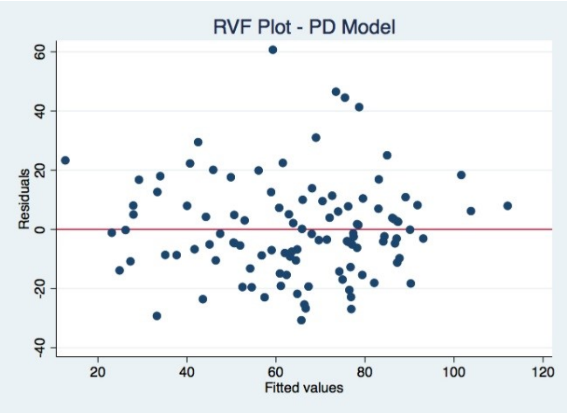
Appendix 5. Plots of regression diagnostics for testing for unusual and influential data, homoscedasticity of residuals and normal distribution of residuals. A. Kernal density plot of residuals for the overall model. B. Kernal density plot of residuals for Parkinson's disease model. C. Kernal density plot of residuals for non-Parkinson's disease model. D) Residuals-versus-fitted plot of residuals for the overall model. E) Residuals-versus-fitted plot of residuals for Parkinson's disease model. F) Residuals-versus-fitted plot of residuals for non-Parkinson's disease model.


A) B) C)

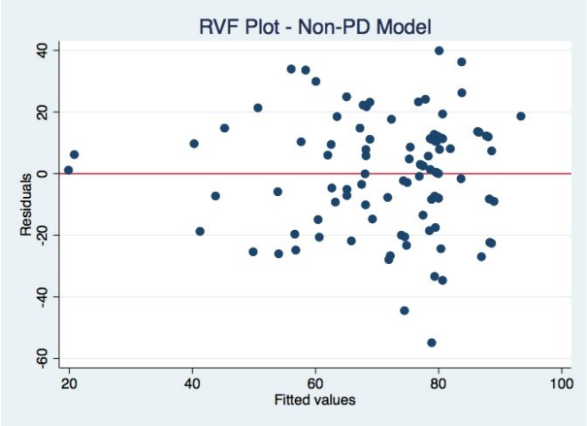
D)


RVF Plot - Overall Model
Residuals
50
0
-50
20
40
60
80
100
Fitted values

E)


RVF Plot - PD Model
Residuals
60
40
20
0
-20
-40
20
40
60
80
100
120
Fitted values

F)


RVF Plot - Non-PD Model
Residuals
40
20
0
-20
-40
-60
20
40
60
80
100
Fitted values

Appendix 7. Semi-structured interview guide.

Interview Guide

Opening remarks for interview
Firstly, I want to thank you for agreeing to speak with me today. I am talking with people living with Parkinson's in Alberta to better understand the experience of moving in and around your home and community.

As mentioned in the consent form which you just reviewed and signed, the interview is part of a larger study and will take about 30 minutes. Over the course of our discussion, I will ask you a set of questions, but I welcome any other input that you would like to provide.

I'd like to highlight that you don't need to answer any questions that you do not want to and your participation in the interview is voluntary so we can stop at any time.

This discussion will be audio-recorded so that it can be transcribed into text and reviewed at a later time by myself and other researchers. Even before it is shared with anyone else on the research team, we will take out any information that could be used to identify you, such as names of people or places.

During the course of the interview, I will be jotting down some short notes about our discussion to help me review what we've talked about with you at the end. I will also be periodically checking the recorder to make sure it is still recording, and I will be checking my watch because I want to be mindful of your time.

Do you have any questions before we begin? May I proceed with the first question?

If the participant says, "yes" and has no questions, proceed with the questions below. If the participant says, "no", ask if they have any further questions or concerns and thank them for their time.

Questions

1. Would you mind telling me about your experience with Parkinson's disease so far?
Probes:
- Can you tell me about how and when you were diagnosed?
- When did you experience an onset of symptoms?
- What are the typical symptoms that you experience?
- What has your experience been with your medications?
- Other than taking medication, are there things that you do to help relieve your symptoms?
- Who are the people that support you in your journey with Parkinson's?

2. As you know, one of the reasons that we're doing this research is to better understand the mobility of people with Parkinson's disease. However, the word "mobility" can mean different things to different people. What does "mobility" mean to you?
Probes:

- Can you describe why "mobility" is important to you?
- Has your understanding of "mobility" changed over the course of your life?

3. Thinking about your own mobility, can you tell me a story about a time when you had a difficult time getting somewhere that you needed to go?
Probes:

- Were there any other (environmental/ financial/ personal) factors that influenced your ability to get to [the place]?

4. Once again, thinking about your own mobility, can you tell me a story about a time when you faced a challenge getting somewhere but you were able to come up with a way to overcome that challenge?
Probes:

- Were there any other (environmental/ financial/ personal) factors that influenced your ability to get to [the place]?
- Has your ability to cope with this challenge changed over time?

8. Those are all of my questions. Is there anything else you think I should know to better understand your experience with Parkinson's, especially in relation to how you move around in your home and community?

9. As we are finishing the interview, is there anything you would like to ask me?

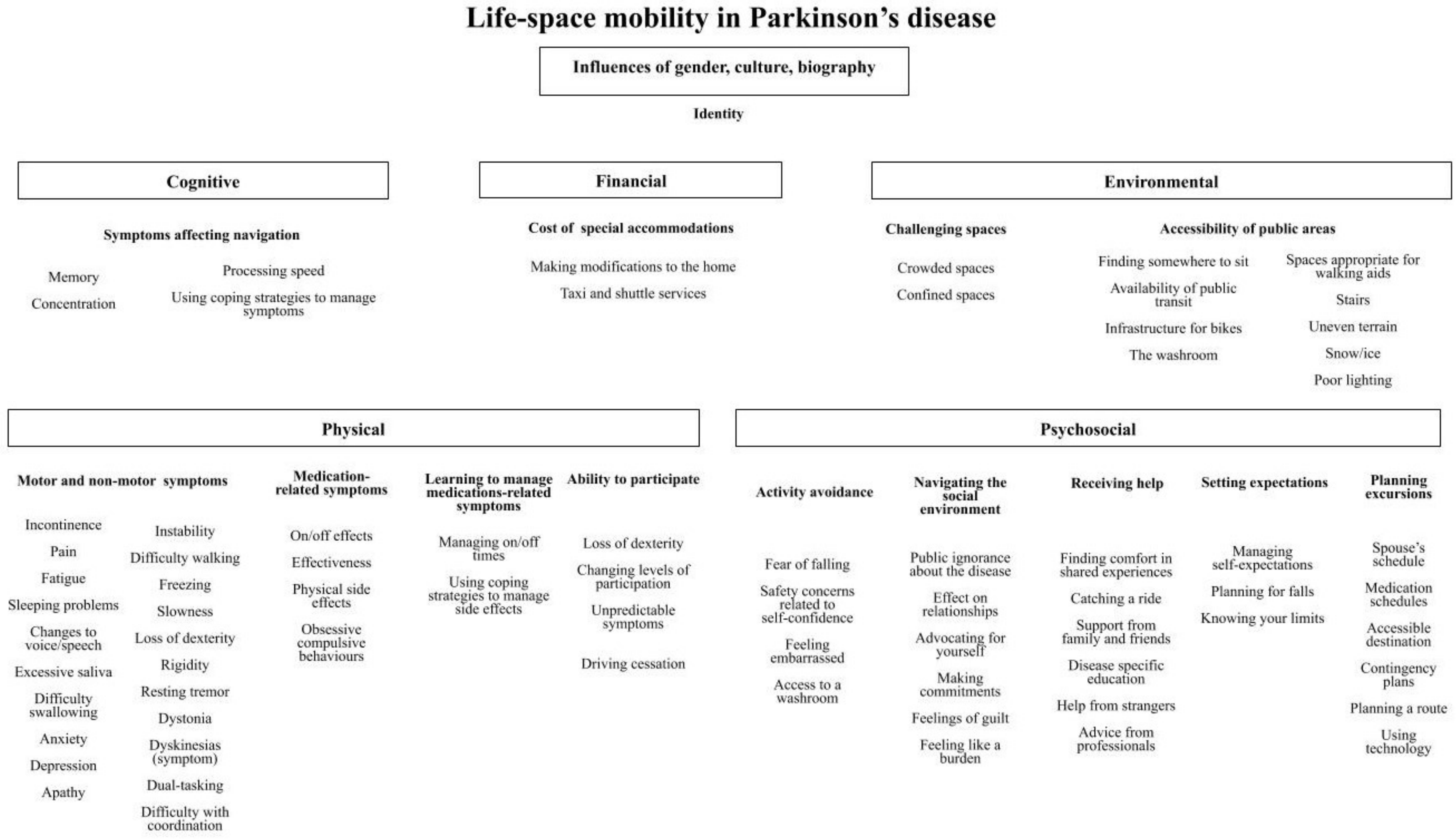
Next, I'm going to review with you some of my notes and what I understood to be some of the takeaways from this discussion.

Review notes and highlights of the discussion.

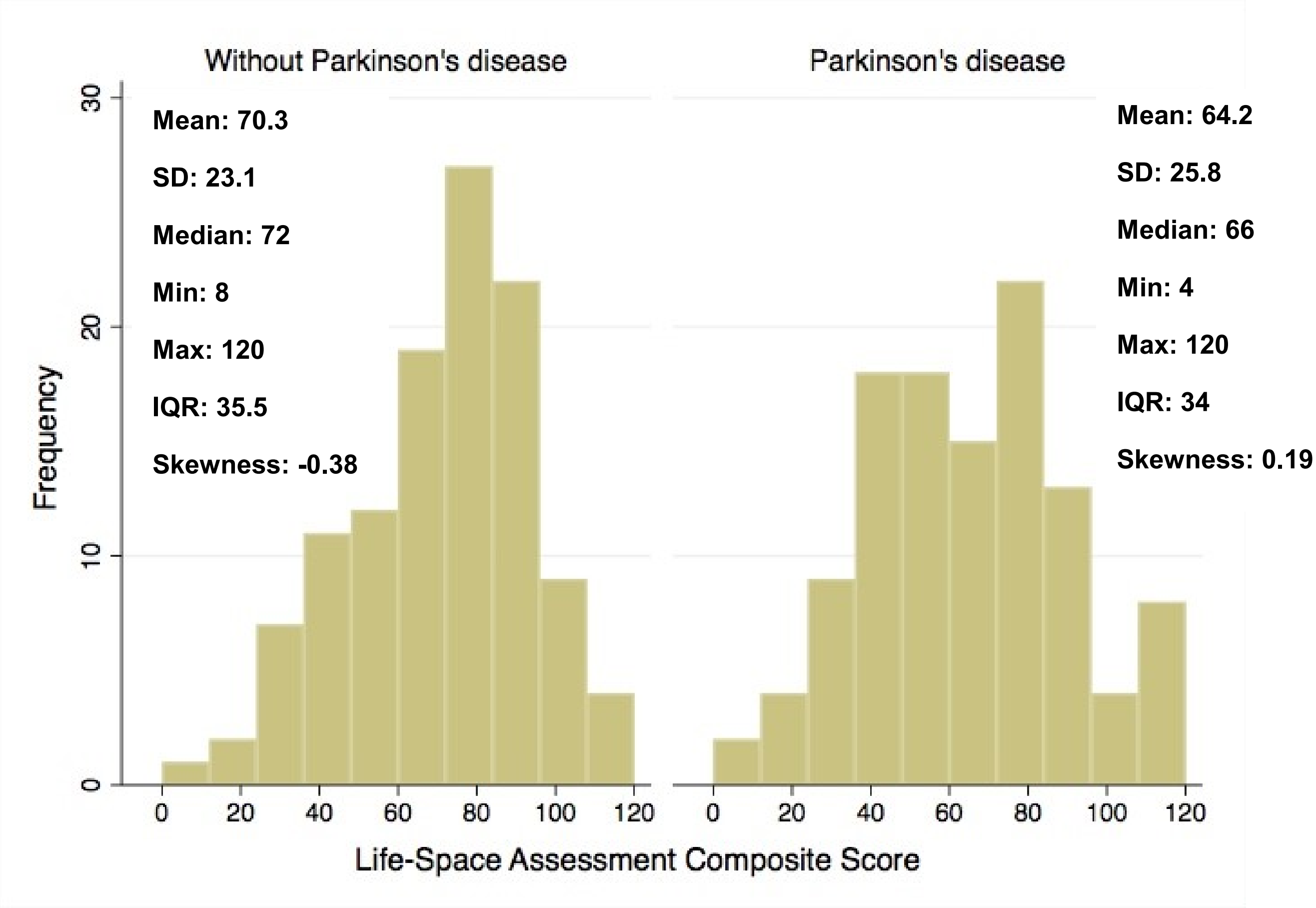
Do you agree that these notes are representative of your interview? Is there anything that you would like me to change or add?

Thank you for taking the time to share your experiences with me today. I really appreciate your help.

Appendix 7. Code tree representing themes and sub-themes emerging from interviews with 10 individuals with Parkinson's disease and relating to Webber's mobility determinants for older adults and including the overarching influence of biography.



Appendix 8. Histograms and summary statistics of life-space assessment composite score (LSA-C) for groups with and without Parkinson's disease.



Appendix 9. Additional univariate associations between covariates and life-space mobility composite score among the overall, PD and without-PD sample.

	Overall			Parkinson's disease			Without Parkinson's disease		
Covariate (reference)	Coefficient *(SE)*	Stan. Beta	95% CI	Coefficient *(SE)*	Stan. Beta	95% CI	Coefficient *(SE)*	Stan. Beta	95% CI
Education (High school or less)									
Some postsecondary	**11.7 (4.3)**	**0.20**	**3.3, 20.3**	4.5 (6.9)	0.07	-9.2, 18.2	**15.5 (5.5)**	**0.30**	**4.7, 26.4**
Completed postsecondary	3.8 (3.7)	0.07	-3.5, 11.1	3.9 (5.4)	0.10	-6.9, 14.6	3.4 (5.0)	0.10	-6.6, 13.4
Employment status (Working or volunteering)									
Retired	**-6.2 (7.1)**	**-0.08**	**-20.1, -7.7**	-7.9 (10.1)	-0.11	-27.9, 12.1	-5.2 (9.6)	-0.06	-24.3, 13.9
On disability or unemployment	-7.8 (9.7)	-0.07	-26.8, 11.3	**1.9 (13.0)**	**0.02**	**-23.9, 27.7**	-27.0 (14.8)	-0.22	-56.4, 2.3
Married (Single/Widowed/Separated)	1.3 (3.5)	0.02	-5.6, 8.1	-2.7 (6.5)	-0.04	-15.6, 10.2	7.6 (4.3)	0.17	-0.9, 16.2
Living situation (Living alone)									
Living with spouse	3.3 (3.8)	0.06	-4.1, 10.7	3.3 (7.4)	0.05	-11.4, 18.0	8.3 (4.6)	0.18	-0.7, 17.4
Living with others	7.4 (6.9)	0.08	-6.3, 21.0	15.4 (13.5)	0.12	-11.3, 42.1	4.3 (7.7)	0.05	-11.0, 19.6
Locale (Rural)	3.6 (7.6)	0.03	-11.5, 18.6	-2.6 (8.6)	-0.03	-19.5, 14.4	33.6 (23.4)	0.14	-12.3, 79.4
Never smoked	-0.3 (3.3)	-0.01	-6.9, 6.2	3.5 (4.9)	0.07	-6.2, 13.2	-3.3 (4.4)	-0.07	-12.1, 5.4
Use of alcohol (<1/month)									
2-4x/month	8.1 (4.2)	0.14	-0.1, 16.3	**16.0 (6.1)**	**0.25**	**3.9, 28.1**	-0.3 (5.6)	-0.01	-11.3, 10.7
2-7x/week	3.9 (4.3)	0.06	-4.5, 12.3	10.5 (6.0)	0.17	-1.5, 22.4	-3.6 (6.0)	-0.06	-15.5, 8.2
Meeting physical activity guidelines (No)	**14.9 (2.0)**	**0.29**	**8.4, 21.5**	**18.9 (4.8)**	**0.35**	**9.4, 28.3**	**11.0 (4.5)**	**0.23**	**2.1, 19.9**
Self-rated overall physical health (Excellent or very good)									
Good	**-8.0 (3.7)**	**-0.16**	**-15.3, -0.8**	**-16.7 (5.9)**	**-0.32**	**-28.3, -5.0**	-1.2 (4.6)	-0.03	-10.3, 7.8
Fair or poor	**-19.5 (4.1)**	**-0.35**	**-27.7, -11.4**	**-22.8 (6.0)**	**-0.43**	**-34.6, -10.9**	**-16.8 (6.2)**	**-0.27**	**-29.1, -4.5**
Self-rated overall physical health (Excellent or very good)									
Good	**-9.8 (4.4)**	**-0.19**	**-16.6, -2.9**	**-20.4 (5.3)**	**-0.39**	**-30.8, -9.9**	0.1 (4.7)	0.00	-9.3, 9.5
Fair or poor	**-17.2 (4.5)**	**-0.27**	**-26.0, -8.5**	**-24.3 (5.9)**	**0.42**	**-35.9, -12.6**	-8.3 (8.2)	-0.10	-24.5, 7.9
Self-rated overall physical health (Excellent or very good)									
Good	**-9.2 (3.6)**	**-0.18**	**-16.3, -2.0**	**-18.1 (5.6)**	**-0.34**	**-29.2, -7.0**	-2.1 (4.7)	-0.05	-11.4, 7.1
Fair or poor	**-18.4 (4.2)**	**-0.32**	**-26.7, -10.0**	**-25.1 (5.8)**	**-0.50**	**-36.7, -13.6**	-9.0 (6.8)	-0.13	-22.5, 4.5
I really feel a part of this area (Agree)									
Neither agree nor disagree	-7.7 (4.8)	-0.11	-17.2, 1.8	-8.4 (6.7)	-0.12	-21.7, 4.9	-5.8 (7.0)	-0.08	-19.6, 8.1
Disagree	-15.3 (7.9)	-0.13	-30.9, 0.4	-12.5 (9.9)	-0.12	-32.2, 7.2	-17.7 (13.8)	-0.12	-45.1, 9.7
Vandalism or graffiti are a big problem in this area (Agree)									
Neither agree nor disagree	-0.8 (5.9)	-0.01	-12.5, 10.9	-12.7 (10.0)	-0.18	-32.6, 7.1	10.1 (7.4)	0.15	-4.7, 24.8
Disagree	-0.3 (4.6)	-0.01	-9.3, 8.6	-4.9 (8.3)	-0.08	-21.3, 11.6	3.1 (5.4)	0.06	-7.6, 13.9
Most people in this area can be trusted (Agree)									
Neither agree nor disagree	-2.0 (5.1)	-0.03	-11.9, 8.0	-13.4 (9.5)	-0.12	-32.2, 5.4	1.0 (5.9)	0.02	-10.8, 12.7
Disagree	8.2 (6.7)	0.08	-5.0, 21.4	10.0 (10.1)	0.09	-10.0, 29.9	6.0 (8.8)	0.07	-11.4, 23.5
People in this area will take advantage of you (Agree)									
Neither agree nor disagree	-6.1 (7.7)	-0.09	-21.3, 9.1	-15.2 (13.4)	-0.20	-41.6, 11.3	0.4 (9.2)	0.01	-17.9, 18.6
Disagree	-0.1 (6.6)	0.00	-13.2, 12.9	-7.6 (11.9)	-0.11	-31.1, 16.0	5.7 (7.7)	0.11	-9.7, 21.0
This area is kept very clean (Agree)									
Neither agree nor disagree	-4.7 (5.1)	-0.06	-14.8, 5.3	-12.5 (8.9)	-0.12	-30.2, 5.1	-1.6 (6.0)	-0.03	-13.5, 10.3
Disagree	-2.1 (5.3)	-0.03	-12.4, 8.3	**-14.5 (7.3)**	**-0.19**	**-29.0, 0.0**	12.4 (7.3)	0.17	-2.0, 26.8
If you were in trouble, there are lots of people in this area who would help you (Agree)									
Neither agree nor disagree	-6.6 (5.0)	-0.09	-16.4, 3.2	-11.4 (7.2)	-0.15	-25.6, 2.7	-1.4 (6.9)	-0.02	-15.0, 12.3
Disagree	-7.1 (6.3)	-0.08	-19.5, 5.5	-11.0 (10.1)	-0.10	-31.0, 8.9	-5.1 (8.0)	-0.06	-20.9, 10.8
People in this area are unfriendly (Agree)									
Neither agree nor disagree	0.7 (7.0)	0.01	-13.1, 14.5	-1.3 (12.5)	-0.02	-26.1, 23.6	1.9 (8.1)	0.04	-14.2, 18.1
Disagree	7.0 (6.2)	0.13	-5.3, 19.2	5.6 (10.9)	0.09	-16.0, 27.3	10.4 (7.3)	0.21	-4.1, 25.0

Appendix 10. Characteristics of interview participants with Parkinson's disease.

	Frequency (n = 10)
Gender (male)	5
Age, mean (SD)	68.9 (6.0)
Years diagnosed, mean (SD)	10.9 (8.0)
Deep brain stimulation	2
Education	
Completed high school	2
Some postsecondary	2
Completed postsecondary	6
Employment status	
Retired	9
Disability or sick leave	1
Marital status	
Married	8
Single or widowed	2
Family finances	
Some money left over	7
No extra money in the house	2
Walking ability	
Unlimited	6
6 to 10 blocks	2
Less than one block	2
Walking limitations	
No limitations	1
Pain and/or discomfort	3
Fatigue	5
Uses assistive device	6
Monthly family finances	
Some money left over	7
Just enough to make ends meet	2
Prefer not to say	1
Receiving formal caregiving	2
Receiving informal caregiving	2
Self-rated overall health	
Excellent	0
Very good	4
Good	4
Fair	1
Poor	1
Number of chronic conditions, mean (SD)	2.5 (1.8)
Social participation index, mean (SD)	12.9 (6.4)
No driver's license	3
Life-space mobility, mean (SD)	64.6 (21.6)

Appendix 11. Additional quotations from semi-structured interviews with participants with PD representing barriers and facilitators to mobility organized by Webber's mobility determinants.

Mobility determinant	Theme	Quote
Psychosocial	Activity avoidance	"If I'm in a restaurant and need help getting up, I feel like everybody is watching, and I feel I'm really on the spot. It's uncomfortable...It makes me feel very vulnerable." (P78, female)
	Navigating the social environment	"Advocating for yourself and checking out resources and figuring out where you go for information and resources, has been one lesson that I've learned well." (P20, female)
	Planning excursions	"Every place I go I have a route planned, that I know where the parking lots are and where there's a coffee shop or something and I can get out of the car and wait for [the shaking] to go away." (P97, female)
	Receiving help	"I probably didn't [come up with coping strategies] individually, but from being in the [Parkinson's] support group...some people will talk about different things that they do. And so, you put those things all together and think, oh I think I'll give that a try." (P4, male)
	Setting expectations	"[It] seemed a bit overwhelming at first, but you know about six months in you kind of get over the anger and realize that's pointless and you start learning more about the disease and realize its not the end of the world, and there are now medications that can help, and that that the tremor is not the worst thing in the world – as annoying as it is."(P38, female)
Physical	Non-motor and motor symptoms	"I've been having some problems recently with falls. And that's cause I freeze and, and in order to get myself going I need to just lean forward and – or I try to take – dragging my legs maybe. And then I end up in vibrating, and then you just start going." (P71, male)
	Experiences with medication	"I had to give up driving… because I couldn't be sure of when my pills were going to work and when they weren't." (P97, female)
	Management of symptoms	"[The walker is] at it's best when I'm in places like West Edmonton Mall, on a busy day...You take that thing and suddenly people take note, but they kind of start moving away from you...It's funny, you know, it really is – there's a whole psychology to this thing." (P2, male)
		"A friend called me last week and said a bunch of us are going to the movie Downton Abbey. And I thought, you know, I would love to go, but I know I have to take my walker, and who knows if there will be stairs... I can go upstairs slowly, but then what happens to my walker?" (P38, female)
	Ability to participate	"[My husband] drives me pretty much where I want to go, but I don't like to be getting him to be – him to do it all; you know all the time. I try and make other arrangements if I can." (P38, female)
Environmental	Challenging spaces	"I find [PD has] impacted me in that I don't, we don't go out as much as we used to because it – some situations are really hard for me, like being in a crowd of people, I get anxiety." (P38, female)
	Accessibility of public spaces	"There's other things like, well, going to the bath – the first you look for any place you've never been, and you find out where the washrooms are. Cause once my system says you need to go to the washroom, I got about 15 seconds to get there." (P41, male)
Financial	The cost of making special accomodations	"I've told the folks, like in charge of the speaker series, let's get out the health care people that provide that service and learn more about what's this going to cost me...what's the feasibility of me getting somebody to help me when I need it? What are the driving services around? Like let's get educated on it now, so it feels like I have to really do all that on my own." (P20, female)
Cognitive	Symptoms affecting navigation and ambulation	"I've had a couple of times where I've been a little flustered and just pulled over to the side of the road and turned off my car and stopped and re-looked at my directions and tried to figure out where I made the mistake...And then to just sort of recalculate and restart." (P4, female)
Influence of biography, gender, culture	Identity	"My independence overall, just - you know - depending on somebody for everything – it's hard cause I was sort of the person to do it in our family. Everybody came to me for things they wanted done." (P38, female)
		"Sooner or later the walls start closing in on you; you can't just jump in the car and go to Winnipeg today." (P2, male)

Appendix 12. Knowledge translation info-graphic for distribution to the public.

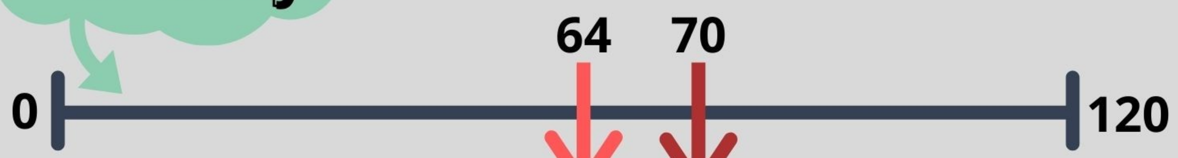
Life-space mobility among Albertans with Parkinson's disease

WHAT: Researchers at the **University of Alberta** conducted a **survey** to understand if and how "life-space mobility" varies between **people with and without Parkinson's disease (PD)**. Some participants also did an **interview** to further share their **experiences with mobility**.

WHO: **113 Albertans with PD** and **114 Albertans without PD**

WHY: To help understand the best way **to help people with PD age-in-place and stay mobile, active and involved in the community!**

Life-space mobility = **The frequency, distance and independence of trips within the home and community in an average week.**



Staying in bed, everyday

people **with** Parkinson's disease

people **without** Parkinson's disease

Going out of town, without any help, everyday

Participants with PD had higher life-space mobility if they...

...were financially comfortable.

...had a valid driver's license.

...had higher levels of social participation.

...were able to live independently without extra help from caregivers.