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Measuring Community Mobility in Older Adults with Parkinson's Disease Using A Wearable GPS Sensor And Self-report Assessment Tools

Lynn Zhu, The University of Western Ontario

Supervisor: Dr. Mark Speechley, *The University of Western Ontario* A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Epidemiology and Biostatistics © Lynn Zhu 2017

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Abstract

Community mobility (CM) is an important instrumental activity of daily living associated with quality of life and independence. Measuring the CM of older adults, particularly those with gait disorders such as Parkinson's disease (PD), is an important way to understand how to help people maintain mobility in the real life setting. CM is measured using self-report measures and emergent technologies, such as wearable Global Positioning System (GPS) sensors. However, the measurement properties of most available assessments have not been compared within a PD population to determine their appropriateness and identify any feasibility issues.

The primary objective of this project was to compare a novel instrumented measure (Wireless Isoinertial Measurement unit with GPS; WIMU-GPS) with a self-report diary and the Life Space Assessment (LSA). To accomplish this aim, a review of literature was first conducted to show that the validity and reliability between mobility measures were seldom assessed in existing comparison studies. Then, seventy people with early to mid-stage PD (67.4 ± 6.5 years, 67.1% men) wore the WIMU-GPS and completed the self-report diaries and LSA for a 14 day period. Moderate agreements were observed between WIMU-GPS and diary for trip frequency and duration (Intraclass correlation coefficient [ICC] = 0.71, 95% CI = 0.51 to 0.82; 0.67, 95% CI = 0.42 to 0.82, respectively). Disagreement between these two measures was higher for duration, particularly among individuals who regularly worked or volunteered. Convergent validity and good reliability was attained for trip frequency (Spearman correlation coefficient $[r_s] = 0.69$, 95% CI = 0.52 to 0.81; ICC = 0.714, 95% CI = 0.51 to 0.82) and duration outside ($r_s = 0.43, 95\%$ CI = 0.18 to 0.62; ICC = 0.674, 95% CI = 0.42 to 0.82) measured by the WIMU-GPS and diary. However, convergent validity was not observed between WIMU-GPS recordings and LSA reported life space size ($r_s = 0.39, 95\%$ CI = 0.14 to 0.60). The LSA exhibited ceiling effects and discrimination issues. It should be avoided as a CM measure when it is feasible to use the WIMU-GPS and diary instead.

The secondary objective was to determine the utility and feasibly of using WIMU-GPS to quantify different dimensions of CM in people with PD. Using a subset of participants, it was first determined that sampling error was minimized in non-discrete continuous outcomes, such as "time outside" and "area size", when daily WIMU-GPS recordings lasted at least 600 minutes. A shorter recording minimum of at least 500 minutes per day was also suitable for discrete

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outcomes, such as "trip count" and "hotspot count". The sample size precluded the determination of the optimal number of days of recording. However, data from at least seven distinct days of recording is required to capture the natural fluctuations in CM between days of the week. From a practical standpoint, a minimum of seven distinct recording days were best attained if the WIMU-GPS was worn for at least eight days. Next, the new minimum GPS recording length was adopted in a larger subset of the sample to show that people living with PD were regularly in their communities, and they preferred vehicular travel over walking when travelling to a destination. Distances walked by people with PD increased when they perceived higher levels of PD-related impact on emotional wellbeing (Pearson correlation [r] = 0.40, p < 0.01) and bodily discomfort (r = 0.30, p = 0.03). Complementary diary data also showed people with PD were making regular weekly visits to medical facilities.

Finally, the body of work described in this Dissertation culminated in a series of practical recommendations for those interested in the CM of an older PD population or wishing to use GPS sensors for assessing real-life CM. The results of this Dissertation also are useful resources for the development of needed standards on how mobility measurements should be compared, and on the study design, data collection, and reporting of health data using GPS sensors.

Keywords:

Parkinson's disease, assessments tools, mobility, measurement comparison, community mobility, mobility assessments, objective assessment, wearable sensors, Global Positioning System, longitudinal recording, recording length, validity, reliability, agreement

Co-Authorship Statement

All four manuscripts in this dissertation were written by Lynn Zhu (LZ) for her doctoral work requirement, under the supervisory guidance of Dr. Mark Speechley and advisory committee members, Drs. Christian Duval, Mandar Jog, GY Zou and Manuel Montero-Odasso.

Study ideas outlined in this Dissertation were conceived by LZ and Dr. Speechley. For Study 1, LZ refined the search strategy with the assistance of John Costella from Taylor library. All data extraction charts, literature searches, literature review, data extraction and interpretation were done by LZ, in consultation with the advisory committee.

For studies 2-4, LZ participated in the designing of the pilot study protocol and advised on the design of the full-scale study. From February to May 2011, and from March to July 2012-2014, LZ also attended Dr. Jog's weekly Movement Disorders Clinic to learn about PD, and to screen participants for study eligibility and recruit participants. She adapted the pilot and full study protocol for a PD population. She also created all research ethics submissions and performed clerical duties including: participant scheduling and follow up, purchasing and organizing study equipment, performing regular upkeep of study kits, organizing data collection logistics and transportation, and preparing/submitting expense claims. For the first 35 participants, she also supervised a research assistant (RA), who assisted her in primary data collection and data entry.

From April to October of 2011 – 2014, LZ drove to participants' homes across Southwestern Ontario 229 times to complete the pilot and full scale study and related troubleshooting tasks. During these visits, she performed all of the data collection protocol described in this study, except for 25 second home visits (completed by RA). She worked with colleagues from the Ecological Mobility in Aging and Parkinson's (EMAP) Grant Team to preprocess, process and troubleshoot each data file obtained using the WIMU-GPS and other EMAP project sensors.

LZ coordinated and performed manual data entry (of diary and questionnaires), cleaning, matching and management, as well as database creation. With guidance from Dr. Speechley, the advisory committee and the EMAP group, LZ planned and performed all data extraction, code writing and analyses. As well, with their feedback, she created all graphs and tables, manuscripts, and presentations on the project results at three yearly team meetings in Montreal, and six national and international research conferences.

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Dedications

I dedicate this work to two groups of people who have motivated me to push through barriers:

First are my grandmothers, my role models in lifelong learning and commitment. Ah-ma taught me that no one can take education away. Niangniang sacrificed her own early education so others can achieve more.

Second are the inspiring and kind community of people living with Parkinson's disease. The participants of my research studies, and my friend Ms. Ma, have taught me unforgettable life lessons about aging, perseverance, resourcefulness, getting back up and self acceptance.

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Table of Contents

Abstract	III
Co-Authorship	V
Dedications	VI
Acknowledgements	VII
Table of Contents	IX
List of Tables	XII
List of Figures	XIV
List of Abbreviations	XVI
Chapter 1: Introduction and Literature Review	1
1.1 Background: Aging, morbidity and mobility	1
1.2 Mobility in an age-related condition: Parkinson's disease and mobility	6
1.3 Measuring community mobility	7
1.4 Measurement theory	10
1.5 Comparing community mobility assessments	15
1.6 References	16
Chapter 2: Research Overview	24
2.1 Objectives	24
2.2 Hypotheses	25
2.3 Contributions of Dissertation	26
2.4 Organization of dissertation	27
Chapter 3: Research Methods	28
3.1 Dataset creation	28
3.2 References	36
Chapter 4: Study 1. Literature Review of Studies Comparing Methods of Measuri Mobility	ing Community 37
4.2 Methods	40
4.6 References	58

Chapter 5: Study 2. Comparing wearable activity sensors and self report measures of real life mobility65	
5.1 Introduction	65
5.2 Methods	67
5.3 Results	70
5.4 Discussion	80
5.5 Conclusions	86
5.6 References	86
Chapter 6: Study 3. Sampling strategies for long duration recording of community mobil	ility91
6.1 Introduction	91
6.2 Objectives	93
6.3 Methods	94
6.4 Results	97
6.5 Discussion	111
6.6 Conclusion	116
6.7 References	118
6.8 Appendix	123
Chapter 7: Study 4. Quantifying community mobility of older adults with Parkinson's d	isease 127
7.1 Introduction	127
7.2 Methods	129
7.3 Results	133
7.4 Discussion	145
7.5 Conclusions	149
7.6 References	150
Chapter 8: Discussion	155
8.1: Summary of Key Findings	155
8.2: Implications of Findings: Recommendations for measuring community mobility	167
8.3: Additional study limitations	170
8.4: Additional study strengths	171
8.5: Future directions	172
8.6: Conclusions	174

8.7: References	175
8.5: Appendix	184
Appendices	185
Appendix A: University of Western Ontario Ethics Approval	186
Appendix B: Lawson Health Research Institute Ethics Approval	186
Appendix C: Letter of Information	188
Appendix D: Participant Consent Form	
Appendix E: Instructions for Participants	
Appendix F: Overview of WIMU-GPS troubleshooting instructions	
Appendix G: Life Space Assessment	
Appendix H: Daily Displacement Diary	201
Appendix I: General demographics questionnaire	204
Appendix J: Comorbidity Index	205
Appendix K: Montreal Cognitive Assessment	206
Appendix L: MOS Social Support Survey	206
Appendix M: SF-12 Health Survey	209
Appendix N: Parkinson's Disease Questionnaire	212
Appendix O: Phone-FITT	215
Curriculum Vitae	221

List of Tables

Chapter 3 Research Methods

Table 3.1. Inclusion and exclusion criteria of participants.

Table 3.2. Data sources of study covariates.

Chapter 4 Study 1

Table 4.1. Search terms according to the topic of interest.

Table 4.2a. Recommended validity measures for studies comparing alternative assessment methods.

Table 4.2b. Recommended reliability, agreement and error measures for method comparison studies.

Table 4.3. Study quality assessment criteria.

Table 4.4. Characteristics of mobility methods comparison studies (n=10), according to date.

Table 4.5. Analysis methods employed by each study (n=10).

Table 4.6. Summary of study quality according to criteria used. (n=10).

Chapter 5 Study 2

Table 5.1. Participant demographics and PD-related covariates (n=54) of Study 2.

Table 5.2. Mean mobility outcomes measured by self-report measures and WIMU-GPS.

Table 5.3. Statistically significant predictors of "hourly frequency" captured by WIMU-GPS and Diary.

Table 5.4. Statistically significant predictors of "daily duration" captured by WIMU-GPS and Diary

Chapter 6 Study 3

Table 6.1. Demographics characteristics of the selected criterion participants compared to all participants.

Table 6.2. The number of individuals who contributed data to each sample subgroup.

Table 6.3. Average community mobility outcomes recorded using different sampling lengths (n=14).

Table A6.1. Two-tail t-test results for mean mobility outcomes recorded (ITV days).

Chapter 7 Study 4

Table 7.1. Demographic characteristics of the full and analysis sample.

Table 7.2. Performance of physical activity of analysis sample participants (n=50).

Table 7.3. Impact of PD in analysis sample participants. A score of 0 denotes no impact and a score of 100 signals total impairment.

Table 7.4. Average community mobility variable measured by the WIMU-GPS.

Table 7.5. Daily community mobility outcomes measured by WIMU-GPS and daily diaries.

Table 7.6 Results of Pearson and Spearman correlation analyses on the relationship between continuous demographic characteristics with community mobility outcomes.

Table 7.7. Mean daily "time outside", "trip count", "hotspot count" and amount of "time sampled" by the WIMU-GPS, according to participants' demographic profiles.

Table 7.8. Mean daily "distance to hotspots (km)", "vehicular distance (km)", "walking distance (km)" and "area size travelled (km²)" measured by the WIMuGPS, according to participants' demographic profiles.

Chapter 8 Discussion

Table 8.1. A summary of the strengths and weaknesses of the Life Space Assessment, daily diary and WIMU-GPS for use in older adults.

Table A8.1. Average community mobility variable measured by the WIMU-GPS and daily diaries each day (n=50).

List of Figures

Chapter 1 Introduction and Literature Review

- Figure 1.1. Continuum of mobility characterization
- Figure 1.2. The wheel model of mobility dimension
- Figure 1.3. Conical model of dimensions of mobility

Chapter 3 Research Methods

Figure 3.1. Screening and selection of patients for data collection.

Figure 3.2. Studies 2-4 data collection schedule.

Chapter 4 Study 1

Figure 4.1. Literature review results on studies comparing alternative versions of comparison methods.

Chapter 5 Study 2

Figure 5.1. Relationship between "*daily duration*", "*hourly frequency*" measured using WIMU-GPS and diary, and between "*life space size*" measured using WIMU-GPS and LSA.

Figure 5.2. Bland-Altman plot of log mean and log difference, and parallel line graphs of directions of disagreement, for *"hourly frequency" and "daily duration"*.

Chapter 6 Study 3

Figure 6.1 Daily variation in "time outside" (minutes), "trip count", "hotspot count", and "area size" (km²) per day (n=14).

Figure 6.2. Variations in mean mobility outcomes by day of the week and time recorded

Figure 6.3. Mean percentage errors for all CM outcomes across different sampling rates relative to sampling length of at least 7 days with 800 or more minutes.

Figure 6.4. Percentage errors in mean daily "time outside", "trip count", "hotspot count", and "area size". Figure A6.1. Difference in amount of minutes collected by criterion participants during weekend days versus week days.

Figure A6.2 Variations in weekday to weekend variation in "time outside" (minutes), "trip count", "hotspot count", and "area size" per day.

Figure A6.3 Variations in daily variation in "time outside" (minutes), "trip count", "hotspot count", and "area size" per day, according to minutes recorded per day.

Figure 6.4. Percentage errors in mean daily "time outside", "trip count", "hotspot count", and "area size" according to different lengths of day and number of days recorded.

Chapter 7 Study 4

Figure 7.1. Average weekly number of visits to particular destinations by participants (n=50).

Figure A7.1 Distribution of average daily "time outside (minutes)".

Figure A7.2. Distribution of average daily "trip count".

Figure A7.3. Distribution of average daily "location count".

Figure A7.4. Distribution of average daily "distance to hotspots", "distance travelled by vehicle (km)",

"distance travelled on foot (km)", and "area size travelled (km²)".

List of Abbreviations

ADL	activities of daily living
СМ	community mobility
CV	coefficient of variation
GPS	global positioning systems
LoA	Limits of Agreement
LSA	Life Space Assessment
MoCA	Montreal Cognitive Assessment
MOSSS	Medical Outcomes Survey Social Support
PA	Physical activity
PD	Parkinson's disease
PDQ-39	Parkinson's Disease Questionnaire
PwP	People with Parkinson's disease
SF-12	Short Form Health Survey [®] - 12 Items
WIMU-GPS	Wireless Isoinertial Measurement unit with GPS

Chapter 1: Introduction and Literature Review

1.1 Background: Aging, morbidity and mobility

Mobility is a complex construct. In older adults, mobility has been defined as "the ability to move oneself, either independently or by using assistive devices or transportation, within community environments that expand from one's home, to the neighbourhood, and to regions beyond"¹. Such a definition acknowledges mobility to encompass physical component manoeuvres involved in movement, such as gait and balance, as well as the cognitive, psychosocial, comorbid, environmental and financial influences that affect one's movement across spatial regions. The World Health Organization² considers the maintenance of mobility to be essential for individuals to lead dynamic and independent lives. Mobility has also been shown to be a crucial determinant of one's ability to independently perform daily activities and is associated with health status and quality of life^{3, 4}.

Mobility continuum

One of the first discussions of a mobility continuum was by Patla and Shumway-Cook⁵. Working within a rehabilitation context, they defined impairments in mobility as the inability to safely move through a continuum of environments. Patla and Shumway-Cook's continuum described the following type of ambulators (Figure 1.1)⁵: "non-functional ambulatory" within the home setting (e.g., a bedridden individual), "household ambulatory" (e.g., an individual who is capable of moving about within the home but not outside), "limited community ambulatory" (e.g. an individual who is capable of driving through the community but not walking), and "independent community ambulatory" (e.g., an individual who is capable of moving about within the community ambulatory.

Mobility Continuum



Figure 1.1 Patla and Shumway-Cook's continuum of mobility characterization for an individual in the real-life setting⁵.

This mobility continuum prompted the separate consideration of home mobility versus community mobility (CM). It presented a hierarchical view of mobility environments, such that the mobility within the community environment was viewed to be more difficult to perform than mobility at home.

Dimensions of mobility

The separation of CM from home mobility allowed researchers to identify specific factors that promote or prohibit CM. Patla and Shumway-Cook again created one of the first conceptual models of community mobility determinants. The Wheel Model of mobility dimensions⁵ is composed of eight different environment dimensions that determine whether an individual is capable of being mobile in his or her community (Figure 1.2). The dimensions are oriented along eight points of a wheel, and the ability to independently manage one's actions within a given dimension is determined by the distance away from the wheel's center. An individual who is fully capable of dealing with a particular dimension will possess a range within that dimension that extends to the perimeter of the wheel.

Using walking as an action of mobility, these dimensions include:

- 1. Minimum walking distance (e.g., the minimum distance to destinations);
- 2. Time constraints (e.g., compatibility of one's walking speed with road safety rules and available time);
- 3. Ambient conditions (e.g., light level and weather);
- 4. Terrain characteristics (e.g. walkability of an environment, including surface characteristics and safety);
- 5. External physical load (e.g., the weight of physical items one carries and the convenience of carrying the items);
- 6. Attentional demands (e.g., other tasks demanding one's attention, and the ability to allocate attention to mobility and other tasks);
- 7. Postural transitions (e.g., the ability and ease of transitioning one's body positioning between sitting to standing, stopping to turning, etc.);
- 8. Traffic level (e.g., the quantities and layout of other objects, animals and people on the road, and the ability to safely avoid them during a travel path).

Dimensions of Mobility



Figure 1.2. The Wheel Model of mobility dimension proposed by Patla and Shumway-Cook⁵.

a. The eight dimensions that an independent community ambulator occupies. This individual's range will cover the entire area of the wheel. An individual who cannot ambulate independently in the community, even one that is undemanding, will situate at the center of the wheel.

b. An example profile of an individual's unique operating range. This person may be someone who is able to walk a certain minimum distance but whose performance of community mobility is limited by the amount of time she or he has, the weather, the quality of the terrain, the heavy load carried, other demands on her or his attention, physical challenges with transitioning between stopping and turning and navigating between pedestrian traffic on sidewalks.

Many individuals with mobility disability or environmental constraints often use other transportation methods to perform community mobility in addition to or in place of walking. Webber, Porter and Menec¹ expanded on the Wheel Model of mobility by taking into consideration the interrelated factors affecting multiple forms of transportation, and their roles in different mobility contexts.

Based on the previously described mobility continuum, the Conical Model of mobility (Figure $1.3)^6$ also orders the context of mobility from home to community. However, seven life-space locations were used to capture the expanded environmental ranges that an individual can occupy.

These life-spaces range from: one's bedroom, the home, the immediate space outside of the home, the neighborhood, the service community (e.g., shops, hospitals), surrounding areas within a country and the world.

The Conical Model further illustrated the influence of five categories of determinants that affect one's mobility within each life-space level. These categories include influences that are:

- 1. Financial (e.g., the ability to retrofit a home with grab bars for balance, or the ability to pay for a car for long distance travel outside the home);
- 2. Environmental (e.g., the slipperiness of wood floors in the home, or uneven sidewalks outside the home);
- 3. Cognitive (e.g., experiences of depression affecting the motivation to get out of bed, selfefficacy towards navigating the neighbourhood);
- 4. Physical (e.g., the ability to get out of bed, or the ability to walk to the mailbox);
- 5. Psychosocial (e.g., someone who is available to help getting out of bed).

The interplay between one's gender, culture and biography also act as additional determinants of mobility through their influence on the other five categories. It reflects the gender disparities in mobility disability, cultural effects on education and occupation, lifestyle and social relationships, and personal life history. This relationship is depicted as an arrow encircling the Conical Model.



Figure 1.3. Conical Model of the different dimensions and life space levels of mobility, updated from the Patla & Shumway-Cook (1999) model. Figure reproduced from: Webber, Porter and Menec (2010)⁶.

1.2 Mobility in an age-related clinical condition: Parkinson's disease

In community-dwelling older adults, mobility impairments and lack of physical activity were shown to be associated with increased relative risk of death and loss of independence⁶. Thus, helping people maintain and improve functioning and performance across various mobility dimensions are often the goals of clinicians, researchers and policy makers working with older populations ⁷⁻¹¹. It was estimated that 28.0% of adults between the ages of 50-89 years lived with a common movement disorder¹², and the majority of adults over 85 years lived with a gait disorder¹³. For older adults living with a movement disorder, the experience of mobility disability often occurs earlier and in a more debilitating fashion ¹³⁻¹⁶. Therefore, it is important to distinctly understand how their mobility dimensions are presented and how changes occur over time.

Parkinson's disease (PD) is one of the most common movement disorders and neurodegenerative diseases in the world¹⁷⁻¹⁹. In 2010 – 2011, it affected 55, 000 Canadians²⁰. The incidence of PD increases with age worldwide^{18, 21}. In Canada, the mean age at symptom detection is 64.4 years and mean diagnosis age is 66.2 years²⁰. PD is typically characterized by hallmark motor

symptoms, such as postural instability – a decreased sense of balance/unsteadiness, bradykinesia - slowness of movement, muscle stiffness and rigidity, and asymmetrical tremors^{22, 23}. However, non-motor symptoms, including pain, sleep disorders²⁴, apathy, depression and cognitive decline ²⁵ are also becoming more understood. Overall, PD symptoms can lead to poor mobility-related health outcomes, such as daily functional limitations, physical disability⁶, and increased risk of falling^{26, 27}. Beyond these functional mobility deficits, these symptoms also could lead to factors associated with decreased CM, such as increased experiences of stigma^{28, 29}, decreased quality of life^{30, 31}, and risk of institutionalization³².

As no curative treatment for PD is currently available, the wellbeing of people with PD (PwP) relies on lifelong signs and symptoms monitoring and outcome prevention. Before this is possible, a good understanding and proper measurement of these signs, symptoms and outcomes are important. Currently, most studies on mobility in PD have focused on laboratory or clinic assessed functional abilities ^{33, 34}. Despite the associations between quality of life and CM^{3, 35-38}, few studies have included the assessment of the actual performance of mobility by PwP within a real-life community setting. This may be due to challenges associated with measuring CM. This is discussed in the following subsections, and this dissertation focuses on addressing these gaps in the literature.

1.3 Measuring community mobility

Mobility is a complex construct to assess due to its multidimensionality. As previously introduced, CM is affected not only by an individual's physical ability to move (*functional mobility*), it also is a "comprehensive framework" comprising multiple factors, including cognition, psychosocial status, and environmental variables¹. Additionally, CM is influenced by gender, culture and the life history of the individual¹. In other words, measurements of mobility need to consider the important distinction between what people can do - capacity or *functional mobility* - and what they really do - performance or *actual mobility*.

As a progressive disorder, lifelong treatment and management for PD are based on regular examinations of clinical features, disease progression, response to medication and treatment. Existing methods to quantify mobility during disease progression commonly involve laboratory instruments, clinical tools and self-reporting. A number of laboratory and clinical assessment tools of mobility have been developed or have been adapted for use in a PD population. Two of the most commonly accepted and used clinical assessments for disease severity and functional mobility are the Movement Disorder Society-sponsored revision of the Unified Parkinson's Disease Rating Scale^{39, 40} and the Hoehn and Yahr staging of disease⁴¹.

Clinicians have reported a lack of congruence between these assessment measures and real-life mobility of persons with PD in the home and community settings⁴². Scores on clinical instruments are often dependent on situations⁴³. For instance, some PD symptoms, such as freezing of gait, could be unpredictably triggered by real-life environmental challenges and tasks that are impossible to fully replicate^{44, 45}. Therefore, although clinical assessments provide important cross-sectional information about the functional mobility of an individual with PD, measures providing information regarding real-life mobility are equally important. In other words, clinical and laboratory measures may be better measures of capacity than of real life performance⁴⁶.

Furthermore, even if laboratory and clinical assessments could mimic the actions required for mobility in one's home, these assessments seldom account for an array of factors affecting the ability of a person to achieve CM^{1, 47}. Therefore, details about patients' CM are often missed during clinical and laboratory assessments.

The following two sections will discuss the available methods for *in situ* assessment of real-life CM.

Self-report Measures of Community Mobility

Community mobility is most regularly captured using quick and inexpensive self-report measures. These include daily mobility diaries or journals completed by patients about their travels, and recall-based questionnaires. Life space is a construct that combines both capacity and performance. Stalvey and colleagues stated that mobility in life spaces are the "spatial extent of one's travel within the environment," and includes "travel in, around, and outside the home as one conducts the business and social aspects of everyday life"⁴⁸. The authors described

physical mobility across various life spaces as estimates of the extent and magnitude of travel into one's community and environment. Examples of life spaces include one's living room (inside one's home) and the nearby neighbourhood (outside one's home).

As well, a comprehensive consideration of mobility considers movement beyond the home, which often requires using some type of assistive device and vehicular transportation^{1, 49}. A common life space measure, the Life Space Questionnaire⁴⁸, is only concerned with how far one travelled, and not with how travel is done. However, for many people with reduced functional abilities, mobility is often completed using some form of assistive devices or with the assistance from another individual, especially as distance outside the home increases. Recognizing the need to consider this, the Life Space Assessment (LSA)⁴⁹ was created based on data from the University of Alabama at Birmingham's Study of Aging. It is a simple and widely used six item scale that assesses the relevant physical spaces which an individual occupied during a typical week in the past month. Each life space is identified as a concentric circle; the size of the same circle (life space) is not defined by any units of distance. This allow the same life space to be larger or smaller depending on whether the LSA is used in rural or urban settings. Furthermore, the LSA builds on the Life Space Questionnaire to include considerations of the use of assistive devices (e.g., canes and walkers).

The LSA does not comprehensively consider the biographical, psychosocial, cognitive and financial influences on mobility discussed by Webber and colleagues¹. As well, like the Life Space Questionnaire, the LSA does not differentiate between movement on foot and in vehicles. This may limit its utility as older adults often rely on vehicles, including transit, to gain access to essential services, activities and social connections⁵⁰. Despite its potential pitfalls, the LSA remains a commonly used cross-sectional instrument of CM due to its brevity and ease of use.

To provide more longitudinal data about daily fluctuations and trip counts, researchers and clinicians have also employed the use of daily diary entries about one's daily displacement from home^{51, 52}. However, as with all self-report measures, both the LSA and diary entries are prone to recall bias⁵³.

Technological Assessments of Community Mobility

Wearable sensor technologies are promising new approaches to study CM, as they can collect continuous and objective data in the real-life setting. Common technologies have included accelerometers, pedometers and Global Positioning System (GPS) devices ⁵⁴⁻⁵⁸. Of these, the use of GPS technology may be more suitable for use to study CM as it provides position information even when the wearer is travelling by vehicle^{59, 60}. GPS technology has been used in transportation and urban planning research to capture trip count and duration since the 1990s^{61.} ⁶². Although GPS technology itself is not novel, recent interest in the development of smaller, more affordable wearable GPS units with multi-sensor functioning have increased their appeal to health researchers. Since 2011, GPS sensors were used to examine CM in post-stroke patients⁵⁷, people with dementia⁶³ and Alzheimer's disease⁶⁴, individuals with mobility disabilities⁶⁵, as well as among older people with cognitive impairment and their caregivers⁶⁶. However, GPS sensors have not been used in a PD context to study CM, despite the current gap in literature regarding real-life mobility of PwP within their communities.

Gaps in Comparison of Measurements

Before using a new measurement or adopting an existing measurement in a new population, it is important to properly assess the measurement's psychometric properties. This gives researchers confidence about the interchangeability of available measurements, and improves the interpretation of research findings⁶⁷.

Numerous methods for comparing different measures currently exist, and are discussed in the next section.

1.4 Measurement theory

Measurement theory is a formal approach to evaluate the numbers assigned by researchers to the attributes of interest. Typically it involves the evaluating a measure's validity, as well as reliability in terms of agreement and concordance between measurement scores⁶⁸.

Validity could be broken down into *content*⁶⁹ and *construct* validity⁷⁰. *Content validity* refers to the ability of a measure to represent all facets of a given construct. It could be established through face validity, and the consultation of experts during the development and judging

10

process of the measure⁶⁹.

A construct is a "cluster or domain of covarying behaviours" ⁷¹. Hence, *construct validity* refers generally to the extent to which a test measures a construct⁷⁰. It can be empirically evaluated by establishing a measure's *criterion validity*. This involves assessing whether a measure is correlated with an external criterion that is known or assumed to be valid (e.g., a 'gold standard'). In the absence of a gold standard criterion measure, *construct* and *criterion* validity could also be established through *convergent validity*, which is evaluated by comparing how well one measurement relates to another measurement that is predicted to co-vary with the theoretical construct. This is based on the assumption that two measures of the same construct or phenomenon will produce the same results or correlate highly with one another^{67, 72}. The opposite of *convergent validity* is *discriminant validity* (also referred to as divergent validity), which refers to the fact that two measures of different constructs will produce different results or show low correlation. *Construct validity* is demonstrated when *convergence* is presented along with *discrimination*.

In addition, an instrument's *construct validity* also can be supported by establishing *concurrent* validity between two measures. This is done by administrating two comparison measures at the same time to reflect the same behaviour under study⁶⁷. It is of interest when one assessment is thought to be more practical or easier to administer than an alternative. For example, the LSA may be a preferred measure of CM as it is easier to complete a questionnaire than having participants wear a continuous monitoring device over several days.

Reliability

Reliability is usually quantified by estimates of correlation coefficients ^{68,73}. By definition, correlation is a measure of association. It refers to the degree of association between two measurements, or how the scores vary together following a linear relationship. However, when assessing reliability, it is not enough simply to consider whether the results of one measurement correlate with the results of another. Two measurements with low reliability could still be highly associated. Portney and Watkins⁶⁷ demonstrated the shortcoming of the correlation coefficient in reliability studies through two scenarios:

11

A. two data sets that differ but vary in sync (e.g., 5 4 3 2 1 and 6 7 8 9 10)B. two data sets that are the same and vary in sync (e.g., 5 4 3 2 1 and 5 4 3 2 1).

In both cases there is perfect correlation (due to the numbers varying together), but only scenario B contained perfect agreement between the two data sets. This is not evident by looking at the correlation coefficient.

Assessing reliability refers to estimating the extent to which observed scores deviate from true scores, or are free from error. Although it is not possible to know the true score, researchers rely on estimating reliability by calculating the differences among scores in a sample (variance)⁶⁷ or by comparing the scores of one measure to the scores of another that has greater psychometric properties in a given context. Thus, knowing about how scores on two comparison assessments vary together (i.e., its correlation) is not enough. When possible, reliability also must be assessed in terms of agreement.

Assessing Agreement

Agreement for discrete data is commonly quantified using *percent agreement* and the *kappa statistic*, while agreement for continuous data is usually quantified using the *intraclass correlation coefficient*.

1. Percent agreement⁷⁴

When comparing assessments, *percent agreement* refers to how often agreements occur between scores of alternative assessments. It is calculated as:

$$Po = \frac{number \ of \ exact \ agreements}{number \ of \ possible \ agreements} = \frac{\Sigma \ fo}{N}$$

where fo is the sum of the frequencies of observed agreements, and N is the number of pairs of scores obtained.

Although simple to calculate and understand, the percent agreement neglects the proportion of

agreements that may be due to chance and thus may overestimate the true reliability.

2. Kappa statistic^{74,75}

A measurement of agreement that corrects for chance is the *kappa statistic*, κ . It does this by considering the proportion of agreement expected by chance (Pc), along with the proportion of observed agreements (Po). Pc is calculated as:

$$Pc = \frac{number \ of \ expected \ agreements}{number \ of \ possible \ agreements} = \frac{\Sigma \ fc}{N}$$

where fc is the sum of the frequencies of agreements expected by change.

The correction factor for chance is applied by: Po - Pc. The *kappa statistic* is calculated for categorical data by:

$$k = \frac{Po - Pc}{1 - Pc} = \frac{\Sigma fo - \Sigma fc}{N - \Sigma fc}$$

The values of k can range from -1 to 1. When agreement between measures is equal to chance, k=0. When agreement is better than chance (or Po>Pc), k>0. When chance is better than agreement is better than chance (or Po>Pc), k>0. When chance is better than agreement, k<0. Typically, excellent agreement is reported by k > 0.80, substantial agreement is reported by $0.80 \ge k > 0.60$, moderate agreement is reported by $0.60 \ge k > 0.40$, and poor to fair agreement is by $k \le 0.40^{-76, 77}$. A few limitations of the kappa statistic exist. First, it cannot tell whether disagreement is due to one measurement more so than the other. As well, the kappa statistic should not be used for very small sample sizes (e.g., disagreement on one observation in a sample of 10 will affect the overall level of agreement more so than in a sample of 100). Furthermore, the level of agreement calculated often decreases with a larger number of categories (e.g., assessments). Finally, the kappa statistic is best used for ordinal or nominal data as it requires two measurements to either agree or disagree on a given item, and it quantifies how close the scores captured by two measurements are.

For ordinal data, it is preferable to account for the ordinal nature of the data by assigning weights to disagreement between measurements. The most commonly use weighting scheme is the quadratic weighting scheme, which bases disagreement weights on the square of the amount of discrepancy. It has been shown by Fleiss and Cohen⁷⁸ that weighted kappa with quadratic weights are virtually identical to the intraclass correlation coefficient.

3. Intraclass Correlation Coefficient 78,79

The *intraclass correlation coefficient* (ICC) improves on traditional correlation coefficients by considering both the correlation and agreement of scores among assessments. The ICC also can be used in studies involving more than two assessments (this is another improvement over the correlation coefficient). It is mainly used for interval and ratio data, but can also be used for ordinal and nominal data under some assumptions.

Furthermore, the ICC is a "comprehensive estimate of reliability"⁶⁷. In its calculations, it incorporates true score variance and random error, as well as considerations for other reasons (facets) that may have led to differences between observed scores. Such reasons include variations in testing conditions, and characteristics of participants and raters. All of these facets are considered to have contributed to the measurement error⁸⁰. Calculating the ICC is complicated, but can be summarized as:

$$ICC = \frac{S_T^2}{S_T^2 + S_F^2 + S_E^2}$$

where S_T^2 and S_E^2 are variances in the true score and errors, and S_F^2 is the variance of the facets of concern.

4. Alternate ways to assess agreement between measurements⁶⁸

The abovementioned methods are most often used for assessing reliability between multiple raters or over time, but are also used to compare assessments. Two special ways of comparing agreements across related measurements have also been derived. The *Limits of Agreement* method requires calculating the difference and mean scores across each individual participant

who was tested using two assessments. Then a 95% limit is constructed using the sample mean and standard deviation. Using this method, how much scores differed on the two measurements in the sample, and the clinical relevance of these deviations, can be appreciated.

The Bland-Altman plots^{68,81,82} builds on the Limits of Agreement by providing a way to visually analyse the agreement between measurements. Scatterplots of individual scores on both assessments are constructed. A "line of identity" is drawn from the origin of the plots to represent perfect agreement, and 95% limits of agreement are calculated. The researcher can then visually determine whether the distribution of agreement scores scatters too far from the agreement line, and whether the scores outside of the limits of agreement are meaningful; then the decision can be made about whether or not the measurements are interchangeable.

1.5 Comparing community mobility assessments

Evaluation and comparison of self-report assessments and technological instruments have become an emerging area of research^{62, 83-85}. For instance, the association between objectively and subjectively measured community walking was evaluated in stroke survivors using Pearson correlation⁸⁶, and measures of sedentary behavior and physical activity were compared using the Bland-Altman plots and kappa statistics⁸⁷. Beyond these examples, the available comparison studies for CM measures remain scarce. Comparisons of agreement in frequencies and duration of trips outside captured by GPS sensors and diaries also have been done in a general population^{62, 88}. However, despite its wide usage, the LSA has never been completed against any CM measures. Further, given that the CM of PwP has seldom been studied using any measure, it is unknown how well objective and subjective measures of CM compare with each other when used in a PD context.

In summary, knowledge about PwP's real-life CM mobility characteristics is needed as mobility preservation is an important clinical goal for this group. Work is also needed to assess the available CM assessment tools for their psychometric properties and feasibility issues when used in a PwP sample.

15

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Chapter 2

Research Overview

2.1 Objectives

The main objectives of this dissertation were to compare the psychometric properties of technological recording and self-reported measures of community mobility, and to measure the CM of older adults with PD using appropriate assessment(s). These objectives were accomplished by conducting four studies:

Study 1. Conduct a scoping review on methods used to compare assessments in order to:

a. Appraise the literature comparing different measures of community mobility. Contribute to the efforts in standardizing best practice methods in comparing alternative measures.

b. Select the optimal measurement method(s) for use in Study 2 to compare instrumented GPS data with self-report data from the Life Space Assessment and Displacement Diary.

Study 2. Determine:

a. How well self-report measures of community mobility correlate and agree with instrumented assessments of community mobility in PwP.

b. Determine which factors affect the agreement and convergent validity uncovered in 2a.

Although instrumented approaches may minimize bias produced by self-report measures, as well as producing large quantities of data, they may be prone to various technical difficulties. Issues such as signal loss or equipment malfunctioning can result in incomplete data collection, leading to missing minutes or missing days or both. However, the presence of even a few hours per day over a few days per week of objective mobility data may provide substantial information value. Therefore, in order to determine CM outcomes in PwPs, the following two studies were conducted: Study 3. Evaluate data loss issues with different WIMU-GPS sampling lengths, and determine the best approach to use for Study 4.

Study 4. Quantify dimensions of community mobility of PwP using either the WIMU-GPS and/or the self-report assessment(s).

2.2. Hypotheses

Although the studies proposed are largely exploratory in nature, a number of initial outcomes can be hypothesized:

Study 2:

1. Validity and reliability between mobility outcomes measured by LSA and WIMU-GPS will be weaker than validity and reliability between the outcomes measured by Displacement Diary and GPS.

2. Agreement between the Displacement Diary and GPS will be higher for the outcome "*trip count*" than the outcome "*time outside (minutes)*".

3. Residence type, presence of depression, overall health status and disease related quality of life may produce the largest effect on the agreement between the Displacement Diary and WIMU-GPS, because they may influence the accuracy of diary entries.

Study 3:

Sampling a minimum of 6 days of 600 minutes is optimal to capture the unstable nature of mobility while minimizing participant burden and data error.

Study 4:

Based on previous literature, car ownership, residence type and disease related quality of life are expected be significant covariates associated with mobility dimensions.

2.3 Contributions of dissertation

a. Comparison of alternative measurements

Researchers and clinicians regularly have to compare and select between alternate measurement instruments of mobility, yet it is unclear what the state of literature is for alternative measures of CM. The review of quality in method comparison studies (Study 1) could bridge this gap, and make suggestions about how to be more consistent in study design or reporting.

Little information about whether widely used self-report based assessments of CM mobility agree with instrumented data in a PD context. Study 2 may provide information about whether the LSA and diary are comparable to the WIMU-GPS for measuring CM.

Study 3 could provide useful recommendations for users of GPS technology about the minimum sampling length that minimizes error. Further, the study could give insights about how many days and minutes per day users of GPS should aim for when measuring different CM outcomes.

b. Mobility of people with Parkinson's disease

Although self-reported and instrumented assessments of mobility have regularly been used in the PD population, long duration free-living recordings of mobility seldom have been accomplished. Furthermore, no research has examined the agreement in mobility measured between these assessments when multiple mobility assessment types are used in the same sample of people with PD. Therefore, results from both Studies 2 and 4 may be used to assist in the interpretation of mobility variables measured by the LSA, Displacement Diaries and the GPS sensors used.

2.4 Organization of dissertation

This dissertation follows the integrated article format, consisting of four related standalone studies examining and evaluating: existing techniques used to compare alternative assessment methods, the comparison of WIMU-GPS and self-report measures, sampling issues with WIMU-GPS and the community mobility of PwPs (Chapters 4-7).

Some repetition among the chapters is inevitable. For example, each manuscript may make common references to the same appendices or contain very similar Background and Methods sections. Additionally, the articles are linked by common introduction, methods, discussion, and conclusion sections.

Chapter 3: Research Methods

3.1 Dataset creation:

Studies 2-4 used the same data collected using the mobility assessments in the homes of older adults with PD, and are discussed below.

3.1.1 Primary data collection

Recruitment:

70 patients with PD (men or women, ages 55-85, stages I, II and III [Hoehn and Yahr Scale]) were recruited, assisted by a trained research assistant during Cycle 1, from the Movement Disorders Clinic of University Hospital (London Health Sciences Centre) over three data cycles. The clinic serves a large geographical catchment area in Southwestern Ontario, and all eligible clinic patients were included in this study. Convenience sampling occurred using patients who most recently visited the clinic, and were able to be contacted by the researchers. Cycle 1 data collection occurred from April to October 2012 (n=35) and Cycle 2 occurred from April to October 2013 (n=21). The last cycle occurred from April to October 2014 (n=14). The inclusion and exclusion criteria for participants are listed in Table 3.1. 835 patients with PD were screened for participation, and 70 participants completed this study (Figure 3.1).

Table 3.1. Inclusion and exclusion criteria of participants.

Inclusion Criteria	Exclusion Criteria
• Willingness and ability to comply with study	• Diagnosis of PD is unconfirmed
requirements.	• Anticipated medication change less than 1
• Able to provide written informed consent.	month before start date of study or during the
 Have a clinical diagnosis of idiopathic 	study
Parkinson's disease according to the UK	Clinical evidence of unstable medical or
Parkinson's Disease Society Brain Bank clinical	psychiatric illness.
diagnostic criteria.	 Clinically significant active and unstable
•Early to mid-stage PD (Stage I, II or III).	psychotic disease (hallucinations or delusions).
•Normal cognition (MOCA score of more than	• Significant tremor present simultaneously with
26/30) at time of recruitment.	levodopa induced dyskinesia (LID).
•Experienced no change in medication one	 Comorbidities hindering ability to understand
month before start of data collection (optimally	or perform the tasks
treated by the movement disorders neurologist)	 Orthopedic condition impeding mobility
• Community dwelling in any municipality type	Regular use of assistive mobility devices, such
that is <200km from London, Ontario	as a walker or cane.
 Normal cognition (MOCA score of more than 26/30) at time of recruitment. Experienced no change in medication one month before start of data collection (optimally treated by the movement disorders neurologist) Community dwelling in any municipality type that is <200km from London, Ontario 	 Significant tremor present simultaneously with levodopa induced dyskinesia (LID). Comorbidities hindering ability to understand or perform the tasks Orthopedic condition impeding mobility Regular use of assistive mobility devices, such as a walker or cane.



Figure 3.1. Screening and selection of patients for data collection.

To minimize an important source of variability, participation in this study required the patient to be optimally stabilized on all medication. In patients who were anticipating a change in their medication regime, this was achieved by scheduling initial data collection for at least one month after they had begun the new routine.

Pilot Study and Sample size:

Since no studies have compared mobility measures and factors affecting variability in measured mobility of people with PD in the natural environment using the proposed methodology, we could not use the standard methods of assessing sample size. Accordingly, the number of participants necessary to obtain power of at least 0.80 was estimated by a pilot study with 6 PD participants recruited from the Movement Disorders Clinic using convenience sampling. This pilot study was conducted during the Fall of 2011. For one week, the mobility of these participants was recorded using a GPS system, LSA and Displacement Diary, which also allowed the feasibility of study protocol to be tested. Since expected CM data was unavailable for people with PD, the result of interest for sample size calculation was the mean time recorded per day (672.3 ± 132.4 minutes). A 100 minute difference in the amount of data recorded was selected as the effect size. Using the standard deviation (SD) of 132.4 minutes, a power $(1-\beta)$ of 0.8, and 95% significance level (α), the sample size needed for an one sided t-test was 22¹. To account for possible participant attrition due to the longer full study protocol and to allow for more than one subgroup comparison, a larger sample size was considered. Given the difficulty with recruitment and retention of participants who fulfilled the strict inclusion/exclusion criteria, a minimum sample size of 70 was adopted. This sample size was deemed appropriate given a previous study using GPS technology to study mobility levels and movement in older adult populations in different locations, which employed convenience sampling of only 20^2 . As well, the goals of these studies were not to produce results that can be generalized to the entire population, but to give a good representation of variability in participants' mobility as detected using different measures, and an idea of what factors influence such variability.

Data collection:

Mobility in the community was objectively tested over 14 days using a GPS-based system. Self-reports using the LSA and a daily Displacement Diary (Diary) took place during the same test period as a way to ensure identical frames of reference between the comparison measures. Studies have shown an association between environmental demands and physical activity in older adults³ and those with mobility disability⁴. Hence, all data collection occurred only between late spring (i.e. begin in April) and early fall (i.e., end in October) to minimize the influence of cold weather in Southern Ontario on mobility (e.g., walkability of the neighbourhood, access to social services and transportation options).

Each participant was visited three times (Days 1, 7, 14) over two weeks in their home by myself (and a research assistant during Cycle 1 of study). Self-reported mobility was recorded in terms of life spaces and the LSA was performed on Days 1 and 14 as the measure of recall in mobility.

Over the 14 day period, participants were also asked to use a Displacement Diary daily to report the timing and destination of each trip taken outside of their home. Participants were asked to indicate in the Diary when they did not leave the home or if they were sick. On the days when participants stayed home, they were asked to indicate why they did not leave.

Objective measures of mobility were conducted over the 14 days using a GPS device (WIMU-GPS) created by Dr. Patrick Boissy and colleagues from L'Université de Sherbrooke⁵. This GPS device also contained an imbedded wireless isoinertial measurement unit (WIMu) composed of a triaxial accelerometer, gyroscope and magnetometer. Together, the three triaxial sensors detect the orientation of the body in space. The WIMu and acceleration measures obtained by the WIMU-GPS distinguishes between travels done on foot versus by transportation. Participants were asked to wear the WIMU-GPS only during the waking moments of each day and to charge the WIMU-GPS overnight. The study cell phone number and troubleshooting instruction sheet were

provided to guide the participants, and they were asked to note abnormalities in functioning in the displacement diary (mentioned below).

Additional factors influencing mobility were collected, for example: marital status, driving status, cognition and comorbidity. These were assessed through the demographics and comorbidity questionnaires and the Montreal Cognitive Assessment (MoCA⁶) on Day 1.

During Day 7, the participants were visited for data quality control purposes (e.g., ensure the Diary was completed and the WIMU-GPS was working). The level of physical activity over the study period, social support, general health and PD-related quality of life were examined on Day 14 using the Phone-FITT⁷, Medical Outcomes Study Social Support Survey (MOSSSS)⁸, Medical Outcomes Study 12-Item Short Form Health Survey (SF-12)⁹ and the Parkinson's Disease Questionnaire – 39 item version (PDQ-39)¹⁰, respectively. Questions related to personal habits, activities and hobbies were also found on the Phone-FITT⁷ (administered on Day 14).

All scales and questionnaires used are found in the Appendices. The time of data collection for each variable, and the method of data collection, are shown in Figures 3.2 and Table 3.2, respectively.

WIMU-GPS, Displacement Diary, SM Armband, weather reports							
Visit 1 (Day 1, 2 hours) ↓	Week 1 (Day 1-7)	Visit 2 (Day 7, 30 minutes) ↓	Week 2 (Day 7-14)	Visit 3 (Day 14, 1 hour) ↓			
 Demographics questionnaire Life Space Assessment Montreal Cognitive Assessment 		MOSSS	 Life Space Assess Phone-FITT (Phy SF-12 (health related the second s	sment ysical Activity) tted quality of life) ted health status)			

Figure 3.2. Studies 2-4 data collection schedule. All data collection took place in participants' homes.

Explanatory variables	Collection Method
Age	Demographics questionnaire
Gender	Demographics questionnaire
Cognitive status	MoCA
Employment status	Demographics questionnaire
Income	Demographics questionnaire
Years since disease diagnosis	Demographics questionnaire
Marital status	Demographics questionnaire
Residence type (rural vs. urban)	Demographics questionnaire
Car ownership	Demographics questionnaire
Social support	MOSSS
Presence of depression	Comorbidity Index
General health related quality of life	SF-12
Disease related quality of life	PDQ-39

Table 3.2. Data sources for covariates of agreement and convergent validity across group- and individual-level and for community mobility in PwPs.

Although built environment was an important factor determining the community mobility, during the pilot study, it was apparent that the study protocol with the inclusion of the Neighbourhood Walkability questionnaire was too lengthy for some participants. To limit the length of the testing protocol, walkability was eliminated and the Phone-FITT was added to capture regular physical activity (including walking). The Phone-FITT was created specifically to capture recreational activities prevalent among older Canadians, according to the 1998-99 Canadian National Health Survey, and activities commonly considered for falls prevention⁷.

Participant Compensation

A total amount of \$100 was provided to each PD patient participant as compensation for their time for participating in all three visits of this community mobility study.

Ethics and confidentiality

Full name were taken to ensure accuracy of records but all participants were assigned a participant number by which their results were filed in a locked and secure facility. Since data collection occurred at the homes of participants, home addresses were collected. Birth dates were collected for determination of age. Clinic chart/records were used specifically to verify medication regimen and other information relevant to Parkinson's disease diagnosis.

Risks of Research to Participants

No known long-term risks associated with this research are anticipated or were discovered during the pilot study. Wearing the WIMU-GPS might be uncomfortable to older adults on days with higher temperatures. Hence, testing was postponed when a high temperature interfered with their normal activities. As well, participants were allowed to briefly take off the WIMU-GPS due to other forms of discomfort or interference with daily routine. Participants are asked to document the time at which they took off any study devices for unusual reasons in the Diary.

Diary data entry

Daily diaries completed by all participants were manually entered and coded for five outcomes: number of trips outside of the home, time spent outside of the home, time spent inside the home, number of purposeful destinations, and type of destinations.

LSA data selection

No missing data were found for participants' LSAs. Each LSA reflected the community mobility achieved during the four weeks prior to administration of the assessment. Therefore, to ensure the appropriate time frame of testing is reflected by the scores, the LSA administered on the last day of testing (LSA2) must be compared to the one

performed on Day 1(LSA1). Analysis required only one score to reflect cross-sectional life space assessment. Hence, the two LSA scores were compared for each participant for the percent change over time. On average, there was a $13.3 \pm 14.4\%$ decrease in LSA2 scores compared to LSA1. However, since paired t-test on the scores revealed a statistically significant change was not found (p = 0.14), only the LSA2 outcomes were used in the analysis.

Data analyses:

The number of participants and the amount of data from each participant used for analyses differed for each study. Analysis steps for each study are described in detail in subsequent study chapters.

3.2. References

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Chapter 4: Literature review of studies comparing methods of measuring community mobility

4.1 Introduction

Mobility is a key instrumental activity of daily living, as impairments in mobility can greatly reduce quality of life¹ and predict other health declines². Appropriate and proper measures of mobility are important tools to help individuals properly manage their independence and achieve optimal health. A large number of mobility measures currently exist, ranging from instrumented measures (e.g., accelerometers, GPS) to clinical observations to self-reported measures (e.g., travel diaries)³. Of these, there is growing interest in developing and using instrumented mobility measures in place of other measurement types. However, it is not always understood how well the different measurements compare against one another in their ability to capture the various dimensions of mobility.

Although a typical lay definition of mobility is "*the ability to move or be moved freely and easily*" ⁴, it is a complex construct. In the context of aging, optimal mobility has recently been defined as "*being able to safely and reliably go where you want to go, when you want to go, and how you want to get there*" ⁵. This suggests that an individual's real-life mobility is not only defined by physical functioning and capacity to move, such as gait qualities and fine motor movements⁶, it also includes how these physical functioning and capacities translate to performance and engagement ^{7, 8}. Together, the concept of mobility centers around the voluntary movement of one's body in space, regardless of whether this is operationalized as the ability to get out of bed, ride a motorized scooter to the coffee shop, walk briskly for several kilometres, or take the bus to a destination.

One way to conceptualize the performance and engagement of mobility is to quantify and qualify one's real-life community mobility (CM). An early definition of CM is: "locomotion in environments outside the home or residence"⁹. At any level of operational detail, CM can be measured using both traditional observer and self-report

based assessment, and new technologies¹⁰. Since observer and self-report assessments are subjective measures, they are susceptible to rater or recall related bias¹¹. Real-life CM often changes over time depending on variations in environmental, social and health factors ¹². When subjective assessments are single cross-sectional snapshots, they cannot capture variability in mobility over time¹³.

Technological measures such as sensors present attractive solutions to these issues. These instruments are often thought to minimize subjectivity and bias, and are used in conjunction with, or in place of, traditional observer or self-report based measures¹⁴. To minimize bias, sensors can be placed on a person's body (e.g., sensor suits) to detect functioning and performance in one's home and community settings¹⁵. Small sensor units, such as global positioning system (GPS) sensors, accelerometers or pedometers can be carried or worn to passively capture real-life CM performance over time^{16, 17}. GPS also has been shown to complement multi-day self-report diaries¹⁸ and provide data on people who would have difficulty completing detailed self-report protocols, such as those with cognitive decline¹⁹ or among children²⁰. Nevertheless, sensors also present challenges. For example, sensor data often exhibit inherent levels of error and data loss that are not detectable until after a study period²¹.

Despite the rapid introduction of new technological assessments each year, proper comparison studies of their measurement properties against existing measures are scarce. Studies comparing mobility assessments typically have focused on using instruments to quantify task specific physical functioning and fine motor movement, and do not always relate to actual real-life CM performance. A review summarizing the results of studies which compare GPS sensors with self-report measures also identified variations in study design and study quality²². However, the authors did not include studies comparing non-GPS CM measures, and they did not comment on the quality of analysis methods used to conduct the comparisons.

A scoping review of the literature comparing measures used for many different health constructs shows validation and reliability studies have not used consistent reporting and appraisal criteria²³. The psychometric and clinimetric properties assessed in a methods comparison study are typically validity and reliability²⁴. Validity refers to how well the measurement tool could accurately capture the outcome of interest²⁵. Reliability refers to the consistency in the outcome recorded. It allows users of multiple measurement methods to understand how well one method consistently reproduce the results of another, even if the individual scores do not match^{25,26}. Determining reliability often requires comparing one assessment against a 'gold standard', or established criterion. When a gold standard is not available, agreement and disagreement (bias) between the existing measurements also should be assessed ^{23, 27}. This allows users to understand how well one metacometation and esting measurement.

Authors of health measurement comparison studies often do not include enough information about sample selection, study design, properties compared or statistical analysis²³. To enhance consistency, Kottner and colleagues proposed the Guidelines for Reporting Reliability and Agreement Studies (GRRAS)²³, which also summarized statistical methods most suited to assess agreement and reliability. However, the GRRAS was created to address inter-rater and intra-rater reliabilities of one measurement method at a time, not comparisons between methods. Regardless of this, many of the approaches mentioned in the GRRAS were also used by other studies on intermodal comparisons ^{27, 28, 29}. Even so, a lack of consistency in inter-modal comparison studies can complicate the interpretation of comparison study results, and this may be an issue that plagues studies comparing CM assessments.

This current review was conducted to identify studies that compared different CM measures, describe how researchers are comparing different community mobility measures, and to critically evaluate gaps and inconsistencies in the comparison methodology or reporting.

This study has the following objectives:

1. Summarize the recent state of literature for mobility assessment methods comparison studies.

2. Assess what, if any, consistent adoption and reporting of comparison methods have been employed in recent mobility assessment studies.

3. Appraise the appropriateness of the techniques used to compare alternative methods of assessing mobility.

4.2 Methods

Literature search strategy

Published literature comparing self-report measures, clinical rating scales, laboratory instruments, laboratory tests and/or technological instrument based assessments in mobility, movement and health research from 2006 to 2016 were searched in Medline, Scopus, PubMed, EMBASE, Google Scholar and CINAHL, and reviewed for the statistical and/or theoretical comparison methods used. A medical librarian assisted with generating key words. Search terms used are listed in Table 4.1.

Table 4.1. Search terms according to the topic of interest.

Topic of interest	Search terms
Study type	Compar* measur* OR Gold standard OR Alternat* measur* OR
	Interchangeability of measur*
	AND
Measures and intermodal	Objective and subjective assess* OR Objective and subjective measur* OR
comparisons	Instrument* and self report measur*
	AND
Measured construct	Mobil* OR Movement OR Ambulat* OR Community mobility OR
	Life space ORActivity sphere
	AND
Potential comparison methods	Reliability between two measur* OR Validation measu* OR Agreement
	measu* OR Agreement between OR Agreement studies OR Assess*
	ORagreement OR Reliabil* OR Reproducibility OR Evaluat* OR
	Intermodality agreement OR Intra class correlation OR kappa

Study eligibility criteria

This review included studies up to June, 2016 that compared two or more methods of assessing community mobility. Studies of internal consistency, inter-rater or intra-rater properties of a *single* method were excluded. Assessments could be conducted in either a patient or general adult population. Since community mobility was the construct of interest, studies were limited to measures administered in a community setting, instead of in a controlled laboratory or within an individual's home.

Methods included in the review must measure community mobility and/or gross movement within the community setting. Although physical functioning, fine motor movements and physical activities are important components of community mobility, they are different constructs than community mobility performance. Therefore, this review excluded studies comparing assessments of task-based physical functioning (e.g., balance, gait characteristics) and performance of non-transport recreational physical activity (e.g. sports related mobility). Studies with physical activity as a primary outcome were also excluded.

As the focus was on comparison methods, the specific results of each comparison study were not of interest for this review. Only assessments published in English were included in the search. Published commentaries, editorials, response papers, and textbooks on measurement, clinical epidemiology and psychometrics from 2006-2016 were also reviewed for authors' recommendations about comparison methods, and any remarks about discrepancies in comparison methods used by other authors were noted. A hand search of reference lists of all articles retrieved was conducted.

The following journals where many mobility and mobility comparison studies appeared were hand searched for materials: *Sensors, Physical Therapy* and *Transportation*. Duplicate results or reprints were not included in the final number. Data saturation was reached when no new articles were generated using the above search methods.

This review follows the PRISMA guideline for reporting systematic reviews³⁰.

Data abstraction

Criteria for data abstraction included items from the GRRAS, as a similar guideline for methods comparison studies is not currently available. Criteria included information about data collected and instruments used (GRRAS item 2), participants (item 11), measurement process or timeframe (item 8), psychometric or clinimetric properties assessed, analysis method used and their rationale (items 5, 10 and 13).

Tables 4.2a and b summarize the most common statistical approaches available to authors for comparing different methods. Although appropriate alternative approaches to assessing these psychometric properties may exist, evaluation of study quality in this review was based on these statistical approaches that are widely published and accessible to authors.

Table 4.2a. Recommended validity measures for studies comparing alternative assessment methods.

Property of interest	Outcome of interest	Type of data	Recommended comparison measure
Validity	Concurrent	Continuous and categorical	N/A
			(Assessment measures should be administered at the same time.) 31
	Convergent and construct	Continuous	Correlation coefficients ^{32, 33}
			Unranked - Pearson correlation
			Ranked - Spearman correlation

Table 4.2b. Recommended reliability, agreement and error measures for studies comparing alternative assessment methods.

Outcome of interest	Type of data	Recommended comparison measure
Reproducibility	Continuous	Intraclass correlation coefficient ^{23, 26, 34, 35}
Reproducibility	Categorical	Kappa statistics ²³
		Ranked intraclass correlation ²³
Internal consistency	Continuous	Cronbach's alpha ³⁵
	Continuous	Bland-altman plots ^{26, 27, 36,}
	Categorical	Proportion of agreement ²³
		Kappa statistics ³⁷
	Continuous	Bland-altman plots ^{26, 27, 36, 38}
		Proportion of agreement ²³
		Least product regression analysis 39
		Standard error of measurement ^{23, 26}
		Coefficient of variation ^{23, 40}
	Categorical	Proportion of agreement ²⁵
		Unordered categories ³⁹
		Unweighted kappa statistics ³⁹
		Ordered categories ³⁹
		Modified McNemar test ³⁹
		Exact single binomial test ³⁹
	Outcome of interest Reproducibility Reproducibility Internal consistency	Outcome of interestType of dataReproducibilityContinuousReproducibilityCategoricalInternal consistencyContinuousContinuousCategoricalContinuousCategoricalContinuousContinuousContinuousContinuousContinuousCategorical

Although quality assessments are typically not done for scoping reviews⁴¹, study characteristics were summarized and described to identify any gaps in reporting and in the existing measure comparison literature to be addressed by this dissertation. Appraisal of the studies was based on applicable quality criteria used by Kelly and colleagues²². In their review of all studies (until 2012) comparing the results of GPS data to self-report measure, appraisal of studies' quality was based on: year of study, population size, number of measured trips, data quality (proportion of collected data retained for analysis), population representativeness, types of measures examined and whether the study was peer reviewed. In the current review, quality will be scored based on *year of study, population size, assessment for validity, reliability and agreement* (Table 4.3). Number of measured trips and data quality are results that are not of interest in this review of comparison methods. Year of study was included as an indicator of the level of development of a device, assuming software and devices used in later studies are upgraded technologies²².

			Possible Score	
Criteria		0	1	2
Publication year		Pre 2011	2011 - Present	
Population size δ		<30	>30, but ≤ 100	>100
Quality of	Assessed for validity and/or	No to both, or	Appropriately assessed but did	Yes to both, or
comparison	provided rationale for	assessed but inappropriate	not give rationale, or rationale	identified previously
methods:	omission?	methods used	given for omission	established validity
	Assessed for reliability	No to both, or	Appropriately assessed but did	Yes to both, or
	and/or provided rationale for	assessed but inappropriate	not give rationale, or rationale	identified previously
	omission?	methods used	given for omission	established reliability
	Assessed agreement when	No to both, or	Appropriately assessed but did	Yes to both, or
	there is no criterion available,	assessed but inappropriate	not give rationale, or rationale	identified previously
	and/or provided rationale for	methods used	given for omission	established agreement
	omission?			
Data quality	Matched sampling timeframe	No, different time points.	Yes, same start and end time	Yes, same timeframe
			but did not match for exact	and same exact time
			time.	points.
	Matched outcome	No	Proxy or different data types ^{β}	Yes

Table 4.3. Study quality assessment criteria. Adapted from Kelly, Krenn, Titze, Stopher & Foster (2013)²².

^{δ} Population size was reduced from Kelly et al. (2012)²² to account for the smaller sample sizes of clinical studies.

 β Different data type refers to if one assessment's outcome was categorically derived (e.g., Life Space Assessment scores are based on assigning scores to categories and aggregating these scores) and the other was continuous (e.g., activity sphere size of 90km²).

4.3 Results

The results of the literature search are outlined in Figure 4.1. In total, 10 articles were included. The numbers reported for each search engine included both unique and duplicate entries, and any resources found after hand searching the reference list of an applicable entry. The studies retrieved exclude duplicates entries.



Figure 4.1. Literature review results on studies comparing alternative versions of comparison methods.

The study characteristics are summarized in Table 4.4. Relevant studies comparing different methods of assessing community mobility were evenly distributed over the 10 year span of this review. The majority (80.0%, 8) of the articles were published within

the last five years. All except two of these studies compared some version of a GPS system against a self-report measure, which was typically a cross-sectional interview or travel log. Only 2 (20%) articles on mobility measurements did not use any technological instrument.

The majority (80.0%, 8) of the comparison studies were completed using data gathered in the community setting. The other two were both conducted more recently and in a clinical population (e.g., people in palliative care, older adults with Alzheimer's disease). One of these studies took place in the clinic setting using two self-report measures⁵⁰, and the other compared sensor systems data obtained in the community against mobility tasks collected in a clinic setting⁵¹. Prior to 2013, all studies included were conducted in a general population, and authors tended to focus on trip frequency, duration, distance and habits. These studies were generally conducted for population based transit and civil planning purposes and the majority (four of the five) were conducted using sample sizes greater than 100.

Since 2013, comparison studies done in health-issue specific sample groups started to emerge $^{47, 50, 51}$. GPS studies are now being considered by health journals, such as the American Journal of Preventative Health, as a viable and valuable tool to characterize physical activity, functioning and real-life mobility 16 . To reflect this, the community mobility outcomes of interest in studies after 2013 have included details that may be more indicative of performance of instrumental activities of daily living by individual patients, such as mode of transportation, location visited, and life space sizes. These health-related studies also tended to have smaller sample sizes than the transportation related studies (i.e., n < 100).

Table 4.4. Characteristics of mobility methods comparison studies (n=10), according to date.

Study (date) ^(ref)	Study sample	Setting	Assessments compared	Outcome of Interest
Bricka & Bhat (2006) ⁴²	377 drivers (228 households, age and sex undisclosed)	Comm.	 In vehicle GPS (Battelle's GPS Leader[™], GeoStats GeoLogger) vs Computer-aided telephone interviews (CATI) 	• Trips outside the home
Stopher, FitzGerald & Xu (2007) ⁴³	118 individuals (>15 years of age, 70 households, sex undisclosed)	Comm.	 GPS (wearable for households members who did not use the vehicle or preferred public transit, and in-vehicle for every vehicle in household) <i>vs</i> Prompted recall survey (participants decide if in person or over the phone or over the internet or by mail) 	 Trip frequency Trip distance Travel start and end time Trip duration Trip purpose
Blanchard, Myers & Porter (2010) ⁴⁴	61 older drivers (67- 92 years, 41% men)	Comm.	 Two in-vehicle recording devices (CarChip E/X®, v.2, Davis Instruments, Hayward, CA; Otto Driving Mate®, Otto; Persen Technologies Inc. Winnipeg, MB) vs Self-report trip logs, 3. daily diaries, 4. questionnaire on usual driving habits, 5. rating of situational driving frequency and avoidance 	 Distance Frequency (number of trips and stops) Habits (driving preference during day vs. night, and type of location)
Stopher & Shen (2011) ⁴⁵	587 trips recorded from 137 individuals (>14 years of age, 76 households, sex. undisclosed) $^{\beta}$	Comm	GPS (model unknown) <i>vs</i> Victoria Integrated Survey of Travel and Activities (VISTA07)	 Same trips from home recorded based on: Start and end location Start and end time, duration Speed and mode of transport (from distance and duration)
Bricka, Sen, Paleti & Bhat (2012) ⁴⁶	265 individuals (from 136 households, age and sex undisclosed)	Comm.	 GPS (GeoStat GlobalSat device) vs Computer-aided telephone interviews (CATI) 	 Trip frequency outside the home Demographics characteristics affecting difference in trip frequency
Wu et al. (2013) 47	56 pregnant women	Comm	GlobalSat DG-100 GPS device (in bag) vs. Questionnaire about demographics, typical environmental and behaviour patterns in the past three months of interview day.	Work-related trip distanceWork-related trip duration

α Standardized assessments included: Timed Up and Go Test, Berg Balance Scale, Dynamic Gait Index, Functional Reach Test, Short Physical Performance Battery, 6- Minute Walk Test, Activities Specific Balance Confidence Scale, fall history questionnaire, gait speed and intra-individual gait variability on the GAITRite.

Study (date) ^(ref)	Study sample	Setting	Assessments compared	Outcome of Interest
Houston, Luong & Boarnet (2014) ⁴⁸	1,230 days from 196 participants (> 12 years for travel log, ≥18 years for GPS, household matched, sex undisclosed)	Comm	 GPS and accelerometer (QSTAR QT-1000x GPS) vs Self-report travel log 	 Daily frequency of trips Daily duration of trips Daily mode of transportation
Paz-Soldan et al. (2014) ⁴⁹	160 participants (7 to 74 years, [mean age undisclosed] 41.3% males)	Comm	 GPS (i-gotU GT120, Mobility Action Technology Inc.) vs Semi-structured interviews (SSIs) 	 Location visited (geographic position) Distance travelled
Phillips, Lam, Luckett & Currow (2014) ⁵⁰	62 people in palliative care (74.9 \pm 9.6 years, 63% males)	Clinic	 Life Space Assessment <i>vs</i> European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 15-Palliative (EORTC QLQ-C15-PAL) and Australia-modified Karnofsky Performance Status Scale (AKPS) 	 Physical ability and participation in society Quality of Life Performance status
Tung et al. (2014) ⁵¹	a. 19 community- dwelling older adults with mild-to-moderate Alzheimer's disease (age=70.7 \pm 2.2 years) b. 22 controls (CTL; age=74.0 \pm 1.2 years)	Lab and comm	 VALMA^a wearable sensor system: (ankle accelerometer, GPS in Google Nexus One cellphone) vs. 1. GAITRite (CIR Systems, Inc.) 2. Apathy Evaluation Scale (AES) 3. Geriatric Depression Scale (GDS) 4. Disability Assessment for Dementia (DAD) functional independence, gait 5. Demographics properties (education, age) ^a VALMA stands for Voice, Activity, and Location Monitoring for Alzheimer's Disease 	 VALMA: GPS-life space/mobility envelope (area, perimeter, % of time from home, mean distance from home) Accelerometer: steps/day GAITRite: gait velocity AES: apathy, depression GDS: Depressive symptoms DAD: Dependency in basic and instrumental activities of daily living

The analysis methods used in the studies, and the quality of the studies are summarized in Tables 4.5 and 4.6, respectively. The timeframe of comparison ranged from hours awake during one 24 hour day to fourteen days. This highlights the capacity of instrumented mobility trackers to generate large quantities of minute level data, even if the total number of individuals sampled was small (n= 43 to 377; 4/10 studies had less than 100 participants). As well, new challenges in using statistical measures and establishing concurrent validity are introduced when the assessments sampled different lengths of time, as was observed in two of the studies $^{47, 49}$.

Commonly assessed psychometric properties were: agreement or disagreement (60%, 6) and validity (30%, 3). Reliability between the measurements was not of primary interest in the studies identified. Of these, two of the three studies used correlation analyses to assess validity. Discrepancy between proposed analysis and the comparisons assessed sometimes occurred. One study ⁴⁵ aimed to validate self-report travel diaries using the GPS, and assessed percentage of disagreement in the trip frequency captured. The authors did not explicitly state that they were examining reliability or agreement. Only 2 of the studies assessed all aspects of validity, reliability and agreement, or explicitly explained why one property was omitted. Less than half of the studies matched for both sampling timeframe and outcome assessed.

Simple proportion of agreement was used instead of more complex methods by authors interested in agreement and disagreement. Coefficient of variation and the Bland-Altman plot were only used in one study to evaluate agreement and bias.

Table 4.5. Analysis methods employed by each study (n=10).

Study (ref)	Variable type (Continuous, categorical, mixed)	Time frame	Psychometric properties measured to compare multiple assessments	Comparison method	Rationale for selecting statistical comparison test (If available.)
Bricka & Bhat (2006) ⁴²	Continuous	24 hours	a) Disagreementb) Validity	 % of difference magnitude of difference plausibility of no travel using follow up questions 	N/A
Stopher, FitzGerald & Xu (2007) ⁴³	Continuous	Waking hours of 1 day (with travel)	Agreement on matched trips captured by self-report vs. GPS data	• Absolute discrepancy (perfect match)	N/A
Blanchard, Myers & Porter (2010) ⁴⁴	Continuous and categorical	1 week	a) Bias b) Agreement	a) Paired t-testsb) Method error andcoefficient of variation,Bland-Altman plots with95% CI	N/A
Stopher & Shen (2011) ⁴⁵	Continuous	Waking hours of 1 day	Validity (validate VISTA07 using gps)	• Disagreement	Looking for % trip mismatch.
Bricka, Sen, Paleti & Bhat (2012) ⁴⁶	Continuous	24 hours of a weekday.	a) Disagreementb) Covariate effects of demographic, work and household characteristics, and day of week	a) Disagreement b) Clayton Copula Model	To adjust for the potential effects of two different trip making propensities, and to allow for data with normal and logistic distributions to be in one model.
Wu et al. (2013) ⁴⁷	Continuous	Questionnaire: one time GPS: waking hours of one week at three gestational timepoints	Disagreement	Differences	N/A. ^α

Study ^(ref)	Variable type (Continuous, categorical, mixed)	Time frame	Psychometric properties measured to compare multiple assessments	Comparison method	Rationale for selecting statistical comparison test (If available.)
Houston, Luong & Boarnet (2014) ⁴⁸	Continuous	7 Day	a) Discrepanciesb) Socio-demographic andhousehold covariates associatedwith discrepancies	a) Disagreementb) Bivariate linear and multivariable logistics regression analysis	N/A
Paz-Soldan et al. (2014) ⁴⁹	Continuous	14 days for GPS, 1 day for SSI	Concordance	Matched locations using GIS	N/A
Phillips, Lam, Luckett & Currow (2014) ⁵⁰	Continuous	Two - three trials over 29 days	Validity	• Spearman and Pearson correlation	AKPS is measured on a percentage scale, and EQRTC QLQ-C15-PAL is continuous.
Tung et al. (2014) ⁵¹	Continuous	2 walking trials for 8 to 12 hours over 3-5 days	Construct validity ("of a GPS-based technology to provide quantitative measurements of global movement")	 Pearson's correlation (GPS-life space with demographic and functional measures) Multivariable linear regression analysis 	Pearson's correlation: To provide associations between VALMA and physical and cognitive functioning indicators based on previous literature.
					Regression: evaluation strength of associations between significantly correlated variables and VALMA

 α Also assessed covariates affecting difference between self-report and GPS-based trip duration using regression models and linear mixed effects models, and toxin exposure effects of misclassification.

Study (ref)	Publication year (0-1)	Population size (0-2)	Study time frame (0-2)	Validity (0-2)	Reliability (0-2)	Agreement (0-2)	Matched sampling timeframe (0-2)	Matched outcome (0-2)
Bricka & Bhat	0	2	1	1	1	2	2	2
Stopher, FitzGerald & Xu	0	2	0	2	0	1	2	2
Blanchard, Myers & Porter	0	1	2	1	0	2	1	2
Stopher & Shen	1	2	0	0	0	2	2	2
Bricka, Sen, Paleti & Bhat	1	2	1	1	0	2	1	2
Wu et al.	1	1	2	1	0	2	0	2
Houston, Luong & Boarnet	1	2	2	1	1	2	1	2
Paz- Soldan et al.	1	2	2	1	0	2	2	2
Phillips, Lam, Luckett & Currow	1	1	0	1	0	0	0	0
Tung et al.	1	1	1	2	0	0	0	0

Table 4.6. Summary of study quality according to criteria used. (n=10). Quality of the studies were described in text.

4.4 Discussion:

This review summarizes recent studies comparing alternative forms of assessing real-life community mobility. Despite the proliferation of wearable sensors and technological assessments of mobility 52 , few studies that formally compare different measures of community mobility were published between 2006 – 2016.

A small number of studies comparing self-reported measures against GPS sensors was found²². However, a slight increase in the number of studies where the GPS was one of the CM measures was observed (3 compared to 1 in each of the previous years). The recent increase in the number of GPS comparison studies indicates a shift away from real-life mobility research using only accelerometers and pedometers as GPS technology becomes more affordable, smaller and easier to use^{16, 22, 45}. Comparison studies included in this review used a diverse array of mobility outcome measures, which further illustrates the diverse ability of GPS technology to capture the multidimensional nature of real-life mobility.

Unlike many established self-report measures, affordable technological instruments often undergo rapid changes in software and hardware. For example, GPS models and versions can vary in terms of the signal fix time, sensors, battery life, data storage and management, and sampling rate. Ideally, each evolution in technological instruments would be accompanied by proper studies on validity, reliability and agreement/disagreement before new instruments were adopted for research or clinical use. Although the pace of comparison studies has been lagging, the small increase in recent studies may signal the beginning of more studies done to assess the performance of GPS against existing measures.

Traditionally, community mobility outcomes collected using the GPS were measured against travel diaries and in a general population^{42, 45}. This review showed that researchers are starting to consider the GPS as an alternative to task-based physical functioning assessments ⁵¹, and that the GPS is suitable for use in patient populations and in clinical settings. However, this review also illustrated the need for more studies evaluating GPS use in special clinical subgroups where mobility disability and mobility changes are key health outcomes.

Attempts to standardize the approaches used in method comparison studies are published ^{38, 39, 40}. This review showed that recent studies comparing alternative assessments of CM have used commonly recommended statistical measures. However, most authors did not explicitly state the intended purpose of their study as validity, reliability or agreement/disagreement assessment. As well, despite the diversity of different statistical methods available for inter-modal comparisons (Table 4.5), the majority (6) of the studies did not identify their rationale for choosing particular statistical methods. The lack of clarity complicated the process to determine appropriateness of the statistical measures used. Although the GRRAS is available for inter-rater and intra-modal assessment, guidelines for reporting inter-modal comparison studies in health research are still lacking.

Few studies attempted to assess validity. This may be due to the lack of an accepted gold standard measurement for community mobility. Therefore, this review also identified reliability as a property seldom studied in recent studies comparing CM assessments. This is expected as reliability is not meaningful in the absence of validity. Agreement and disagreement determination appeared to be a standard evaluation approach in studies comparing long duration tracking methods (e.g., GPS and diary) to compare discrete outcomes (e.g., trip frequency) and some continuous outcomes (e.g., trip duration). However, researchers comparing GPS and other long duration trackers to cross-sectional questionnaires or task-based physical functional measures may be required to adopt complex statistical methods to control for the differences in types and quantities of data gathered. As well, the ability to compare certain psychometric properties between the GPS and another measurement may be limited by the type of CM outcome of interest. For example, different GPS models present with different margins of error in the accuracy of detected location. Thus, data from two different GPS sensor types may not be able to show agreement on CM outcomes such as exact location coordinates and life space sizes.

Limitations

Bias is an important consideration of all systematic reviews⁵³. This study did not include dissertations, conference proceedings, or articles preceding 2006. It is likely that some peer reviewed comparison studies were not published in a journal. As well, instrumented measures of community mobility, such as the GPS, were available prior to 2006. Limiting the year of studies

to the last decade was to reflect the recent developments in instrumented CM measures. Earlier devices tended to be bulkier and less feasible to use outside of a controlled setting and over a period of greater than one continuous day. Therefore, studies employing earlier devices may not be comparable to recent studies using newer devices. However, the adoption of sensor based technology to study mobility by disciplines such as transportation and civil planning greatly preceded health care^{54, 55}. Therefore, the publication range used by this review may have led to the exclusion of some comparisons studies of CM that were not for health purposes.

The strict inclusion criteria applied for this review has limited its sample size to a small number of studies. For example, there are more comparison studies of methods used to assess physical activity ⁵⁶, sports performance ^{57, 58} and fine motor movement. As well, studies performed only in a laboratory, clinic or the home were also excluded. This also led to the exclusion of studies that were in a place that approximated the natural setting⁵⁹.

Further, the criteria used by this review may have excluded some potentially informative information when comparing different methods. For example, the studies were not evaluated for the data quality obtained by the assessments, such as the amount of data loss. As well, conclusions from comparison studies about the feasibility of implementation was also not considered.

4.5 Conclusions:

Technological advances provide many new opportunities to assess different aspects of real-life CM in older adults⁵². Thorough comparisons of new technologies against established measurement methods are critically needed in order to understand if and how to best use different measurements methods. The review of the literature showed few CM measurement method comparison studies were published between 2006 and 2016. Trip count, duration and distance were the most common CM outcomes of interest, but a small number of studies also evaluated travel mode and destination. Most CM measurement method comparison studies focused on evaluating the exact agreement and disagreement between different methods. Very few studies to establish reliability and validity for CM assessments were found, perhaps because of the lack of a gold standard CM assessment. As well, very few studies attempted to match the
start and end timeframe under evaluation when comparing the same CM outcome.

Still lacking are studies comparing CM measurements in diverse populations, in particular populations vulnerable to mobility disability. Researchers should also continue to conduct method comparison studies for more CM assessment tools and on a variety of additional mobility outcomes. Researchers would benefit from a guideline, like the GRRAS but for methods comparison studies, that discuss topics to include and appropriate way to compare different assessments. The current review could serve as a reference for the creation of such an intermodal comparison guideline.

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Chapter 5: Comparing wearable activity sensor and self-report measures of real life mobility

5.1. Introduction:

Mobility declines have serious consequences including increased falls, fractures, loss of independency, institutionalization, morbidity and mortality^{1, 2}. Such declines are usually the result of musculoskeletal aging, accelerated by neurodegenerative conditions such as Parkinson's disease (PD). In the context of PD, deterioration in mobility is an important predictor of reduced health-related quality of life³, and current therapeutic interventions for PD mainly target improvements of motor function. Therefore, valid and reliable assessment tools are essential to objectively capture the functional impact of mobility decline and its impacts on daily lives of individuals. Appropriate tools are also vital for evaluating the effectiveness of interventions aiming at maintaining optimal mobility levels.

Measuring mobility is complicated by its multidimensional nature: real-life *mobility* includes both capacity and actual performance of mobility within one's home and community^{4, 5}. The latter comprehensive view of mobility, termed community mobility (CM), is considered a key instrumental activity of daily living^{6,7}. Various aspects of CM are measureable, including trip frequency⁸, duration and area^{9, 10, 11, 12}.

The effects of PD on CM are highly variable among patients, which complicates accurate assessment. The most frequently used assessments are self-reports (e.g., daily diaries or cross-sectional questionnaires). One rubric is to define CM as concentric circles ("life spaces") that expand as an individual moves outward from the bedroom to the wider community^{9, 10}.

^{*} A version of this chapter is under review for publication in the *Journal of Parkinson's Disease* as: Zhu L, Duval C, Boissy P, Montero Odasso M, Zou GY, Jog M, Speechley M. Valid and reliable community mobility was captured in Parkinson's disease using Global Positioning System data. *2017*.

The referent time window for self-report measures ranges from the past week to the time since last clinical visit. Retrospective measures are subject to random (e.g. memory) error, as well as recall bias due to social desirability, and floor effects¹³. Alternatively, concurrent daily diary entries may reduce memory error but fail to account for changes in mobility across time¹⁴. Since no 'gold standard' measure of CM currently exists, self-reporting remains the most common approach to CM assessment^{15, 16}.

Wearable sensor platforms incorporating accelerometers and global positioning system (GPS) receivers are promising tools to prospectively assess the CM of people with PD (PwPs) over time periods not possible with self-report measures^{13, 17}. As physical devices, sensors should be free of measurement biases due to perceived social desirability, memory or other cognitive challenges. Moreover, wearable sensor platforms may also capture aspects of real-life motor symptoms and mobility outcomes that are not feasible through self-report.

Available advanced multi-purpose wearable sensors platforms, such as the WIMU-GPS (wireless inertial motion unit with GPS¹⁸), can be used to capture the ecological mobility of an individual. The WIMU-GPS combines 3D inertial measures of motion (accelerometers, gyroscope and magnetometers) with a Sirf 3 GPS receiver into a wearable pager size platform. Due to its small size, it can be worn at the hip or trunk. The fusion of motion data with GPS data allows the extraction of specific metrics such as location outcomes (inside versus outside the home), activity outcomes (frequency and duration of trips, destinations and physical activity levels), transit outcomes (distance travelled on foot versus in a vehicle) and geospatial outcomes of mobility in the community (community mobility lifespace sizes)¹⁹.

Despite these advances, proper comparisons of new versus older mobility assessment methods remain scarce, especially in clinical populations^{17, 20}. Comparisons of validity, reliability and agreement should be conducted between alternative assessment methods before new measures replace established ones. The lack of such studies of community mobility measures may be partly due to the absence of a consensus gold standard assessment of CM. Conventional measurement evaluation uses a gold standard to determine empirical types of validity (e.g., criterion validity). However, criterion validity is not required for initial evaluations of new

approaches; much can be learned by examining the level of agreement between existing measures without meeting the assumptions that underlie the test-criterion framework (i.e., establishing the convergent validity) ^{17, 21}.

This is the first study to systematically compare data from a wearable sensor GPS platform to self-report measures for validity, reliability and agreement in a PD population. The objectives of this study were to:

1. Assess the construct validity (in terms of convergent and concurrent validity), reliability, agreement and disagreement between self-reported and instrumented measures of community mobility in individuals with PD.

2. Identify individual characteristics that affect the *agreement* between assessments.

5.2 Methods:

Reporting of this study follows the Guidelines for Reporting Reliability and Agreement Studies (GRRAS) ²² and the Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN)^{23, 24}.

Participants

A convenience sample of 70 community dwelling older adults with early to mid-stage PD (Hoehn & Yahr Stages I to III) were recruited in person or over the phone from the Movement Disorders Clinic of London Health Sciences Center.

All patients were presented with the same opportunity to participate if they fulfilled the inclusion/exclusion criteria (Table 3.1 of Section 3). Written informed consent was obtained from all participants and ethical approval was obtained from Western University's Human Subjects Research Ethics Board (HSREB #102337).

Assessments and Common Outcomes

Over 14 days, all participants wore the WIMU-GPS during hours awake as they navigated their homes and communities. They also recorded daily diary entries¹⁴ about the start and end time of each trip taken outside. On Days 1 and 14, participants completed the Life Space Assessment $(LSA)^{10}$. This cross-sectional scale quantifies the size of one's life space in the past four weeks as a score of 0 to 120 (0 = confined to bed, 120 = daily travel to places outside of one's city/town).

Convergent validity, reliability and agreement between the WIMU-GPS and diary recordings were assessed for *"hourly frequency"* (number of trips taken from home per hour sampled) and *"daily duration"* (percentage of total time sampled per day that they were outside of home). 19 hours were used as the daily sampling period for the diary to standardize time during which sensors may have been off-body and not recording (e.g., sleeping, bathing).

The displacement and life space mobility of an individual was measured by the GPS coordinates recorded during the time sampled. The recorded data was modelled using a geospatial statistical approach based on the computation of a minimum span ellipse that fitted all the recorded data points for a given individual. The surface area of the minimum span ellipse (geometric 2D area in km²) was used as a direct quantifier of life space size. In comparison, the LSA uses single scores to represent relative life space sizes. The LSA has shown good test-retest reliability (ICC = 0.72)²⁵. This study's average Day 1 and 14 LSA scores were not statistically different (*p* = 0.14). Therefore, Day 14 LSA scores were compared against WIMU-GPS recorded "*life space size*".

To ensure sampled data averaged variability in mobility across hours of the day and days of the week, analysis included only participants whose WIMU-GPS recorded a minimum of six days with at least 600 minutes (10 hours) of data. For participants who met this criterion, any remaining days with less than 600 minutes of data were removed from analysis. Shorter recording lengths were used to define a "valid GPS day" in previous GPS activity tracking studies^{26, 27}. However, these studies did not focus on average travel time and distance, nor did they account for the sampling period of self-reported measures (typically 24 hours). Further,

sampled days without both WIMU-GPS and diary data were removed from the analysis. In total, 54 participants were included in the analysis, providing a total of 592 days of *frequency* and *life space size* data, and 573 days of *duration* data.

Additional Covariates

Discrepancies between GPS and self-report mobility measures were previously observed to be due to socio-demographic characteristics such as race, age, gender, employment or volunteering status, education, income, mode of travel, day of travel^{17, 28}, and travel behavior²⁹. These demographic characteristics were assessed, along with the impact of PD using the Parkinson's Disease Quality of Life rating scale (PDQ-39)³⁰.

Analysis

From this, 54 community dwelling PwPs (Hoehn & Yahr Stages I to III) were selected as they fulfilled the 6 days of 600 minutes criterion. Concurrent validity between the WIMU-GPS and self-report measures was established by analyzing simultaneously collected data³¹. Convergent validity was assessed through Spearman correlation analyses.

Reliability determines how well one assessment can duplicate another's ability to detect variability in outcomes³². It was assessed between the WIMU-GPS and diary using the intraclass correlation (ICC). Reliability was not examined for LSA scores as there was no analogous measure produced by the WIMU-GPS. Agreement between "*hourly frequency*" and "*daily duration*" captured by WIMU-GPS and diaries was visually compared using parallel line plots³³, and quantified using Bland-Altman (B-A) plots^{21,34,35} on *frequency* and *duration* data after log-transformation, respectively ^{21, 36}. The 95% limits of agreement (LoA) were calculated using adjusted standard deviation for multiple sampling²¹. Since no meaningful cutoff values for trip frequency and duration are available in existing literature, bias was evaluated by examining the distribution of disagreement scores within the LoA. Coefficient of variation (CV) defined as standard deviation divided by mean allowed comparison of variability among the measurements after adjusting for means of different sizes expressed in different measurement units. Subgroups validity was examined using partial correlations. Incidence rate ratios (e^{θ}) estimated using Poisson regression models were used to determine covariate effects on agreement. Offset

corrections were applied to account for the unequal number of matched days included for analysis for each participant.

Analyses were conducted using SAS (v9.3, SAS Institute Inc., 2011), SPSS (v20, IBM Corp, 2011), and MS Excel 2013.

5.3 Results

Demographics

Participant demographic characteristics and PD symptoms are in Table 5.1.

Table 5.1. Participant demographics and PD-related covariates (n=54). MOCA scores suggest some participants may have undetected mild cognitive impairment, even though it did not appear to affect their activities of daily living performance or performance on the orientation section of the MOCA.

Demographics covariates	n (range or %)			
Age (years)	67.5 ± 6.3 (55 - 79)			
Sex				
Male	38 (70.4%)			
Female	16 (29.6%)			
Marital status	0.(1 < 70)			
Unmarried/widowed/separated	9(10.7%) 45(83.3%)			
	(1, 5, 5, 7, 7, 7, 7, 7, 7, 7, 7, 7, 7, 7, 7, 7,			
income	\$20,000 - \$39,999 = 12(20.4%)			
	\$40,000 - \$59,999 = 14 (25.9%)			
	\$60,000 - \$89,999 = 11 (20.4%)			
	>\$90,000 = 6 (11.1%)			
Employment status	Fully retired = $46 (85.2\%)$			
	Partial or full employment = $8 (14.8\%)$			
Education	< High school = 11 (20.4%)			
	High school graduate = $11 (20.4\%)$			
	Some college = $3(5.6\%)$			
	College diploma = $9(16.7\%)$			
	Undergraduate degree = $8 (14.8\%)$			
	Post-graduate program = $1 (1.9\%)$			
	Graduate degree = $11 (20.4\%)$			
Residential setting	Urban = 15 (27.8%)			
	Suburban = $11 (20.4\%)$			
	Rural, in town = 18 (33.3%)			
	Rural, outside of town = $10 (18.5\%)$			
Living situation	Alone = $9(16.7\%)$			
	With family/friends = $45 (83.3\%)$			
Driving status	Drives = 52 (96.3%)			
	Do not drive = $2(3.7\%)$			
MOCA	25.6 ± 2.7 (22-30)			
Demographics covariates (con'd)	n (range or %)			
Time since PD diagnosis (years)	$6.2 \pm 5.7 (0-30)$			
Impact of PD on (PDQ-39 scores):	(0 = no impact, 100 = total impairment)			
1. Mobility	1. $17.9 \pm 20.9 (0-70.0)$			
2. Activities of daily living	$2.23.2 \pm 18.4 (0-70.8)$			
3. Emotional well being	3. 19.1 ±16.6 (0-66.7)			
4. Perceived stigma	4. 13.3 ± 16.0 (0-68.8)			
5. Social Support	5. 8.3 ± 12.3 (0-50.0)			
6. Cognition	6. 24.1 ± 19.3 (0-68.8)			
7. Communication	$7.20.7 \pm 19.0 (0-75.0)$			
8. Bodily discomfort (e.g., pain)	8. 26.6 ±23.4 (0-100.0)			
9. Overall quality of life	9. 19.1 ± 13.7 (1.8-64.7)			

Community mobility outcomes

"Hourly frequency", *"daily duration"* and *"life space size"* results are presented in Table 5.2. Two additional outcomes measured were added for comparison with existing literature. *"Daily frequency"* refers to the absolute number of trips outside of the property per day. *"Daily trip duration"* was computed by dividing the mean daily minutes outside by number of *"daily frequency"*, for days with 1 or more trips recorded.

WIMU-GPS captured greater "*daily duration*" and "trip duration" than diaries, and both differences were significant (p < 0.05). When frequency was based on raw daily counts, the mean "*daily frequency*" was higher using diaries than the WIMU-GPS. However, after accounting for sampling duration, a significant difference between "*hourly frequency*" captured by WIMU-GPS and diary was not found.

B-A analysis of agreement requires normally-distributed difference scores. Shapiro-Wilk tests showed that LSA scores and mean "*hourly frequency*" differences were the only normally distributed outcomes; hence, subsequent Bland-Altman analyses of agreement were performed on log transformed difference scores. The estimated CVs suggested similar dispersion for "*hourly frequency*" measured by WIMU-GPS and diary. Diary recordings of "*daily duration*" and WIMU-GPS recordings of "*life space sizes*" were notably more variable than WIMU-GPS and LSA measures, respectively.

Convergent validity

Good convergent validity ($r \ge 0.4$) was detected only between WIMU-GPS and diary on "daily duration" ($r_s = 0.693$, 95% confidence interval [CI] = 0.52 to 0.81; Figure 5.1a) and "hourly frequency" (r_s =0.427, 95% CI = 0.18 to 0.62; Figure 5.1b). Adequate convergent validity was not observed between the WIMU-GPS and LSA on "life space sizes" ($r_s = 0.393$, 95% CI = 0.14 to 0.60; Figure 5.1c). Validity was not affected by demographic covariates as partial correlation coefficients did not change more than 5% from the crude correlation.

Table 5.2. Mean mobility outcomes measured by self-report measures and WIMU-GPS. Primary outcomes ofinterest are in bold. Trip duration and daily frequency are included for comparison.

Community Mobility Outcome	Mean ± Standard deviation (range)	Shapiro-WilkNormality test(S-W; normaldistribution: $p \ge$ 0.05)	Coefficient of Variation (CV)	Mean difference in comparable outcomes (WIMU-GPS – Diary) ± Standard deviation (range)	Wilcoxon Signed Ranks test of difference		
WIMU-GPS "daily duration"	25.0 ±11.6% (6.2%, 60.8%)	p = 0.04 log transformed: p = 0.1618	0.46	4.8% ± 11.4% (-41.6%, 25.1%)	$W < W_{\alpha=0.05,53} = 500.5,$ p<0.0001 [†] .		
Diary "daily duration"	20.3 ±12.2% (0.2%, 57.4%)	p = 0.01 log transformed: p < 0.0001	0.60	Shapiro-Wilk test: <i>p</i> < 0.0001 [‡]			
WIMU-GPS "trip duration" ^β	134.73 ± 57.51 mins (45.6, 298.8 mins)	<i>p</i> = 0.0066	6.19	24.86 ± 53.21 (-105.76, 132.38)	$W < W_{\alpha=0.05,53} = 384.5,$ $p < 0.0006^{\dagger}$		
Diary "trip duration" ^β	112.36 ± 52.11 mins (1, 279.3 mins)	<i>p</i> = 0.0229	6.72				
WIMU-GPS "hourly frequency"	0.12 ± 0.06 (0.03, 0.28)	p = 0.0002 log transformed: $p = 0.6071$	0.50	0.01 ± 0.05 (-0.15, 0.16)	$W < W_{\alpha=0.05,53} = 149.5,$ p < 0.2		
Daily "hourly frequency"	0.11 ± 0.06 (0.03, 0.34)	p = 0.0005 log transformed: p = 0.9327	0.55	Shapiro-Wilk test: p = 0.1056			
WIMU-GPS "daily frequency" ^β	1.5 ± 0.7 (0.43,3.7)	<i>p</i> < 0.0001	7.16	-0.7±0.9 (-3.3, 1.5)	$W < W_{\alpha=0.05,53} = -512,$ $p < 0.0001^{\dagger}$		
Diary "daily frequency" ^β	2.2 ± 1.1 (0.6, 6.4)	<i>p</i> = 0.0005	7.29				
LSA "life space size" (Maximum = 120)	84.8 ± 16.3 (48, 120)	<i>p</i> = 0.36	0.19	[†] Statistically significant differences in comparison pairs, shown using the Wilcoxon Signed Ranks test ($p \le 0.05$). Non-normal distribution of differences remained after log ar logit transformations (both S-W tests yielded <i>p</i> 0.0001). ^β Included to show the importance of accountin for the different daily start and end time of WIMU-GPS and diary recordings.			
WIMU-GPS "life space size" (km ²)	4 048.8 ± 6 432.3 8.2, 29 448.6)	<i>p</i> < 0.0001	1.59				





b. (middle) Relationship between "hourly frequency" measured using WIMU-GPS and diary. Good convergent validity ($r \ge 0.4$) was shown using Spearman correlation analysis.

c. (bottom) Relationship between *"life space size"* measured using WIMU-GPS and LSA. Good convergent validity $(r \ge 0.4)$ was not detected using Spearman correlation analysis.

Reliability and agreement

Good reliability was demonstrated for both "daily duration" (ICC = 0.674, 95% CI = 0.42 to 0.82) and "hourly frequency" (ICC = 0.714, p=0.00006, 95% CI = 0.51 to 0.82). B-A plots were constructed to evaluate the imperfect agreements (i.e., ICC \neq 1) between the WIMU-GPS and diary records.

Figures 5.2a and c are B-A plots of log base 10-transformed data. The mean difference and 95% LOA for log *"hourly frequency"* is 0.03, and 0.51 to -0.45, respectively (Figure 5.2a). Hence, WIMU-GPS *"hourly frequency"* averaged 1.07 times the diary reports, and was between 0.35 to 3.2 times of the diary reports 95% of the time. ICC values for both outcomes did not change more than 10% after the removal of outliers.

The mean difference and 95% LOA, for "*daily duration*" is 0.14 and -0.62 to 0.90, respectively (Figure 5.2c). Antilog of difference between two log values yields a ratio. Therefore, mean WIMU-GPS "*daily duration*" is 1.38 times the mean reported using the diary, and 95% of the WIMU-GPS recorded "*daily duration*" were between 0.24 to 7.9 times of diary reported values.

Higher mean WIMU-GPS recordings of both outcomes were observed in the majority of the participants (Figures 5.2b and 5.2d). For *"hourly frequency"*, 36 (66.7%) PwPs recorded higher WIMU-GPS outcomes compared to 18 (33.3%) with higher diary reports. For *"daily duration"*, 43 (79.6%) participants had higher WIMU-GPS recordings compared to 12 (22.2%) with higher diary reports.

As well, daily agreement between WIMU-GPS and diary seldom occurred. Agreement occurred more often for "*hourly frequency*" than for "*daily duration*" (10.1% of days vs. 0.07% of days, respectively). The WIMU-GPS recorded greater "*hourly frequency*" and "*daily duration*" than the diary across majority of the days (67.0% and 75.6% of days for *frequency* and *duration*, respectively).



Figure 5.2. Bland-Altman plot of agreement between log mean and log difference on "*hourly frequency*" (a) and "*daily duration*" (c). Majority of participants recorded higher WIMU-GPS "*hourly frequency*" (b) and "*daily duration*" (d) than the Diary (66.7% and 79.6% respectively). All n=54.

A summary of the statistically significant demographic and disease-related covariates affecting the agreement types are presented in Tables 5.3 and 5.4. No significant predictors of higher WIMU-GPS recordings of *"hourly frequency"* were found (Table 5.3). Agreement was not assessed for *"daily duration"* due to too few days of occurrence (Table 5.4).

For "*hourly frequency*", women and low income PwPs were less likely to over self-report in the diary. For "*daily duration*", rural PwPs were less likely to over self-report when they lived in town versus outside.

Employment status was the only common predictor of most disagreement types for both outcomes. Higher diary reports of "*hourly frequency*" and "*daily duration*" than WIMU-GPS recordings were 1.66 and 1.93 times more likely to occur in working PwPs than retired PwPs. WIMU-GPS recordings of working PwPs were 0.75 times less likely to be higher than self-reported for "*daily duration*", and was not significant for "*hourly frequency*".

Income disparity affected disagreement differently. Compared to PwPs whose income exceeded \$90, 000, those whose income was between \$60, 000 - \$89, 999 were 1.78 to 2.02 times more likely to over self-report on both outcomes. Those with the lowest income over self-reported 0.55 times less often on *"hourly frequency"*, and those in the second lowest income strata were 1.92 more likely to over self-report *"daily duration"*.

Increased impact of PD on mobility, activities of daily living (ADLs), discomfort and overall quality of life were significant predictors of slightly lower incidence of over-self-reporting on both outcomes. Longer disease duration also predicted a similar lower incidence of over self-reporting on frequency but not duration.

Measurement agreement on "*hourly frequency*" was more likely to occur in PwPs who were older, completed some college (compared to those with graduate degrees) and had experienced stigma and challenges with ADLs due to PD. However, it was 0.40 times less likely to occur among working PwPs versus retirees. Agreement was not assessed for "*daily duration*" due to too few days of occurrence.

Table 5.3. Statistically significant predictors of *"hourly frequency"* captured by the WIMU-GPS and Diary.Significant predictors of higher WIMU-GPS recordings were not found.

Participant characteristics	Higher Diary				Agreement			
	Log estimate (β)	Incidence rate ratio (e ^β)	95% CI	p	Log estimate (β)	Incidence rate ratio (e^{β})	95% CI	p
Age ^β	-0.0300	0.97	(-0.0576, -0.0023)	0.0336 [†]	0.0583	1.06	(0.0163, 0.1002)	0.0065 [†]
Sex (referent: females)	-0.3697	0.69	(-0.7236,-0.0158)	0.0406 [†]	0.1270	1.135	(-0.4452, 0.6992)	0.6635
Employment status ^β	0.5049	1.66	(0.0973, 0.9124)	0.0152 [†]	-0.9203	0.398	(-1.9346, 0.0941)	0.0754 ^{††}
(referent: retired)								
Education								
(referent: graduate degree)								
< High school	-0.2694	0.76	(-0.8862, 0.3474)	0.3919	0.2859	1.331	(-0.4922, 1.0639)	0.4714
High school graduate	0.3876	2.41	(-0.1385, 0.9137)	0.1487	-0.1276	0.880	(-0.9839, 0.7288)	0.7703
Some college	-0.5287	0.59	(-1.7318, 0.6744)	0.3891	1.1897	3.286	(0.2790, 2.1004)	0.0105 [†]
College diploma	0.3623	1.44	(-0.1988, 0.9233)	0.2057	-0.0788	0.924	(-0.9895, 0.8319)	0.8654
Undergraduate degree	0.2704	1.31	(-0.3212, 0.8620)	0.3703	0.0429-	1.044	(-0.8678, 0.9536)	0.9264
Post-graduate program	0.8801	2.41	(-0.0870, 1.8472)	0.0745**	23.6849	5.17x10 ⁻¹¹	(-273645, 273597)	0.9999
Income β (referent:>\$90,000)								
0 - \$19, 999	-0.6011	0.55	(-1.3184, 0.1162)	0.1005**	0.5463	1.727	(-0.4445, 1.5371)	0.2799
\$20, 000 - \$39, 999	-0.3707	0.6903	(-1.0610, 0.3197)	0.2926	0.1994	1.221	(-0.8439, 1.2427)	0.7079
\$40,000 - \$59,999	-0.2468	0.781	(-0.8719, 0.3783)	0.4391	0.0589	1.061	(-0.9453, 1.0631)	0.9085
\$60, 000 - \$89, 999 ^β	0.5767	1.78	(-0.0172, 1.1707)	0.0570**	-0.0883	0.915	(-1.1815, 1.0049)	0.8743
Years since diagnosis	-0.0515	0.95	(-0.0893, -0.0136)	0.0077 [†]	0.0262	1.027	(-0.0110, 0.0635)	0.1671
Impact of PD on:								
(based on PDQ-39 scores) $^{\beta}$								
1. Mobility ^β	-0.0084	0.992	(-0.0177, 0.0008)	0.0727**	0.0063	1.006	(-0.0049, 0.0176)	0.2698
2. Activity of daily living β	-0.0101	0.99	(-0.0200, -0.0001)	0.0470^{\dagger}	0.0104	1.010	(-0.0027, 0.0235)	0.1203
3. Emotional well being	-0.0034	0.9966	(-0.0141, 0.0072)	0.5293	-0.0082	0.992	(-0.0247, 0.0083)	0.3294
4. Perceived stigma	-0.0120	0.988	(-0.0242, 0.0003)	0.0557**	0.0156	1.016	(0.0024, 0.0289)	0.0210 [†]
5. Social Support	0.0091	1.009	(-0.0035, 0.0218)	0.1571	-0.0131	0.987	(-0.0368, 0.0106)	0.2804
6. Cognition	-0.0089	0.991	(-0.0185, 0.0008)	0.0717 ^{††}	0.0040	1.004	(-0.0089, 0.0170)	0.5415
7. Communication	-0.0026	0.997	(-0.0119, 0.0066)	0.5785	0.0021	1.002	(-0.0109, 0.0151)	0.7497
8. Bodily discomfort ^β	-0.0079	0.992	(-0.0160, 0.0002)	0.0555**	-0.0018	0.998	(-0.0127, 0.0090)	0.7395
9. Overall quality of life β	-0.0115	0.989	(-0.0248, 0.0019)	0.0919**	0.0055	1.0055	(-0.0119, 0.0229)	0.5367
† Significant at $p = 0.05$. †† Significant at $p = 0.1$. ^{β} Covariate was significant for both community mobility outcomes.								

Table 5.4. Statistically significant predictors of *"daily duration"* captured by the WIMU-GPS and Diary. Significant predictors of agreement between the measurements were not found.

Participant characteristics	Higher WIMU-GPS			Higher Diary				
	Log estimate (β)	Incidence rate ratio (e ^β)	95% CI	p	Log estimate (β)	Incidence rate ratio (e ^β)	95% CI	p
Age ^β	0.0078	1.0078	(-0.0073, 0.0228)	0.3121	-0.0264	0.974	(-0.0533, 0.0006)	0.0552 **
Employment status ^β (referent: retired)	-0.2897	0.748	(-0.5771, -0.0023)	0.0482 †	0.6586	1.932	(0.2776, 1.0395)	0.0007 [†]
Income ^β (referent: >\$90,000)								
\$0 - \$19, 999 \$20, 000 - \$39, 999 \$40, 000 - \$59, 999 \$60, 000 - \$89, 999 ^β	-0.0285 -0.1829 -0.1441 -0.2020	0.972 0.833 0.866 0.817	(-0.3763, 0.3192) (-0.5439, 0.1782) (-0.4784, 0.1902) (-0.5613, 0.1574)	0.8722 0.3208 0.3983 0.2707	0.1529 0.6524 0.5358 0.7007	1.165 1.920 1.709 2.015	(-0.6670, 0.9729) (-0.1249, 1.4296) (-0.2189, 1.2905) (-0.0695, 1.4708)	0.7147 0.1000 ^{††} 0.1641 0.0746 ^{††}
Residential setting (referent: Rural, outside of town)								
Urban Suburban Rural, in town	-0.0578 0.0940 0.1260	0.944 1.099 1.134	(-0.3522, 0.2366) (-0.2114, 0.3995) (-0.1416, 0.3937)	0.7004 0.5463 0.3561	0.1455 -0.3010 -0.4128	1.157 0.740 0.662	(-0.3125, 0.6035) (-0.8512, 0.2491) (-0.8943, 0.0687)	0.5336 0.2835 0.0929 ^{††}
Impact of PD on: (based on PDO 30 seconds)								
 Mobility^β Activity of daily living^β Emotional well being Perceived stigma Social Support Cognition Communication Bodily discomfort^β Overall quality of life^β 	0.0032 0.0041 -0.0000 0.0022 -0.0017 0.0014 0.0017 0.0020 0.0035	1.003 1.004 1.000 0.998 1.001 1.002 1.002 1.002	(-0.0012, 0.0076) (-0.0010, 0.0091) (-0.0057, 0.0057) (-0.0036, 0.0080) (-0.0097, 0.0062) (-0.0035, 0.0064) (-0.0032, 0.0065) (-0.0019, 0.0059) (-0.0032, 0.0101)	0.1553 0.1141 0.9982 0.4522 0.6674 0.5691 0.5079 0.3119 0.3084	-0.0127 -0.0141 -0.0005 -0.0074 0.0048 -0.0049 -0.0049 -0.0049 -0.0071 -0.0121	0.987 0.996 0.9995 0.993 1.005 0.995 0.995 0.993 0.988	(-0.0223, -0.0030) (-0.0242, -0.0040) (-0.0107, 0.0097) (-0.0189, 0.0041) (-0.0084, 0.0180) (-0.0141, 0.0043) (-0.0143, 0.0046) (-0.0150, 0.0008) (-0.0254, 0.0012)	0.0100 [†] 0.0060 [†] 0.9264 0.2068 0.4726 0.2992 0.3131 0.0782 ^{††}
[†] Significant at $p = 0.05$. ^{††} Significant at $p = 0.1$. ^β Covariate was significant for both community mobility outcomes.								

5.4 Discussion:

This is the first study to systematically compare the mobility outcomes recorded by wearable GPS technology and self-report measures in a clinical population.

Community mobility of PwPs

Large variations in *frequency* and *duration* of time spent outside of home were observed; such variations were higher for *duration* than *frequency outside*. The effects of environmental, lifestyle or disease specific characteristics on CM were unclear.

Discrepancies between assessments

In the absence of a gold standard, assessment validation is done against existing measures of a common outcome^{21, 22}. WIMU-GPS was a valid way to record *hourly frequency* and *daily duration* outside the home when compared with travel diaries. Both WIMU-GPS and diary also showed similar ability to distinguish participants' *frequency* and *duration outside* (ICC = 0.714 and 0.674, respectively).

Methods seldom agree exactly²¹. Disagreements between the measures were detected across the majority of the sampled days for both outcomes. More agreement was found for *frequency* than *duration*. This may be due to the increased complexity of duration recall. As well, WIMU-GPS recorded longer *daily* and *trip duration* than diary report. This is contrary to other studies of GPS and self-report measured duration, which consistently showed greater diary self-reported trip duration than GPS recordings³⁷.

In terms of "hourly frequency", mean WIMU-GPS measurements were also higher than diary reports, but this difference was not significant. Previous studies often compared assessments in terms of *daily frequency* and *duration*¹⁶, which do not account for the different time length sampled due to variations in actual sensor wear time, sensor time without data interference or loss, and diary completion. When hours sampled was not considered, a significant difference on "*daily frequency*" was found. Contrary to "*hourly frequency*", higher diary "*daily frequency*" was observed compared to WIMU-GPS recordings.

The importance of using matched common time is highlighted by this study. The results differed when sampled time was standardized between the assessments. Matching for common time sampled or trips recorded is very important for comparison studies. A population study comparing trip level matches showed matches in origin and/or destination among only 64% of trips recorded by GPS and diaries ³⁷. Although this study did not employ trip level matching¹⁶, it accounted for the different lengths of actual sampled time by the assessments.

Finally, it is possible that by being aware of the simultaneous GPS recordings, participants may become more diligent with completing their diary recordings. Thus, independent diary recordings may be less reliable as a solo assessment method.

Limitations of cross-sectional measures

Good convergent validity was not found when comparing WIMU-GPS and LSA assessed *"life space size"*, indicating an inherent issue with the LSA's discriminatory power. The sizes of life space area often differ widely among individuals with the same LSA score (Figure 5.1c). For example, the area of mobility of individuals with a LSA score of 100 spanned a wide range, from 104.12km² to 18, 509.57km².

Possible reasons for this imprecision may include: issues with LSA's discriminatory ability when measuring life spaces greater than respondents' communities, difficulties of participants to remember distance travelled, especially when trip chaining (visiting multiple locations during one commute) or when travel activities increased during warmer weather.

Despite following the LSA instructions by providing examples of neighbourhood boundaries, subjective interpretation of questions may influence self-reporting. Participants of this study were located in diverse settings. When participants in a larger municipality report no travel outside of town (lower LSA), the WIMU-GPS recorded area of travel may remain large (higher recorded area by WIMU-GPS). Similar issues could arise even between individuals living in the same location. Floor effects are already common in retrospective measures¹³, and is further illustrated in Figure 5.1c. This comparison study has made the additional flaws with the LSA apparent.

Subgroup variations

Working PwPs were more likely to over self-report their mobility outcomes than their retired peers. As well, agreement between the WIMU-GPS and diary on *frequency* was more likely among retired PwPs than those who worked. Hence, the assessments can likely be interchangeably used among retirees. People who worked may be less able to comply with the recording protocol during work hours. A difference in agreement between GPS and self-report has been shown to be dependent on the type of work performed in the general population²⁸. Compared to those who volunteered, people with paid work were more likely to self-report more trips than GPS recordings. Therefore, those without formal paid work may be travelling more, often in a trip-chaining pattern, which can complicate record keeping. Such stop-go traffic patterns may also lead to possible trip over-detection by GPS, which increases the amount of disagreement in the results.

Incidence of diary over-reporting also was more sensitive to education, income, and place of residence. These characteristics may have influenced participants' understanding of study requirements and technology use. Female participants were more likely to over self-report frequency than men. In the general population, age was a significant predictor of disagreement between GPS and self-report²⁸, and led to higher probability of more GPS-derived trips¹⁷. Age distribution of this sample was homogenous relative to general population samples in existing studies; this may be why age was not shown to be a strong predictor of inter-assessment agreement and disagreement.

Time since diagnosis and PD's effects on quality of life were significant predictors, but did not produce notable change the incidence of agreement or disagreement between WIMU-GPS and Diary. Hence, the effects of PD likely do not affect agreement between assessments.

WIMU-GPS Data quality

60.4% (592/980) of sampled days were included for analysis. Sampled days excluded from the analysis were due to insufficient recorded time by the GPS. However, this was to be expected, and it was within the 2.5 - 92% data loss range reported in existing GPS studies ^{38, 39}.

Current WIMU-GPS issues causing insufficient recordings were consistent with other studies³⁸, and included: participant noncompliance issues (e.g., not charging the GPS battery nightly, discontinuous wear on the body), equipment issues (e.g., spurious and inaccurate data loss occurred during 7 days from 6 PwP). The impact of including incomplete data collection days will be examined in a subsequent study.

Diary data quality

7.7% (75/980 days) of diary entries were observed to be missing or incorrect. This was likely an underestimation, as the accuracy of diary entries was not always apparent to the transcriber. An inconsistent quality of diary completion was observed, with high variability in how much detail and precision was given. Digit preference was seen as participants often rounded time to nearest 15 minutes, and provided incomplete location details (e.g., no information given about origin locations). Almost all participants expressed uncertainty or displeasure with the task of diary completion.

Common reasons for diary under-reporting are known to be survey length, recall issues, compliance, judging trips to be unimportant, unwillingness for full disclosure and reporting error^{29, 37, 40}. Short trips, especially when occurring in sequence (trip chaining), and trips by non-motorised modes were often omitted or forgotten in the general population^{28, 29}. Recall based assessments are also prone to recall bias due to social desirability, floor effects and subjective interpretations⁴¹.

Strengths of study

This study minimized selection and recall bias by breaking down the data collection to 3 home visits, and providing follow up phone calls with reminder slips. All participants' data were collected by the same trained researcher to minimize interrater bias.

Many commercial GPS models provide users with ready-processed aggregate data, without the ability to calibrate settings and appraise data quality. This also limits users' ability to generate percentage of time sampled to create time-standardized outcomes. Hence, accounting for unmatched start and end times is often not done. The WIMU-GPS allows users access to raw

data to identify and filter out common GPS signal noise. By standardizing sampling time, validity, reliability and agreement between *frequency* and *duration* data reported by this study may be more accurate than previously reported.

Many studies limit GPS sampling to one week or less^{39, 40} due to GPS design limitations, to minimize participant burden and inevitable data loss (the latter of which increases with sampled time). However, mobility is unstable over time, and the best approximation of real-life mobility requires longer duration recordings. This study optimized the trade-off between capturing representative data and data loss by using a data collection protocol of two weeks, and then applying a minimum sampled criteria for the analysis.

Study Limitations

Generalizability of findings may be limited as participants were high functioning, community dwelling older adults with PD who did not use any mobility aids. Subsequent studies are needed to determine if similar validity, reliability and agreement outcomes are repeatable in other clinical populations. Also, this study's interpretation of acceptable error was greatly limited by the lack of a predetermined clinically relevant cutoff limit.

This study's interpretation of acceptable error was limited by the lack of a predetermined clinically relevant cutoff limit. As well, trip level matching was not conducted. The longest daily WIMU-GPS recording was just under 19 hours. Hence, the start and end times of each day's WIMU-GPS recording and diary reports were matched, but the percentage *frequency* and *duration* reported by the diary were calculated based on 19 hours and not 24 hours.

Clinical and Research Recommendations

Wearable sensors may be able to improve the ability to track individual mobility changes by traditional clinical and laboratory assessments⁴³. The absence of clinically significant cutoff scores and a gold standard measure of CM^{42} limited the interpretation of values contained within the 95% LOAs for their clinical relevance²¹. However, the difference between trip frequency was small (i.e., mean difference and LOA ranges were all <1 trip per day). Hence, the WIMU-GPS could be used to replace the diary to measure *trip frequency* when burden and recall

bias of diaries are issues.

Previous findings of diaries' over-reporting of *trip duration*, relative to GPS recordings, were not duplicated¹⁶. Mean difference between diary and WIMU-GPS detected was low (4.77% of sampled time). However, this difference between WIMU-GPS and diary may be clinically relevant for individuals confined to the home who wish to increase time outside.

Furthermore, diary use to capture *trip duration* presents a high amount of participant burden as respondents must record every time of arrival and departure. In this study, many participants mentioned they found writing down trip timing to be the most cumbersome task. Participant burden may hamper the quality of the self-report data. For this reason, the WIMU-GPS should also be considered as a reasonable alternative measure to capture trip *duration*.

Despite the LSA's wide use, its discriminatory power is inadequate. Therefore, it should only be used to capture change within the same person, and not inter-individual differences. Non-standard environmental and neighbourhood characteristics also hinder its ability to capture different mobility space sizes.

Research and clinical assessments of real-life mobility typically rely on even fewer questions than the LSA. Therefore, it is reasonable to assume that most ways of approximating mobility through simple patient recall are not representative of their community mobility. Accuracy in life space size measurement may be improved through more contextual questions or longer duration assessments; both are possible when using GPS sensors.

5.5. Conclusions:

The WIMU-GPS shows good construct and convergent validity with long duration self-report measures, and could reasonably replace self-report diaries to capture *trip frequency and duration* in PwPs. When trying to understand the size of life space, researchers and clinicians should avoid simply asking cross-sectional questions as this type of inquiry cannot accurately gauge individuals' span of mobility below and above a certain distance threshold.

Employment status significantly affect the agreement between WIMU-GPS and self-report, so WIMU-GPS are best used for retiree populations. This may be also true for other GPS models. Although agreement is also affected by other demographics characteristics, severity of disease did not greatly affect agreement.

Overall, GPS technology is a promising health research and clinical measure of real-life mobility in PwPs⁴⁴. This study adds to the emerging field of research on GPS utility by: 1. comparing GPS and self-report measures in a clinical population, and 2. serving as a guide for future comparison studies using instrumented assessments.

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Chapter 6:

Study 3. Sampling strategies for long duration recording of community mobility

6.1 Introduction

Community mobility (CM) outside of one's home is an important instrumental activity of daily living^{1, 2, 3}. Declines in CM are related to decreases in quality of life⁴, mental health⁵ and independence^{6,7,8}, as well as increased risk of disability and death^{6, 9}. Therefore, assessing and maintaining CM is often a goal of many public health initiatives and clinical treatment plans¹⁰. As well, adequate measurement of mobility in real life community setting is a key challenge in health research.

CM is a complex and multidimensional construct¹¹, composed of several different components such as time spent outside the home, distance travelled, number of destinations, etc. Each component can be measured in terms of frequency¹², duration^{13, 14, 15,} and in some cases, intensity (e.g. speed of travel)¹⁶. Components of CM may vary in a given individual hourly, diurnally, weekly, and seasonally, for reasons including pain, functional and cognitive impairment and health declines^{17, 18, 19, 20}, as well as lifestyle effects due to changes in habits, personal events, holiday or employment factors, as well as weather^{10, 11} and the physical environment²¹.

CM studies often rely on self-report questionnaires^{9, 13, 22, 23} or daily diaries^{24, 25} that ask for recall of past mobility over a set timeframe. These self-report assessments are easy to administer but are prone to recall and respondent bias^{26, 27, 28}, may not be sufficiently long to capture variability in mobility, and may be cumbersome to complete if it involves multiple time points²⁹. As Study 2 of this Dissertation has shown, they may also lead to over-reporting and floor and ceiling effects.

The goal of measuring any construct in a person is to capture his or her individual true value (ITV) for the different components of that construct. Theoretically, the ITV can be attained when a CM component is measured over a large number of days with an accurate assessment. The average value calculated would represent all known and unknown sources of variation in the CM component, and can serve as a person's ITV. In reality, ITVs must be estimated because

life-long long duration recording is impractical, and it is often unknown how each CM component will vary for each individual. Best practices should focus on determining the optimal length of recording to estimate the ITV with sufficient accuracy for a given set of research objectives. For example, it is reasonable to assume that assessments based on only one day's data cannot capture CM variation very well, and the estimates of ITV produced using only one day's data will likely include errors of unknown direction and magnitude.

Emergence of wearable Global Position System (GPS) technology with data recorders allows researchers and clinicians to easily and passively capture a person's CM in his or her real-life setting over multiple hours and days^{30, 31, 32, 33}. These devices can provide data on numerous CM components, such as trip frequency^{34, 35}, duration ^{26, 27, 36}, distance ^{37, 38, 39, 40} and size of activity area³³. A GPS continuously records data, often every second. Hence, measuring mobility over multiple days generates an enormous amount of real-time data not attainable using recall methods. As discussed, CM is a dynamic construct, and data captured on an individual can vary greatly, even from one day to the next. Thus, even a highly accurate GPS could produce daily recordings with some level of error relative to the average habitual ITV.

Larger data quantities (e.g., increasing sample sizes) can reduce the average error around the mean and improve the certainty that data collected represents a population parameter⁴¹. Maximizing the number of sampled minutes, hours or days to improve the precision of the ITV estimate functions exactly the same as increasing the sample size of a study to improve measurement precision of a population parameter. Similar to study sample sizes, increasing sampling frequency may also produce a diminishing return, whereby above a certain point the increase in information is not worth the costs of data collection.

Inherent technical issues compromise the quality of large datasets produced by GPS units. An issue specific to the GPS is that increase in sampling frequency may decrease precision. This is because increasing the number of GPS recording days may introduce greater data loss and compromise data quality⁴⁰. For example, GPS studies typically report loss of data due to low battery, signal drop out, and participant non-compliance ^{40, 42, 43}. Reports of missing GPS data after 1 week of data collection have ranged from 46.7% (549 of 1176 days with \geq 50% complete

data)⁴⁴ to 88.8% (95/107 participants with fixed signal GPS data)⁴⁵. Such large data loss may introduce bias, decreases study power, compromises the quality of the overall dataset and data yield, and may not be the best use of resources.

Despite common data loss issues, researchers have not employed a standard length of recording when using GPS to study CM because no recommendations regarding this are available. Set recording lengths have varied from 1 day^{40, 46} to 1 week^{36, 45}. Within the same study, recording length can also vary³⁸. Researchers also seldom account for any potential differences in weekday to weekend CM. Studies that do consider daily variations have opted for capturing only one weekend day, in addition to one or more weekdays, that best represent participants' mobility⁴⁷. However, this approach may be prone to selection bias as participants may choose a weekend day based on convenience or social desirability, rather than a day that is representative of typical mobility.

Therefore, for users of GPS to study CM, the questions remain: Do shorter lengths of recording produce differences in CM compared to longer lengths? How much variability in common mobility components occurs on a daily or weekly basis? Can a minimum appropriate recording length when assessing CM be identified?

6.2 Objectives

The objectives of this study were to:

- 1. Compare and contrast four CM outcomes obtained using different recording lengths.
- 2. Quantify day-to-day and day of the week variabilities in CM.
- 3. Determine whether a minimum recording length could be recommended.
6.3 Methods:

6.3.1 Data collection

70 people with Parkinson's disease wore a wireless inertial motion unit with GPS (WIMU-GPS) during waking hours over 14 days. Since it is more likely non-typical mobility would be includedmeasured over the course of one week, as opposed to two, it is reasonable to assume that 14 days of sampling allowed for greater opportunities to capture typical day-to-day mobility, including the diversity of weekend activities.

Participants were instructed to wear the WIMU-GPS with as little disruption to their daily life as possible. To capture as much free-living mobility as possible, no standard start and end times were used. Participants were allowed to remove the WIMU-GPS device in the evenings to charge the battery, and when bathing, swimming or other close contact with water. These approaches were consistent with other GPS studies ^{48, 27}. In general, free-living recordings yielded different amounts of data between participants, even in absence of any missing data.

6.3.2 Equipment:

The WIMU-GPS is a multi-purpose wearable sensor platform, combining 3D inertial measures of motion (accelerometers, gyroscope and magnetometers) with a Sirf 3 GPS receiver⁵⁰. Its small pager size allows the unit to be worn non-intrusively around an individual's torso using a flexible clip-enclosure strap.

6.3.3 Outcomes of interest:

Common community mobility outcomes occurring outside of the home were the focus of this study. They included daily total "time outside" (minutes) ^{26, 27, 36}, "trip count" (i.e., number of trips taken from home) ^{34, 35}, "hotspots count" (i.e., number of hotspots visited) and "area size travelled" (km²) ³³. Hotspots are geographical locations on Earth where an individual has stopped for 3 minutes or more, as derived from satellite coordinates⁵⁰. It allows the identification of purposeful destination, as opposed to stops at traffic lights. The area travelled was derived from a best-fit ellipse drawn around 95% of the GPS points captured⁵⁰.

WIMU-GPS also generated indicators on number of trips taken by car or on foot, average distance to hotspots and amount of time active. These outcomes were not properties commonly

assessed in other GPS studies, and were excluded from the present study.

6.3.4 Criterion and comparison group selection

To understand which sampling rate is optimal, mobility outcomes recorded using different sampling lengths must be compared against each other, and against the true value. Since mobility is highly individualistic, mobility outcomes recorded using different lengths must be separately compared for each individual participant.

A. Criterion Group

As per the Law of Large Numbers, the best estimates of true CM outcomes (i.e., the ITV) is achieved when the number of minutes measured per day *and* number of days measured per sampling period are both maximized. This allows both intra- and inter-day variations in mobility to be captured.

In this study, the best estimates of the ITVs were assumed to be based on the complete data set: 14 days with up to 24 waking hours of recording. However, this is impossible to achieve due to inconsistent GPS wear time, undefined start and end time for each participant and potential missing data. Therefore, proxy IVTs must be used that can maximize the total amount of sampled time.

Among the 70 participants, the longest recordings completed in one day lasted over 1000 minutes (16.7 hours). Since this only happened during 8 separate days for 5 participants (each contributing 1, 1, 1, 3, 2 days of \geq 1000 minutes of recording), proxy ITVs that included days during the week and on weekends could not be created. As a result, the proxy ITV was based on days with fewer than 1000 minutes per day. Further, seven days were chosen as the minimum number of sampled days needed for the ITV. This maximizes the number of participants who could meet the criterion cut-off, and reflects weekend and week day variations in mobility.

Each participant's data were assessed to determine the longest daily recording length with at least seven days of recording. As discussed, no one produced 7 days of \geq 1000 minutes. Only 1 (1.43%) participant had \geq 7 days of \geq 900 minutes (15 hours), whereas 14 participants (20.0%)

recorded \geq 7 days of \geq 800 minutes (13.3 hours). The latter participants were chosen as the *criterion participant group* whose data provided the best available estimates of ITV. Analysis on *criterion group* data was based on 156,483.9 minutes of data over 205 days.

Errors produced by shorter recording lengths were systematically compared against the ITVs of the *criterion group*. The means and standard deviations of each *criterion* individuals' CM outcomes were calculated using all days with \geq 800 minutes of recording time. This formed each individual's ITVs. Selecting only days with \geq 800 minutes ensured the ITV data were as robust as possible, although number of days used to calculate the ITVs may differ between individuals. This also alleviated the issue of having to select which \geq 800 minutes day(s) to exclude from the analysis. A manual check was done to ensure at least 1 weekend day was included in the ITV outcome calculation.

B. Comparison Groups

Criterion participants also recorded days that are shorter than 800 minutes. These "non-ITV days" were categorized based on the number of minutes recorded and the number of days of each daily recording length. For example, individuals with 2 days of 600-699 minutes belonged to one sampling subgroup. Those with only 1 day of 600-699 minutes were included in a separate subgroup.

It was impossible for this study to evaluate every possible day and minute range permutation because missing data often occurred randomly. In total, 19 sampling subgroups were formed.

6.3.5. Data Analysis

A. Variation in mobility

Graphical comparisons of the day to day variations in mobility outcomes were done. The variability in each outcome was quantified using the coefficient of variation (CV). Mean weekday to weekend variations in mobility outcomes were quantified using two-tailed t-tests with p < 0.05.

B. Outcome analysis

Demographic characteristics of the criterion group were compared to the non-criterion group using Fisher's exact test for categorical variables, and the two-tailed t-test for continuous variables (p < 0.05).

C. Subgroup comparisons

Absolute percentage error calculations for each sampling length subgroup used only the "daily time outside" recorded for each individual and each person's ITV "daily time outside".

ITV "daily time outside" was calculated for each individual by taking the mean of all days with recordings of 800+ minutes. Only "non-ITV" subgroups with more than 1 individual were included in the analysis. Within each "non-ITV" subgroup, mean "daily time outside" was calculated. The ITV "daily time outside" of each individual in these "non-ITV" subgroups were summed and averaged as the "mean of ITV" value.

Absolute percentage error was calculated for each subgroup using the following formula:

(mean – mean of ITV)/mean of ITV x 100.

The same procedure was repeated for "trip count", "hotspot count", and "area size". Analyses were conducted using SAS (v9.3, SAS Institute Inc., 2011), SPSS (v20, IBM Corp, 2011), and MS Excel 2013.

6.4 Results

6.4.1 Demographics

Table 6.1 shows the difference between the demographic profiles of criterion participants (n=14) versus participants who did not fulfill the criterion requirements (n=56). Fisher's exact tests and t-test analyses did not show a statistically significant difference between the full sample and criterion participants (all $p \ge 0.05$).

	Criterion participants (n=14)	All participants (n=56)	
Demographics covariates	n (range or %)		
Age (years)	69.2 ± 6.5 (57-79)	67.1 ± 6.3 (55 - 79)	
Sex			
Male	8 (57.1%)	39 (69.6%)	
Female	6 (42.9%)	17 (30.4%)	
Marital status			
Unmarried/widowed/separated	6 (42.9%)	7 (12.5%)	
Married/common law	8 (57.1%)	49 (84.4%)	
Employment status	Fully retired = $12 (85.7\%)$	Fully retired = $47 (83.9\%)$	
	Partial or full employment = 2	Partial or full employment $= 9$	
	(14.3%)	(16.1%)	
Residential setting	Urban = 5 (35.7%)	Urban = 12 (21.4%)	
	Suburban = $1 (7.1\%)$	Suburban = 15 (26.8%)	
	Rural, in town = 5 (35.7%)	Rural, in town = 19 (33.9%)	
	Rural, outside of town $= 3$	Rural, outside of town $= 10$	
	(21.4%)	(17.9%)	
Living situation	Alone = $5(35.7\%)$	Alone = $8 (14.3\%)$	
	With family/friends = 9	With family/friends = $48 (85.7\%)$	
	(64.3%)		
Driving status	Drives = 14 (100%)	Drives = 51 (91.1%)	
	Do not drive = $0 (0\%)$	Do not drive = $5(8.9\%)$	
MOCA	26.6 ± 2.5 (23-30)	25.3 ± 3.0 (18-30)	
Time since PD diagnosis (years)	5.4 ± 4.0 (<1 - 14)	6.4 ± 5.6 (<1 - 30)	
Impact of PD on overall quality of			
life (PDQ-39 scores; $0 = no impact$,	13.9 ± 15.8 (2.1-64.7)	20.8 ± 12.4 (1.8-51.4)	
100 = total impairment)			

Table 6.1. Demographics characteristics of the selected criterion participants compared to all participants.

6.4.2 Daily variation analysis

In total, data representing 205 days of varying length were collected from the 14 participants, which amounted to a total of 156, 483.9 minutes of data (mean = 763.33 ± 210.03 minutes per day). The criterion ITV for each participant was the mean outcome from all days with at least 800 minutes of data, and it was based only on days with at least 800 minutes of data. For each participant, this ranged from 7 to 13 days, amounting to 113, 466 minutes of data (mean = 872.82 ± 73.8 minutes per day).

A. Day to day variations

Figures 6.1 a – c show large variations in daily interpersonal "time outside", "trip number", "hotspots number" and "area size" travelled. If mobility was habitual, relatively straight lines across the range of the outcome (y-axis) would be observed. The line plots shown in the figures indicated high degrees of day to day variability within individuals across all mobility outcomes. The coefficient of variation for each outcome's ITV days ranged from 39.27% ("time outside") to 133.44% ("area size"), which quantifies the high variability observed in the figures (Table 6.3) and indicated some mobility outcomes were more constant than others for a given individual.

Graphically "time outside" varied the most each day compared to other outcomes. As well, a given person's "hotspots number" often differed from their "trip number", suggesting individuals were visiting multiple destinations when they leave their residences. Furthermore, individuals travelled different distances outside each day.

The Figures only showed IVT days collected from the criterion individuals. Except for one individual, observable gaps were found in every time-trend line. These gaps reflected data collection days with less than 800 minutes recorded. Insufficient data were observed for all individuals on Day 14 because the last data collection visit often took place mid-day, so data collection on Day 14 was shortened.



Figure 6.1 Daily variation in a. "time outside" (minutes), b. "trip count", c. "hotspot count", and d. "area size" (km²) per day among individuals over the 14 days sampling period (n=14). Daily records are depicted as dots, and days with <800 recorded minutes are represented by breaks in the graph.

B. Weekday to weekend variations

On average, GPS recordings were 43.15 ± 122.64 minutes longer during a day on the weekend than on a day during the week. Although a statistically significant difference in minutes recorded was not observed (p = 0.098), longer recordings on weekend days were observed for the majority of the *criterion group* (78.6%, n=11; Figure A6.1 of the Appendix). The difference in average length of recordings ranged from 5.18 hours (310.54 minutes) shorter to 2.38 hours (143.03 minutes) longer on weekends. This suggested that lifestyle differences during weekdays versus weekends exist among the criterion participants, even though most were retired. As well, the rate of compliance with GPS wear protocol differed by day of the week.

Figures 6.2 a – d show mean "time outside", "trip count", "hotspot count" and "area size" travelled slightly differed depending on if sampling occurred during the week or on weekends. The greatest change in mobility outcomes collected during on weekends relative to weekdays was observed for "area size" travelled (+59.25%). The smallest change was observed for "time outside" (-2.65%). The figures suggested that on weekends, criterion participants tended to decrease their "time outside" by 2.65% (Figure 6.3a) and the number of hotspots visited by 8.66% (Figure 6.3c). However, they also were making more frequent and further trips outside (+4.85% more trips, Figure 6.3b; +59.25% increase in area travelled, Figure 6.3d).

Statistically significant differences in mean weekday versus weekend differences were not found for any of the mobility outcomes (Table A6.1 of Appendix). However, Figures A6.2a – d (Appendix) show mean weekday versus weekend differences in mobility outcomes could be observed on the individual level. The direction of these differences often changed depending on the outcome. For example, participant CM020 spent 200 minutes outside (Figure A6.2a) and visited over 4 hotspots on average (Figure A6.2c) during week days. However, he spent almost 0 minutes outside and visited less than 2 hotspots on average during weekends. As well, although the same individual took a slightly higher average number of trips outside on weekends compared to during weekdays (Figure A6.2b), he tended to stay closer to home on weekends than during the week (Figure A6.2d).

Figure 6.2 also suggested an underestimation in mean "time outside" (-17.96%), "trip number" (-9.33%), "hotspots number" (-15.80%) and "area size" (-19.66%) occurred when the shorter

non-ITV days were used for analysis compared to when only ITV days were used. Although statistically significant differences were not found for any of the mean outcomes, consistent underestimation suggested shorter recording lengths may introduce a level of error in recorded outcomes. This will be further examined later in this Section.



Figure 6.2. Variations in mean mobility outcomes occurred depending on when sampling occurred during the week, and which days were included in the calculations. Mean weekday to weekend change occurred in a. "time outside" (minutes; -2.72% from weekday to weekend), b. "trip count" (+5.19%), c. "hotspot count" (-8.79%), and d. "area size" (km^2 ; +37.2%) over the sampling period (n=14). An increase in mean outcome occurred when only ITV days were used compared to when all days were used, including the shorter non-ITV days (+15.23% for "time outside", +8.54% for "trip count", +13.64% for "hotspot count", and +16.43% for "area size"). None of the changes reported for day of the week and type of day included were observed to be statistically significant (p > 0.05).

6.4.3 Mean community mobility outcomes

Since participants contributed varying recording lengths each day, a total of 19 subgroups were created based on the sampling lengths available. The number of individuals who supplied data for each subgroup are listed in Table 6.2. Only one participant recorded data over the course of the six longest sampling lengths, so these sampling lengths were excluded from the assessment.

Table 6.2. The number of individuals who contributed data to each sample subgroup. Number of individual data will not sum to 14 because each individual may have contributed data to multiple subgroups.

Subgroup by sampling length	Number of individuals with data (total n=14)
1 day < 100 minutes	4
1 day of 100 - 199 minutes	3
1 day of 200 - 299 minutes	3
1 day of 300 – 399 minutes	3
1 day of 400 – 499 minutes	3
1 day of 500 – 599 minutes	5
1 day of 600 – 699 minutes	5
1 day of 700 – 799 minutes	3
2 days of 200 – 299 minutes	1
2 days of 400 – 499 minutes	1
2 days of 500 – 599 minutes	1
2 days of 600 – 699 minutes	1
3 days of 600 – 699 minutes	1
3 days of 700 – 799 minutes	5
4 days of 300-399 minutes	1
4 days of 700 – 799 minutes	1
5 days of 700 – 799 minutes	1
7 days of 700-799 minutes	1
\geq 7 days of \geq 800 minutes (ITV)	14
Mean ± s.d. (range)	$2.33 \pm 1.44 \ (1-5)$

Table 6.3 shows the mean community mobility outcomes observed according to different sampling subgroups. Average recordings on ITV days lasted 872.82 (\pm 73.76) minutes whereas an average non-ITV day produced recordings that lasted 573.57 (\pm 233.59) minutes. Compared to ITV days, shorter sampling lengths produced lower mean daily "time outside", "trip count", "hotspot count" and "area size" outside the home. This was most notable for "area size" (182.68km² for non-ITV days versus 671.63km² for ITV days). Relative to recordings from ITV days, non-ITV recordings captured an average of 124.95 fewer minutes outside the home (or, over 2 hours outside was not captured by non-ITV recordings), 0.5 fewer trips, and 2.56 fewer

hotspots per day. The range of outcome values across sampling lengths for each CM outcome were large. This was likely due to interpersonal variability since not all participants provided data for every sampling length. CV analyses show "area size" to be the most variable mobility construct. This supports the findings of Figure 6.1d which graphically illustrated high variations in day to day "area size" travelled.

Figures 6.3a-d of the Appendix used the full sample (n=70) to show increases in mean number of minutes recorded daily were associated with statistically significant decreases in variability in "trip count" (r = -0.248, p = 0.039) and "hotspots count" (r = -0.238, p = 0.047). A decrease in variability in "time outside" was also observed when time recorded daily increased (r = -0.226, p = 0.060). Although it was not found to be statistically significant, mean number of minutes recorded and variations in "area size" shared a slight positive association (r = 0.093, p = 0.045).

Analysis using a full sample could not account for different types of missing data (e.g., shorter days, shorter number of days) because ITV approximation was only achievable for the 14 participants in the *criterion group*. Therefore, analyses comparing different sampling length subgroups to ITV approximations were only done for *criterion* participants.

When comparing the outcomes recorded using ITV versus shorter non-ITV days, the CV values of ITV days were smaller by 13.55 to 138.96% points across the outcomes. This suggested that CM estimates collected on ITV days were more precise than the estimates on shorter non-ITV days. Since shorter sampling lengths created greater variability around the mean, this may indicate the mean ITV is more representative of the individual values.

Table 6.3. Average community mobility outcomes recorded using different sampling lengths (n=14). Days with 800 or more minutes of recording constitute ITV days, and those with less are non-ITV days. Coefficient of variation for ITV days used the mean and s.d. of all ITV days in the formula: s.d./mean*100. Non-ITV mean values were calculated using the average for all non-ITV subgroups, and this mean was used to calculate the non-ITV CV.

СМ	All non-ITV days		ITV days	
outcomes				
Mobility Outcomes	Mean	Coefficient of Variation (s.d./mean*100)	Mean	Coefficient of Variation (s.d./mean*100) of the ITV
Time outside in minutes (range)	119.95 ± 135.34 $(0.7 - 465.02)$	112.83%	244.9 ± 169.95 (0.03 - 712.47)	69.40%
Trip count (range)	1.19 ± 1.49 (0 to 8)	83.31%	1.68 ± 1.40 (0 - 7)	83.33%
Hotspot count (range)	3.19 ± 2.93 (0 to 16)	78.30%	5.75 ± 4.50 (1 - 27)	78.26%
Area size in km ² (range)	182.68 ± 732.12 (0 to 4241.77)	400.77%	671.63 ± 1758.4 (0 - 10250)	261.81%

Both subgroup and full sample analysis indicated that the degree of variability in outcomes is associated with amount of time sampled. Section 6.4.2 showed these mobility components are already highly variable from day to day. This suggested a high CV may not indicate a recording length affected data quality. To evaluate if recording lengths affected the amount of error in outcome measured, comparison analyses using the criterion group's ITV (n=14) were done.

6.4.4 Comparing sampling to criterion: Absolute comparison

A. Overall CM outcomes

Figure 6.3 summarized the mean error rates in mobility outcomes according to each sampling subgroup. All shorter sampling subgroups yielded negative mean percentage errors relative to the criterion sampling rate of 7 days of 800 minutes. This suggest when recording lengths are shorter than the criterion, overall CM outcomes were underestimated by an average of 39.66% to 96.92%.

Decreased error rates in mean mobility outcomes occurred when recording lengths were increased from 100 minutes daily to 300 - 399 minutes daily, and from 400 - 499 minutes daily to 600 - 699 minutes daily. However, increased recording length daily also produced unexpected overall increases in error on three occasions. This occurred from <100 minutes to 100-199 minutes (4.31% point increase), 300 - 399 minutes to 400 - 499 minutes (32.8% point increase), and from 600 - 699 minutes to 700 - 799 minutes (5.05% point increase).

The longest recording length (700-799 minutes for 3 days) produced the smallest mean error rate of -39.66%. Increasing the number of days with 700-799 minutes from 1 to 3 days also produced a 21.97% decrease in overall CM error rate. Since Figure 6.3 used the mean of all outcomes, a given sampling length may differently affect each CM outcomes. Hence, the previously described error increase from 100 - 199 minutes to 300 - 399 minutes and 400 - 499 minutes to 600 - 699 minutes may not be observed across all outcomes.

Outcome specific 3D plots are shown in the next section to assess whether the similar error patterns are observed between different outcomes.



Figure 6.3. Mean percentage errors for all CM outcomes across different sampling rates relative to sampling length of at least 7 days with 800 or more minutes. Mean percentage error rates for each sampling subgroup is listed above each cluster of bars. Number of participants in each sampling length subgroup are indicated below the x-axis (n=14).

B. Specific CM Outcomes

3D plots in Figures 6.4 a - d depict the percentage error rates relative to the ITV (y-axis) during different minutes (z-axis) and days (x-axis) of recording, according to the CM outcome. Similar to Figure 6.3, each subgroup in the 3D plots was composed of 3 to 5 different individuals, which means that any individual may have contributed data to more than one subgroup.

Every sampling subgroup yielded negative percentage error rates for all outcomes, except when "1 day of 300-399 minutes" and "3 days of 700 – 799 minutes" were collected for "trip count" data. Recordings of this length produced percentage error rates indicating an overestimation of +23.7% and +1.34%, respectively. All other sampling subgroups produced negative percentage error rates of -9.77% to -100.00% (Figure 6.4b). For "time outside", -14.73% to -99.71% error rates were attained (Figure 6.4a). For "hotspot count", the error rate ranged from -32.98% to - 87.97% (Figure 6.4c). As well, for "area size", the error rate ranged from -91.94% to 100.00% (Figure 6.4d). Overall, shorter sampling subgroups tend to underestimate all CM outcomes relative to the ITV. This was consistent with the underestimation observed when the CM outcomes were aggregated (Figure 6.3).

Within a single sampling day, longer sampling lengths tend to yield smaller error rates across most outcomes. As first observed in Figure 6.3, this pattern was inconsistently observed across the four outcomes. At 300 - 399 minutes, "trip count" was overestimated by 23.7%, whereas at 400-499 minutes, "trip count" was underestimated by 60.77% (a change of 356.41%; Figure 6.4b). This suggested that the 32.8% increase in overall underestimation observed between these recording ranges was mostly due to the change in "trip count" (Figure 6.2).

When the number of days sampled was increased from 1 to 3, the percentage error rate decreased for "trip count" by 96.94% (Figure 6.4b) and "hotspot count" by 12.93% (Figure 6.4c). However, the percentage error rate for "time outside" and "area size" increased by 8.47% (Figure 6.4a) and 3.79% (Figure 6.4d), respectively.

The average percentage error rates observed across all sampling subgroups were highest for "area size" (-97.18 \pm 3.02%; Figure 6.4d) and smallest for "hotspot count" (-58.21 \pm 22.62%; Figure 6.4c). "Time outside" (Figure 6.4a) and "trip count" (Figure 6.4b) produced average error rates of -58.92 \pm 32.12% and -43.56 \pm 41.77%. The standard deviations of error rates were the highest for "hotspot count" and smallest for "area size".



Figure 6.4. Percentage errors in mean daily a. "time outside", b. "trip count", c. "hotspot count", and d. "area size" according to different lengths of day and number of days recorded (total n=14). The mean error rates over all subgroups were $-58.92 \pm 32.12\%$, $-43.56 \pm 41.77\%$, $-58.21 \pm 22.62\%$ and $-97.18 \pm 3.02\%$, respectively.

6.5 Discussion:

GPS sensors are being increasingly used in health research⁵¹, especially in studies of ecological determinants of health, such as physical activity, built environment and accessibility ^{40, 45, 47,}. Their utility is dependent on the quality of the data sampled, which in turn is affected by the length of sampling obtained⁴⁰.

Missing data is an inherent part of GPS studies^{40, 42, 43}. Sampling strategies using GPS units should aim to be representative of the true mobility (e.g., outcomes measured should be close to the ITV mean and CV), be short enough to minimize participant burden, attrition and cost (e.g., study size cannot be too large and sampling cannot be too long⁵¹) yet achieve sufficient power (e.g., enough recorded time and participants for representative samples and to meet the assumptions of statistical tests). Under these constraints, one way to assess representativeness is to minimize the study's sampling error, which is the difference between a sample statistic and the population parameter.

6.5.1 Sampling rate by outcome

The results of this study suggested that shorter daily GPS recordings tend to underestimate CM outcomes and produce larger percentage errors. Decreases in percentage error with longer GPS recordings were observed for all outcomes, except when 500 – 599 minutes of "hotspots count" data was recorded. This suggested that minimum daily recording lengths should not be less than 500 minutes (8.3 hours) long. For "time outside", "hotspots count" and "area size", 600-699 minutes of recording may be even better at reducing error.

Recording length affected each mobility construct differently. "Trip count" yielded the smallest mean error rate (-43.56%), and the highly variable outcome "area size" appeared to be the most sensitive to shorter recording lengths as it had the largest mean error rate (-97.18 \pm 3.02; range of -91.94% to 100%). Increasing the daily recording length appeared to improve the error rate in general, but the effects were very small compared to the other outcomes. Increasing the number of days sampled from 1 to 3 also improved the error rate for all outcomes, except "area size". It is possible that a threshold number of days may exist for "area size" but this study lacked the statistical power to determine it.

Further, the high degree of day to day variability observed for "area size" may be unique to this study sample. Participants of this study usually traveled outside by car (also see Chapter 7: Study 4), and it may be possible that how far people travelled by car often varied. So a study with participants who preferred walking may not exhibit such variability in the "area size" occupied per day. As well, studies that used shorter or fewer days also may not capture such a high degree of variability in "area size".

Increasing the sampling length did not always improve the accuracy in outcome. This was evident from a lack of consistent pattern in error rate observed across the subgroups for "trip count". Across all shorter sampling subgroups, the mean number of trips taken by participants was 1.19 ± 1.49 trips (versus 1.68 ± 1.40 trips during the ITV days). It is possible shorter daily sampling lengths can still capture a small number of trips taken daily.

6.5.2 Variability in mobility

Previous research has shown mobility to be a variable construct ^{52, 53}, but day to day variability has not been quantified in PwPs. This study demonstrated daily variations exist in "time outside", "trip count", "hotspot count" and "area size" in older adults with PD.

Although statistically significant differences in mean outcomes were not shown according to day of the week when participants were aggregated, sizeable variations in individual mean mobility outcomes during weekdays versus weekends were graphically observed. This was consistent with reports of day of week variation in physical activity^{54, 55}, and trip count recorded on Fridays versus other days³⁵. As well, the level of discrepancies in GPS recording of "trip count" ³⁶, "duration of walking trip" ³⁶ and "trip travel time" ⁴⁴ compared to self-reporting have also been shown to differ between weekdays and weekends. The magnitude of the day to day variability in mobility outcomes⁵² is not of interest in this study and was not quantified.

It was unclear if the day of week differences in mobility observed in this study were because of set weekly schedules. If participants organize their mobility patterns according to the day of the week, sampling less than one week can lead to systematic bias in mobility based on the days of recording. For example, an individual may only go outside of the home on Wednesdays but not

any other day. This study also used a sample of retired older adults with PD, whose day to day activities may be different from working individuals. As well, the largest variation in the mobility of retired people may not be between weekdays and weekends.

Regardless, daily mobility patterns cannot be fully captured with recordings of less than one week. A review of studies using GPS to study various mobility constructs in adults and children suggested that missing data increased beyond 4 days of recording⁴⁰. However, the number of minutes recorded per day were not considered by the review authors. Given the importance of capturing daily variations in mobility, future studies using the GPS should account for the daily and day of the week variations by recording at least one full week of data.

Motor symptoms of PD tend to affect individuals' overall mobility ³⁴, and are optimized through medications such as levodopa ³⁵. Therefore people with PD often schedule physical activities around the different medication times throughout a day. For example, people who take levodopa at 7am, 11am, 3pm and 7pm often would wait until levodopa's peak physiological absorption time of around 7:30am (ON-medication state) to get out of bed. Similarly, she or he may schedule appointments or activities outside of the house until after the ON-medication state during the remainder of the day. In this population, and in other types of mobility disability, it is also important to determine if mobility fluctuations occur through the day. The analyses reported used aggregate data generated every 24 hour cycle, as smaller segments of mobility using custom sampling rates (e.g., 250 minutes, 300 minutes). These limit the ability to evaluate smaller segments of diurnal variability.

6.5.3 Recommended recording length

Based on the results of this study, daily recordings of less than 500 minutes should be avoided for "time outside", "trip count", "hotspot count" and "area size" travelled per day. Ideally, analysis should based on days with at least 600 recorded minutes for non-discrete continuous outcomes, such as "time outside" and "area size".

This study is one of the first to quantify intra-individual variability in "time outside", "trip

count", "hotspot count" and "area size" travelled per day. Past comparison studies of GPS have included one day to one week of recording²⁶. Although the optimal number of days of recording remains unclear, results of this study suggested increasing the number of days recorded likely reduced the sampling error observed for discrete outcomes as "trip count" and "hotspot count". Interestingly, for the continuous outcomes "time outside" and "area size", increasing the number of days recorded from one to three slightly increased the error rates by 8.47% and 3.78%, respectively.

Despite the last finding, GPS users should aim for at least eight days of GPS recording, especially when interested in "trip count" and "hotspot count". Eight days of recording will capture the day to day variability in mobility by including one week of multiple weekend days and week days. As well, the first and last recorded days of data collection are often shortened due to study logistics. Despite this, most GPS studies have not accounted for these interruptions to mobility. In this study, no data were recorded on Day 14 for any of the criterion participants because they removed the GPS just prior to the last home visit by researchers on Day 14. Many participants also altered their mobility patterns on study start days and end days in order to meet with researchers and comply with other study protocols. Including an extra day will improve the chance that a full week of data collection was completed.

6.5.4 Limitations

A. Outcomes used

For clarity, this study focused on assessing the impact of sampling length on commonly reported GPS outcomes. The WIMU-GPS also provided information on mobility outcomes such as "distance travelled by foot", "distance travelled by car" and "distance to hotspots". Similar sampling length assessment will be done in the future for these mobility outcomes as the findings of this study may affect these outcomes differently.

B. Sampling subgroup and sample size

Sampling subgroups used in this study were composed of a small number of individuals. The number of participants within sampling subgroups also were unbalanced. This meant comparisons between ITV and non-ITV subgroups were made based on group means, and not between the same individuals. The small and unbalanced subgroup sizes also violated assumptions of many statistical tests of comparison, so comparisons were limited to descriptive analysis. The attempt to improve the ITV value required excluding many participants who did not provide a sufficient amount of data for the *criterion group*. ITV is an approximation based on the assumption that increasing data size decreases the sampling error. It is possible that the ITV could be based on a shorter criteria (e.g., at least 7 days of at least 700 minutes rather than 800 minutes). However, some levels of error remained after both one and three days of 700 – 799 minutes, so it is possible the 800 minutes criterion is optimal.

As well, the small number of participants in the *criterion group* prevented more subgroups from being included. This limited the amount of quantitative results available on the impact of increasing the number of days sampled. Future studies using a more robust and balanced number of individuals in each subgroup should be done to determine whether the pattern of shorter recording lengths leading to underestimation persists. Both of these improvements are only possible if the overall study sample size could be increased. However, GPS data collection is costly and heavily resource intensive. The current *criterion group* was achieved after recording 980 days of data (70 participants x 14 days), which is greater than many other GPS studies^{38, 40, 47}. Therefore researchers wishing to improve the subgroup sample sizes may wish to assign participants to specific predefined subgroups *a priori* instead of *post-hoc*.

6.5.5 Strengths

A. Criterion and ITV

Although analysis using the full sample (n = 70) also showed that degree of variability in outcomes is associated with amount of time sampled, a high CV in outcomes was not indicative of data quality alone as the mobility components were intrinsically variable from day to day (Section 6.4.2). Therefore error rates relatively to ITVs were needed. This study recognized the inter-individual variability in mobility, and was the first to use ones' own mobility outcomes for comparison. The ITV construction included weekends and weekdays, which also helped to improve the approximation of true mobility. The few available assessments of missing data have limited their focus to the number of days failing to meet a set daily recorded minutes criterion ⁴⁰. This study extends these approaches by separately examining the effect of the different sources

of error (e.g., shorter days, shorter number of days).

Although the *criterion group* was composed of only 14 individuals, they contributed 205 days of data used for analyses (totalling 156, 483.9 minute-level data points). Of this, 150 were used for the ITV group (ranged from 7 to 13 days of data). This study maximized the amount of data included for the criterion by using at least 7 days of at least 800 minutes. The number of minutes and days recorded likely need to decrease in order to increase the number of participants eligible for the *criterion group*. Hence, a sample size of greater than 14 may result in fewer number of minutes included for analysis.

B. Two weeks of sampling

Some GPS studies have sampled more than 70 individuals but over a smaller number of days³³. Although other GPS studies have used one week of recording for analysis^{33, 40, 51}, it is possible that week to week, or even month to month, variation in mobility patterns may occur due to life events or seasonality. The collection of two weeks of data in this study allowed more data to be included in the overall analysis to reduce the chance of anomalous mobility. As well, two weeks of data collection allowed more data to be included in the ITV and more subgroups to be created. Given the high data loss rate, the number of subgroups created may not be possible to achieve with just one week of data.

6.6 Conclusion

This study demonstrated GPS sampling lengths directly affect the accuracy of CM outcomes collected. By showing that percentage error rates tend to increase when sampling time lengths decrease, this study illustrated the importance of using an appropriate sampling length that optimizes feasibility, data quantity and representativeness of real-life mobility.

Recommendations for minimum number of monitoring days are available for physical activity trackers such as pedometers, accelerometers and self-report logs ⁵⁴. However, no recording length recommendations have been made for any GPS models. Until recommendations are available for GPS units that are different from WIMU-GPS, GPS users wishing to collect

information about "time outside", "trip count", "hotspot count", and "area size" should ensure daily recordings used for analysis are not less than 500 minutes in length. For "time outside" and "area size", GPS recordings should be at least 600 minutes. CM outcomes were differentially affected by shorter sampling per day, so different minimum cut offs according to the outcome may still be needed.

Future studies with larger sample sizes are still needed for firm recommendations about the optimal number of recorded days. However, GPS studies should aim to capture a minimum of seven distinct days of the week, especially when frequency variables are of interest, such as "trip count" and "hotspot count". This may be best achieved if participants were asked to use the GPS for a minimum of eight days, which would allow the exclusion of any atypical mobility observed at the beginning and end of the study period.

6.7 References

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6.8 Appendix

Table A6.1. Two-tail t-test results for mean mobility outcomes recorded on weekdays versus weekends, and outcomes captured during every recorded day versus only on days with 800 minutes (ITV days).

Mobility outcome	P value for Two-tail t-test (p > 0.05)		
	Weekday vs weekends	All days vs Only ITV days	
"Time outside" (minutes)	0.83	0.34	
"Trip count"	0.79	0.77	
"Hotspot count"	0.67	0.52	
"Area size" (km ²)	0.62	0.72	



Figure A6.1. Difference in amount of minutes collected by the GPS of criterion participants during weekend days compared to week days (both ITV and non-ITV days were used). An average of 748.79 ± 53.38 minutes (median = 748.60 minutes) were collected during a weekday versus 791.94 ± 133.32 minutes (median = 817.91 minutes) during a weekend day. On average, 43.2 ± 122.6 more minutes was collected during a weekend day. A statistically significant difference was not observed, but more minutes collected during weekend days among the majority of criterion participants (11 of the 14).



Figure A6.2 Variations in weekday to weekend variation in a. "time outside" (minutes), b. "trip count", c. "hotspot count", and d. "area size" (km²) per day among individuals over the 14 days sampling period (n=14).



Figure A6.3 Variation in a. "time outside" (minutes), b. "trip count", c. "hotspot count", and d. "area size" (km²) per day according to mean minutes recorded daily among all participants over the 14 days sampling period (n=70). Statistically significant correlation coefficients were highlighted in bold.

Chapter 7

Study 4. Quantifying community mobility of older adults with Parkinson's disease

7.1 Introduction:

Mobility disability is a common health concern for older adults^{1, 2, 3, 4}, especially those with a movement disorder, such as Parkinson's disease (PD) ^{5, 6}. Community mobility (CM) is a concept that describes the mobility outside of one's home, regardless of mode of transport and destination. CM is necessary for individuals to stay socially connected^{3, 7}, maintain mental wellbeing⁸ and access resources independently. Decline of mobility in the community setting often leads to poor quality of life, as well as greater risk of illness, loss of independence and death⁹. Among people with PD (PwP), motor and non-motor disease symptoms often progress over time to affect quality of life and inhibit performance of mobility-related actions^{10, 11}. However, it is unknown how the inherent challenges in mobility affect PwP's mobility in a real-life setting. This cannot be reliably determined in a clinic or laboratory because of the fluctuating nature of PD motor symptoms¹². Yet, it is of clinical importance to answer: Are PwP regularly confined to their homes? What impacts of PD on quality of life are most associated with mobility? This information could be useful to suggest targeted approaches in therapy for PwP to maintain optimal levels of mobility.

Assessing the mobility of PwP around their communities remains complicated for two reasons. First, CM is a multidimensional construct ¹³. It can be conceptualized in many different ways, including how many times one leaves the home ¹⁴ and how long one stays out in the community¹⁵. CM is also a multilevel construct, and a common way to conceptualize its different levels is by quantifying the distance one travels from home ^{13, 16}.

Second, a gold standard tool for measuring CM currently does not exist. Affordable self-report assessments often are affected by recall bias¹⁷ and can be cumbersome for participants to complete¹⁸. They also cannot quantify the absolute size of people's mobility levels in kilometers. Wearable mobility sensors, such as ones using Global Positioning Systems (GPS), are promising options for prospective and passive CM tracking in general older adult populations and in PwP ^{16,19, 20}. However, data loss is common when using these sensors²¹, and the lengths of

usable recorded time using GPS trackers are often shorter than the lengths of time the devices were used^{15,21}. Investigators often include sparse data in analysis of GPS data, which may introduce errors in mobility estimates^{21,22}. Despite this, standard protocols to capture mobility using these devices and recommendations about how long GPS recordings should be to minimize errors were not previously available.

A standard recording length of at least 7 distinct days of the week, with 600 minutes of recording each day, was proposed in Chapter 6. This recording length was specifically evaluated using a novel instrument called the Wireless Isoinertial Measurement unit (WIMU-GPS²³). This is a comprehensive wearable sensor that combines technology for assessing location (GPS) with walking and physical activity (accelerometer) and three dimensional body orientation (gyroscope and magnetometer). Chapter 5 of this dissertation also validated a number of CM outcomes generated using the WIMU-GPS against other common mobility measures, such as the Displacement Diary²⁴. The present study was conducted to apply the proposed recording standard, and determine if it could be feasibly applied without sacrificing sample size and losing statistical power.

Another knowledge gap in CM measurement using instrumented trackers is that few studies have simultaneously measured more than two CM outcomes (see Chapter 4). Limiting the number of evaluated outcomes also limits the ability to achieve a more comprehensive multidimensional understanding of individuals' real life mobility. For example, although frequency and duration of travel are important, information regarding the nature of the travel, such as destination and mode of travel, also are important CM dimensions^{25,26}. These outcomes are not easily obtainable using a sensor. For example, participants may be uncomfortable to have their exact locations tracked over a long period of time²⁷. Some recent CM studies also have recommended that researchers should use GPS sensors and diaries together as complements^{26, 28, 29}.

This study was conducted to test the WIMU-GPS recording length recommended in Chapter 6 in PwP. It will also take advantage of data from both the WIMU-GPS and diary to provide a more comprehensive exploration of the performance of PwPs on multiple CM outcomes. Doing so can provide some information to start addressing the questions posed at the beginning of this

section: Are PwP regularly confined to their homes? What effects of PD on quality of life are most associated with mobility? This study has the following objectives:

1. Determine whether the WIMU-GPS recording recommendations made in Chapter 6 could be feasibly applied to study CM in PwP.

2. Quantify multiple real life CM outcomes over a long duration in PwP using a wearable GPS sensor (WIMU-GPS).

3. Evaluate if and how CM outcomes are associated with PD's impact on quality of life, and with other common mobility covariates.

4. Qualify the CM destinations visited by PwP using mobility diaries.

7.2 Methods

7.2.1 Participants and Data Collection Overview

Seventy individuals (\geq 55 years, of both genders) with a confirmed diagnosis of early to midstage PD (Hoehn and Yahr stages I to III) were recruited from the PDF Centre of Excellence Movement Disorders Clinic of London Health Sciences Centre to participate in this study, in person or by phone. Participants were assured that refusal to participate would not affect their current or future treatment. The inclusion and exclusion criteria for participation were the same as in Chapter 3 (Table 3.1) of this Dissertation. Data collection and management protocols were the same as described in Chapter 3 of this Dissertation, and are summarized below.

Home visits to each participant were completed three times over two consecutive weeks. During the 14 days, all participants wore the WIMU-GPS²³ and completed the Displacement Diary²⁴ to track their travels outside of their homes. To minimize an important source of variability in PD mobility, participation in this study required participants to be optimally stabilized on all medications. For patients who were anticipating a change in their medication regime, this was achieved by scheduling initial data collection at least one month after they had begun the new routine. Data collection occurred only between April to October to minimize seasonal effects on mobility ^{30,31, 32}.
7.2.2 Assessments of Community Mobility

A. WIMU-GPS

Participants were asked to wear the WIMU-GPS only during waking hours of each day and to charge the battery overnight. They were asked to remove the unit when engaging in water-based activities, such as bathing or swimming. Every two minutes, the WIMU-GPS records a wide variety of CM outcomes using the location coordinates of the wearer relative to coordinates of the home. Commonly reported CM outcomes collected by the WIMU-GPS, and evaluated in Chapters 5 and 6, were:

- 1. "*time outside*" (the number of minutes spent outside of one's home per day)¹⁵
- 2. "*trip count*" (the number of trips taken outside of one's home per day)¹⁴
- "area size travelled" (the area size of a best fit ellipse that covers 95% of the locations visited outside of one's home per day) ^{13, 16, 23}

The WIMU-GPS also had the capability to provide additional daily CM outcomes such as:

- "hotspot count" (number of locations where an individual has stopped for 3 minutes or more²³)
- 5. "distance to hotspots" (mean distance to hotspot locations)
- 6. "vehicular distance" (mean distance travelled not on foot in kilometers)
- 7. "walking distance" (mean distance travelled on foot in kilometers).

Although total distances travelled are commonly reported GPS measured CM outcomes in the literature^{33, 34}, distances are seldom reported separately by mode of transportation. Inertial motion sensors in the WIMU-GPS allowed the separation of distance by vehicle and walking. Chapter 5 did not compare the last three CM outcomes to analogous measures as it was not feasible to ask participants to separately carry validated sensors for walking or vehicular travel. The WIMU-GPS accelerometers and inertial motion units have been tested for validity and reliability in the laboratory setting using a gimbal table²³. Since outcomes 4-7 were not subjected to the same agreement analyses as the first three (see Chapter 5: Study 2), they were included in this study to explore their value as novel CM outcomes.

B. Diary

Over the 14 day period, participants were also asked to use a Displacement Diary every day to report the timing and destination of each trip taken outside of their home. When participants did not leave the home on a given day, they were asked to clearly state that they stayed home.

7.2.3 Covariates of Community Mobility Assessments

Additional factors potentially influencing mobility were collected, including: age³⁵, sex³⁶, education, income, marital status³⁷, driving status^{36,38, 39}, geographic setting³⁷, and cognition³⁷. These were assessed using a demographics form and the Montreal Cognitive Assessment (MoCA)⁴⁰ on Day 1. During Day 7, the participants were visited for data quality control purposes (e.g., to ensure the diaries were completed and the armband and GPS were working). They also completed a questionnaire on perceived level of social support (Medical Outcomes Study Social Support survey [MOSSS]⁴¹. Social support was included to determine perceived adequacy of the level of assistance available for each participant. On Day 14, self-reported physical activity level was also evaluated using the Phone-FITT⁴², and general health related quality of life was examined using the Medical Outcomes Study 12-Item Short Form Health Survey[®] (SF-12^{43,44}). Participants also were asked to rate their perceptions of PD's effects on eight domains of quality of life during the last month using the Parkinson's Disease Questionnaire – 39 item version⁴⁵ (PDQ-39). Each domain's score was separately calculated⁴⁶, with higher scores corresponding to greater impact of PD. The time of data collection for each covariate is shown in Figure 3.2 of Chapter 3 (Common Methods).

7.2.4 Data sampling and sample size

WIMU-GPS data processing and data management were completed as per Chapter 3 (Research Methods). Destinations visited recorded by the diary were manually entered and categorized by type for analysis.

Data loss due to technological and human errors are common in studies using long duration recording devices ^{15, 21}. Although participants were asked to wear the WIMU-GPS for 14 days, Chapters 5 and 6 of this dissertation have shown the quantity of data recorded using the WIMU-GPS varied among participants and between each day of recording.

The minimum lengths of recording proposed in Chapter 6 aimed to minimize the sampling error in CM results. Therefore, only participants who provided at least 600 minutes (10 hours) of recording each day, for at least seven distinct days of the week were included for analysis. Although the results of Chapter 6 were inconclusive about an ideal minimum number of days, seven distinct days were used so every week day and both weekend days were accounted for.

The quality and completion rate of participants' daily diary entries also varied. Some participants forgot to provide times of departure and return, or did not fully identify each trip taken or the destinations visited outside. This occurred when participants labelled origins and destinations only as "in" and "out", or when destinations were labelled using only the name of the community. This complicated the ability to deduce amount of time inside and outside of one's home, the numbers of trips made and destinations visited. In Chapter 5 (Study 2), sufficiency in diary entries required documentation of at least one completed trip record to and from the home, or explicitly recording when trips outside did not occur. From each participant, only days that fulfilled both the minimum WIMU-GPS recording and sufficient diary entries criteria were included for analysis.

Area of life space measured by the WIMU-GPS was available in terms of the size of the "span ellipse" or "standard deviation ellipse". The span ellipse describes the area covered by all travels, while the standard deviation ellipse includes locations within one standard deviation of the mean distance from home. This analysis included only the span ellipses because by including all locations visited, it allows a better comparison with participants' life space as measured through self-report measures which considers only the furthest point of travel.

7.2.5 Data analysis

The relationship between covariates and CM outcomes were assessed using SAS V9.3 software (SAS Institute Inc., 2011). Simple Pearson and Spearman correlation analyses were used to detect any significant relationships between the WIMU-GPS captured CM outcomes and variables that were interval or ordinal, respectively. One way ANOVA analyses were conducted to assess group-level differences in CM according to categorical covariates. Bonferroni post-hoc

tests were performed when possible to assess differences in variables with more than two categories. All statistical tests were performed using a significance level of 0.05.

7.2.6 Ethical approval and consent

Approval for this study was obtained from the Research Ethics Board of Western University, and approval for data collection with patients was obtained from the Lawson Health Research Institute. Informed written consent was obtained from all participants prior to data collection.

7.3 Results

7.3.1 Participant demographics

Data were collected on 70 participants, but only a partial sample of 50 met the analysis inclusion criteria. Table 7.1 compares the demographic profiles of participants included for analysis to the total sample. Overall, the analysis sample was similar (p > 0.05) to the 20 individuals who were not selected in terms of common demographic variables such as sex, marital status, places of residence, income, education and employment status. In both groups, most of the participants had access to facilitators of social connection (e.g., living with someone, ability to drive and access to a vehicle).

Table 7.1. Demographic characteristics of the full and analysis sample. Independent t-tests and chi-squared analyses of those included in the analysis sample (n=50) and those excluded (n=20) showed no statistically significant differences (all p > 0.05) between the two groups on any of the variables.

Demographics	Full sample (n= 70)	Analysis sample (n=50)											
covariates													
	Mean ± standard deviation (Lowest-highest)												
Age (years)	67.4 ± 6.5 (55 - 84)	67.8 ± 6.3 (55 - 79)											
Cognitive status	24.3 ± 2.4 (18 - 30)	25.7 ± 2.7 (18 – 30)											
Disease duration (years)	7.6 ± 6.2 (0-30)	5.9 ± 5.5 (0-30)											
	n (%)												
Gender	Women = 23 (32.8) Men = 47 (67.1)	16 (32.0) 34 (68.0)											
Marital status	Unmarried/widowed/separated = 12 (17.1) Married/common law = 58 (82.9)	8 (16.0) 42 (84.0)											
Place of Residence	Urban = 17 (24.3) Suburban = 17 (24.3) Rural (in town) = 24 (34.3) Rural (outside of town) = 12 (17.1)	Urban = 13 (26.0) Suburban = 11 (22.0) Rural, in town = 16 (32.0) Rural, outside of town = 10 (20.0)											
Income	0 - \$19, 999 = 12 (17.1) \$20, 000 - \$39, 999 = 15 (21.4) \$40, 000 - \$59, 999 = 19 (27.1) \$60, 000 - \$89, 999 = 16 (22.9) >\$90,000 = 8 (11.4)	0 - \$19, 999 = 10 (20.0) \$20, 000 - \$39, 999 = 10 (20.0) \$40, 000 - \$59, 999 = 14 (28.0) \$60, 000 - \$89, 999 = 11 (22.0) >\$90,000 = 5 (10.0)											
Education	< High school = 13 (18.6) High school graduate = 17 (24.3) Some college = 2 (2.9) College diploma = 11(15.7) Undergraduate degree = 11(15.7) Post-graduate program = 3 (4.3) Graduate degree = 13 (18.6)	< High school = 10 (20.0) High school graduate = 10 (20.0) Some college = 2 (4.0) College diploma = 8 (16.0) Undergraduate degree = 8 (16.0) Post-graduate program = 1 (2.0) Graduate degree = 11 (22.0)											
Living situation (include married but living separately and unmarried and living with family/friends)	Alone = 12 (17.1) With family/friends = 58 (81.9)	Alone = 8 (16.0) With family/friends = 42 (84.0)											
Retirement status	Working = 13 (18.6) Retired = 57 (81.4)	Fully retired = 43 (86.0) Partial or full employment = 7 (14.0)											
Driving status	Drives = 65 (92.8) Do not drive = 5 (7.1)	Drives = 49 (98.0) Do not drive = 1 (2.0)											
Family ownership of car	Yes = 70 (100) No = 0 (0)	Yes = 70 (100) No = 0 (0)											

Tables 7.2 and 7.3 show the self-reported levels of physical activity and PD impacts on quality of life among participants, respectively. Phone-FITT data showed participants in this study spent more time performing household activities, such as chores and errands, than recreational activities, such as sports, conditioning or exercise.

On average, participants experienced low to moderate levels of disruption to daily life due to PD. However, large variability remained among participants, shown by the large range of scores observed. Greatest PD-related impairments were to activities of daily living, bodily comfort (e.g., experiences of pain) and cognition (e.g., memories, concentration and experiences of daytime lethargy). In this sample, the quality of life dimension least affected by PD was the amount of social support received.

able 7.2. I erformatice of physical activity of analysis sample participants (n=50).									
Types of regular physical activity (PA)	Mean ± SD (Min - Max)								
1. Household	$26.2 \pm 10.1 \ (10.3 - 44.0)$								
2. Recreational	$19.4 \pm 11.0 \ (0 - 62.5)$								
3. Summative PA	$45.6 \pm 16.7 (15.5 - 102.0)$								

Table 7.2. Performance of physical activity of analysis sample participants (n=50).

Table 7.3.	Impact of PD	in analysis sample	participants (n=50).	A score of 0	denotes no i	impact and a	a score of	100
signals tota	al impairment.							

Impact of PD on:	Mean ± SD (Min - Max)
1. Mobility	17.6 ± 20.7 (0-70.0)
2. Activities of daily living	22.5 ± 18.5 (0-70.8)
3. Emotional well-being	18.5 ±16.6 (0-66.7)
4. Perceived stigma	13.3 ± 15.8 (0-68.8)
5. Social Support	7.6 ± 12.4 (0-50.0)
6. Cognition	23.9 ± 19.3 (0-68.8)
7. Communication	20.3 ± 19.7 (0-75.0)
8. Bodily discomfort (e.g., pain)	26.9 ±24.0 (0-100.0)
9. Overall quality of life	18.8 ± 13.8 (1.8-64.7)

7.3.2 Response rates and missing data

A total of 682 days were recorded by the WIMU-GPS (n=50). Of these, 578 WIMU-GPS recorded days were retained for analysis. This was derived after removing the 148 recording days with less than 600 minutes of data. The mean recording length was 752.73 ± 75.61 (606.17 to 974.37) minutes, or 12.55 hours, per day. Of the 700 possible days with diary recordings, 19 missing diary days were observed. A missing diary day was noted when the diary page was blank, and no other records were available to infer the activities of participants. In total, 681 diary days were used.

7.3.3 Community mobility results

Table 7.4 shows community mobility outcomes as measured by the WIMU-GPS and the mobility diary. Some CM outcomes were more consistently observed among participants than others. For example, participants' mean daily walking distance was more variable than their driving distance (CV of 157.47 versus 77.75, respectively).

Mean daily mobility outcomes	WIMU-GPS (Mean ± SD [min to max])	Coefficient of Variation
Time outside (minutes) (hours) Trip count Hotspots count	$184.37 \pm 88.6 \ (60.65 \ to \ 646.70) \\ 3.07 \ \pm 1.48 \ (1.01 \ to \ 10.78) \\ \hline 1.49 \pm 0.75 \ (0 \ to \ 4) \\ \hline 4.73 \pm 1.82 \ (2 \ to \ 11) \\ \hline$	48.06 48.21 50.34 38.48
Distance to hotspots (km)	9.27 ± 7.91 (1 to 46)	85.33
Distance by vehicle (<i>km</i>)	28.81 ± 22.40 (4 to 131)	77.75
Distance on foot (<i>km</i>)	$0.87 \pm 1.37 (0 \text{ to } 7.0)$	157.47
Life space size (km ²)	343.78 ± 533.25 (1 to 2491.0)	155.11

Table 7.4. Average community mobility variable measured by the WIMU-GPS (n=50).

Average hotspots were located 9.27 (\pm 7.91) kilometers from a person's home. It appears that participants were quite mobile outside of the home: the average distance travelled by vehicle was 28.81 (\pm 22.40) km compared to 0.87 (\pm 1.37) km walked, and their mean life space size spanned 343.78 km² per day. Largest variations between the participants were observed for daily distance on foot (CV of 157.47) and life space sizes (CV of 155.11). Number of hotspot locations visited was the most consistently reported (CV of 38.48).

The average weekly number of trips to each location type reported in the diaries are shown in Figure 7.1. The most frequent reason for leaving home was to do errands (8.3 ± 11.5) . Example of destination types falling into this category included "grocery stores", "bank" or "hardware stores". Visits to sport arenas, theatres or other recreational facilities $(5.4 \pm 5.3 \text{ times})$, going for a drive $(5.4 \pm 5.3 \text{ times})$ and going to work or volunteering activities $(3.6 \pm 6.1 \text{ times})$ also were frequently reported reasons. Travel to medical facilities (e.g, doctor's office, pharmacies, physiotherapy) occurred around 1.3 ± 1.8 times per week, a rate that is similar to how often people visited their family and friends $(1.3 \pm 1.7 \text{ and } 1.6 \pm 2.2, \text{ respectively})$. Overall, destination types visited were highly individualistic and lifestyle dependent. For all destinations, large ranges were observed; for example, participants reported between 0 and 65 trips outside of the home to errand-related destinations.

Figure 7.1. Average weekly number of visits to different destination types by analysis sample participants (n=50). "Other" destinations include entries where participants only indicated the city or town names, without providing names or details about the type of establishments or locations frequented.



7.3.4 Relationships between community mobility outcomes

The relationships between daily amount of time recorded by the WIMU-GPS and each of the CM outcomes are shown in Table 7.6. Increases in the daily amount of time recorded by the WIMU-GPS was weakly associated with an increased amount of time outside (r = 0.29, p = 0.04).

Table 7.6 also shows the associations between different CM outcomes. The strongest relationships among CM outcomes were observed between how many minutes participants spent outside daily and their daily "hotspot count" (r = 0.86, p < 0.01) and how far hotspot distances were from home and "area size travelled" (r = 0.87, p < 0.01).

Daily "time outside" was positively associated with "trip count" (r = 0.64, p < 0.01), distance travelled by vehicle (r = 0.65, p < 0.01), hotspot distance and life space size (r = 0.52, p < 0.01 for both). However, a significant relationship was not observed between "time outside" and walking distance (r = 0.17, p = 0.23).

Daily trip frequency was positively associated with both vehicle distance (r = 0.50, p < 0.01) and walking distance (r = 0.35, p = 0.01). People who went out more frequently also visited more hotspots (r = 0.69, p < 0.01), but their life space sizes were not significantly larger (r = 0.23, p = 0.11).

Total area size travelled was moderately correlated with vehicle distance (r = 0.52, p < 0.01) and number of destinations visited (r = 0.87, p < 0.01) but not with increased walking distance. The number of destinations visited also was correlated with vehicular distance (r = 0.72, p < 0.01), but not with walking distance.

Table 7.5. Pearson's correlation matrix for mean daily CM outcomes measured by the WIMU-GPS (n=50).

Average outcomes (n=50)	Time Outside (mins)	Trip Count	Hotspot Count	Total Distance to Hotspots (km)	Total distance by vehicle (km)	Total distance on foot (km)	Area size travelled (km ²)	Time Sampled (mins)
Time Outside (mins)	1.00	0.64**	0.86**	0.52**	0.65**	0.17	0.52**	0.29*
Trip Count		1.0	0.69**	0.11	0.50**	0.35*	0.23	0.15
Hotspot Count			1.0	0.48**	0.72**	0.19	0.53**	0.19
Distance to hotspots				1.0	0.49**	-0.07	0.87**	0.20
(km) Vehicular distance					1.0	0.07	0.52**	0.17
Walking distance (km)						1.0	-0.03	-0.34
Area size travelled							1.0	0.20
(Km ²) Time recorded								1.0

** Correlation was significant at the 0.01 level (2 tailed)

*. Correlation was significant at the 0.05 level (2-tailed)

7.3.4 Relationships between community mobility outcomes and personal characteristics

The relationships between amount of time recorded and CM outcomes with age, time since PD diagnosis, cognition, self-reported social support, quality of life and effects of PD are presented in Table 7.6. Only mean daily trip count and walking distance were related to cognition and certain effects of PD, respectively. Age, gender, time since diagnosis, self-perceived social

support, quality of life, as well as categorical characteristics of income level, retirement status, driving status were not significantly related to any of the CM outcomes (p > 0.05).

Differences in the average time recorded and CM outcomes according to demographic categories are shown in Tables 7.7 and 7.8. For characteristics with more than two categories, post-hoc analysis was performed using each category as the reference group, although only one reference group was presented in the table. CM outcomes with significant covariate relationships are discussed in greater detail below.

A. Length of recordings

On average, recordings from PwP who were married or in a common law relationship were 79.55 \pm 24.04 minutes shorter than recordings from PwP who were unmarried, widowed or separated (p < 0.01). Similarly, PwP who live with family and friends produced recordings that were 60.49 \pm 27.76 minutes shorter than PwP who lived alone (p < 0.05).

B. Time outside

When education was analyzed using all seven categories, statistically significant differences were observed in the amount of "time outside" (p = 0.01). However, all possible post-hoc analyses were not conducted as only 1 to 2 participants completed "some college" and "post-graduate program". After reducing education to four and five categories, the statistically significant differences in time outside were no longer observed.

C. Trip Count

The number of trips taken outside significantly decreased when cognition scores improved (r=-0.31, p = 0.03).

D. Walking distance

Participants' walking distances were longer when they self-reported greater PD related effects on emotional wellbeing (r=0.40, p = 0.004) and bodily discomfort (r=0.304, p = 0.032), and when the duration and intensity of their recreational activities were higher (r=0.391, p = 0.005).

E. Vehicular distance

The distance travelled by vehicle was 24.4km further among rural than urban participants (p < 0.05). However, significant differences were not observed in vehicle distance travelled across any other setting types. Significant differences in life space sizes were also not observed between any of the geographical settings.

Table 7.6 Results of Pearson and Spearman correlation analyses on the relationship between continuous demographic characteristics with community mobility outcomes (n=50).

		Time Outside (mins)	Trip Count	Hotspot Count	Total Distance to Hotspots (km)	Total distance by vehicle (km)	Total distance on foot (km)	Area size travelled (km²)	TimeSampled (mins)
Age		-0.079	-0.117	077	031	045	231	041	.120
Time since diagnosis (years)		-0.041	-0.094	043	.026	.109	132 .361	.060	079
Cognition		0.69	-0.309* 0.029	0.033	0.016	.099	188	.056	.104
Social support $^{\alpha}$		-0.095	221	131	.152	.115	075	.138	.102
SF12 ^α		-0.199	005	210	.025	069	069	101	.229
Self-reported effects of Parkinson's disease ^a	Summative score	.094	.030	.169	.102	.105	.250	.053	175
	Mobility	.046	016	.049	.040	.088	.203	034	098
	ADL	.002	033	.066	.103	.123	.067	.085	085
	Emotion	.223	.099	.245	.097	.094	.404** .004	.069	140
	Stigma	074	229	.055	.222	.087	.019	.042	277
	Social Support	.157	018	.203	.116	.112	.080	.128	114
	Cognition	027	006	.031	.017	094	.171	017	194
	Communication	.062	.085	.079	.029	.053	.113	.055	089
	Bodily discomfort	.238	.214	.219	.201	.227	.304* .032	.165	.038
Self-reported Physical Activity ^α	Summative score	.181	004	.258	.125	.232	.228	.148	130
	Household	020	159	010	.086	.068	089	.016	003
	Recreational	.193	.074	.269	.065	.252	.391** .005	.146	242

 α Spearman correlation coefficient was reported.

**. Correlation was significant at the 0.01 level (2-tailed).

*. Correlation was significant at the 0.05 level (2-tailed).

Table 7.7. Mean daily "time outside", "trip count", "hotspot count" and amount of "time sampled" by the WIMU-GPS, according to participants' demographic profiles. Significant differences between the categories were identified using one way ANOVA analysis ($p \le 0.05$ and $p \le 0.01$) with Bonferroni post-hoc test for more than two categories (n=50).

-				Time Outside		Trip	Trip Count		Hotspot Count		TimeSampled (mins)	
Covariate	Categories	n	%		(mins)	-		-		-		
				mean	s.d	mean	s.d.	mean	s.d.	mean	s.d.	
Gender	Women	16	32.0	197.83	116.53	1.38	0.70	5.02	2.09	770.89	67.99	
	Men	34	68.0	178.04	73.23	1.54	0.78	4.59	1.69	744.19	89.38	
Marital status	Unmarried/widowed/separated	8	14.0	209.38	89.97	1.82	1.02	5.28	1.92	819.55**	90.38	
	Married/common law	42	68.0	179.61	88.66	1.43	.69	4.62	1.80	740.00**	66.34	
Place of Residence	Urban (ref)	13	26.0	157.81	84.4	1.27	0.42	4.39	1.93	773.47	86.12	
	Suburban	11	22.0	191.25	71.94	1.56	0.70	4.77	1.42	738.01	72.79	
	Rural, in town	16	32.0	201.55	110.56	1.77	1.02	50.00	2.20	753.70	70.81	
	Rural, outside of town	10	20.0	183.85	74.40	1.25	0.51	4.70	1.53	740.41	77.07	
Income	0 - \$19, 999 (ref)	10	20.0	181.20	93.54	1.54	.99	4.76	1.84	776.41	67.45	
	\$20, 000 - \$39, 999	10	20.0	155.38	72.53	1.28	0.43	3.84	1.01	737.93	77.71	
	\$40, 000 - \$59, 999	14	28.0	174.92	76.66	1.54	.813	4.67	2.19	755.06	84.61	
	\$60, 000 - \$89, 999	11	22.0	200.48	83.67	1.54	.848	5.12	1.64	740.83	85.30	
	>\$90,000	5	10.0	239.74	145.31	1.54	.425	5.73	2.09	754.63	48.96	
Education 3 categories	< High school (ref)	10	20.0	177.40	79.49	1.53	0.73	4.27	1.06	785.50	58.06	
	High school	10	20.0	177.44	74.86	1.33	0.36	4.53	1.60	742.35	75.57	
	> High school	30	60.0	189.01	97.55	1.53	0.86	4.95	2.07	745.27	79.86	
Education 5 categories	< High school (ref)	10	20.0	177.40	79.49	1.53	0.73	4.27	1.06	785.50	58.06	
0	High school graduate	10	20.0	177.44	74.86	1.33	0.36	4.53	1.60	742.35	75.57	
	Some college	10	20.0	177.42	79.99	1.41	0.83	4.53	1.85	721.46	65.85	
	Undergraduate degree and post-	8	16.0	148.41	99.97	1.49	1.09	4.55	2.67	749.55	74.48	
	graduate program											
	Graduate	12	24.0	225.72	103.46	1.65	0.76	5.57	1.81	762.25	94.29	
Education 7 categories	< High school (ref)	10	20.0	177.40	79.49	1.53	0.73	4.27	1.06	785.50	58.06	
	High school graduate	10	20.0	177.44	74.86	1.33	0.36	4.53	1.60	742.35	75.57	
	Some college	2	4.0	77.55	23.90	0.92	0.01	2.68	0.20	708.07	98.79	
	College diploma	8	16.0	202.39	67.69	1.53	0.89	4.99	1.78	724.80	64.16	
	Undergraduate degree	8	16.0	148.41	99.97	1.49	1.09	4.55	2.67	749.55	74.48	
	Post-graduate program	1	2.0	464.70	n/a	1.82	n/a	8.27	n/a	767.42	n/a	
	Graduate degree	11	22.0	204.00	74.45	1.64	0.80	5.32	1.68	761.78	98.88	
Living situation	Alone	8	16.0	181.02	97.01	1.69	1.07	4.60	1.80	803.54*	96.02	
	With family/friends	42	84.0	185.01	88.19	1.45	.68	4.75	1.838	743.05*	68.26	
Retirement status	Fully retired	43	86.0	191.71	91.76	1.53	0.76	4.83	1.90	755.15	73.39	
	Partial or full employment	7	14.0	139.28	49.52	1.25	0.72	4.08	1.07	737.84	93.22	
Driving status	Drives	49	98.0	185.10	89.40	1.50	0.76	4.74	1.83	753.09	76.36	
	Do not drive	1	2.0	148.98	n/a	1.08	n/a	4.00	n/a	735.33	n/a	

**. Difference in mean was significant at the 0.01 level (2-tailed). *. Difference in mean was significant at the 0.05 level (2-tailed).

Table 7.8. Mean daily "distance to hotspots (km)", "vehicular distance (km)", "walking distance (km)" and "area size travelled (km²)" measured by the WIMuGPS, according to participants' demographic profiles. Significant differences between the categories were identified using one way ANOVA analysis ($p \le 0.05$ and $p \le 0.01$) with Bonferroni post-hoc test for more than two categories. (n=50).

Covariate	Categories	n	%	Total Distance to Hotspots (km)		Total distance by vehicle (km)		Total distance on foot (km)		Area size travelled (km ²)		
				mean	s.d.	mean	s.d.	mean	s.d.	mean	s.d.	
Gender	Women	16	32.0	9.71	10.90	26.70	19.09	1.21	2.088	341.26	637.58	
	Men	34	68.0	9.06	6.24	29.80	24.00	.71	.854	344.97	487.28	
Marital status	Unmarried/widowed/separated	8	14.0	7.07	5.74	26.75	17.49	.45	.437	270.10	360.49	
	Married/common law	42	68.0	9.68	8.25	29.20	23.37	.95	1.48	357.82	562.49	
Place of Residence	Urban (ref)	13	26.0	5.51	5.12	16.22	11.52	0.42	0.34	111.09	282.52	
	Suburban	11	22.0	11.07	7.97	25.92	12.27	1.26	2.000	575.78	692.24	
	Rural, in town	16	32.0	8.86	5.42	40.58*	31.25	1.19	1.65	319.52	362.33	
	Rural, outside of town	10	20.0	12.82	12.16	29.52	16.52	0.49	0.52	429.91	732.94	
Income	0 - \$19, 999 (ref)	10	20.0	13.05	12.81	33.89	21.63	0.37	0.28	482.24	728.26	
	\$20,000 - \$39,999	10	20.0	9.21	7.89	20.56	12.36	0.63	.983	266.49	490.36	
	\$40,000 - \$59,999	14	28.0	8.36	5.25	35.30	30.52	1.15	1.763	322.18	426.19	
	\$60,000 - \$89,999	11	22.0	5.99	5.16	16.67	7.59	1.26	1.870	126.30	249.29	
	>\$90,000	5	10.0	11.53	5.20	43.69	22.66	0.68	0.596	760.41	769.29	
Education 3 categories	< High school (ref)	10	20.0	10.95	4.22	28.72	16.20	0.56	0.43	295.78	202.92	
	High school	10	20.0	10.83	12.98	27.88	18.28	0.53	0.46	356.64	759.00	
	> High school	30	60.0	8.18	6.71	29.15	25.73	1.08	1.71	355.50	536.57	
Education 5 categories	< High school (ref)	10	20.0	10.95	4.22	28.72	16.20	0.56	0.43	295.78	202.92	
	High school graduate	10	20.0	10.83	12.98	27.88	18.28	0.53	0.46	356.64	759.00	
	Some college	10	20.0	6.87	4.76	25.55	15.00	1.62	2.58	301.99	639.00	
	Undergraduate degree and	8	16.0	5.71	4.91	32.23	41.08	0.91	1.26	286.01	486.43	
	post-graduate program											
	Graduate	12	24.0	10.93	8.40	30.10	21.63	0.75	0.94	446.43	509.15	
Education 7 categories	< High school (ref)	10	20.0	10.95	4.22	28.72	16.20	0.56	0.43	295.77	202.92	
	High school graduate	10	20.0	10.83	12.98	27.88	18.28	0.53	0.46	356.64	759.00	
	Some college	2	4.0	2.43	2.69	15.69	16.84	3.39	4.13	20.97	27.62	
	College diploma	8	16.0	7.98	4.59	28.02	14.63	1.17	2.23	372.24	704.76	
	Undergraduate degree	8	16.0	5.71	4.91	32.23	41.08	0.91	1.26	286.01	486.43	
	Post-graduate program	1	2.0	15.68	n/a	79.39	n/a	0.50	n/a	680.61	n/a	
	Graduate degree	11	22.0	10.50	8.67	25.62	15.81	0.77	0.98	425.14	528.37	
Living situation	Alone	8	16.0	4.82	2.78	21.97	16.04	0.45	0.43	140.93	183.685	
	With family/friends	42	84.0	10.11	8.30	30.11	23.34	0.95	1.48	382.42	569.67	
Retirement status	Fully retired	43	86.0	9.80	8.40	29.57	23.69	0.88	1.39	377.42	567.86	
	Partial or full employment	7	14.0	6.00	1.67	24.17	11.77	0.82	1.36	137.14	83.86	
Driving status	Drives	49	98.0	9.37	7.96	29.09	22.54	0.88	1.38	349.99	536.95	
	Do not drive	1	2.0	4.19	n/a	14.93	n/a	0.27	n/a	39.70	n/a	

**. Difference in mean was significant at the 0.01 level (2-tailed).

*. Difference in mean was significant at the 0.05 level (2-tailed).

7.4 Discussion

Previous chapters of this Dissertation have shown the WIMU-GPS to be a valid and reliable *in situ* assessment of CM in PD (Chapter 5), and that minimum recordings of at least 600 minutes of data over seven distinct days were needed to minimize errors when estimating true CM values (Chapter 6). This recommendation was then applied in this study to achieve a sample that was sufficiently large for bivariate statistical tests.

This study was also one of the first to prospectively quantify the real life CM of PwP over multiple days using a wearable GPS sensor unit. Previous research typically analyzed single parameters of CM such as duration outside the home¹⁵, frequency of trips¹⁴ or life space size outside the home^{13, 16, 23}. This study was one of the first to evaluate relationships between these and other CM domains.

7.4.1 Travel patterns of PwP

A. Frequency, duration and life space sizes

This study suggested that average older adults with early to mid-stage PD were not confined to their homes. The mean number of daily trips taken by older adults with early to mid-stage PD (mean = 1.5) was similar to that of an older adult population without PD (mean = 1.4)⁴⁷. For travel duration, similar studies done in older adults with and without PD were not available for comparison.

The life spaces of PwP extended far beyond their homes. For example, the lowest mean daily area size observed was 1 km². This was achieved because participants of this study regularly travelled to one or more hotspot destinations that were far from home (e.g., the closest distance to hotspots was 1km), or multiple hotspot locations that were not as far but were located in opposite directions. Life space sizes were related to time outside (r = 0.52, p < 0.01) and not to trip count (r = 0.23, p = 0.11). Therefore, CM studies that evaluate only one of these outcomes would be insufficient to capture the multidimensional nature of the construct.

Due to the individualistic nature of mobility, outliers in mean mobility were expected. This also may have led to overestimations in mean life space sizes when days with extraordinarily high or low mobility were included for analyses. It was difficult to properly identify outlying mobility patterns and assess the habitualness of each individual's mobility. For example, it is possible that seemingly abnormal days were habitual occurrences if observed over a longer time period (e.g., the participant visits family out of town every other Tuesday).

B. Mode of transportation

The results strongly suggested PwP preferred vehicle travel over walking, especially when commuting to a specific location^{47, 48}. For example, the number of hotspot destinations and life space sizes increased only with vehicle distance, and not with walking distance. As well, the average daily distance travelled by vehicle was more than 30 times further than the distance walked, and people who travelled further by vehicle did not walk further (r = 0.07, p = 0.6). It was likely that walking was being used only for light exercise (e.g., going for a walk) or for short trips near the home (e.g., to the mailbox).

Active transport refers to walking or cycling $^{33, 47, 49}$, and is linked to functional and cardiovascular health^{14, 25} and independence²⁶. Although active and passive transport both may achieve the same end goal of allowing individuals to engage in the community, they each imply different qualities about individuals' ability, physical functioning and activity levels. This study showed that PwPs who engaged in greater recreational activities also walked further, but walking distance was not associated with active performance of more household chores. Vehicular distance recorded by the WIMU-GPS included both car and bicycle distance, however very few (< 5) participants reported on the Phone-FITT to have ridden a bicycle more than once during the study period. Hence, vehicular distances captured are assumed to refer to travel by car.

Community mobility in rural older adults is associated with walkability, driveability and transportation⁵⁰. In this study, 52% of participants resided in a rural setting where services and resources are further apart, and the walkability is worse than in a suburban or urban setting. Walkable neighbourhoods are key promoters of walking. However, residential setting differences were not associated with differences in walking behaviour. PwP walked more only when they went outside more often, and not when they spent more time outside. This may be because individuals leave the home more often when less planning is involved. For early to mid-stage PwP, walking outside may be easier to execute than driving or being driven, and walking trips occurred closer to one's home (e.g., visiting the communal mailbox). Overall, trip count

may be a better indicator of *walking* distance than duration or life space area size.

A preference for vehicle use also was found among older adults without PD who resided in mixed geographical settings^{47, 51}. In this study, the geographic settings of participants were used as proxy measures of walkability and built environment. Statistical significance was only observed between in-town rural residents and urbanites, such that the mean daily distances travelled by people in a rural town were more than twice as far as those in an urban setting (Table 7.8). This may be because participants in rural settings often maintain farms or commute between towns to meet their needs. Therefore, reliance on vehicles may reflect distance to target destinations, instead of PD or any functional health decline.

C. Travel behaviour: leisure driving, trip chaining and destinations

The travel patterns of participants could be inferred by comparing different outcomes captured using WIMU-GPS and diary. Table 7.4 showed the mean distance travelled by vehicle was over three times longer than mean distance to hotspots. This suggested vehicle trips were not always taken with a destination in mind. Confirmation using diary records showed the value of combining instrumented measures and diary reports, as many participants indicated that they "went for a drive".

Trip chaining is a travel pattern commonly observed in GPS studies. It refers to the act of visiting several destinations during the same trip without returning to the origin after each destination^{15,29}. Without trip chaining, average number of hotspots visited per day should be similar to the distance travelled divided by the average distance to hotspots. In this study, the average daily distance travelled by PwP using only vehicles was almost three times the average distance to hotspots, yet they visited five hotspots per day on average. Trip chaining would also explain why mean distance travelled by vehicle was three times greater than mean distance to hotspots. This is because if a participant visits two hotspots that are in opposite direction from the home, the distance travelled during trip chaining would be longer than the distance from home to either hotspot. Diary entries also captured information about trip origins and destinations. Therefore, the type of travel behaviour adopted by participants over a given period of time also could be elucidated by checking with the diary entries.

Destinations visited were highly individualistic. However, the most frequently visited destinations by older adults with early to mid-stage PD were similar to non-PD older adults, with one unique difference. Previous research has shown trip chaining occurred more often for trips related to errands than for recreation⁵². In another Canadian study, the most frequent destinations for non-PD older adults were grocery stores²⁵, restaurants, malls/marketplaces and other personal homes. Errand related locations, such as grocery stores, banks or hardware stores also were most frequented by PwP (Figure 7.1). However, results also showed that visits to medical facilities were as much a part of the weekly routine of older adults with PD as visits to family and friends (mean weekly frequency of visits were 1.3, 1.3 and 1.6, respectively). The increase in relative frequency of medical facility visits may be due to PD and additional comorbidities, and/or differences in geographic setting. Participants of this study may be limited in the variety of destinations that were close in proximity.

D. PD effects on quality of life and Community mobility

Older adults with cognitive decline often have lower community mobility ^{37, 53}, potentially to avoid unfamiliar situations and reduce physical harm². This study found PwPs with better cognitive scores tended to take fewer trips outside. This unexpected result may be due to the increased needs of those with worse cognition. The independence of older adults with lower cognitive function is often decreased inside and outside of the home^{54, 55}, as they are often brought along on trips by a spouse or a caregiver. They also may have more comorbidities that required numerous visits to medical or respite settings. A future study examining spousal dyads' travel patterns is possible using WIMU-GPS data.

PwPs who walked further during the two week recording period also reported worse emotional wellbeing (e.g., depression, isolation, loneliness, anger, anxiety and worry) or physical discomfort (e.g., muscle cramps, spasms, aches and pains, feeling hot or cold) as a result of PD in the past month. The PDQ-39 was administered on day 14 and retrospectively asked about the effects of PD during the recording period and the two weeks prior to the first day of recording. It was possible that PwPs could be taking walks to ease the discomfort felt in the preceding days. It also was possible that difficulties with walking longer distances led to experiences of poor emotional wellbeing and discomfort, or due to unassessed confounders. Overall, the inability to infer causal relationships is a limitation of the study design.

E. Missing data and recorded time:

On average, PwP who shared a home or were in a relationship with someone recorded over one hour less of data per day. Relationship status and living situations affected the amount of time recorded as those not in a relationship may have more flexibility in personal time to adhere to the study protocol. Similar patterns of missing data was not found for the diary.

7.5 Conclusions:

The WIMU-GPS recording length of 600 over 7 distinct days was a reasonable criterion to quantify CM outcomes in PwP. Older adults with early to mid-stage PD were mobile in their communities. PwP preferred travel by vehicle over walking, especially when commuting to a specific location. A higher relative frequency of medical facility visits among PwP were reported using the diary.

CM outcomes were associated only with PD's effects on emotional wellbeing and bodily discomfort, such that walking distance increased with adverse PD effects. The impact of PD on mobility was not significantly related to the performance of CM in people with early to moderate stage PD.

Overall, this study was one of the first to demonstrate the feasibility of recording up to seven different CM outcomes over a long duration. This advantage of the WIMU-GPS was necessary to comprehensively capture the multidimensional nature of CM.

7.6 References

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Chapter 8: Discussion

Preceding chapters of this dissertation described a series of studies conducted to serve as a reference for researchers, health providers and industry members wishing to assess the mobility of older adults with PD in their real-life community setting.

The primary objectives were to compare the psychometric properties of common community mobility assessments, and use appropriate assessment(s) to quantify various community mobility outcomes in PwP. Secondary objectives were to assess methodological considerations when using these assessments in epidemiological research focused on an older clinical population.

These goals were approached beginning with a review of the appropriate multi-assessment comparison methods used in mobility research (Chapter 4), followed by systematically comparing and contrasting three examples of cross-sectional and instrumented measures for commonly measured CM outcomes (LSA, diary, WIMU-GPS) (Chapter 5). An optimal length of recording using the WIMU-GPS was described in Chapter 6, and applied, along with daily diaries, to quantify multiple CM outcomes in a sample of older adults with PD in Chapter 7.

The following sections summarize and discuss the results of these chapters in greater depth.

8.1. Summary of Key Findings:

8.1.1 State of literature for mobility assessment comparison studies

A Google Scholar search using the terms "wearable technology" and "health" yielded 23, 600 references between 2006 to 2016. Nevertheless, Chapter 4 found only a small number of CM studies used wearable sensors during this period (10 studies)¹⁻¹⁰. A slight increase in the number of studies that featured a wearable GPS sensor reflected the recent proliferation and researcher interest in wearable technologies¹¹⁻¹⁴.

Although "gold standard" assessments can be impractical for widespread use¹⁵ and may change over time¹⁶, more formal validation studies might be conducted if there was a widely accepted best available standard CM assessment. In lieu of one at the present time, commonly accepted

assessments are used as comparison tools to estimate convergent validity, reliability, agreement and disagreement. Comparison studies reviewed often did not match data collected using different CM assessments before analysis, and used inconsistent minimal GPS recording lengths. Studies comparing CM measures in populations vulnerable to mobility disability were lacking.

Trip count, duration and distance were the most common CM outcomes reported in comparison studies. A small number of studies also evaluated destinations or accounted for travel mode³. Researchers should continue to compare different CM assessment tools against each other, especially on CM outcomes beyond trip count and duration. A standard intermodal comparison guideline would also be valuable, and should address appropriate strategies to compare assessments in absence of a gold standard.

8.1.2 Comparison of *trip frequency* and *duration* measures: WIMU-GPS vs Diary Longer times outside were observed in 79.6% of participants using the WIMU-GPS, compared to only 22.2% who self-reported longer time outside using the diary. Previous research showed trip *duration* was consistently higher when reported using the diary than with GPS recordings¹⁷. However, mean percentage of daily *duration* outside recorded by the WIMU-GPS was 1.38 times of diary reporting (38% higher; Chapter 5). Unlike some comparison studies^{6, 9, 10, 17}, Chapter 5 matched the assessments for the day of recording, and expressed *duration* captured as a percentage of time sampled. Therefore, Chapter 5's contrary results may be due to the extra care taken with the design of the comparison, and may not be due to differences in GPS model used or participants sampled. All of Chapter 7's 50 participants were included in Chapter 5, but as assessment comparison was not of interest, time sampled by the diary and WIMU-GPS were not matched. The outcomes also were not expressed as a percentage of recorded time for ease of interpretation. When these were not done, greater *duration* was self-reported using diaries than recorded by the WIMU-GPS (Appendix 8.1), similar to previous studies.

When frequency was reported in terms of the hours sampled by each assessment, GPS and diaries recorded similar absolute trip frequencies. Although it was difficult to know which assessment was closer to the truth, the mean difference and LOA ranges were all very small (<1 trip per day), which suggested that the WIMU-GPS could be used to replace the diary to measure

trip frequency when burden, recall bias and social desirability are concerns, and for individuals with cognitive decline¹⁰.

A. Employment influences agreement between CM assessments

Participants' employment status should be taken into consideration when tracking daily mobility using either a diary or GPS sensor. Research showed paid workers self-reported more trips than their GPS recorded, compared to volunteers⁵. Chapter 5 found PwP who engaged in any work, paid *or* unpaid, self-reported more trips than their WIMU-GPS recorded. There are two possible explanations: i) working or volunteering participants may experience greater difficulties adhering to a GPS recording protocol during work hours, and ii) consistent work schedules may simplify recall because of their structure, whereas fully retired participants may experience greater difficulties recalling the daily variability in their tasks and mobility patterns (e.g., trip-chaining or frequent travel). Therefore, a combination approach (both diary and GPS)^{3, 5} may be still needed for those who engage in paid and unpaid work.

The geospatial tracking ability of WIMU-GPS allowed it to quantify a greater number of CM outcomes than the diary, such as distance, mode of travel, area size and active time (not analyzed in this dissertation as not all activity tracked may be mobility related)¹⁸. However, diary usage enabled the inclusion of destination information. As with other measurement choices, researchers should be guided in their selection by optimizing the match between measures and research objectives. Overall, more research is needed to determine the exact reasons for the discrepancy between *trip duration* and *frequency* data collected using the diary and WIMU-GPS, as well as using other GPS models.

8.1.3 Comparisons of life space measures: WIMU-GPS versus LSA

The LSA provides a composite mobility score to capture a person's maximal life-space mobility in relation to trip frequency, duration, relative spatial area and dependence¹⁹. Despite its wide use ^(e.g., 20-27) and the potential to become "a standard assessment tool in clinical practice and geriatric research"²⁸, the LSA has not been evaluated against a CM measure. Its validity and reliability were evaluated using measures associated with mobility, such as functional health, functional mobility, mental health, and demographic and clinical characteristics ^{19, 27, 29}. After

comparing results from the LSA against the spatial life space sizes captured by the WIMU-GPS, its limitations became apparent, as discussed below.

A. Limited Discriminatory Power and Ceiling Effects

Chapter 5 showed that individuals with widely different WIMU-GPS-recorded spatial life space sizes were frequently assigned the same composite LSA scores. Thus, good convergent validity was not observed between the LSA scores and WIMU-GPS recordings of life space sizes. Overall, the LSA exhibited poor inter-individual discriminatory ability because it did not provide enough standard reference sizes for respondents living in diverse settings, and it did not ask respondents to estimate the actual distance travelled.

Suburban or urban respondents typically needed to travel further than their rural peers in order to receive credit on the LSA for the same life space attained, using any of the LSA scoring methods. Residents of smaller towns may also leave town more often than city dwellers in order to access goods and services. The composite LSA scoring system assigns scores for frequency, duration and assistance for mobility within a life-space¹⁹. Regardless of the true geographical size of the life-space attained by individuals, larger multipliers are assigned to frequency, duration and assistance scores reported for larger life-space levels. Therefore, LSA scores are prone to bias, because: a) just one trip outside of the neighbourhood could notably increase the score²⁰, and b) the CM of those in a larger municipality will be underestimated compared to those in smaller municipalities. This also may explain the relatively large LSA scores observed among people with smaller WIMU-GPS recorded life space sizes in Chapter 5.

LSA scores also presented a ceiling effect. Its maximum score is 120 regardless of how far respondents travelled. However, individuals whose life spaces spanned 5km versus 500 km "outside of town" likely exhibited very different mobility characteristics. This project confirmed a previous study on older adults that suggested greater resolution at larger life-spaces levels outside of one's property is required³⁰. This may be done by adding reference distances (e.g., 10km, 100 km from home)³⁰ and by adding more categories (e.g., neighbouring town/city, region, neighbouring region, province/state, country). Therefore, the LSA should probably only be used to capture change in CM performance within individuals over time^{19, 23, 31}. It should not

be used for cross-sectional comparisons of different populations²⁹, as some authors have done^{20, 28, 32, 33}.

B. Flaws in the Internal Logic

The scoring of the LSA assumed individuals move linearly through successively larger concentric life space circles. Respondents who reported visiting areas *outside* their neighborhood (life space level 3) must also have visited areas *within* their neighborhood (life space level 4) ^{19, 34}. This logic was noted as flawed in a recent commentary³⁵. Respondents who travel through level 3 to visit level 4 may not report having visited level 3, and were termed "jumpers" ^{35, 36}. This concept was refuted by the LSA's authors³⁷ as being based on simulated data. They insisted that the LSA is not destination specific³⁷. Other researchers insisted "responses have meaning to participants" and that "potential anomalies may occur in a small portion of people"³⁸.

Real-life evidence of "jumpers" was observed among the participants of this project. During each of the two separate administrations, 15 (21.4%) of 70 participants reported no visits to a more proximal life space before visiting a distal life space. Most often, respondents visited places outside of their neighborhood or town (levels 4 or 5) without having been to places within or outside of their neighborhoods (levels 3 or 4). The author's intentions to capture *any* presence within a life space level (i.e., both passing through and stopping) were not always intuitive to respondents, even after following the written LSA instructions. For instance, the LSA instructions asks respondents if they "have been to places outside [their] neighborhood, but within [their] town" and "have often have [they] been to (name of appropriate life-space)". This implies each life-space and places within it should be considered as destinations.

C. Data Creation and Scoring Issues

The scoring algorithm of the LSA imputes responses to account for missing data ^{35, 36}. A proposed non-data-edited composite scoring system³⁵ has not yet been widely adopted or validated. So the present project used the edited methods provided by the LSA authors. It has been shown that data on older adults calculated using this edited method were relatively consistent with non-edited data³⁸. However, this still overlooks the fact that questions were inconsistently interpreted by respondents. Further, complete data may be less accurate than

missing data. Inferences about the frequency and duration of travel to a missing or underreported life-space can lead to artificial data creation and editing^{35, 36}.

Consider if over a typical week, respondent "A" visited locations within his town (level 4) twice, before travelling outside of town (level 5) three times without stopping anywhere within town (level 4). Should "A" says he visited level 4 five times, even when it doesn't match the three trips to level 5? Or should he report only the 3 trips through level 4 and 5? Alternatively, if "A" did not make any prior visits to locations within town, should he still report 3 visits to level 4 (thus making him a "jumper")?

The issues discussed above are common to many questionnaires using binary questions and cumulative scaling. One example is the Guttman scale³⁹. It was created with the view that some cognitive and behavioural constructs could be ordered into successively more extreme levels. Respondents are asked to state whether they agree or disagree with an ordered list of items representing each escalating level. It assumes that agreement on a higher level item also implies agreement with all lower level items. This way, a single unidimensional summary score could be created, based on most extreme level reported, to describe a behavioural construct. However, many constructs are not perfectly scalable, as the performance of one behaviour does not guarantee the performance of all lower-order behaviours⁴⁰. When a construct is not scalable⁴¹, is multidimensional or when there are missing values^{42, 43}, cumulative scales, like the Guttman and LSA, can lead to errors.

Given the multidimensional nature of CM, and these issues with cumulative scaling, the assumptions underlying the validity of the LSA should be re-examined. The additional instructional prompts provided by LSA authors were insufficient to avoid "jumpers" or to provide relevant context for respondents in diverse settings. LSA questions should be precisely revised to refer to both movements within *and* through life space levels.

8.1.4 Minimum WIMU-GPS recording length

GPS studies often report a shorter recording time than wear time ¹⁰, and no peer-reviewed consensus on recording length is currently available. In Chapter 6, data error was minimized when daily recordings were at least 600 minutes long for non-discrete continuous outcomes, such as "time outside" and "area size". Daily recordings of "time outside", "trip count", "hotspot count" and "area size" that are less than 500 minutes long should probably not be used for analysis. Chapter 7 showed that a sufficient sample size could be retained after applying this common minimum daily recording length.

Variability in daily patterns depended on the type of mobility dimension considered. For instance, *area size* of participants differed greatly from day to day compared to *trip* and *hotspots count* (Figure 6.1; Table 7.4). This also suggested PwPs tended to take a similar number of trips to a similar number of destinations each day, but where they go and the purpose of visits may differ each day. Chapter 7 also showed that not all CM dimensions were significantly associated with each other. For instance, daily *life space sizes* correlated with *time outside* but not *trip count*. This shows the importance of accounting for a number of outcomes in order to capture the multidimensional nature of mobility ^{44, 45}. Research shows GPS data spanning at least seven distinct days of the week will account for daily mobility fluctuations^{7, 46}, and 7-15 days of GPS recording also could reduce sample size and cost compared to one-day diary report⁴⁶. More work is needed to determine if the outcomes are differently affected by the number of recording days.

8.1.5 Community mobility of older adults with PD

Mobility limitations and gait disorders are highly prevalent among community-dwelling older adults^{47,48}. Those with PD are at higher risk of developing mobility limitations due to changes in gait⁴⁷, as well as other motor⁴⁹ and non-motor⁵⁰ signs and symptoms. Therefore, PwP were an ideal study sample to understand real life mobility disability, and to test the application of mobility assessments in a population at risk of mobility disability.

A comprehensive approach to quantify and qualify the real life CM of PwP showed older adults with early to mid-stage PD were routinely mobile in their communities. Their daily life spaces encompassed an area of at least 1 km² around the home, and they also showed similar trip

frequencies and patterns of frequenting errand-related locations outside as the general older population^{51, 52}. However, unlike the general population, PwPs also visited medical facilities as often as visits to the homes of family and friends.

Categorization of visit purpose based on destination reported by participants may lead to overestimation of certain visit purposes. For instance, a destination labelled "grocery store" may not reflect visits also to an on-site medical facility or restaurant. Studies interested in capturing purpose of visits, as well as destinations visited, as important aspects of CM should standardize ways of reporting trip purpose and allow participants to select from predefined classifications of trip purpose or destination types⁵¹.

All participants were ambulatory community-dwellers who were mobile without the aid of assistive devices or a support person. They reported less PD-related impact on their mobility and experiences of bodily discomfort, compared to other samples of people with early to mid-stage PD⁵³. Despite their functional status, participants relied on motorized vehicles, instead of walking, to reach hotspot destinations and to achieve or maintain higher life space sizes. A preference for driving was previously shown among older adults ^{20, 51}. However, walking was the main mode of transportation when older adults lived in a highly walkable urban setting⁵². Residential setting did not affect walking distance in this project. The overall mean daily distances travelled by people in a rural setting were more than twice as far as those in an urban setting. Hence, reliance on vehicles may have reflected proximity to target destinations, instead of being due to PD or functional health decline. In general, Chapter 7 suggested older adults with PD preferred to walk for leisure and exercise, or for errands that could be accomplished close to the home. This was consistent with previous findings showing active trips (e.g., by walking) were more frequently performed by older adults who lived near more amenities⁵¹.

Efforts by clinicians and researchers to improve or maintain mobility in PD have largely focused on walking^{54,55,56,57} and physical activity⁵⁸. This project showed the real-life performance of mobility by PwP was also dependent on external factors. Previous qualitative results have shown environmental factors to be major barriers to community walking for PwP⁵⁹. In particular, findings of this project highlighted two areas of focus that are relevant for PwP:

1) The density of the built environment is a key promoter of walking and community mobility among older adults^{39, 52,60}, especially those with mobility disability ^{55,61,62}.

2) PwP are at risk of losing their driver's license due to age⁶³ or PD-related⁶⁴ declines in health. Preventative or rehabilitative efforts to help PwP maintain and adapt to changes in driving ability may be vital to prevent restrictions in life space²⁰, promote independence⁶⁵ and maintain quality of life⁶⁶.

Overall, the travel mode reported in this project may not be generalizable to other populations who differ by age, comorbidity, geographical setting, built environment, access to services and motorized transportation, and cultural and personal preference towards travel mode types. Nevertheless, the importance of future CM studies to consider measures of different mode of transportation was shown by this project.

8.1.6 Sample

Data for this dissertation were sourced from a systematic search of literature comparing mobility assessment methods published between 2006 - 2016 (Chapter 4), and from primary data collection with 70 older adults with PD across Southwestern Ontario (Chapters 5-7).

Sample sizes retained for analyses differed according to the study. Overall, demographics of participants included in Chapters 5-7 were not significantly different from individuals excluded. A total of 70 participants contributed 980 days of data for analysis. They were mostly men (67.1%), which is reflective of the PD population^{67, 68}. With a mean age of 67.4 ± 6.3 years, participants were slightly younger than the average community-dwelling PD population in Canada, who were mostly \geq 80 years old⁶⁸. Among Canadian PwP, the mean age of symptom onset was 64.4 years and the mean age of diagnosis was 66.2 years⁶⁸. Therefore, it was reasonable that participants were younger to capture the earlier stages of PD.

On average, participants received their PD diagnosis 7.6 years before study participation. Time since diagnosis was not used as a recruitment criterion because individuals with similar time

since diagnosis often exhibit different signs, symptoms and disabilities⁶⁹. In-clinic recruitment was done to individually verify PD diagnosis, and participants' level of independence matched the characteristics of early to mid-stage PD (Hoehn and Yahr stages I to III^{70,71}).

The study inclusion criteria included a "normal" MoCA score of 26⁷² based on participants' latest clinical chart report, which often was conducted during prior years. A movement disorders specialist also reviewed the participants' clinical profiles during the in-clinic recruitment dates to ensure their cognitive status and functioning were suitable for study participation. In-clinic recruitment dates were scheduled one week to three months before first home visit. During the study, cognitive status was re-evaluated as a covariate using the MoCA. Discrepancies between the two MoCA scores may indicate cognitive decline over time, or may be due to differences in testing location, time of day and medication pharmacokinetics. PwP may present unique challenges when completing the MoCA⁷³. In this study, participants with fine motor impairments had difficulties completing the visuospatial section (e.g., drawing a round clock contour and filling in numbers within the contour). No signs of misunderstanding of the study protocol were observed during the three home visits. Hence, all participants were retained, including those who scored <26 on the in-clinic MoCA.

8.1.7 Data Quality

Missing data occur in all multiday GPS studies^{74,75}. It was suggested that a greater number of days recorded yielded greater proportion of data loss⁷⁴. In the present project, missing or unusable data were observed for 122 of 700 total days collected using the WIMU-GPS (17.4% total data loss). After applying the minimum recording criteria, Chapter 7 showed usable data made up 97.4% of the GPS recording time. Both of these rates were within the range of the data loss rate reported for other GPS sensors (2.5-92%⁷⁴).

Incomplete or illegible diary entries were observed on 75 (7.7%) of the 980 study days. When the minimum recording criteria were applied in Chapter 7, missing or unusable diary data was reduced to 2.7%. Reasons for missing diary data included: nonresponse, insufficient details captured, incorrect details or illegible writing⁷⁶. However, the accuracy of diary entries was not always obvious to detect, and the apparent quality of record-keeping varied greatly.

8.1.8 Data collection issues and recommendations

Issues uncovered during the data collection process are summarized below.

A. Daily diary completion

Daily diary completion was noted by 20 participants as the most difficult and cumbersome aspect of this project's data collection protocol. Reasons for this included difficulties remembering to keep track of trips, the time of departures and arrivals, and writing difficulties. The approaches taken by participants to complete the diaries varied. Some took notes throughout the day, and others completed the diary once at home or at a later time point. For PwPs, and individuals with osteoarthritic pain, completing written diary entries carried an extra burden. Increased participant burden can lead to lower participation rates and higher refusal rates¹. Manually transcribing diary entries by researchers was also a cumbersome process. Participants provided inconsistent amounts of details about their travels each day and some entries were too illegible to transcribe. Passive data recording using the WIMU-GPS minimized these issues. This project supported previous findings showing GPS sensors could be feasibly adopted in samples of older adults⁷⁷.

B. Recommended improvements to GPS sensor systems

The issues and recommendations outlined below were identified during the data collection process. As these issues may not be unique to the WIMU-GPS, the recommendations may also be useful to consider when using other GPS sensor models.

1. Manual entry option and combination approach

Recent studies on CM and functioning have started to capture more outcomes by concurrently using GPS sensors with an accelerometer ^(e.g., 46, 78,79,80) or diary ^(e.g., 5, 78,81). The WIMU-GPS combines GPS with accelerometers in one unit (along with a gyroscope and magnetometer). Thus, it is more comprehensive than previous approaches and reduces burden. It could be improved by adding a data entry capability, similar to what has been accomplished using GPS-enabled cell phones ^(10, 82, 83). However, the accuracy of cell phone sensors still requires further investigation. To reduce participant burden, voice recording or preselected options could be used instead of manual data entry.
2. Wireless transmission of data

WIMU-GPS encountered the following issues: spurious signal drops, accidental shut down of the unit by user, and battery loss. Data storage loss occurred in three participants for a portion of the study when two separate data storage microSD cards became corrupted before data were retrieved, and one card was accidentally displaced during data collection. Real-time wireless transmission of data may have prevented these sources of data loss. Concerns about tracking-related privacy violations may be alleviated by educating participants about data security protocols and avoiding real-time monitoring ⁽⁸⁴⁾.

3. Recalibration of origin locations

Overestimation of life space areas may have produced the extremely large life space areas observed in Chapter 7. Like other GPS sensors, the WIMU-GPS cannot automatically change the reference trip start location (e.g., participants' homes) without manual calibration^{78,85}. Typically, calibration for origin locations requires turning off the WIMU-GPS and restarting the satellite "zeroing" process¹⁸. This is a problem if participants stayed at a location outside of their home community overnight. During the following day, the WIMU-GPS will continue to record *life space size* relative to the last calibrated home origin, and not based on their new home location.

The procedure to start or turn off the WIMU-GPS was not intuitive and manual calibration by participants would likely increase burden. Improvements to sensor technology could include daily auto-calibration of new origin locations. Nevertheless, daily *distance* was likely unaffected as it was based on absolute kilometers travelled per day, not relative to any fixed origin.

4. Error detection

Quality assurance procedures were done by manually checking preprocessed outputs for signs of low battery and signal losses. This was time consuming, and issues may not be detected until it is too late to remedy. Further, visual inspection of data completeness may be inaccurate. Machine learning may allow the automatic detection of data quality issues and feedback to users, and simplify the processing of 'big data' from sensors. For instance, machine learning algorithms were previously employed to separate PD subgroups based on mobility sensor data ⁸⁶.

166

8.2 Implications of Findings: Recommendations for measuring community mobility

Previous guideline for studies using mobility assessments to study CM in the real-life setting were not available. To address this gap, recommendations were proposed based on field notes and project results, and should be weighed against feasibility considerations (e.g., cost and time). Many of the following recommendations are not exclusive to a PD population or the assessments used in this project. They may be modified and applied to study CM in other older adult populations or populations with a higher risk of mobility disability.

8.2.1 Study design:

Chapter 7 showed that CM outcomes were differentially associated with each other. CM studies should account for multiple outcomes in order to sufficiently capture the multidimensional nature of the CM construct^{44,45}. The selection of the outcomes should be based on the research objectives. Studies should take place over at least one week to capture any habitual fluctuations. Single day studies and studies using cross-sectional assessments should be limited to studies of changes from baseline, and avoided for descriptive or analytic studies.

CM assessments and study protocols should be tested for compliance and feasibility issues in a pilot test. This is especially important if a similar protocol has not been used in the same population before. Sample size calculations should be based on pilot test results, and account for attrition and data loss based on published literature using the same or similar assessments. Subsequent studies of CM also should consider participants' setting types (e.g., in town versus outside of town) by including assessments of built environment factors, such as walkability ^{61,62,87}, proximity to services and transportation accessibility ^{20, 61}, as well as weather and seasonal effects^{30, 88,89}.

8.2.2 Instrument selection:

Endorsement of one assessment over another was not a main aim of this project. The choice of assessment can confer an advantage over others, depending on the context. The strengths and weaknesses of the LSA, diary and WIMU-GPS observed through this project are summarized in Table 8.1. Selection should suit study outcome(s) of interest, while considering the length of study timeframe, data quality and the employment status of the population of interest.

167

Table 8.1. A summary of the strengths and weaknesses of the Life Space Assessment, daily diary and WIMU-GPS for use in older adults.

	Outcome (s)	Recording time frame	Strengths	Weaknesses
Life Space Assessment ¹⁹	Maximal life space level and independence of mobility (0-5) Composite life space score (including frequency, duration and independence of mobility; LS-C score, 1-120)	Monthly (over past four weeks) Recorded retrospectively	 Low cost Low time commitment Low participant burden Best used to detect changes over time in the same individual Captures assistance required Available in many languages 	 Cannot easily detect duration and frequency differences Ceiling effect for travel outside town Cross sectional Scores could be heavily influenced by non- habitual long-distance trips Cannot compare travel "outside of town" Limited inter-individual discriminatory ability Mean group scores may be biased Restriction based on same geographical area is needed (bias towards respondents in small towns) Face validity issues needs investigating Prone to recall bias and social desirability issues Require manual data entry Cannot detect daily and weekly variations No information about trip mode Retrospective recording Complex composite scoring method may lead to data creation
Daily diary ⁹⁰	Trip level and daily duration, frequency, destinations	Minutes to Daily Recorded daily	 Low cost Long duration recording Captures trip duration, frequency and destination visited Easy to detect and impute obvious missing data Easy to record new origin locations (no need for calibration) 	 Higher time commitment Higher participant burden than LSA and WIMU-GPS Difficult for people with cognitive or mobility challenges Prone to recall bias and social desirability issues Manual data entry and cleaning is time consuming Accuracy of recalling time of travel may be an issue and difficult to detect inaccuracies in reported records Inconsistent reporting of destination, requiring interpretation by researchers Real-time data collection is hard to enforce, and timing of diary completion may vary between participants

	Outcome (s)	Recording	Strengths	Weaknesses
		time frame		
WIMU-GPS ¹⁸	Trip and daily duration, frequency, distance travelled, mode of transportation, hotspots frequency, life space area size	Seconds ^α Recorded prospectively in real-time	 Less intrusive and passive Low to medium burden of use Higher resolution to capture individual variations Useful for people with motor or cognitive challenges^{10, 81} Simultaneously captures trip duration, frequency, and additional CM outcomes not feasible through self report Provide exact timestamps for CM performed Simple manual data transfer (no manual entry) Low researcher interpretation required Could track geographic location coordinates of destinations No recall bias No ceiling effect Report of missing data available Data loss is lower than many other GPS reported (17.4%) Availability of pre-processed data Could be reliably used instead of diaries for trip frequency 	 Battery issues Signal dropout, particularly within buildings Cannot correct for or auto-detect missing data Recordings on participants who lived with someone or are married may yield less data than participants who lived alone or are not married Time consuming data pre-processing and processing steps Equipment and data processing steps often require troubleshooting and monitoring Recorded time is typically less than wear time (common to GPS sensors) Cannot evaluate assistance needed for mobility Compliance may be affected by employment or volunteering status

 $^{\alpha}$ Position data is recorded per second and can be auto aggregated to provide hourly or daily outcomes.

8.2.3 Data collection:

Multi-day CM studies using GPS sensors should aim to record eight consecutive days of data collection. This is to ensure that data captured from every day of the week only reflects routine mobility, and any study related activities. Chapter 6 indicated that WIMU-GPS recordings used for analyses should be at least 10 hours (600 minutes) long, especially for *time outside* and *area size*. To account for shorter than anticipated recording time¹⁰, and especially by those who were married or cohabiting, participants should be asked to wear the WIMU-GPS for 10.5 or 11 hours per day for *time outside* and *area size*. However, 10 hours of recording may be sufficient for *trip count* and *hotspot count*, as these were more resistant to errors due to short sample length.

CM studies should aim to use GPS models that have been systematically compared to other community mobility assessments. During data collection, the importance of protocol adherence and data completeness should be explained to participants in plain language⁷⁴. Efforts should be taken to ensure spare sensors are available at all times in case of equipment failure and malfunctioning. At least one check-in with participants is needed during the first few days of data collection to troubleshoot issues and address concerns about study protocol.

8.3 Additional study limitations

Beyond the limitations noted in each chapter and already mentioned in this chapter, some additional limitations in the studies were noted.

In Chapter 5, discrepancies in WIMU-GPS and diary data may be better appreciated if trip-level matching was used¹⁷. A larger sample size in Chapter 6 would allow more sampling subgroups and optimal number of sampled days to be evaluated.

Due to the complexity and time required for data processing and analysis, some of the WIMU-GPS outcomes used in Chapter 7 were not compared against the diary. The lack of a gold standard community mobility measure hampered the ability to determine errors in the assessments used. Due to this, it was important to study agreement among existing assessments, and use a multi-instrument approach to capture CM. Strict inclusion and exclusion criteria were used to recruit the participants, so the exploratory CM outcomes described in Chapter 7 were not intended to be generalizable to all individual PwP or older adult populations. CM changes in older adults have been documented. Since a longitudinal study was not conducted and pre-PD CM data was unavailable, PD's effects on observed CM patterns remain unknown^{63, 91}.

Finding and recruiting PwPs who fit the strict inclusion and exclusion criteria was difficult, so many covariate subgroups were unbalanced. This may have masked true covariate effects and distort relationships. As well, the studies in Chapters 5-7 were not large enough to account for confounding or interactions between two or more covariates. Thus, the potentially important differences in time recorded and agreement between WIMU-GPS and diary due to marital, living or retirement status should be re-examined in a future study with more participants.

8.4 Additional study strengths

This is one of the first projects to study CM in a PD population using both objective and selfreport measures. The individual studies discussed here were strengthened through a pilot test in a PD population, which minimized issues related to compliance and participant burden.

During data collection, quality and compliance were strengthened by breaking down the data collection to 3 home visits, and providing follow up phone calls with reminder slips. Rater bias was minimized with data collected by the same trained researcher.

The number of covariates assessed in Chapter 2 and 4 were selected to reflect the multidimensional model of CM⁴⁴. As well, non-PD related influences on mobility, such as chronic pain, cold weather, and use of mobility assistive devices were controlled as these factors can affect where and how far individuals went, what method they used to travel and how long they were away from home. In this project, the inclusion of participants who represent the diverse real-life geographic setting of patients from the London Health Sciences Center catchment area strengthened the ability to interpret the observed CM patterns. WIMU-GPS provides a comprehensive approach to capture multiple common and novel CM outcomes using one device. GPS models have sometimes been adopted as a standard, in absence of a consensual gold standard⁴. Since this practice may be premature⁵, this project was conducted without assuming any CM instrument to be the standard. This project completed one of the longest real-life GPS recordings on a clinical population. This provided opportunities to evaluate the ability of different CM instruments and recording lengths to capture mobility variations, and explore simple associations.

Chapter 6 showed mean trip count changes in an individual depending on how many minutes were included. Comparison studies do not always account for differences in recording length, so it is possible that any mean difference between two comparative groups could be due to differences in available observation time. Therefore, efforts to standardize the sampling time in Chapter 5 may improve the accuracy of the validity, reliability and agreement results reported.

8.5 Future directions

Since the inception of the work summarized here, many more wearable devices with GPS capabilities are now available, and are becoming more affordable and functional for public use^{14, 56,74,83,92,93,94}. Research that systematically assesses the accuracy, precision, validity and reliability of the sensors is needed before recommendations can be made for clinical, research or consumer use. As well, additional comparisons should be carried out using the WIMU-GPS, diary and other mobility assessment methods in other clinical populations.

A reporting guideline for studies comparing multiple assessment measures should be developed based on the literature gaps identified in Chapter 4, Chapter 5 and existing inter-rater and intrarater reliabilities reporting guidelines^{95,96}. Further study are needed to determine the optimal number of days for GPS recording, and to check if the proposed minimum daily recording minutes minimizes error in a larger sample.

Participants in the studies described reported receiving a high degree of social support. Informal caregivers such as spouses, family members and friends may help each other with mobility performance, and may also affect each other's study performance⁹⁷ (e.g., helping with diary

172

reporting, affecting the length of GPS recordings). Previous literature has shown older spousal partners to have similar levels of social activities⁹⁸. After retirement, partners may spend more time together, and can influence each other's performance of physical activity and domestic chores⁹⁹. Some PD studies also use spouses as a control due to their similar lifestyles and environmental exposures¹⁰⁰. Future studies can compare the recorded and self-reported travel patterns of spouses to determine the interdependence of spousal partners on mobility and study performance.

A qualitative study to describe the impact of PD on CM can be helpful to understand how different signs and symptoms affect different dimensions of CM. Studies are also needed to find the associations between CM outcomes and PD severity and symptom subtypes (e.g., akinetic rigid, tremor dominant or mixed⁶⁹). Effects of PD progression on CM could be assessed by repeating the study protocol from Chapter 7 on the same individuals in the future. These types of studies can help care providers anticipate CM declines, and plan supportive or management strategies according to patients' goals.

In older adults, the capacity to be mobile does not always equal performance of mobility⁸³. As well, performance of mobility may not always suggest the same degree of capacity, health and wellbeing. A person living in a service and resource-dense community may have smaller CM, or reduced life-space mobility, compared to people in a remote area. People who travel to medical establishments may be in worse health than people with a similar number of trips to recreational facilities. Additional covariates for future studies should include the intention and value placed on destinations visited.

8.6. Conclusions

Helping older adults with PD maintain their CM is an important clinical objective. It requires a measurement that can capture the natural fluctuations in a range of CM outcomes, while minimizing error, bias and cost. Wearable GPS technologies are promising new assessment tools for this purpose. This project showed the WIMU-GPS sensor to be a valid, reliable and feasible assessment of the real-life CM in PwP over a long duration. Unlike the LSA, it was sensitive to differences, free of ceiling effects and can minimize recall bias. It also lacked the heavy participant burden of the diary.

Overall, this dissertation described one of the most comprehensive community mobility measurement project completed in any population. It provided an important contribution to the literature by compiling a list of practical recommendations that could be used to standardize and strengthen the design and results of future CM studies. It also added much needed information about how long GPS recordings should be to minimize error and participant burden, as well as novel exploratory data about the free-living mobility of older adults at risk of mobility disability due to a neurodegenerative disorder. It also is one of the first to assess the validity and reliability of the LSA against other measures of *life spaces* and actual geographic sizes. Finally, in the absence of a gold standard CM measure, a summary of the strengths and weaknesses of the WIMU-GPS, LSA and diary was synthesized to guide individuals interested in studying CM.

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Appendix

Table A8.1 Average community mobility variable measured by the WIMU-GPS and daily diaries each day (n=50). All outcomes were significantly different between the WIMU-GPS and diary ($p \le 0.05$).

Mean daily mobility outcomes	WIMU-GPS (Mean ± SD [range])	Diary	Difference (p and 95% CI)	
Time outside (minutes) (hours)	184.37 ± 88.6 (60.65 to 646.70) 3.07 ± 1.48 (1.01 to 10.78)	261.5 ±151.8 (65 to 684.5) 4.4 ± 2.5 (1.1 to 11.4)	<i>p</i> = 0.046 CI: (1.17, 2.33)	
Trip count	$1.49 \pm 0.75 \ (0 \text{ to } 4)$	3.4 ± 4.3 (0.8 to 11.8)	<i>p</i> < 0.05 CI: (-2.74, -1.46)	
Location count ^a	4.73 ± 1.82 (2 to 11)	2.1 ± 2.0 (0.5 to 8)	<i>p</i> < 0.05 CI: (1.24, 2.58)	
Distance to hotspots (km)	9.27 ± 7.91 (1 to 46)	N/A	N/A	
Distance by vehicle (km)	28.81 ± 22.40 (4 to 131)	N/A	N/A	
Distance on foot (km)	0.87 ± 1.37 (0 to 7.0)	N/A	N/A	
Life space size (km ²)	343.78 ± 533.25 (1 to 2491.0)	N/A	N/A	

"Location count" refers to "hotspot counts" for WIMU-GPS and "destinations count" for diary.

Appendices

Researc V	Vestern	Use of Human Participants - Ethics	Approval Notice							
	Principal Investigator:Dr. Mark Speechley Review Number: 18833 Review Level:Full Board Approved Local Adult Participants:100 Approved Local Minor Participants:0 Protocol Title:Mobility of Patients with Parkinson's Disease Department & Institution:Schulich School of Medicine and Dentistry\Epidemiology & Biostatistics,Western University Sponsor:Canadian Institutes of Health Research									
	Ethics Approval Date:April 17, Ethics Expiry Date:December 3	2012 31, 2013								
	Documents Reviewed & Appro	oved & Documents Received for Information	on:							
	Document Name	Comments	Version Date							
	Vestern University Protocol	(Including Instruments noted in section 6.1)								
	Letter of Information & Consent	Community Mability Study								
	Letter of Information & Consent	Community Mobility Study - Patients								
	Letter of monnation & consent	Community Mobility Study - Spouses								
	Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this HSREB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations. The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request form.									
	Member of the HSREB that are r discussions related to, nor vote of	named as investigators in research studies, o on, such studies when they are presented to	or declare a conflict of interest, do not participate in the HSREB.							
	The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.									
	Signature									
		Ethics Officer to Contact for Furth	er Information							
	Janice Sutherland	Grace Kelly	Shantel Walcott							
	This is an official document. Please retain the original in your files.									
	The University of Western Ontario									
	Conce of Research Ethics									
	Support Servi	ces building Room 5150 • London,	Untario • CANADA - NoG IG9							
1	PH: 519-661-3036 • F: 519-850-2466 • ethics@uwo.ca • www.uwo.ca/research/ethics									

Appendix A: University of Western Ontario Ethics Approval

Appendix B: Lawson Health Research Institute Ethics Approval

LAWSON HEALTH RESEARCH INSTITUTE

FINAL APPROVAL NOTICE

RESEARCH OFFICE REVIEW NO .: R-12-144

PROJECT TITLE: Mobility of Patients with Parkinson's Disease

PRINCIPAL INVESTIGATOR:	Dr. Mark Speechley
DATE OF REVIEW BY CRIC:	April 20, 2012
Health Sciences REB#:	18833

Please be advised that the above project was reviewed by the Clinical Research Impact Committee and the project:

Was Approved

PLEASE INFORM THE APPROPRIATE NURSING UNITS, LABORATORIES, ETC. BEFORE STARTING THIS PROTOCOL. THE RESEARCH OFFICE NUMBER MUST BE USED WHEN COMMUNICATING WITH THESE AREAS.

Dr. David Hill V.P. Research Lawson Health Research Institute

All future correspondence concerning this study should include the Research Office Review Number and should be directed to Sherry Paiya, CRIC Liaison, LHSC, Rm. C210, Nurses Residence, South Street Hospital.

cc: Administration

Appendix C: Letter of Information

Movement Disorders Program



339 Windermere Rd, A10-026 London, Ontario, Canada N6A 5A5 http:\\mdc.lhsc.on.ca

Letter of Information

Study Title: Community Mobility in Patients with Parkinson's Disease

Principal investigator: Dr. Mark Speechley, Dept. of Epidemiology and Biostatistics, University of Western Ontario

Co-investigator: Dr. Mandar Jog, Movement Disorders Clinic, London Health Sciences Centre; Dr. Christian Duval, Dept. of Kinanthropology, University of Quebec at Montreal

Introduction

We are asking you to voluntarily participate in a research project examining the challenges of community mobility in people with Parkinson disease. Prior to participating in this project, please take the time to read the following information. The present document may contain words or phrases that may be difficult to understand. Do not hesitate to ask questions or to ask for more detailed explanations if certain elements are unclear to you.

Nature of the research project and tasks involved

The goal of this study is to provide a new perspective on mobility challenges facing aging individuals and those with Parkinson disease when navigating in their natural environment, such as your community. This study will involve 70 patients diagnosed with Parkinson disease. (This study is a part of a larger project in which 210 older adults, with and without Parkinson disease, will take part). Your participation in this study will occur around your community. Three visits to your home by the research team will be necessary.

The first visit should last approximately 2 hours and will consist of the following evaluations: We will assess your fitness with a questionnaire, measure your height and weight and determine your amount of body fat using a scale commonly used in gyms, and fill out some other questionnaires. You

1 of 4 Participant Initial _____

Study Title: Community Mobility in Patients with Parkinson's Disease

will be asked to wear a global positioning system (GPS) across your chest for 14 days, from the moment you wake up in the morning to the time you go to bed at night. The GPS will record your displacement around your home and within your community. Each night you or your caregiver will have to recharge the device as you would for a cellular phone by plugging a cable from the device to an electrical outlet. During the 14 days you will also be asked to wear an armband, during all the waking and sleeping hours, that will measure your energy expenditure. You will also be asked to maintain a journal of different events (what time you took you medication, what time you went out of your home, what time you went to sleep or took naps).

The second visit will occur approximately 7 days (1 week) after the first visit. It will take place in your home. The researcher will check to see if the equipment is working and will confirm the third and last visit.

The third visit will occur approximately 7 days (1 week) after the second visit. You will be asked to return all of the equipment given to you, as well as the diary, and complete two questionnaires about your activities. It will take appropriately 1 hour.

Benefits, risks and inconveniences

You will not benefit directly from participation in this study. However, the results may contribute to our understanding of how Parkinson disease affects individuals.

There are no known risks associated with the type of equipment used in the present study. The only inconvenience you may encounter is some fatigue after the experiment. However, wearing the armband and GPS might be somewhat uncomfortable on days with higher temperatures. For this reason, we have decided that testing will be postponed if temperature is above 30°C.

Withdrawal from the study by the researcher

Dr. Jog or the researcher may decide to take you off the study if either of them feels your continued participation would impair your wellbeing.

Monetary compensation

You will receive an amount of \$100 for your participation in all three visits of this study. This compensation is to reimburse you for the time and inconvenience associated with participating in the study. If you withdraw voluntarily or are asked to withdraw, you will receive a prorated compensation proportional to your participation.

2 of 4

Participant Initial _____

Study Title: Community Mobility in Patients with Parkinson's Disease

Confidentiality

In order to preserve your confidentiality, only the researchers in the study, namely Drs. Mandar Jog, Christian Duval, Mark Speechley and Patrick Boissy, and graduate students involved in data collection, will have access to your research information. This will include personal information such as your name, address, age, gender, handedness, daily medication, and participant number. AT NO TIME will your name be used in scientific presentations or publications. The recordings done with either instrument will not reveal your identity in any way. The GPS sensor records position data. This information will only be used to evaluate your mobility in and around your home. AT NO TIME will these data be used in other studies without your written consent. These records will be kept for a minimum of 7 years and, if discarded, will be disposed of in a proper fashion afterwards such that your personal information and any document allowing your identification is shredded or deleted. Recorded data will only be identified using your participant number. Your personal information will not be transported off-site, only the participant code you have been assigned and your performance data will be taken to Université du Québec à Montréal for analysis by Dr. Duval. Note that when the data is taken off-site, it can no longer be withdrawn from the study. All personal information and the master list linking participant code to participant name will remain in a secure facility accessible only to Dr. Jog. Representatives of The University of Western Ontario Health **Sciences Research Ethics**

Board may contact you or require access to your study-related records to monitor the conduct of the research.

Voluntary participation and freedom of removing oneself from the study

Participation in this study is voluntary. You may refuse to participate, refuse to answer any question or withdraw from the study at any time with no effect on your future care.

<u>Liability</u>

You will not be held liable in case of damage to the GPS or the Armband unless negligence is observed.

3 of 4

Participant Initial _____

Study Title: Community Mobility in Patients with Parkinson's Disease

Persons to contact with questions

For more information about this research project, you may call Lynn Zhu (graduate student) at <u>XXX-XXXX</u>. You may also wish to email her at <u>XX@schulich.uwo.ca.</u>

If you believe that you may have a research related injury or experience any side effect as a result of participating in this study, you may call Dr. Mandar Jog at <u>XXX-XXX-XXXX</u>.

If you have questions about the conduct of the study or your rights as a research participant, you may call Dr. David Hill, Scientific Director, Lawson Health Research Institute at <u>XXX-XXXX-XXXX</u>.

You do not waive any legal rights by signing the consent form. You will receive a copy of the letter of information and consent form for your records.

4 of 4

Participant Initial

Appendix D: Participant Consent Form

Study Title:

Community Mobility in Patients with Parkinson's Disease

I have read the letter of information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Signature of research participant	Printed name	Date

Signature of investigator/person obtaining consent Printed name Date

Appendix E: Instructions for Participants

Dear Sir/Madam,

The study which you are going to participate in is funded by the Canadian Institute of Health Research. The objective of this study is to evaluate the mobility in the community of individuals with Parkinson disease. The consent form you have signed provides more information about the objectives of this study.

This document reminds you of the instructions that have already been given to you during the first visit made to your home by the researcher. Information about wearing the two measuring devices, the GPS (Global Positioning System) and Armband, are included below. The duration of the experiment is 14 days and you have to wear both devices daily (please wear the Armband even during sleep).

The second meeting will take place in your home 7 days after the start of the experiment. The researcher will pick up the measuring devices (the Armband and GPS), the GPS charger and the two cardboard reminders, and will be asking you to perform a few physical ability tests. Make sure to wear comfortable clothing for the physical ability tests. This visit will take approximately one hour.

GPS



The GPS is a geolocalisation device. The data will enable us to calculate your sphere of mobility, which is also known as your *life space*. This refers to the area which encompasses all of your daily travels outside of your home during the duration of the experiment. For example, if you live in Montreal, your life space could be represented by a circle on the map of the city. The edges will defined by the distance of each of your travels. It is therefore essential for us that you attentively wear the GPS carefully at all times.

How to wear the GPS?

It must be worn with its harness around your sternum, below the chest. It should be adjusted

so that it stays comfortably in place.

How to charge the GPS?

For the GPS to function normally, it is very important for you to charge it every night. You have to plug the black charger directly into an electrical outlet and the other end into the GPS. While it charges, we recommend that you put it into a place where it will not be damaged in any way (for example, due to shock, water...). <u>Charging the GPS will take about 8 hours</u>.

When charging, lights on the side of the GPS (blue, red, green and maybe orange) will be on. When it is done charging, please wait until a blinking orange light comes on before you take the GPS outside of your home. If it does not come on after 10 to 15 minutes, please contact the researcher at any time of the day or night (but please don't be alarmed, these things happen!).





Reminders

To help you remember to charge the GPS, place the reminder on your bedside table. When you wake, put on your GPS. Wear it throughout the day, and remove it before you go to bed. Throughout the duration of this study, carry on your daily tasks as you normally would. Avoid touching the red and green buttons on the case.

Armband

The armband measures your energy expenditure. To produce a representation of your daily energy expenditure, we require you to wear the armband according to the following instructions.

How to wear the armband?

Like the GPS, the armband will not tolerate water. It is therefore crucial that you remove it when you take your bath/shower. Moments when the armband could be in contact with water

are the **only** times when you should take it off. For example, if you go to the beach or if you plan to swim, be sure to remove your armband and your GPS. Also avoid contact with sand. Always remember to put it back on afterwards!

The armband must be worn on your **right arm**. Make sure that your arm is clean, dry and free of traces of lotion or cream. The cuff is worn on the back of the right arm (on the triceps). To ensure proper function, **the logo of the armband should be turned upwards, towards the shoulder, and the silver sensors located on the inside should make contact with the skin.** Adjust the strap so that the cuff fits comfortably, and secure the Velcro flap. Make sure that the sensors on the inside of the cuff are in constant contact with the skin and that the armband does not slip off your arm. The



strap should not be too tight. We should be able to pass two fingers between the strap of the armband and your arm. When it is in contact with the skin, the armband will vibrate when it is activated and emit a beeping sound. The same vibration will occur when it is taken off (this means that the armband is off; to "turn" it back on, just put it on the arm again). Sometimes it does not start instantaneously and will require you to wait for a few minutes for it to start.

Armband maintenance

In the unlikely event that you need to clean your armband, please perform the following steps: gently wipe the face of the cuff that comes in to contact with the skin with a soft cloth or towel moistened with water and mild soap. Wipe with a soft clamp cloth to remove excess soap. Use a towel or a soft, dry cloth to clean the equipment completely before wearing again.

Reminder

As explained above, it is crucial to remove the armband and the GPS during your bath/shower or during other times when they might be in contact with water and sand as this will irreversibly damage the measuring devices. Please remember that both devices are expensive and valuable for collecting data. It is also important to put the armband back on after your bath/shower. That is why we have provided you with two other reminders. One is specifically designed to hang on the door of your bathroom. The other is to hang on the door inside your home. It will remind you to always carry your GPS and your armband when leaving the house. The researchers thought this would be helpful as we, ourselves, are sometimes distracted when leaving the home.

Please also remember to complete the Travel Diary, as this allows us to verify the GPS data.

NE PAS SE BAIGNER AVEC LE ARMBAND ET LE GPS



Contact

For questions, in case of problems, please contact the researcher (Lynn Zhu) by phone or email.

Thank you very much for participating!

Appendix F : Overview of WIMU-GPS troubleshooting instructions

- 1. Wear during waking hours only.
- 2. Do not expose to water.
- 3. Leave it **ON** at all times.
- 4. Do not press any buttons.
- 5. Charge unit every night.



When charging:

1. Plug one end of charger into the GPS and the other directly into the outlet.

2. When charging, red and blue lights will turn on. An orange or green light will flash periodically to indicate that the GPS is still on.





Take home message:

GPS is normal if:

- orange light flashes every second <u>or</u>
- when charging: blue and red light is on *with* flashing orange or green light

If no flashing orange light:

- Put the GPS outside for about 10 minutes.
- Put the GPS on charge (if a yellow light is slowly flashing) for a couple of hours.
- Call Lynn at any time if the issue is not resolved!

Appendix G: Life Space Assessment (p.1/2)

Living environment: _____

City: _____

Life Space Assessment

LSA Guidelines: Next questions will be about displacement habits in different environment.

First of all, I'd like to know if you use any of these technical aids (check items that apply) □Cane □Crutches □Walker □Folding walker □Manual wheelchair □Motorised wheelchair □Three wheel scooter, four wheel scooter □Lift chair/lift cushion □Ramp □Orthesis □Prothesis □Grab bar (eg., bathroom, bath, shower) ⊓Bath seat □Shower without threshold □Commode chair or raised toilet seat □Hospital Bed □Bowl □Fan □Oxygen / Respiratory Assist Device (eg., inhaler, spray) □Others

(Proceed with the following questions)

Next questions con	A. During the last 4 weeks,			How did you get there?								
only your last month activity			how many times have you			B. Did you use			C. Did you need			
Since the last 4 we	been?			technical assistance			help from another					
you been				or equipment to			perso	person to get?				
						get?						
	Yes	No	Less than 1 time a week	1 to 3 times a week	4 to 6 times a week	Every day	Yes	No	Don't know or preferred not to answer	Yes	No	Don't know or preferred not to answer
In your residence, in another room besides the room where you sleep?	0	0	0	0	0	0	0	0	0	0	0	0
LIFE SPACE I	(LS	51)	(LS1F)			(LS1A)			(LS1H)			
Around your residence, your porch, deck or patio, hallway (of an apartment building), or garage, in your yard, court's entrance? LIFE SPACE 2	0	0	0	0	0	0	0	0	0	0	0	0
	(LS	52)		(LS	52F)			(LS	2A)		(LS	2H)
In your neighbourhood, other than your own yard or apartment building?	0	0	0	0	0	0	0	0	0	0	0	Ο
LIFE SPACE 3	(LS	53)	3) (LS3F)			(LS3A)		(LS3H)				
In your town, outside your neighbourhood? LIFE SPACE 4	0	0	0	0	0	0	0	0	0	0	0	0
	(LS	54)	(LS4F)			(LS4A)			(LS4H)			
Outside your town?	0	0	0	0	0	0	0	0	0	0	0	0
LIFE SPACE 5	(LS	\$5)	1	(LS	55F)		1	(LS	5A)	1	(LS	5H)

Appendix H: Daily Displacement Diary

The purpose of this diary is to record your movements during each day for the duration of the experiment. In this diary, we are interested in your activities and movements after leaving the home beyond your apartment / house, venturing past your garden / courtyard / terrace / balcony. For example, an entry could be about going to work, to run errands in a shopping center, going to a sports club, going out to eat, etc.

Each day's activities should be separately recorded. Be sure to list your daily activities outside your home using the following guidelines:

1) Please indicate if you are out of your home by checking the appropriate box. If yes, indicate the time of departure and time of final return to your home. If you checked the 'no' box, there is no need to write other details.

2) If you left your home, please list your every movement in the table as follows :

- In column A, please circle the time and note the approximate time and minutes at the start of your trip.

- In column B, please note where you began the trip (e.g., home, work, the mall, etc.)

- In column C, enter the destination of your trip.

- In column D, circle the time and note the approximate minutes at the end of your trip.

3) An extra day of entry is provided for you at the end of the diary should you need it.
EXAMPLE :

Date :17/02/2011

Did you leave your house today? YES

- NO O
- 1) If YES, at what time?: <u>8 hours : 00 minutes</u>. Then, what time did you return to your home at the end of the day? : <u>22 hours : <u>32 minutes (10 : 32pm)</u>.</u>
- 2) Please record your travels in the following table:

A.You	r trip	B.You were at (the starting	C.You were going to (the	D.You	r trip
began a	at :	point of travel):	destination of travel):	ended a	at:
Hour	Min			Hour	Min
1 am				1	
1 am				1	
2 am				2	
2 am				2	
3 am				3	
3 am				3	
4 am				4	
4 am				4	
5 am				5	
5 am				5	
6 am				6	
6 am				6	
7 am				7	
7 am				7	
(8 am)	00	Home	Work	8	25
8 am				8	
9 am				9	
9 am				9	
10 am				10	
10 am				10	
11 am				11	

11 am]	11	
12nm				12	
12pm				12 12nm	
12pm				12pm	
1 pm				Ipm	
1 pm				1pm	
2 pm				2pm	
2 pm				2pm	
3 pm				3pm	
3 pm				3pm	
4 pm		Work	Gym	4pm	30
4 pm				4pm	
5 pm				5pm	
5 pm				5pm	
6 pm	10	Gym	Mall	6pm	10
6 pm	45	Mall	Home	6pm	
7 pm				7pm	5
7 pm				7pm	
8 pm				8pm	
8 pm				8pm	
9 pm	30	Home	Neighbour's (9pm	32
9 pm				9pm	
10pm	30	Neighbour's	Home (10pm	32
10pm				10pm	
11pm				11pm	
11pm				11pm	
12am				12am	
12am				12am	

Age: Sex: F / M					
Family	Marital status:				
	Number of children:				
	Number of grand children:				
	Does the participant have a dog? Yes No				
Disease History	Age of diagnosis :				
Housing	Number of stairs:				
	Does the participant have an elevator?				
CV	Profession:				
	Age of retirement :				
	Education:				
	Annual income:				
Smoker? Yes No	How many cigarettes/day?				
Watch TV? Yes No	How many hours/day ?				
Use a computer ? Yes No	How many hours/day ?				
On a diet? Yes No	What kind ?				
Own a car? Yes No	Do you drive? Yes No				
Waist circumference					
Hip circumference					
Grip strength	RH 1 : LH1 : RH 2 : LH4 : RH 3 : LH3 :				

Appendix I: General Demographics Questionnaire

Appendix J: Comorbidity Index

Have you ever been affected by or has your doctor ever told you that you were diagnosed with one or more of the following conditions? Please place a checkmark in the appropriate case.

		Yes	No
1	Arthritis (rheumatoid and/or osteoarthritis)		
2	Osteoporosis		
3	Asthma		
4	Chronic obstructive pulmonary disease (COPD), acute respiratory distress syndrome (ARDA) or emphysema.		
5	Angina (heart related chest pain)		
6	Congestive heart failure (or heart disease)		
7	Myocardial infarction		
8	Neurological disorder (e.g., Multiple sclerosis or Parkinson)		
9	Stroke or cerebral ischemia		
10	Peripheral vascular disorder (or claudication/limping)		
11	Diabetes		
12	Gastrointestinal disorder (hernia, ulcer, reflux, severe heartburn necessitating medication)		
13	Depression		
14	Anxiety or panic attack		
15	Visual trouble (glaucoma, cataracts, macular degeneration)		
16	Hearing impairment (Major difficulties with hearing despite hearing aids)		
17	Disc degeneration (spinal stenosis, chronic back pain)		
18	High or Low Blood Pressure		
19	High or Low Heart Rate		
20	High Cholesterol		



Appendix K: Montreal Cognitive Assessment

Appendix L: MOS Social Support Survey (p.1/2)

MOS Social Support Survey

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Circle one number on each line.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Emotional/informational support					
Someone you can count on to listen to you when you need to talk	1	2	3	4	5
Someone to give you information to help you understand a situation	1	2	3	4	5
Someone to give you good advice about a crisis	1	2	3	4	5
Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
Some whose advice you really want	1	2	3	4	5
Someone to share your most private worries and fears with	1	2	3	4	5
Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
Someone who understands your problems	1	2	3	4	5
Tangible support					
Someone to help you if you were confined to bed	1	2	3	4	5
Someone to take you to the doctor if you needed it	1	2	3	4	5
Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5
Someone to help with daily chores if you were sick	1	2	3	4	5
Affectionate support					
Someone who shows you love and affection	1	2	3	4	5
Someone to love and make you feel wanted	1	2	3	4	5
Someone who hugs you	1	2	3	4	5

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Positive social interaction					
Someone to have a good time with	1	2	3	4	5
Someone to get together with for relaxation	1	2	3	4	5
Someone to do something enjoyable with	1	2	3	4	5
Additional item					
Someone to do things with to help you get your mind off things	1	2	3	4	5

MOS Social Support Survey (p.2/2)

Appendix M. SF-12 Health Survey (p.1/3)

SF-12® Patient Questionnaire

-				Page 1 of 3
Patient Initials	Date of Birth:	/	_/	Patkey:
Surgeon Name:				Date:
Examination Period:	Preop (1) Immediate Postop (2) 1 Year (3)		3 Year (4) 5 Year (5) Other (specify) (6)	:

SF-12®:

This information will help your doctors keep track of how you feel and how well you are able to do your usual activities. Answer every question by placing a check mark on the line in front of the appropriate answer. It is not specific for arthritis. If you are unsure about how to answer a question, please give the best answer you can and make a written comment beside your answer.

1. In general, would you say your health is:

 Excellent (1)
Very Good (2)
Good (3)
 Fair (4)
 Poor (5)

The following two questions are about activities you might do during a typical day. Does YOUR HEALTH NOW LIMIT YOU in these activities? If so, how much?

2. MODERATE ACTIVITIES, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf:

____ Yes, Limited A Lot (1)

- Yes, Limited A Little (2) No, Not Limited At All (3)
- 3. Climbing SEVERAL flights of stairs:
 - Yes, Limited A Lot (1)

 - Yes, Limited A Little (2) No, Not Limited At All (3)

During the PAST 4 WEEKS have you had any of the following problems with your work or other regular activities AS A RESULT OF YOUR PHYSICAL HEALTH?

4. ACCOMPLISHED LESS than you would like:

5. Were limited in the KIND of work or other activities:

Surgeon Initials _____ Date: _____

SF-12 Health Survey (p.2/3)

SF-12®				Page 2 of 3
Patient Initials	Date of Birth:	1		Patkey:
Surgeon Name:				Date:
Examination Period:	Preop (1) Immediate Postop (2) 1 Year (3)		3 Year (4) 5 Year (5) Other (specify) (6)	:

SF-12® Cont'd:

During the PAST 4 WEEKS, were you limited in the kind of work you do or other regular activities AS A RESULT OF ANY EMOTIONAL PROBLEMS (such as feeling depressed or anxious)?

6. ACCOMPLISHED LESS than you would like:

_____ Yes (1) _____ No (2)

7. Didn't do work or other activities as CAREFULLY as usual:

During the PAST 4 WEEKS, how much did PAIN interfere with your normal work (including both work outside the home and housework)?

 Not At All (1)
A Little Bit (2
Moderately (3)
O 1 1 D 1 1

____ Quite A Bit (4)

Extremely (5)

The next three questions are about how you feel and how things have been DURING THE PAST 4 WEEKS. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the PAST 4 WEEKS -

- 9. Have you felt calm and peaceful?
 - _____ All of the Time (1)
 - Most of the Time (2)
 - A Good Bit of the Time (3)
 - Some of the Time (4)
 - A Little of the Time (5)
 - None of the Time (6)

Surgeon Initials _____ Date: _____

SF-12 Health Survey (p.3/3)

SF-12®		Page 3 of 3
Patient Initials	Date of Birth://	Patkey:
Surgeon Name:		Date:
Examination Period:	Preop (1) 3 Year (4) Immediate Postop (2) 5 Year (3) Year (3) Other (5)	4) 5) pecify) (6):

SF-12® Cont'd:

10. Did you have a lot of energy?

- _____ All of the Time (1)
- Most of the Time (2)
- A Good Bit of the Time (3)
- Some of the Time (4)
- A Little of the Time (5)
- None of the Time (6)
- 11. Have you felt downhearted and blue?
 - _____ All of the Time (1)
 - Most of the Time (2)
 - A Good Bit of the Time (3)
 - Some of the Time (4)
 - A Little of the Time (5)
 - None of the Time (6)
- 12. During the PAST 4 WEEKS, how much of the time has your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your social activities (like visiting with friends, relatives, etc.)?
 - All of the Time (1)
 - Most of the Time (2)
 - A Good Bit of the Time (3)
 - Some of the Time (4)
 - A Little of the Time (5) None of the Time (6)

Surgeon Signature

Date_

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Appendix N. Parkinson's Disease Questionnaire (p.1/3)



PDQ-39 QUESTIONNAIRE

Please complete the following

Please tick one box for each question

Due to having Parkinson's disease, how often <u>during the last month</u> have you		Never	Occasionally	Sometimes	Often	Always
1	Had difficulty doing the leisure activities which you would like to do?					at all
2	Had difficulty looking after your home, e.g. DIY, housework, cooking?					
3	Had difficulty carrying bags of shopping?					
4	Had problems walking half a mile?					
5	Had problems walking 100 yards?					
6	Had problems getting around the house as easily as you would like?					
7	Had difficulty getting around in public?					
8	Needed someone else to accompany you when you went out?					
9	Felt frightened or worried about falling over in public?					
10	Been confined to the house more than you would like?					
11	Had difficulty washing yourself?					
12	Had difficulty dressing yourself?					
13	Had problems doing up your shoe laces?					

Please check that you have ticked one box for each question before going on to the next page

Page 3 of 12

Questionnaires for patient completion

Parkinson's Disease Questionnaire (p.2/3)

Due to having Parkinson's disease,		Please tick <u>one</u> box for each question					
have y	you	Never	Occasionally	Sometimes	Often	Always or cannot do	
14	Had problems writing clearly?					at all	
15	Had difficulty cutting up your food?						
16	Had difficulty holding a drink without spilling it?						
17	Felt depressed?						
18	Felt isolated and lonely?						
19	Felt weepy or tearful?						
20	Felt angry or bitter?						
21	Felt anxious?						
22	Felt worried about your future?						
23	Felt you had to conceal your Parkinson's from people?						
24	Avoided situations which involve eating or drinking in public?						
25	Felt embarrassed in public due to having Parkinson's disease?						
26	Felt worried by other people's reaction to you?						
27	Had problems with your close personal relationships?						
28	Lacked support in the ways you need from your spouse or partner? If you do not hav partner	ve a spouse o tick here					
29	Lacked support in the ways you need from your family or close friends?						

Please check that you have ticked one box for each question before going on to the next page

Page 4 of 12

Questionnaires for patient completion

Due to having Parkinson's disease,		Please tick <u>one</u> box for each question				
have y	you	Never	Occasionally	Sometimes	Often	Always
30	Unexpectedly fallen asleep during the day?					
31	Had problems with your concentration, e.g. when reading or watching TV?					
32	Felt your memory was bad?					
33	Had distressing dreams or hallucinations?					
34	Had difficulty with your speech?					
35	Felt unable to communicate with people properly?					
36	Felt ignored by people?					
57	cramps or spasms?					
38	Had aches and pains in your joints or body?					
39	Felt unpleasantly hot or cold?					

Parkinson's Disease Questionnaire (p.3/3)

Please check that you have ticked one box for each question before going on to the next page

Thank you for completing the PDQ 39 questionnaire

Page 5 of 12

Questionnaires for patient completion

The Phone-FITT

Now I'd like to ask you about some physical activities and find out how often you do them, for how long, and how out of breath you feel.

Household Activities

First, I'd like you to think about activities you did **around your home**, in a **typical week** in the **last month.**

[Interviewer: Ask about each activity listed in the following 2 charts. If respondent answers yes to engaging in activity (Q1), ask Q 2–4 for that activity; otherwise, skip to the next activity. Record answers in charts.]

- 1. In a **typical week** in the **last month**, did you engage in _____?
- 2. How many times/week did you do this?
- 3. About how much time did you spend on each occasion? [read categories]
- 4. On average when doing this activity, how did you feel? Were you . . . [read categories]

Phone-FITT (p.2/6)

Activity	(Q1) Participated?	(Q2) Frequency (x/wk)	(Q3) Duration [Mark one only]	(Q4) Intensity [Mark one only]
A. Light house- work such as tidying, dusting, laundry, or iron- ing	□ Yes □No		□ 1–15 min □ 16–30 min □ 31–60 min □ 1 hr +	□ Breathing <i>normally</i> and able to carry on a conver- sation □ <i>Slightly</i> out of breath <i>but</i> still able to carry on a conversation
B. Making meals, setting and clearing the table, and wash- ing dishes	□Yes □No		□ 1–15 min □ 16–30 min □ 31–60 min □ 1 hr +	 □ <i>Too</i> out of breath to carry on a conversation □ Breathing <i>normally</i> and able to carry on a conversation □ <i>Slightly</i> out of breath <i>but</i> still able to carry on a conversation □ <i>Too</i> out of breath to carry on a conversation
C. Shopping (for groceries or clothes, for example)	□Yes □No		□ 1–15 min □ 16–30 min □ 31–60 min □ 1 hr +	Breathing normally and able to carry on a conver- sation Slightly out of breath but still able to carry on a conversation Too out of breath to carry on a conversation
D. Heavy house- work such as vacuuming, scrubbing floors, mopping, wash- ing windows, or carrying trash bags	□Yes □No		□ 1–15 min □ 16–30 min □ 31–60 min □ 1 hr +	 Breathing normally and able to carry on a conversation Slightly out of breath but still able to carry on a conversation Too out of breath to carry on a conversation
E. Home main- tenance such as painting, raking leaves, or shov- eling snow	□Yes □No		□ 1–15 min □ 16–30 min □ 31–60 min □ 1 hr +	□ Breathing <i>normally</i> and able to carry on a conver- sation □ <i>Slightly</i> out of breath <i>but</i> still able to carry on a conversation □ <i>Too</i> out of breath to carry on a conversation
F. Caring for another person (such as pushing a wheelchair or helping person in/out of a chair/ bed)	□Yes □No		□ 1–15 min □ 16–30 min □ 31–60 min □ 1 hr +	□ Breathing normally and able to carry on a conver- sation □ Slightly out of breath but still able to carry on a conversation □ Too out of breath to carry on a conversation

Phone-FITT (p.3/6)

Recreational and Conditioning Activities

Next, I'd like you to think about activities you did for recreation or conditioning in a typical week in the last month.

Activity	(Q1) Participated?	(Q2) Frequency	(Q3) Duration	(Q4) Intensity
G. Lifting weights to strengthen your legs H. Other exer- cises designed to strengthen your legs (such	Participated? Yes No Yes No No	(×/wk)	[Mark one only] □ 1–15 min □ 16–30 min □ 31–60 min □ 1 hr + □ 1–15 min □ 16–30 min □ 31–60 min	[Mark one only] □ Breathing normally and able to carry on a conversation □ Slightly out of breath but still able to carry on a conversation □ Too out of breath to carry on a conversation □ Breathing normally and able to carry on a conversation □ Slightly out of breath
as standing up/ sitting down several times in a chair or climb- ing stairs)			0 1 hr +	<i>but</i> still able to carry on a conversation <i>Too</i> out of breath to carry on a conversation
I. Lifting weights to strengthen your arms or other exercises to strengthen your arms (such as wall push-ups)	□ Yes □ No		□ 1–15 min □ 16–30 min □ 31–60 min □ 1 hr +	 Breathing normally and able to carry on a conversation Slightly out of breath but still able to carry on a conversation Too out of breath to carry on a conversation
J. Other home exercises not already men- tioned such as stretching or balance exer- cises	□ Yes □ No		□ 1–15 min □ 16–30 min □ 31–60 min □ 1 hr +	 Breathing normally and able to carry on a conversation Slightly out of breath but still able to carry on a conversation Too out of breath to carry on a conversation
K. Walking for exercise	□ Yes □ No		□ 1–15 min □ 16–30 min □ 31–60 min □ 1 hr +	 Breathing normally and able to carry on a conversation Slightly out of breath but still able to carry on a conversation Too out of breath to carry on a conversation

Phone-FITT (p.4/6)

L. Dancing	Yes No	□ 1−15 min □ 16−30 min	Breathing normally and able to carry on a conversation
		□ 31–60 min □ 1 hr +	Slightly out of breath but still able to carry on a conversation
			□ Too out of breath to carry on a conversation
M. Swimming	□ Yes	□ 1–15 min	Breathing normally
	🗆 No	□ 16–30 min	and able to carry on a conversation
		□ 31–60 min	□ Slightly out of breath
		🛛 1 hr +	but still able to carry on a conversation
			□ <i>Too</i> out of breath to carry on a conversation
N. Bicycling	Yes	□ 1–15 min	Breathing normally
	🗆 No	□ 16–30 min	and able to carry on a conversation
		□ 31–60 min	□ Slightly out of breath
		🛛 1 hr +	but still able to carry on a conversation
			□ Too out of breath to carry on a conversation

Phone-FITT (p.5/6)

Seasonal Recreational Activities

Now I would like to ask you about two specific activities that are seasonal and about any other activities that you do.

[Interviewer: Ask about each activity listed in the following chart. If the respondent answers yes to engaging in activity (Q5), ask Q 6–8 for that activity; otherwise skip to the next activity. Record answers in chart.]

- 5. Do you ____?
- 6. (a) When you do this activity, how many times in a typical week do you do it?
 - (b) How many months in this past year did you do this activity?
- 7. About how much time did you spend on each occasion? [read categories]
- On average when doing this activity, how did you feel? Were you . . . [read categories]

Activity	(Q5) Participated?	(Q6) Frequency	(Q7) Duration [Read categories, mark one only]	(Q8) Intensity [Read categories, mark one only]
O. Golf	□ Yes	A	□ 1–15 min	Breathing normally and able to carry on a
Mark:	□ No	(×/wk)	□ 16–30 min	conversation
use cart		B	□ 31–60 min	□ Slightly out of breath
do not use cart		(# mo./yr)	0 1 hr +	but still able to carry on a conversation
				□ <i>Too</i> out of breath to carry on a conversation
P. Garden	□ Yes	A	□ 1–15 min	Breathing normally
	D No	(×/wk)	□ 16–30 min	and able to carry on a conversation
		B	□ 31–60 min	□ <i>Slightly</i> out of breath
		(# mo./yr)	0 1 hr +	<i>but</i> still able to carry on a conversation
				□ Too out of breath to carry on a conversation

Phone-FITT (p.6/6)

Other Physical Activities

9. Do you participate in any other regular physical activities that we haven't asked you about?

Yes

No [Go to closing remarks]

[Interviewer: If respondent answers yes to Q 9, ask what the activity is, followed by Q 6–8 (as listed previously). Repeat this process for up to three "other" activities. Record answers in chart.]

Activity	(Q6) Frequency	(Q7) Duration [Read categories, mark one only]	(Q8) Intensity [Read categories, mark one only]
Q. Other #1:	A (×/wk) B (# mo./yr)	□ 1–15 min □ 16–30 min □ 31–60 min □ 1 hr +	 Breathing normally and able to carry on a conversation Slightly out of breath but still able to carry on a conversation Too out of breath to carry on a conversation
R. Other #2:	A (×/wk) B (# mo./yr)	 1-15 min 16-30 min 31-60 min 1 hr + 	 Breathing normally and able to carry on a conversation Slightly out of breath but still able to carry on a conversation Too out of breath to carry on a conversation
S. Other #3:	A (×/wk) B (# mo./yr)	 1-15 min 16-30 min 31-60 min 1 hr + 	 Breathing normally and able to carry on a conversation Slightly out of breath but still able to carry on a conversation Too out of breath to carry on a conversation

Thank you very much for taking the time to complete this interview.

Curriculum Vitae

Name	Lynn Zhu
Post-secondary Degrees	Ph.D., Epidemiology & Biostatistics The University of Western Ontario, 2017 (anticipated)
	M.Sc., Health & Rehabilitation Sciences (Health and Aging stream) The University of Western Ontario, 2010
	B.Sc. (Honours)., Integrative Biology, Neurosciences, Health Studies University of Toronto, 2007
Additional Training	Postdoctoral Fellow, Women's College Research Institute Women's College Hospital, 2017 - Present
	Postdoctoral Trainee, Chronic Disease & Pharmacotherapy Research Program Institute for Clinical Evaluative Sciences, 2017 - Present
	Western Certificate in University Teaching and Learning The University of Western Ontario, 2017 (anticipated)
	Nutritional Epidemiology, Epidemiology and Population Health Institute Columbia University in the City of New York, 2014
	From GPS and Google Maps to Spatial Computing short course Coursera/University of Minnesota, 2014
	International Summer School on Ageing The National Institute on Health and Ageing (Italy), 2012
	Putting Parkinson's Into Perspective Seminar Parkinson Society Canada, 2011
	Student Transitional Executive Program The University of Western Ontario, 2011
	McMaster Summer Institute on Gerontology McMaster University, 2009

Scholarships	Joseph A. Scott Studentship in Mobility and Aging Parkwood Hospital (London Health Sciences Centre), 2014-2015
	Ontario Graduate Scholarship Ontario Ministry of Training, Colleges and Universities, 2013-2014
	Queen Elizabeth II Graduate Scholarship in Science and Technology Ontario Ministry of Training, Colleges and Universities, 2011-2012
	Graduate Research Assistantship Ecological Mobility in Aging and Parkinson Research Group (Canadian Institutes for Health Research Team Grant), 2010-2014
	Western Graduate Research Scholarship Department of Epidemiology and Biostatistics The University of Western Ontario, 2010-2014, 2009-2010
	Student Mentorship Program National Initiative for the Care of the Elderly, 2010
Honours and Awards	Canadian Society for Epidemiology & Biostatistics Travel Bursary, 2015
	Canadian Association on Gerontology's Margery Boyce Bursary, 2014
	Society for Graduate Students Travel Bursary, 2014
	Ontario University Athletics Academic Achievement Award, 2013, 2012
	Western University Athletics First and Second Colour Award, 2013, 2012
	International Summer School on Ageing Stipend, 2012
	CIHR Mobility in Aging Meeting Travel Award, 2011
	Michener Institute for Applied Health Sciences Culture of Innovation Award, 2010
	University of Toronto Scarborough Letter Award, 2007
	Scarborough Campus Students' Union Vice Presidents Award, 2007
Related Work Experience	Epidemiology Consultant Canadian Epidemiology Services, 2015-2016

Sessional Lecturer Health Studies Program, Department of Anthropology University of Toronto, 2015 Graduate Teaching Assistant Department of Epidemiology and Biostatistics Western University, 2013-2014

Graduate Research Assistant Department of Epidemiology and Biostatistics Western University, 2010-2015

Graduate Research Assistant Parkinson Society of Canada Centre of Excellence Movement Disorders Laboratory London Health Sciences Center, 2011-2012

Graduate Teaching Assistant Faculty of Health Sciences Western University, 2009

Research Associate Institute of Health Policy, Management, and Evaluation University of Toronto, 2008-2009

Research Associate Applied Educational Research Department Michener Institute for Education at UHN, 2007-2010

Research Assistant Department of Politics and Public Administration Ryerson University, 2008

Research Assistant Institute of Health Policy, Management, and Evaluation University of Toronto, 2007

PublicationsZhu L., Duval C., Boissy P., Montero-Odasso M., Zou GY, Jog M. &
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	Zhu, L., Salmoni, A. & Hobson, S. (2013). Aging attributions and familism influence long-term care placement decisions by spousal caregivers of older adults [Abstract #OP25 420-S-4]. <i>Journal of Nutrition, Health and Aging.</i> 17(1): S370.

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	Rahimi, F., South, A., Bell-Boucher, D., Bapat, P., Mohammad, Y., Zhu , L., Vyas, M., Jog, M. & Jog, M. (2012). Characterization of gait freezing in Parkinson disease using a novel foot-sensor based methodology in laboratory and in patients' homes [Abstract]. <i>Movement Disorders</i> . 27 Suppl 1: 1556.
	Jog M., Rahimi F., South A., Zhu L. , Bee C. & Duval C. (2012). Impact of levodopa on improving limb symmetry during walking in Parkinson disease [Abstract #2.251]. <i>Parkinsonism & Related Disorders</i> . 18: S127 – 8.
	Rahimi F., South A., Bell-Boucher D., Bapat P., Mohammed Y., Vyas M., Jog M., Zhu L . (2012). Pre-post treatment effect of rasagiline on freezing of gait during controlled and free walking [Abstract]. <i>Movement Disorders</i> . 27 Suppl 1: 821.
	Zhu L. , South A., Bee C., Rahimi M., Speechley M., Jog M., Bapat P., Bell Boucher D., Daneault J-F., Hall L., Edwards R., Boissy P., Duval C. & Jog M. (2011). <i>Interaction of cognition and in-home mobility as a</i> <i>function of clinical medication changes in Parkinson disease</i> . 553.06 D39. Neuroscience Meeting Planner. Washington D.C.: Society for Neurosciences. Online.
Invited Talks	<u>Zhu, L.</u> Lessons from evaluating the Maternal, Newborn and Child Health program in rural Liberia. Guest speaker for HLTB16H3: Public Health, University of Toronto Scarborough. March 2017.
	<u>Zhu, L.</u> <i>Still/ uncomfortable? The restless legs syndrome</i> . Oral presentation at Rivera Chartwell Windermere on the Mount Retired Living Facility. July 2014.
	Brown H., Zhu L. , Goodwin, S., Campbell, MK. <i>Fetal</i> <i>environment and adult disease: a life-course perspective</i> . Invited group oral presentation at: (1) Western University Department of Epidemiology and Biostatistics Seminar Series, London, ON, January 2012 and (2) Western University Department of Physiology and Pharmacology Seminar Series, London, ON, December 2011.
	<u>Zhu, L.</u> Food Security in Southwestern Ontario Between 2001-2007: A Time Trend Analysis. Oral presentation at the London-Middlesex Health Unit. London, ON, March 2011.

Presentations

Presenting author(s) is (are) underlined.

<u>Zhu L.</u> Alder R., Roche M., Beukeboom C., Sohani S. Assessing the impact of general community health volunteers in three Liberian counties during the Ebola outbreak. Poster presentation at the 2017 The Society for Epidemiologic Research annual meeting, Seattle, WA, June 20-23, 2017.

Zhu, L., Boissy, P., Lavigne-Pelletier, C., Jog, M., Edwards, R., Duval, C. & Speechley, M. Improving mobility assessment of Parkinson patients using the WIMuGPS system. Poster presentation at the 19th International Congress of Parkinson's Disease and Movement Disorders, San Diego, CA, June 14-18, 2015.

Zhu, L., Boissy, P., Lavigne-Pelletier, C., Jog, M., Edwards, R., Duval, C. & Speechley, M. Comparing wearable activity sensors and self-report measures of mobility*. Poster and oral presentation at the 19th International Congress of Parkinson's Disease and Movement Disorders, San Diego, CA, June 14-18, 2015. * *Selected by Congress organizers for the Guided Poster Tour*

<u>Duval, C.</u>, **Zhu, L.**, Boissy, P., Lavine-Pelletier, C., Jog, M., Edwards, R. & Speechley, M. Measuring community mobility of people with Parkinson's disease and their spouses using WIMuGPS. Poster presented at the 19th International Congress of Parkinson's Disease and Movement Disorders, San Diego, CA, June 14-18, 2015.

Zhu, L., Boissy, P., Duval, C., Jog, M., Edwards, R., Lavigne-Pelletier, C. & Speechley, M. Capturing mobility using wearable technology versus self-report assessments: implications for research and clinical use. Oral presentation at the 2015 Canadian Society for Epidemiology and Biostatistics Conference, Toronto, ON, June 1-4, 2015.

Zhu, L. *Measuring health and disease*. Guest lecture for ANTC67H3: Foundations in Epidemiology, University of Toronto Scarborough. January 2015.

Zhu, L., Lavigne-Pelletier, C., Rahimi, F., Blamoutier, M., Briere, S., Boissy, P., Jog, M., Duval, C. & Speechley, M. *Quantitative assessment of home and community mobility of persons with Parkinson disease and their spousal caregivers.* Poster session presented at: 2014 Canadian Association on Gerontology Annual Scientific and Educational Meeting, Niagara Falls, ON, October 2014. <u>Duval, C.</u>, Rahimi, F., **Zhu, L.**, Lavigne-Pelletier, C., Boissy, P., Jog, M. (2013). *Presence of spousal caregivers in mobility of persons with Parkinson's disease: a Global Positioning System (GPS) Approach.* Abstract accepted by the the XX World Congress on Parkinson's Disease and Related Disorders. Geneva, Switzerland, December 8-11, 2013.

Zhu, L., Lavigne-Pelletier, C., Rahimi, F., Blamoutier, M., Briere, S., Boissy, P., Jog, M., Duval, C. & Speechley, M. *Quantitative assessment of home and community mobility of persons with Parkinson disease and their spousal caregivers.* Poster presentation at the World Parkinson Congress. Montreal, Canada, October 2013.

Zhu, L., Salmoni, A. & Hobson, S. *Aging attributions and familism influence long-term care placement decisions by spousal caregivers of older adults.* Oral presentation at the 20th World Congress of Gerontology and Geriatrics. Seoul, South Korea, June 2013.

Zhu, L., <u>Rahimi, F.</u>, Jog, M., Jog, M.S., Speechley, M., Duval. *Postural instability in akinetic rigid versus tremor dominant Parkinson patients.* Poster presentation at the 2012 Society for Neuroscience Annual Meeting. New Orleans, La, October 13-17, 2012.

Rahimi, F., South, A., Bell-Boucher, D., Mohammad, Y., Jog, M., Bapat, P., Deshpande, N., **Zhu, L.**, Vyas, M., Jog, M. *Characterization of gait freezing in Parkinson disease using a novel foot-sensor based methodology in laboratory and in patients' homes*. Poster presentation at the 2012 Society for Neuroscience Annual Meeting. New Orleans, La, October 13-17, 2012.

<u>Aur, D.</u>, Boissy, P., Edwards, R., Jog, M.S., Rahimi, F., **Zhu, L.**, Duval, C. *Biomechanical 'fingerprint' recognition*. Poster presentation at the 2012 Society for Neuroscience Annual Meeting. New Orleans, La, October 13-17, 2012.

Zhu, L. & the Ecological mobility in Aging and Parkinson (EMAP) group. *Ecological Mobility in Parkinson Disease: an overview.* Oral presentation at the Intl Summer School on Ageing, Ancona, Italy, September 2012.

Zhu L., South A., Bee C., Rahimi M., Speechley M., Jog M., Bapat P., Bell Boucher D., Daneault J-F., Hall L., Edwards R., Boissy P., Duval C. & Jog M. *Interaction of cognition and in-home mobility as a function of clinical medication changes in Parkinson disease*. Poster presented at the Society for Neuroscience Annual Meeting. Washington, D.C., November 2011. **Zhu, L.,** Salmoni, A., Hobson, S. *The Pessimistic Attributional Style - An Underlying Factor in the Premature Long Term Care Institutionalization of Older Adults?* Poster presentation at: (1) Canadian Association on Gerontology Annual Scientific and Educational Meeting, Montreal, QC, December 2-4, 2010 [withdrawn]; (2) National Initiative for the Care of the Elderly Annual Knowledge Exchange, Toronto, ON, June 2010; and (3) Western University Graduate Research Forum, London, ON, February 2010.

Bandali K., Zhu L., Dizon S. *Migration of Health Professionals from the Hospital to the Community: Fact or Fiction?* Oral presentation at the CIHR Team in Community Care and Health Human Resources Symposium, Toronto, ON, November 2009.

Bandali, K., <u>Zhu, L.</u>, Dunnington, S., Dizon, S. *Implementing a new health profession: anesthesia assistants in Ontario*. Poster presented at the CIHR Team in Community Care and Health Human Resources Symposium, Toronto, ON, November 20 2009.

Zecevic, A., Cullum, I., UWO HAMS*. *Knowledge Exchange in Gerontology: Supporting Research via the BioPsychoSocial Assessments in Aging Website*. Poster presented at the 2009 Canadian Association on Gerontology Scientific and Educational Meeting, Winnipeg, MB, October 2009.

*UWO HAMS refers to the Western University Health and Aging Masters Students

Burns, P., Parker, K., <u>Zhu, L.</u>, & Peacock, S. *Implementing a new health profession: anesthesia assistants in Ontario*. Poster presented at the Ontario Ministry of Health and Long-Term Care's Celebrating Innovations in Health Care Expo, Toronto, ON, April 2008.

Research Reports Alder R., **Zhu L.**, Roche M., Beukeboom C., Kei J.Q. & Taylor D.O. (2016). *Improving maternal, newborn, and child survival in Liberia, 2012-2015: Endline Survey.* [Submitted to the Canadian and Liberian Red Cross.]

Williams A.P., Deber R., Lum J.M., Montgomery R., Kuluski K., Morton-Chang F., Peckham A., Watkins J., Williams A., Ying A. & **Zhu L.** (2009). Mapping the state of the art: integrating care for vulnerable older populations. Canadian Research Network for Care in the Community. Retrieved from Ryerson University, Canadian Research Network for Care in the Community website: http://www.ryerson.ca/crncc/knowledge/related_reports/pdf/MappingtheSt ateoftheArt.pdf

	Bandali, K., Zhu, L. , Dunnington, S. & Dizon, S. (2011). <i>Implementing a new health profession: anesthesia assistants in Ontario</i> . [Submitted to the CIHR and the Michener Institute for Applied Health Sciences.]
	Bandali, K., Zhu, L. & Dizon, S. (2011). <i>An analysis of practice patterns for allied health professionals and licensed practical nurses: implications for curriculum design: Respiratory therapists.</i> [Submitted to the CIHR Team in Community Care and Health Human Resources and the Michener Institute for Applied Health Sciences.]
	Bandali, K., Zhu, L. & Dizon, S. (2011). An analysis of practice patterns for allied health professionals and licensed practical nurses: implications for curriculum design: Medical Laboratory Technologists. [Submitted to the CIHR Team in Community Care and Health Human Resources and the Michener Institute for Applied Health Sciences.]
Academic Services	Journal Article Reviewer Journal of the American Geriatrics Society, Drugs and Aging, 2017
	Grant Reviewer Mitacs Accelerate Grant, 2017
	Member Twitter Initiative, Publications Committee Society for Epidemiological Research; 2016-Present
	Cofounder and Co-organizer Alternative Early Careers in Epidemiology Initiative, 2014-Present
	Co-chair and Co-organizer "Alternative Career Paths/International Opportunities" panel Epidemiology Congress of the Americas, 2014-2016
	Committee Member; Abstract Reviewer Student and Early Career Planning Committee Epidemiology Congress of the Americas, 2014-2016
	Abstract Reviewer Central East Ontario Regional Specialized Geriatric Services Conference, 2014
	Logistics Volunteer London Health Research Day The University of Western Ontario, 2012

	Co-Chair	
	Retiring with Strong Minds Subcommittee Strong Bones, Strong Minds, Strong Muscles Charity Committee Schulich School of Medicine & Dentistry, Western University, 2011-2014	
	Peer Mentor	
	Graduate Program in Health and Rehabilitation Sciences	
	Faculty of Health Sciences	
	Western University, 2009-2010	
	Student Representative	
	UTSC Council	
	University of Toronto, Scarborough Campus, 2005-2007	
Professional		
Affiliations:	Canadian Geriatrics Society	2017 - Present
	Society for Epidemiologic Research	2014 - Present
	Canadian Association of Epidemiology and Biostatistics	2011 - 2015
	Canadian Association on Gerontology	2009 - 2015
	National Initiative for the Care of the Elderly	2008 - Present