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# EVALUATION OF PHYSICAL ACTIVITY PARTICIPATION AMONG INDIVIDUALS WITH PARKINSON'S DISEASE USING THE PHYSICAL ACTIVITY SCALE FOR INDIVIDUALS WITH PHYSICAL DISABILITIES

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# EVALUATION OF PHYSICAL ACTIVITY PARTICIPATION AMONG INDIVIDUALS WITH PARKINSON'S DISEASE USING THE PHYSICAL ACTIVITY SCALE FOR INDIVIDUALS WITH PHYSICAL DISABILITIES

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## ABSTRACT

Engaging in physical activity is generally thought to be beneficial to individuals with Parkinson's disease (PD). There is, however, limited information regarding current rates of physical activity among individuals with PD. The present study had two goals: (1) to evaluate the suitability of the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) for the measurement of physical activity within this population; and (2) to evaluate the amount of physical activity engaged in by individuals with PD. The PASIPD was demonstrated to be a reliable and valid assessment of physical activity within this population. Evaluation of PASIPD scores suggests that individuals living with PD exceeded recommended minimum levels of physical activity for seniors with limited mobility. Interestingly, individuals with PD expressed dissatisfaction with current levels of participation, and were motivated to increase physical activity levels. This information is likely to be valuable to researchers, program planners, and health care providers. [150 words]

Keywords: Parkinson's disease, Physical Activity Scale for Individuals with Physical Disabilities, PASIPD, factor analysis, physical activity, physical activity participation.

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# Chapter 1: INTRODUCTION

## 1.1 Physical Activity

Physical activity is defined as any movement generated by the skeletal muscles that produces energy expenditure (Caspersen, Powell, & Christenson, 1985). Physical activity thus includes a range of activities such as housework, yard work, child-care, transportation, occupational activity, sport and exercise and leisure-time activity. To reduce disease risks and enhance health, the American College of Sports Medicine and the American Heart Association recommends that healthy individuals aged 18–65 years, engage in moderate intensity aerobic physical activity for a minimum of 30 minutes per day, five days per week, or vigorous intensity aerobic activity for a minimum of 20 minutes per day, three days per week (Haskell et al., 2007). Motivating individuals to meet and maintain recommended levels of physical activity is, however, a well-documented public health concern (Matsudo et al., 2004). For example, the World Health Organization (WHO) estimated that the prevalence of low levels of physical activity (less than 2.5 hours per week) ranges from 31% to 51% (Matsudo et al., 2004). In Canada, this percentage increases to 60% among adults older than 65 years of age (Statistics Canada, 2005). Unfortunately, these levels of inactivity may leave this segment of the population vulnerable to chronic diseases associated with aging, and preventable deaths; as inactivity tends to carry on as individuals age (Edwards & Mawani, 2006).

## 1.2 Benefits of Physical Activity for Older Adults

A variety of studies have found that physical activity in older adults is health promoting for a variety of outcomes, including: cognitive functioning (Colcombe & Kramer, 2003; Kramer et al., 1999), age-related decay in brain structure (Colcombe & Kramer, 2003), physical performance (Brandon, Gaasch, Boyette, & Lloyd, 2003; Miszko et al., 2003), disease prevention and management (Edwards & Mawani, 2006) as well as social and emotional well-being (Jancey et al., 2008). Colcombe and Kramer (2003) conducted a meta-analysis to examine the effect of exercise on sedentary healthy seniors performing tasks classified within four cognitive processes: (a) mental speed (simple reaction time tasks); (b) visuospatial processing (transform or remember visual and spatial information); (c) controlled processes (choice reaction time task); and (d) executive function (planning, inhibiting, and scheduling mental processes). Studies were excluded if: (a) the design was cross-sectional; (b) participants were not randomly assigned; (c) the exercise program was unsupervised; (d) the intervention did not involve aerobic fitness training; or (e) participants were not 55 years of age or older. As a result, 18 studies conducted from 1996 to 2001 were selected for further examination. The studies included interventions that were conducted in clinical and non-clinical settings, as well as duration times from 1 month to 6 months or more. This meta-analysis revealed that exercise significantly improved scores in all four cognitive domains, with the greatest effect shown for executive function. These results, together with current animal literature (Colcombe et al., 2004), provide evidence to support the hypothesis that fitness training improves (or at least maintains) cognitive vitality among seniors.

Pahor et al. (2006) recently described the effects of a physical activity intervention in a sample of older adults between the ages of 70 and 89 years. Using the Short Physical Performance Battery (SPPB; Guralnik et al., 1994), the authors assessed the effects of a 26-week physical intervention (including aerobic, strength, balance, and flexibility exercises) on aspects of physical performance, including walking, balance, and strength tasks. A low SPPB score is a risk factor for hospitalization, morbidity (Guralnik et al., 1994), mortality (Guralnik, Ferrucci, Simonsick, Salive, & Wallace, 1995), and disability (Guralnik et al., 2000), and this correlation appears to be independent of other health conditions and socioeconomic factors. Pahor et al. (2006) found that seniors who participated in the physical training program had significantly improved SPPB scores at a one-year follow up visit, as compared with participants that received a health education course (and no physical intervention) over the same period of time. Moreover, people who participated in the physical activity intervention were less likely to be at risk of major mobility disability. This confirms earlier findings that have suggested that moderate exercise in older adults may delay disability development for as long as 16 years (Berk, Hubert, & Fries, 2006). Other studies have found that these benefits may stem from the improvement that exercise has on debilitating diseases such as cardiovascular disease and depression (Singh et al., 2005). Also, there may be a direct effect on impairments such as decreased muscle strength (Binder et al., 2005; Miszko et al., 2003; Rantanen, Era, & Heikkinen, 1997), low cardiorespiratory fitness (Haykowsky et al., 2005; Huang et al., 1998), and impaired balance (Gauchard, Gangloff, Jeandel, & Perrin, 2003; Morgan, Virnig, Duque, Abdel-Moty, & Devito, 2004; Orr et al., 2006). These improvements in physical performance enhance the ability for seniors to stay independent and engage in more activities. This is important, especially for seniors, as autonomy and independence are key determinants in the maintenance of good quality of life (Pahor et al., 2006).

Equally important to physical performance are emotional and social well-being. Interestingly, the literature shows that the benefits of exercise for older adults go beyond physical improvement, providing gains in psychological, emotional and social well-being.

Temple et al. (2008) conducted a study to examine these effects, in which subjects participated in a 12-week exercise program, followed by assessments conducted over a three month period. Participants demonstrated a significant improvement in perceived self-efficacy after participating in the exercise program – an important finding, given that self-efficacy has been suggested to be a determinant of engaging in health behaviours (Maibach & Murphy, 1995), and is conducive to better physical (McAuley, Blissmer, Katula, Duncan, & Mihalko, 2000) and mental health (Kocken & Voorham, 1998). Furthermore, this increased self-efficacy appears to produce gains within daily tasks that require some degree of physical activity (Dawson & Brawley, 2003).

The foregoing outlines just some of the evidence that supports the benefits conferred upon older adults by regular physical activity. In addition, there is increasing attention being paid to older adults with chronic diseases such as Parkinson's disease (Ashe, Eng, Miller, & Soon, 2007). Not surprisingly, available research evidence does suggest that there are significant benefits of physical activity to be had by individuals with these chronic diseases.

**1.3 Parkinson's Disease**

Parkinson's disease (PD) is a chronic, progressive, and neurodegenerative process that affects 1% of Canadian adults (Bioportal Canada, 2008). Approximately 20% of people with Parkinson's disease are under the age of 50 and half of those affected in Canada are under the age of 65 (Bioportal Canada, 2008). The median age of onset is 60 years and the mean duration from the time of diagnosis to death is 15 years (Katzenschlager et al., 2008). As Canada's baby-booming population continues to age, the incidence of Parkinson's disease is expected to rise. From the year 1991 to 2016, the projected increase of Canadians over 65 has been translated into a 92 percent projected increase in the number of individuals living with Parkinson's disease (Bioportal Canada, 2008). Furthermore, a study conducted in Norway (n=105) suggested that individuals with PD are five times more likely to live in a nursing home, are admitted earlier in life and therefore spend more time in nursing homes before death than their matched peers (Vossius, Nilsen, & Larsen, 2009). In addition, this study found the costs for nursing home placement to be almost 5 times higher for individuals living with PD, due to the unique care needs of this population.

### 1.3.1 Parkinson's Disease Symptoms and Stages

Parkinson's disease has not been correlated with race, and historical accounts of the disease suggest that it is unlikely to be a result of industrialization in Western civilization (Stern, 1989). The literature has shown some correlation between PD and head injury, rural living, middle-age obesity, well-water ingestion, herbicide and insecticide exposure, as well as lack of exercise (Elbaz & Tranchant, 2007; Thacker et al., 2008).

The symptoms of Parkinson's disease are caused by a lack of dopamine within the brain. Dopamine is a neurotransmitter that regulates the substantia nigra and striatum, thereby mediating balance and general locomotion (Baatile, Langbein, Weaver, Maloney, & Jost, 2000). Motor symptoms include gait alterations (Schrag, Jahanshahi, & Quinn, 2000), progressive bradykinesia, postural instability, tremors, freezing, and rigidity (Olanow & Koller, 1998). Bradykinesia involves difficulties planning, initiating and performing movement, and sequential and simultaneous tasks (Berardelli, Rothwell, Thompson, & Hallett, 2001). Consequently, daily activities that require fine motor movement such as buttoning and using utensils are affected. Other signs of bradykinesia include loss of spontaneous movements, drooling caused by affected swallowing, lack of facial expression, diminished blinking, and decreased arm swing while walking (Jankovic, 2008). Postural instability is caused by the loss of postural reflexes and is usually identified in the late stages of PD. This symptom along with frozen gait is the most common cause of falls, which in turn increases the risk of hip fracture (Jankovic, 2008). Freezing (i.e., spontaneous akinesia during motor activity) is one of the most disabling symptoms of PD, as it affects the legs while walking, and sometimes the arms and eyelids (Giladi et al., 2001). Rigidity refers to the increased resistance of passive movements executed by the limbs or neck, shoulders or hips. Rigidity can be painful, but is usually misdiagnosed as arthritis (Jankovic, 2008).

In addition to motoric symptoms, 90% of individuals with Parkinson's disease experience a variety of non-motoric symptoms (Shulman, Taback, Bean, & Weiner, 2001) such as depression, cognitive impairment (Chrischilles, Rubenstein, Voelker, Wallace, & Rodnitzky, 2002; Schrag et al., 2000), sleep disturbances (Karlsen, Larsen, Tandberg, & Maeland, 1999), and social limitations (Morimoto et al., 2003). Unfortunately, these symptoms are not only debilitating to the individual's quality of life, but also intensify caregiver stress. Non-motor symptoms appear to be a result of PD's effect on non-mesencephalic brain areas and the peripheral autonomic system (Braak et al., 2003).

Hoehn and Yahr (1967) created a Guttman scale to describe the different stages of PD. Stage one is characterized by minimal functional impairment caused by unilateral motor symptoms such as tremor, muscle stiffness, and slower movement. Stage two involves both sides of the body, and minor swallowing and facial expression difficulties may be identified. In stage three, the individual presents with balance impairment and worsened stage two symptoms, but is still able to independently carry out daily activities. During stage four, the individual requires assistance to carry out some daily activities, but is still able to walk and stand. At stage five, the individual requires full assistance and is confined to a wheelchair or bed.

**1.3.2 Parkinson's Disease Treatment**

Currently, the most common treatment option is the prescription of levodopa; a precursor of the dopamine biosynthesis pathway that functions to restore dopamine concentrations among individuals with PD (Pinel, 2007). This treatment does not, however, stop the progression of the disease (Crizzle & Newhouse, 2006). Furthermore, it has been suggested that non-motor symptoms such as hallucinations, daytime sleepiness, and leg edema, as well as motor difficulties such as dystonia (involuntary muscle contractions), dyskinesia (slow, writhing movement affecting hands and feet), and chorea (abnormal, involuntary movement of the limbs) are associated with long term antiparkinsonian medication treatment (Lohle, Storch, & Reichmann, 2009). Alternatively, other methods of treatment that can be used to complement pharmacotherapy include: physical therapy, cognitive training, and physical activity; which have been shown to improve gait, balance, muscle power and joint mobility (Keus et al., 2007).

**1.3.3 Parkinson's and Physical Activity**

There is increasing evidence to support the benefits of physical activity in relation to neuroplasticity (brain's ability to reorganize neurons by forming new neural connections) and the ability of the brain to self-repair (Smith & Zigmond, 2003). Studies with animal models found that exercise can prevent the onset of symptoms in PD (Faherty, Raviie Shepherd, Herasimtschuk, & Smeyne, 2005). This protective benefit may come from the release of neurotrophic factors and increased cerebral oxygenation, which promote new cell growth and cell survival (Dishman et al., 2006; Fox et al., 2006). Goodwin et al. (2008) identified 5 key conclusions related to physical activity and the promotion of neural plasticity in relation to PD: (a) intensive activity maximizes synaptic plasticity; (b) complex activities promote graded structural adaptation; (c) activities that are rewarding increase dopamine levels and therefore promote learning and relearning; (d) dopaminergic neurons are highly responsive to exercise and activity; and (e) implementing an exercise intervention at an early stage of the disease slows progression. Additionally, the literature suggests that moderate physical exercise increases neural levels of dopamine, which would be beneficial for individuals with PD (Baatile et al., 2000). In recognition of the potential benefits that exercise can bring upon individuals with PD, physiotherapy has been implemented as part of PD treatment. The aim of such physiotherapy is to maximize functional ability by increasing the longevity of muscles and to minimize secondary symptoms (Deane, Jones, Playford, Ben-Shlomo, & Clarke, 2004). Usually, physiotherapists implement programs that include gait training, training in appropriate methods for performing activities of daily living, relaxation therapy, and breathing exercises. Physiotherapy as a component of PD treatment may potentially counteract some of the undesirable side effects of increased drug doses (associated with the progression of the disease; Miyai et al., 2002).

A meta-analysis exploring the effectiveness of exercise interventions among individuals with PD found that there is considerable support for gains in physical function (including muscle strength, balance, gait), and quality of life measures (Goodwin et al., 2008). Programs that include muscle strengthening and aerobic activities break the cycle of immobility and inability to perform everyday tasks, caused by the disease (Kligman & Pepin, 1992; Teixeira-Salmela, Olney, Nadeau, & Brouwer, 1999). Improvements in everyday tasks include: turning over, moving in bed, standing from a sitting position, reaching forward while sitting or standing, and walking. Although studies have explored the effectiveness of different kinds of programs including physiotherapy (Crizzle & Newhouse, 2006), resistive exercise (Falvo, Schilling, & Earhart, 2008), pole striding (Baatile et al., 2000) and a combination of aerobic and strength exercises (Goodwin et al., 2008), the end result appears to be improvement in physical functioning that facilitates performance of everyday tasks. It is not surprising, therefore, that these benefits impact quality of life measures.

Rodrigues de Paula et al. (2006) explored the effects of a 12-week group exercise intervention on PD symptoms, quality of life, and emotional and social well-being, within a sample of individuals with PD. Participants were assessed before and after enrollment, using the Nottingham Health Profile (NHP), a generic questionnaire of quality of life that provides an indicator of individuals' perceptions of their physical, emotional and social lives. The NHP contain six domains based on the WHO definition of disability: (1) energy level; (2) pain; (3) emotional reactions; (4) sleep; (5) social interaction; and (6) physical activities (Rodrigues de Paula et al., 2006). Upon completion of the exercise program, subjects reported improvements in their total NHP scores, especially with regards to physical activities, emotional reactions and social interaction. Also, improvements were identified on objective measures such as lower-limb muscle strength, gait speed, ability to manage stairs, and the Unified Parkinson's Disease Rating Scale. The authors state that the group component of this intervention provided a positive setting for socialization (Rodrigues de Paula et al., 2006). Others studies have recognized socialization and enjoyment as contributors to successful programs with high compliance rates (Berger & Motl, 2001), possibly due to the process of sharing the training experience that provided support for group members (Barry & Eathorne, 1994). Furthermore, the improvement observed in physical fitness positively affected self-confidence, self-efficacy, and improved memory (Baatile et al., 2000).

The literature thus provides extensive support for the benefits that physical activity confers upon individuals with PD – not only at the physical level, but also within social, psychological, and emotional domains. However, there is also evidence that suggests that many individuals have difficulty meeting and maintaining recommended levels of physical activity – and that this is especially problematic among older adults. Although there has been little research done to describe the physical activity of individuals with PD, after conducting retrospective interviews with 32 individuals with PD, Fertl et al. (1993) suggested that the physical activity levels of these individuals show a substantial decline from pre-diagnosis levels. In addition, there are no physical activity measurement tools that have been validated within this population – a measurement issue that probably contributes to the lack of studies within this area.

**1.4 Measurement of Physical Activity**

Wilcox et al. (2009) proposed four major reasons to measure physical activity within the health field: (1) to examine physical activity as a protective or risk factor for disease development; (2) to assess physical activity changes within a particular population over time; (3) to evaluate the relationship between individual, socio-environmental factors and physical activity to enable program planners and policy makers to design appropriate interventions; and (4) to establish the effectiveness of individual and population based interventions. Given the importance of measuring physical activity, it is essential to develop tools that accurately and appropriately measure it within a target population. When designing or selecting a measurement tool there are a few aspects to be considered. First, the tool should assess physical activity in the dimension (i.e., cardiovascular fitness, strength, endurance, or leisure activities) that reflects the focus of the study. Second, it is important to evaluate the psychometric quality of the tool including its reliability, validity (construct, content, and criterion), sensitivity to change, feasibility, reactivity, and potential sources of bias (Wilcox et al., 2009). Third, given the variability that may exist within populations under study, it is critical that physical activity measures be validated within the population of interest.

### 1.4.1 Types of Physical Activity Measures

Physical activity is typically measured through different dimensions, such as frequency, duration, intensity, and type of activity performed (Wilcox et al., 2009). Frequency is the number of sessions or days per week or per month in which the individual engaged in a certain activity. Duration is indicated by the amount of time spent performing a particular activity. Intensity refers to the amount of effort required to complete a certain activity, and it is usually expressed in metabolic equivalents (METs). One MET is the ratio of the energy expenditure of an activity over the energy cost of the resting metabolic rate, which is approximately equivalent to consuming 1 kcal per kilogram body weight per hour (1 kcal/kg/hr; Taylor et al., 1978). Most exercise recommendations within the literature are scaled in terms of moderate physical activity – for example, the American College of Sports Medicine and the American Heart Association suggests that adults aged 18 to 65 years old should engage in moderate activity at least 5 days per week for 30 minutes, as well as in muscle strength exercise, in order to gain health benefits (Haskell et al., 2007). Moderate physical activity has been defined as all of those activities that expend 3 to 6 METs, and vigorous physical activity has been defined as all of those activities that expend more than 6 METs (Pate et al., 1995).

There are two types of physical activity measures: direct and indirect. Direct measures include: accelerometers, pedometers, and direct observation. Indirect measures include: self–report, self-report through interview, as well as physical activity records and logs (Wilcox et al., 2009). An accelerometer is a battery-powered tool that the subject wears at the hip to measure directionality and velocity of movement. This device can assess movement at different intervals of time (e.g., every minute) and intensity, and can store data for long periods of time (a maximum of 28 days of minute-by-minute recording; Wilcox et al., 2009). The advantages of using an accelerometer include removing the recall process from the subject and lack of feedback on performance, which help to minimize biases. In addition, accelerometers have been found to have high validity and reliability when compared to oxygen consumption and similar measures, especially for dynamic activities such as walking and running (Matthew, 2005). On the other hand, these devices are not as valid and tend to underestimate energy expenditure when used to track activities that involve upper body movement, strength training, and life-style related activities (Trost, McIver, & Pate, 2005). Biases can still be present as the mere action of being recorded can influence the participant's behavior. Even though the burden to the participant is considered to be modest, accuracy can still be compromised by the participant's consistency in wearing the device (Trost et al., 2005). These devices may be too expensive for a large-scale study, as the cost of an accelerometer ranges between $300 and $600 (Wilcox et al., 2009).

The pedometer is a small device worn at the waist which is triggered by vertical accelerations of the hip that generate a horizontal spring-suspended level arm to move up and down, which allows for counting "steps" (Wilcox et al., 2009). This device is most commonly used to obtain the number of steps taken within a specific period of time, usually a day. It has been suggested that healthy younger adults are expected to take 7000 to 13000 steps per day; healthy older adults are expected to take 6000 to 8000 steps per day, and individuals with disabilities and chronic diseases are expected to take 3500 to 5500 steps per day (Tudor-Locke & Myers, 2001). Pedometers are relatively inexpensive ($20-$30) and pose a minimal burden on the participant, which can make them more feasible as a measurement tool. If walking is the activity of focus, then pedometers are quite valid and reliable. To obtain an acceptable reliability coefficient one should collect data for a minimum of three days (Tudor-Locke & Myers, 2001). Pedometers, however, are not as accurate for very slow walkers (e.g., obese individuals, among others) and activities that involve upper body and strength training (Crouter, Schneider, & Bassett, 2005). As with accelerometers, this tool is highly dependent upon participant compliance (i.e., consistently wearing the device, diligently recording the daily number of steps in a log, and resetting the device every day). It also may affect the participant's behavior as it provides feedback. A way to address this source of bias is to instruct the subject to wear the device for longer than needed, and use the data recorded in the last days in which the novelty of the device may have subsided (Wilcox et al., 2009).

Direct observation is most commonly used in the context of physical activity in children. Usually activities are evaluated as being sedentary, walking, and very active behavior. Activity counts are then transformed into estimates of calorie expenditure. Researchers should be extensively trained to obtain an acceptable reliability coefficient (Wilcox et al., 2009). Although direct observation can be helpful in understanding the context in which physical activity takes place, it imposes a great time burden on the researcher, which makes it infeasible for population-based studies (Wilcox et al., 2009).

Indirect measures of physical activities such as self-report questionnaires and self-report through interview, are commonly used methods for assessing physical activity (Wilcox et al., 2009). There are different measures designed for specific populations, and they vary in complexity, length, assessment time, activity domain, and physical activity expression (e.g., leisure and everyday activities versus formal exercise training). It is recommended that the researcher choose a measure that has a recall time frame, and an activity domain and expression that fits the context of the research focus and population (Wilcox et al., 2009). Although shorter time frames (24 hours to 7 days) are desirable for reducing recall bias, they may not provide an accurate representation of the participant's typical physical activity (Wilcox et al., 2009). Given that leisure-time and everyday activities may be more representative of the physical activities undertaken within populations that have some difficulty engaging in formal exercise training, it is important that a physical activity questionnaire include this domain within the list of assessed activities (Wilcox et al., 2009). In terms of reliability and validity, questionnaires are fairly reliable in adult populations and their validity depends on the availability of reference measures, and one's understanding of the construct being measured (Sallis & Saelens, 2000). Self-report tools are highly feasible due to their low cost and minimal burden to the participant. The potential for bias is a main concern within self-reported measures. Recall bias, social desirability bias, and demand characteristics (tendency to fit answers to the hypothesis of the study) are the most cited concerns for these measurement tools (Wilcox et al., 2009). It has been suggested that recall calendars (e.g., inquiring about educational and occupational activities, and life events), or cues, can help reduce recall bias. Social desirability and demand characteristics may be reduced by including activities that are not typically considered as physical activity like reading or working on a computer. This allows the participant to respond positively to some items, thus reducing the need to respond more favorably to questions that may not apply to their circumstances (Stewart et al., 2001). Finally, it is important to use questionnaires that clearly define the activities, frequency, and intensity of physical activity the researcher is interested in, such that error is not introduced due to participants' distraction or exhaustion from unclear questions (Wilcox et al., 2009).

Lastly, physical activity records are reports written by the participants, to provide thorough descriptions of activities completed within the recent past (i.e., the past few days or weeks; (Wilcox et al., 2009). Physical activity logs are usually checklists of activities and their intensity levels completed by the participants. Due to their brevity, they tend to pose a lower burden on participants than physical activity records (Wilcox et al., 2009). The psychometric quality of these methods has not been widely studied, yet it is suggested that the degree of recall bias is diminished due to the small time frame for completion – and this bias reduction enhances the validity and reliability of these measures (Wilcox et al., 2009). In addition, when compared to accelerometer reports, physical activity records have fairly high validity coefficients (Richardson, Leon, Jacobs, Ainsworth, & Serfass, 1995). Participant burden depends on the duration of record keeping. In addition to participant burden, the longer the records are kept, the more time researchers have to invest in data entry and coding (Wilcox et al., 2009). Longitudinal studies may, therefore, provide interesting and useful information, but may also be less feasible than short-term studies when using physical activity records. Furthermore, reactivity, social desirability, and demand pressures remain key measurement considerations when using this method of measurement (Wilcox et al., 2009).

### 1.4.2 Measuring Physical Activity in Older Adults and Individuals with Chronic Diseases and/or Disabilities

There are unique issues to be considered when measuring physical activity in populations that include older adults and/or individuals with chronic diseases/disabilities. In general, older adults tend to engage more in low to moderate intensity physical activity as opposed to high intensity activities. This can pose a problem in recall and inclusion of appropriate activities in self-report measures, and may result in an underestimate of the amount of physical activity undertaken within these populations (Masse et al., 1998). In addition to low availability of appropriate measurement tools, cognitive and sensory age-related impairments pose another challenge to obtain accurate estimates of physical activity prevalence. Therefore, it is important to consider time frame and type of activities when choosing a measurement tool for this population. It is recommended that one choose a measure that asks about the past week or a typical week, and includes household, yard, and caregiving activities (Wilcox et al., 2009).

Chronic disease and disability add another level of complexity to physical activity measurement (Warms, 2006). The UN Convention of the Rights of Persons with Disabilities (2008) states that: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." Accordingly, chronic disease and disability change the nature of physical activity – specifically how muscles are used, the amount of energy required, and the type of activities that can be performed (Warms, 2006). Furthermore, people with disabilities have a lower level of activity, move differently, and may use assistive devices, or have difficulties related to cognition or fine motor control (Warms, 2006). When assessing individuals in these populations, therefore, it is important to utilize measurement techniques that assess low-intensity, low-frequency activity, as well as alternative ways of movement (Warms, 2006). The three most widely-cited measures for individuals with physical activity restrictions are: (a) the Human Activity Profile (Fix & Daughton, 1988); (b) the Physical Activity and Disability Survey (PADS; Rimmer, Riley, & Rubin, 2001); and (c) the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD; Washburn, Zhu, McAuley, Frogley, & Figoni, 2002).

The Human Activity Profile is a measure that consists of 94 items evaluating regular activities that are listed in order of energy expenditure from lowest to highest. The participant is asked to indicate, for each item, whether he or she is performing the activity, has previously performed the activity but is no longer doing so, or if he or she has never done the activity (Fix & Daughton, 1988). Although the scale is well established, it is more useful for the assessment of physical ability, than the assessment of physical activity engagement (Warms, 2006).

The Physical Activity and Disability Survey is a 46-item semi-structured interview (30 to 40 minutes) that measures typical weekly activity. It contains 3 subscales that measure exercise, leisure time physical activity, and household activity. Internal consistency estimates (Cronbach's alpha) range from 0.67 to 0.77, and the overall scale test-re-test reliability (1 week interval) ranges from 0.78 to 0.95 (Rimmer et al., 2001).

Finally, the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) is the most recently developed measure. This measure consists of a 13-item questionnaire that records the number of days per week and hours per day of participation in leisure activities, household activities, occupational activities, and stationary activities over the past seven days. Factor analysis and group differentiation have supported its construct validity. Five factors were identified: (a) home, lawn, garden repair; (b) housework; (c) light exercise through sport and recreation; (d) vigorous exercise through sport and recreation; and (e) occupational activity. These factors accounted for 63% of the variance in the total score. In addition, this scale was able to differentiate individuals with excellent health from those with poor health, as well as between moderately and extremely active individuals and inactive subjects. The PASIPD has also demonstrated test-retest reliability (0.77) and criterion validity (0.30 with an accelerometer; van der Ploeg et al., 2007) comparable to well-established self-report physical activity measures used within the general population (Sallis & Saelens, 2000), and within populations experiencing debilitating conditions such as chronic obstructive pulmonary disease (Steele et al., 2000) and brain injury (Tweedy & Trost, 2005). This measure has appropriate activities and psychometric quality that make it a suitable choice for a large scale study within a population that lives with different degrees of disability such as individuals living with Parkinson's disease.

**1.5 The Current Investigation**

Before proceeding to the development of widespread interventions designed to improve physical activity among individuals with PD, it is first necessary to gather information as to current physical activity levels within this population. This provides a starting point for future research that may address issues of motivation, compliance, and sustainability of physical activity. This information is also valuable to exercise program planners, and health care providers, as it may help them to better understand and serve this population. There is, unfortunately, a dearth of research in this area, and no large scale studies to date have explored the current rate of engagement in physical activity within this population – possibly due to a lack of measurement tools that accurately assess physical activity levels appropriate to a population with Parkinson's disease.

The primary goal of this study was to collect information concerning the amount of physical activity undertaken by a group of individuals with Parkinson's disease, in an attempt to estimate current levels of physical activity within this population. Although it was not designed explicitly for individuals with Parkinson's disease, the Physical Activity Scale for Individuals with Physical Disabilities has demonstrated excellent construct validity (Washburn et al., 2002), criterion validity, and test-retest reliability (van der Ploeg et al., 2007). As this measurement tool has not been applied within a population with Parkinson's disease, a secondary goal of this study was to evaluate the reliability and factor structure of this scale among individuals with Parkinson's disease. In this way, the present project will provide important information to future policy-makers, researchers, and clinicians working within this population.

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# Chapter 2: VALIDATION OF THE PHYSICAL ACTIVITY SCALE FOR INDIVIDUALS WITH PHYSICAL DISABILITIES, IN A SAMPLE OF INDIVIDUALS WITH PARKINSON'S DISEASE

The positive impact of physical activity on Parkinson's disease (PD) symptoms such as gait impairment, loss of balance, decreased strength, poor movement speed and coordination, as well as on quality of life, is well supported within the literature (Goodwin, Richards, Taylor, Taylor, & Campbell, 2008). Interestingly, there are no references within the literature as to the actual amount of physical activity in which individuals with Parkinson's disease engage. The lack of research in this area is likely due to a general lack of population-appropriate measurement tools. This dearth of appropriate measurement tools is not surprising, given the unique considerations that must be taken into account when measuring physical activity within a population that includes individuals with chronic (and progressive) motoric dysfunction. The assessment of physical activity among individuals with Parkinson's disease must take into account: (a) a probable tendency to engage in low to moderate intensity physical activity, as compared with higher intensity physical activity; (b) a potentially limited memory (particularly with regards to recall); and (c) the types of physical activity that these individuals are able to perform (Masse et al., 1998). When assessing individuals with Parkinson's disease, therefore, it is important to utilize measurement techniques that assess low-intensity, low-frequency activity, and alternative ways of movement such as: household, yard, and caregiving activities, and it is critical that any recall be limited to a relatively short time frame (e.g., last seven days or a typical week) (Warms, 2006).

Although not specifically designed for assessing the physical activity of individuals with Parkinson's disease, the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD; Washburn, Zhu, McAuley, Frogley, & Figoni, 2002) is a measure of physical activity that takes into account the previously mentioned recommendations. This measure consists of a 13-item questionnaire that records the number of days per week, and hours per day, of participation in leisure activities, household activities, and occupational activities, over the past seven days. Factor analysis and group differentiation supported its construct validity within a sample of 372 individuals with physical disabilities between the ages of 35.8 and 63.6 (145 women; *M* age = 48.4, *SD* = 12.6). Disabilities such as vision impairment, hearing impairment, paraplegia, cerebral palsy, spinal cord injury, amputations, and muscular dystrophy were reported within the sample (Washburn et al., 2002). The sample was predominantly white (92%) and highly educated (i.e., 60% of men and 70% of women held graduate degrees). Washburn et al. (2002) identified five factors within the PASIPD: (a) home, lawn, garden repair; (b) housework; (c) light exercise through sport and recreation; (d) vigorous exercise through sport and recreation; and (e) occupational activity. These factors accounted for 63% of the variance in the total score. In addition, Washburn et al. (2002) tested the construct validity of the PASIPD through the use of a group differentiation analysis to determine whether the PASIPD varied by age, self-rated health status, self-rated physical activity, gender, annual family income, presence or absence of care attendant, or type of disability. The results of this initial validation study suggested that the scale was able to differentiate individuals with excellent health from those with poor health, between younger and older participants, between moderately and extremely active and inactive subjects, as well as between those who received attendant care and those who did not

(Washburn et al., 2002). Gender differences were found in sub-scale scores, with men being more active in activities involving home repair, and lawn and garden care; while women obtained higher scores in activities involving housework. Not surprisingly, individuals with hearing or vision impairments obtained significantly higher scores for sport and recreational activities than individuals with spinal cord injury or other locomotor disabilities. Finally, the PASIPD was found to be invariant across levels of annual household income (Washburn et al., 2002). The PASIPD has also demonstrated test-retest reliability (0.77) and criterion validity (0.30 with an accelerometer; van der Ploeg et al., 2007) comparable to well-established self-report physical activity measures used within the general population (Sallis & Saelens, 2000), and within populations experiencing debilitating conditions, such as chronic obstructive pulmonary disease (Steele et al., 2000) and brain injury (Tweedy & Trost, 2005). Thus, the PASIPD not only takes into account the challenges of assessing physical activity within an older adult and/or disabled population, but has also been demonstrated to be psychometrically sound for use with individuals with various physical disabilities (van der Ploeg et al., 2007; Washburn et al., 2002).

Even though the PASIPD was validated within a diverse sample of individuals with physical disabilities, individuals with Parkinson's disease were not included. Given the physically debilitating symptoms of Parkinson's disease, it is likely that this scale could be used to assess physical activity within this population. The purpose of this study is to assess discriminative validity, internal consistency, and factor structure of the PASIPD when administered to a sample of individuals with Parkinson's disease.

## Methods

*Participants*

A package containing the PASIPD, a letter of information, and an engraved pen (included as a token of appreciation for participants) was mailed to 120 individuals with Parkinson's disease. All prospective participants were drawn from the practice of a single movement disorder specialist, and were sampled non-purposively, except for the following inclusion/exclusion criteria: (1) confirmed diagnosis of Parkinson's disease; (2) not currently hospitalized; and (3) not in a residential care, or long-term-care facility. Sixty-three individuals with Parkinson's disease between the ages of 52 and 87 (31 women; *M* age = 70.97, *SD* = 7.53) returned surveys for an overall return rate of 52.5%.

The letter of information underscored that completion of the questionnaire would have no impact on the participant's medical care, and consent to participate was implied with survey return. The procedures, questionnaire, and consenting practices described herein were approved by the Health Sciences Research Ethic Board at the University of Western Ontario.

*Instrumentation*

The Physical Activity Scale for Individuals with Physical Disabilities consists of 13 items that document the number of days per week and hours per day of participation in leisure activities, household activities, occupational activities, and inactivity over the past 7 days (Washburn et al., 2002). The scoring process is based on intensity values known as the 'metabolic equivalent of the task' (MET) - one MET is the ratio of the energy expenditure of an activity over the energy cost of the resting metabolic rate, which is approximately equivalent to consuming 1 kcal per kilogram body weight per hour (Taylor et al., 1978). The scale's total score is obtained by multiplying the average hours per day of each item by the

MET value associated with the intensity of the activity and adding these values across items 2 through 13. The maximum possible score is 199.5 MET hours per day (Washburn et al., 2002). Activities that included the use of a wheelchair were removed from items 2, 4, 5 in the original PASIPD template, as those activities were not relevant to the current sample. In addition, three 5-point Likert scale items were included: (1) a question inquiring about the participant's perception as to the effects of Parkinson's disease on his or her physical activity; (2) an item that queried an individual's satisfaction with his or her current level of physical activity; and (3) a question that evaluated the representativeness (as compared with typical activity levels) of the last seven days' worth of activity. In addition to these Likert items, a close-ended (yes/no) question was added to the end of the questionnaire, which was intended to evaluate the survey's ability to allow participants to describe current levels of physical activity, as well as an open-ended item inquiring the total number of hours per week engaged in physical activity. These additional items are presented in Table 2.1.

Table 2.1

*Additional Items*

| Likert Scale Items (5 point) | | Close-ended Item (Yes/No) | Open-ended Item |
|---|---|---|---|
| I am satisfied with my current physical activity level. | From '*Strongly Disagree*' to '*Strongly Agree*' | This survey allowed me to properly describe my current levels of physical activity. | How many hours in total (i.e., for all activities) per week, do you usually devote to these activities? |
| The amount of physical activity in which I have engaged over the past 7 days is typical of my usual activity. | From '*Strongly Disagree*' to '*Strongly Agree*' | | |
| To what extent has Parkinson's disease affected your level of physical activity? | From '*Greatly Decreased*' to '*Greatly Increased*' | | |

*Data Analysis*

'Physical activity behaviors' was considered the underlying construct of interest. An exploratory factor analysis was conducted to examine possible reasonable factors on which individual items could load. This analysis was conducted with principal component extraction, and varimax orthogonal rotations. The number of factors to be included in the final factor solution was derived after examining four criteria: (1) Kaiser's criterion (eigenvalues of 1 or higher); (2) interpretability of factors (factor loading of 0.4 or higher (without loading on more than one factor); (3) scree plot; and (4) Monte Carlo parallel analysis. Internal consistency was estimated for each extracted factor by calculating Cronbach's alpha values. In addition, correlation values were obtained to examine discriminative validity.

## Results

*Factor Analysis*

Given that the Kaiser-Meyer-Olkin (KMO) value (0.55) falls below the threshold described by Kaiser (1970) as being indicative of adequate sampling (0.60), the results of this factor analysis should be interpreted with caution. Bartlett's test of sphericity, however, was found significant, which is an indication of interdependence among items (Bartlett, 1954). For each of the factor analyses presented in this section, correlations were calculated between the item and the total score, and were reported along with the eigenvalues (experimental and Monte Carlo generated), the percentage of variance accounted for by each factor, and the factor loadings for each item within the solution. Additionally, Cronbach's alpha was computed for each factor, using a unit-weighting of the principally loading items within each factor. Kaiser's criterion suggests that only those factors with eigenvalues exceeding 1 should be retained for further examination. Cattell (1966), on the other hand, recommends keeping those factors located above the "elbow" in a "scree plot" (a plot of all eigenvalues, arranged from largest to smallest). The scree plot for this data is presented in Figure 2.1. Five factors satisfy the criteria mentioned above: (1) *home repairs and home outdoors activities* (items 9, 10, 11); (2) *housework* (items 7, 8); (3) *recreational activities* (items 3, 4, 5, 6); (4) *occupational activities* (items 12, 13); and (5) *walking with assistance* (item 2). The interpretability of this factor solution is marred by the cross-loading of item 5 (strenuous recreational activities) on multiple factors within the solution. Similarly, item 10 loads almost equally on factors 1 and 2. Finally, this factor solution identifies one item (*walking with assistance*) as being its own factor, which is problematic for factor identification. The five-factor solution is presented in Table 2.2.

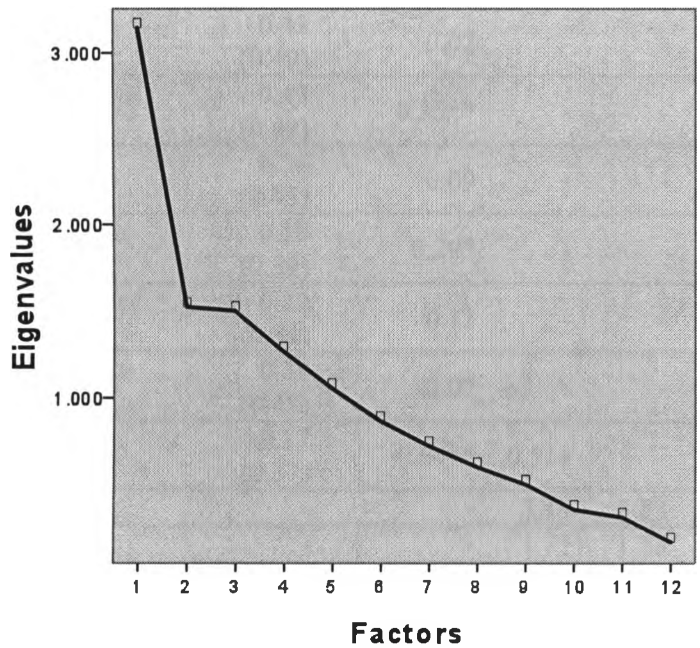


*Figure 2.1.* Scree Plot

Table 2.2

*Item Correlation with Total Score Factor Loading, Eigenvalues, Percentage of Variance Explained, and Cronbach α for Physical Activity Scale for Individuals with Physical Disabilities (PASIPD), 5-Factor Solution*

| Item | Mean (SD) (MET hr/d) | Item-Total Correlation | Factor Loading | | | | |
|---|---|---|---|---|---|---|---|
| | | | Fac 1 | Fac 2 | Fac 3 | Fac 4 | Fac 5 |
| Q09. Home repairs | 0.13 (0.28) | 0.42** | 0.82 | - | - | - | - |
| Q10. Lawn and yard work | 0.21 (0.31) | 0.57** | 0.83 | - | - | - | - |
| Q11. Outdoor gardening | 0.27 (0.38) | 0.61** | 0.52 | 0.56♦ | - | - | - |
| Q07. Light housework | 0.74 (0.54) | 0.29* | - | 0.85 | - | - | - |
| Q08. Heavy housework | 0.22 (0.35) | 0.37* | - | 0.73 | - | - | - |
| Q03. Light sport and recreation | 0.43 (0.49) | 0.02 | - | - | 0.83 | - | - |
| Q04. Moderate sport and recreation | 0.49 (0.49) | 0.35** | - | - | 0.65 | - | - |
| Q06. Muscle strength & endurance training | 0.34 (0.45) | 0.09 | - | - | 0.69 | - | - |
| Q12. Care for another person | 0.19 (0.39) | 0.29* | - | - | - | 0.70 | - |
| Q13. Work for pay/volunteer | 0.22 (0.59) | 0.11 | - | - | - | 0.83 | - |
| Q02. Walking with assistance | 0.37 (0.48) | -0.07 | - | - | - | - | 0.87 |
| Q05. Strenuous sport and recreation | 0.17 (0.37) | 0.64** | 0.51♦ | - | 0.39 | 0.38♦ | 0.40♦ |
| Eigenvalue | - | - | 3.14 | 1.53 | 1.51 | 1.27 | 1.06 |
| Parallel analysis eigenvalue | - | - | 1.77 | 1.53 | 1.38 | 1.25 | 1.14 |
| % variance | - | - | 26.17 | 12.75 | 12.58 | 10.58 | 8.83 |
| Cumulative % variance | - | - | 26.17 | 38.92 | 51.5 | 62.08 | 70.91 |
| α | - | - | 0.74 | 0.60 | 0.60† | 0.49 | N/A |

† Cronbach α includes "Strenuous sport and recreation" * $p < 0.05$ ** $p < 0.01$ ♦ Other high loadings

Factor 1: Home Repairs and Home Outdoors Activities
Factor 2: Housework
Factor 3: Recreational Activities
Factor 4: Occupational Activities
Factor 5: Walking with Assistance

A more rigorous test of the stability of the factor structure is, however, found within a Monte Carlo parallel analysis (Velicer, Eaton, & Fava, 2000; Zwick & Velicer, 1986). In this method, a set of random correlation matrices are generated (for this study, 100 runs were performed) based upon the number of variables in the measure, and the number of participants in the sample. Several principal components analyses are then performed, using these randomly generated correlation matrices. Finally, the average of the eigenvalues (from the unrotated factor loading matrix) derived from these principal component analyses are compared to the eigenvalues found within the experimental data (Watkins, 2006). A factor is extracted if its corresponding experimental eigenvalue is higher than the one generated by the parallel analysis (Ledesma & Valero-Mora, 2007). For the present study, this method suggested a four-factor solution, due to the fact that only the first four factors obtained higher eigenvalues than the ones generated by the Monte Carlo parallel analysis.

Accordingly, 3-factor and 4-factor solutions were also evaluated, and are presented in Tables 2.3 and 2.4 respectively. Examination of these matrices suggests that the 3-factor solution provides the most theoretically sound and interpretable solution, with distinctive item loadings, and high Cronbach's α coefficients. The three factors identified are: (1) *housework and home outdoor activities* (items 2, 7, 8, 9, 10, 11); (2) *recreational and fitness activities* (items 3, 4, 5, 6); and (3) *occupational activities* (items 12, 13). These factors accounted for 51.5% of the variance. As was the case within the 5-factor solution, Item 2 (*"walking with assistance"*) is problematic for both the 3-factor and the 4-factor solutions, given that it does not fit with the theoretical definition of the factor on which it loads. Similarly, the Cronbach α coefficient considerably improves if this item is deleted (from 0.488 to 0.721, in the 3-factor solution). In addition, factor analysis and Monte Carlo parallel

Table 2.3

*Item Correlation with Total Score Factor Loading, Eigenvalues, Percentage of Variance Explained, and Cronbach α for Physical Activity Scale for Individuals with Physical Disabilities (PASIPD), 3-Factor Solution*

| Item | Factor 1: Housework and Home Outdoors Activities | Factor 2: Recreational and Fitness Activities | Factor 3: Occupational Activities |
|---|---|---|---|
| Q09. Home repairs | 0.73 | - | - |
| Q10. Lawn and yard work | 0.76 | - | - |
| Q11. Outdoor gardening | 0.73 | - | - |
| Q07. Light housework | 0.44 | - | - |
| Q08. Heavy housework | 0.65 | - | - |
| Q03. Light sport and recreation | - | 0.81 | - |
| Q04. Moderate sport and recreation | - | 0.66 | - |
| Q05. Strenuous sport and recreation | - | 0.46 | - |
| Q06. Muscle strength & endurance training | - | 0.66 | - |
| Q12. Care for another person | - | - | 0.76 |
| Q13. Work for pay/volunteer | - | - | 0.72 |
| Q02. Walking with assistance | -0.47 | - | - |
| Eigenvalue | 3.14 | 1.53 | 1.51 |
| Parallel analysis eigenvalue | 1.77 | 1.53 | 1.38 |
| % variance | 26.17 | 12.75 | 12.58 |
| Cumulative % variance | 26.17 | 38.92 | 51.5 |
| α | 0.72† | 0.60 | 0.49 |

† Cronbach α excludes "Walking with assistance"

Table 2.4.

*Item Correlation with Total Score Factor Loading, Eigenvalues, Percentage of Variance Explained, and Cronbach α for Physical Activity Scale for Individuals with Physical Disabilities (PASIPD), 4-Factor Solution*

| Item | Factor 1: Home Repairs and Home Outdoors Activities | Factor 2: Housework | Factor 3: Recreational Activities | Factor 4: Occupational Activities |
|---|---|---|---|---|
| Q09. Home repairs | 0.84 | - | - | - |
| Q10. Lawn and yard work | 0.83 | - | - | - |
| Q11. Outdoor gardening | 0.55 | 0.54♦ | - | - |
| Q07. Light housework | | 0.79 | - | - |
| Q08. Heavy housework | | 0.74 | - | - |
| Q03. Light sport and recreation | | - | 0.82 | - |
| Q04. Moderate sport and recreation | | - | 0.65 | - |
| Q06. Muscle strength & endurance training | | - | 0.68 | - |
| Q12. Care for another person | | 0.43♦ | - | 0.65 |
| Q13. Work for pay/volunteer | | - | - | 0.78 |
| Q02. Walking with assistance | -.402 | - | - | - |
| Q05. Strenuous sport and recreation | - | - | 0.37 | 0.56♦ |
| Eigenvalue | 3.14 | 1.53 | 1.51 | 1.27 |
| Parallel analysis eigenvalue | 1.77 | 1.53 | 1.38 | 1.25 |
| % variance | 26.17 | 12.75 | 12.58 | 10.58 |
| Cumulative % variance | 26.17 | 38.92 | 51.5 | 62.08 |
| α | 0.74* | 0.60 | 0.60† | 0.49 |

† Cronbach α includes "Strenuous sport and recreation" ♦ Other high loadings

* Cronbach α excludes "Walking with assistance"

analysis conducted excluding item 2, supported the 3-factor solution as being the most theoretically sound model, as the extracted items load correctly into their theoretical corresponding factor, without loading onto other factors. Thus, the removal of item 2 does not affect the interpretability of the PASIPD's factor structure. This is likely due to the bias introduced by poor question wording, which may have caused participants to misinterpret its meaning. The 3-factor solution excluding item 2 is presented in Table 2.5.

*Validation*

Seventy nine percent of participants reported that physical activity within the last seven days is typical of their usual activity. Furthermore, 74.6% of subjects completed the survey without any assistance. These high rates are an indication of representativeness of the captured physical activity, as well as its comprehensibility within the Parkinson's population. Similarly, 85.7% of participants reported that this survey allowed them to properly describe their physical activity; providing some evidence of content validity. A significant negative correlation was found between the total PASIPD score and the extent to which the individual perceived Parkinson's disease to have affected his or her physical activity level, and a significant positive correlation was found between the total PASIPD score, and the self-report estimate of total number of hours per week spent in physical activity. In addition, a significant negative correlation was found between the frequency of stationary activities and the total PASIPD score. These correlation values (presented in Table 2.6) provide evidence of convergent validity.

Table 2.5

*Item Correlation with Total Score Factor Loading, Eigenvalues, Percentage of Variance Explained, and Cronbach α for Physical Activity Scale for Individuals with Physical Disabilities (PASIPD), 3-Factor Solution excluding item 2: "Walking with assistance"*

| Item | Factor 1: Housework and Home Outdoors Activities | Factor 2: Recreational and Fitness Activities | Factor 3: Occupational Activities |
|---|---|---|---|
| Home repairs | 0.72 | - | - |
| Lawn and yard work | 0.77 | - | - |
| Outdoor gardening | 0.76 | - | - |
| Light housework | 0.52 | - | - |
| Heavy housework | 0.64 | - | - |
| Light sport and recreation | - | 0.81 | - |
| Moderate sport and recreation | - | 0.66 | - |
| Strenuous sport and recreation | - | 0.46 | - |
| Muscle strength & endurance training | - | 0.67 | - |
| Care for another person | - | - | 0.74 |
| Work for pay/ volunteer | - | - | 0.74 |
| Eigenvalue | 3.01 | 1.53 | 1.49 |
| Parallel analysis eigenvalue | 1.79 | 1.53 | 1.35 |
| % variance | 27.35 | 13.88 | 13.52 |
| Cumulative % variance | 27.35 | 41.23 | 54.75 |
| α | 0.72 | 0.60 | 0.49 |

Table 2.6

*Correlation Coefficients (Pearson's r)*

| | PASIPD Score |
|---|---|
| Extent to which Parkinson's has affected level of physical activity | -0.39** |
| Total number of hours per week spent in physical activity | 0.50** |
| Frequency of engagement in stationary activities | -0.30* |

* $p < 0.05$
** $p < 0.01$

**Discussion**

There are few available tools for the measurement of physical activity among individuals with Parkinson's disease. Given the nature of this disease, special considerations have to be taken into account when assessing physical activity within this population. The PASIPD was originally designed for individuals with physical disabilities, in response to the need for a practical method of evaluating the physical activity of individuals with limited physical capacity (Washburn et al., 2002). This survey thus includes daily activities such as housework, home outdoor activities, and occupational activities, in addition to formal physical activity training. The simplicity of the measure (13 items), and its consideration of physical activities more relevant to populations with limited mobility, made it feasible for the assessment of physical activity among individuals with Parkinson's disease.

Results of a Monte Carlo parallel analysis supported the extraction of three factors within a principal components factor analysis. Examination of these three factors suggests that this solution is theoretically sound, and appears to provide a good explanation of the construct of physical activity within the Parkinson's population. These three factors include *housework and home outdoor activities*, *recreational and fitness activities*, and *occupational activities*. The item assessing walking with any type of assistance was found to be problematic; possibly due to poor wording leading to misinterpretation. The solution obtained in the present study varies from the original solution suggested by Washburn et al. (2002), which presented a 5-factor solution (*home repair and lawn and garden work*, *housework*, *vigorous sports and recreation*, *moderate sport and recreation*, and *occupation and transportation*). The current study focused on obtaining a parsimonious solution in which at least 50% of the variance was explained by an interpretable model. Given that the measure captures intensity through the scaling of the measure (i.e., it is scaled on METs), the factor structure grouped items in dimensions that pertain more to the type of activity engaged, rather than the intensity levels. When dealing with individuals with chronic conditions and/or seniors, the focus of physical activity assessment changes, as these individuals are more likely to engage in low-intensity activities (Warms, 2006). Given the nature of the present population, therefore, a model that provides insight into the types of activities individuals are more likely to engage, may be more useful to program planners and health practitioners aiming to increase physical activity engagement.

Evidence of convergent validity was provided by the moderate correlation found between the PASIPD score and the self-reported extent to which Parkinson's disease has affected level of physical activity, the total number of hours per week spent in physical activity, and rate of engagement in stationary activities. In addition, some evidence of content validity was presented by the high percentage (85.7%) of individuals who reported that the survey allowed them to properly describe their physical activity. In addition, this survey was reported to be easily comprehensible, which is likely to reduce bias (Wilcox, Ainsworth, Shumaker, Ockene, & Riekert, 2009). Additional studies should be conducted to examine other external measures such as motion sensors or activity diaries to further establish the scale's validity within this population.

Although this study is an important adjunct to the literature on physical activity in Parkinson's disease, some limitations must be noted. First, the sample size did not fulfill the suggested 10 participants per item for an optimal factor analysis (Nunnally, 1978), and Kaiser's sample adequacy criterion value obtained, only approximated the minimum required for an adequate factor analysis. Second, although the removal of one problematic item within the questionnaire did not appear to substantively alter the factor structure of the three-factor solution, this item may have produced subtle effects within the experimental sample, during the completion of the questionnaire. Future studies should be conducted with a larger sample, and with a different version of the problematic item.

Finally, since this population usually engages in non-formal physical activity, future scale development processes should take into account technological resources such as videogame systems. Specifically, videogame systems such as the Nintendo Wii have become popular among seniors to engage in recreational physical activity (Yin-Leng, Amirrudin Bin, Meutia Latifah, & Thant Zin, 2009). Such activities may also be used as a source for validation information (i.e., through activity logs stored within the game console).

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# Chapter 3: PHYSICAL ACTIVITY ENGAGEMENT IN INDIVIDUALS LIVING WITH PARKINSON'S DISEASE, AND BARRIERS AND FACILITATORS TO ENGAGEMENT

Parkinson's disease (PD) is a chronic, progressive, and neurodegenerative process that affects 1% of Canadian adults (Bioportal Canada, 2008). The median age of onset is 60 years and the mean duration from the time of diagnosis to death is 15 years (Katzenschlager et al., 2008). As Canada's population continues to age, the prevalence of PD is expected to increase. From the year 1991 to 2016, the projected increase of Canadians over 65 has been translated into a 92 percent projected increase in the number of individuals living with PD (Bioportal Canada, 2008). Not surprisingly, this is expected to have a significant impact on the demand for efficient delivery of optimal health care services.

The symptoms of PD are caused by a lack of dopamine within the brain. Dopamine is a neurotransmitter that regulates the substantia nigra and striatum, thereby mediating balance and general locomotion (Baatile, Langbein, Weaver, Maloney, & Jost, 2000). In addition to motoric symptoms, such as gait alterations (Schrag, Jahanshahi, & Quinn, 2000), akinesia, tremors, rigidity, progressive bradykinesia, and postural instability (Olanow & Koller, 1998), individuals with PD experience a variety of non-motoric symptoms such as depression, cognitive impairment (Chrischilles, Rubenstein, Voelker, Wallace, & Rodnitzky, 2002; Schrag et al., 2000), sleep disturbances (Karlsen, Larsen, Tandberg, & Maeland, 1999), and social limitations (Morimoto et al., 2003). Currently, the most common treatment option is the prescription of levodopa; a precursor of the dopamine biosynthesis pathway that acts to restore dopamine concentrations among individuals with PD (Pinel, 2007). This treatment does not, however, stop the progression of the disease (Crizzle & Newhouse, 2006).

Interestingly, there is an increasing amount of evidence supporting the benefits of exercise within the PD population. These benefits include improvements in physical functioning, quality of life, strength, balance and gait speed (Goodwin, Richards, Taylor, Taylor, & Campbell, 2008). Coupled with the debilitating side effects of long-term drug therapy, such as hallucinations, daytime sleepiness, leg edema, dystonia (involuntary muscle contractions), and dyskinesia (abnormal, involuntary movement of the limbs; Lohle, Storch, & Reichmann, 2009), there is a great need for novel research on topics related to increasing physical activity levels among individuals with PD.

Despite evidence that physical activity is a positive adjunctive medical treatment for the disease, the literature has limited information regarding the current rate of physical activity of individuals with PD. For example, Fertl et al. (1993) found that physical activity levels greatly decrease from pre-diagnosis levels. This study was, however, small in size (n=32) and was conducted using retrospective interviews. Retrospective interviews are likely to be subject to recall bias, response bias, and social desirability bias. The authors also failed to specify how these 32 participants were recruited, which makes it difficult to determine the representativeness of this sample. These results must, therefore, be confirmed through larger scale studies that are conducted using population-appropriate tools.

There is also a dearth of literature regarding the appropriate measurement of physical activity among individuals with PD. In the absence of a measure that has been specifically validated within a PD population, an alternative scale that assesses physical activity within a population with limited mobility should be selected. A likely source for such a measurement tool is the literature surrounding the assessment of physical activity among individuals with physical disabilities.

There are three measures designed for individuals with physical disabilities: (a) the Human Activity Profile (Fix & Daughton, 1988); (b) the Physical Activity and Disability Survey (Rimmer, Riley, & Rubin, 2001); and (c) the Physical Activity Scale for Individuals with Disabilities (Washburn, Zhu, McAuley, Frogley, & Figoni, 2002). The Human Activity Profile measures ability to engage in physical activity, rather than quantity of physical activity engagement (Ng & Kent-Braun, 1997), and does not assess frequency or duration of activity (Warms, 2006). The Physical Activity and Disability Survey is not a feasible tool for a large scale study (particularly one involving mailed questionnaires), since it consists of 46 items conducted through a semi-structured interview that requires 30 to 40 minutes to administer (Warms, 2006). The Physical Activity Scale for Individuals with Physical Disabilities, however, is a simple 13-item survey that quantifies physical activity in terms of the metabolic equivalent of the task (MET) values (Washburn et al., 2002), and assesses the low intensity activities that are the most common activities among individuals with disabilities (Warms, 2006). Accordingly, the Physical Activity Scale for Individuals with Physical Disabilities is possibly the most appropriate choice to conduct a large scale study within a population like individuals living with PD. Thus, given the need to understand current levels of physical activity among individuals with PD, and the lack of PD population validated measurement tools, this study aims to examine physical activity levels, facilitators, and barriers to engagement within the PD population using the Physical Activity Scale for Individuals with Physical Disabilities.

# Methods

*Participants*

A package containing the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD; Washburn et al., 2002), a letter of information, and an engraved pen (included as a token of appreciation for participants) was mailed to 120 individuals with PD. All prospective participants were drawn from the practice of a single movement disorder specialist, and were sampled non-purposively, except for the following inclusion/exclusion criteria: (1) confirmed diagnosis of PD; (2) not currently hospitalized; (3) not in a residential care, or long-term-care facility; and (4) having a Hoehn and Yahr score of 3 or less. Sixty-three individuals with PD between the ages of 52 and 87 (31 women; *M*=70.97, *SD*=7.53) returned surveys for an overall return rate of 52.5%.

The letter of information underscored that completion of the questionnaire would have no impact on the participant's medical care, and consent to participate was implied with survey return. The procedures, questionnaire, and consenting practices described herein were approved by the Health Sciences Research Ethic Board at the University of Western Ontario.

*Instrumentation*

The PASIPD consists of 13 items that document the number of days per week and hours per day of participation in leisure activities, household activities, occupational activities, and inactivity over the past 7 days (Washburn et al., 2002). The scoring process is based on intensity values known as the 'metabolic equivalent of the task' (MET) - one MET is the ratio of the energy expenditure of an activity over the energy cost of the resting metabolic rate, which is approximately equivalent to consuming 1 kcal per kilogram body weight per hour (Taylor et al., 1978). The scale's total score is obtained by multiplying the average hours per day of each item by the MET value associated with the intensity of the activity and adding these values across item 2 through 13. The maximum possible score is 199.5 MET hours per day (Washburn et al., 2002). Activities that included the use of a wheelchair were removed from items 2, 4, 5 in the original PASIPD template, as those activities were not relevant to the current sample. In addition, three Likert scale items were included: (1) a question inquiring about the participant's perception as to the effects of PD on his or her physical activity; (2) an item that queried an individual's satisfaction with his or her current level of physical activity; and (3) a question that evaluated the representativeness (as compared with typical activity levels) of the last seven days' worth of activity. In addition to these Likert items, a close-ended (yes/no) question was added to the end of the questionnaire, which was intended to evaluate the survey's ability to allow participants to describe current levels of physical activity, as well as an open-ended item inquiring the total number of hours per week engaged in physical activity. Finally, five open-ended questions concerning types of physical activity, and facilitators and barriers to physical activity were included to gain insight into the specific needs and physical activity conditions of the Parkinson's population. These additional items are presented in Table 3.1.

Table 3.1

*Additional Items*

| | Item | Response |
| --- | --- | --- |
| Likert Scale Items (5 point) | I am satisfied with my current physical activity level. | From '*Strongly Disagree'* to *'Strongly Agree'* |
| | The amount of physical activity in which I have engaged over the past 7 days is typical of my usual activity. | From '*Strongly Disagree'* to *'Strongly Agree'* |
| | To what extent has Parkinson's disease affected your level of physical activity? | From '*Greatly Decreased'* to *'Greatly Increased'* |
| Close-ended Item | This survey allowed me to properly describe my current levels of physical activity. | Yes/No |
| Open-ended Items | If you take part in any physical activities, please list them below. Examples might include physical therapy, walking, dancing, aerobic exercise, muscle strength exercise, swimming, aquafit classes, yoga, sports, household work, gardening, grocery shopping, or going to the mall. | N/A |
| | How many hours in total (i.e., for all activities) per week, do you usually devote to these activities? | |
| | In what physical activities would you like to participate, but don't feel capable of performing? | |
| | In what physical activities would you like to participate, but don't have access to? | |
| | What factors facilitate (or would facilitate) your regular participation in physical activity? | |
| | What factors prevent you from engaging in regular physical activity? | |

*Data Analysis*

Descriptive statistics were computed for the PASIPD total score, as well as each individual item score, to determine the amount of physical activity in which the participants usually engage. Correlation values (Pearson's r) between selected items and the total

PASIPD score were also examined. Descriptive statistics (means, standard deviations, and percentages where appropriate) were also computed for the additional close-ended items. Open-ended questions were subjected to a thematic analysis, and main themes were extracted and evaluated.

**Results**

*Quantitative Analysis of PASIPD*

The descriptive characteristics of the sample are presented in Table 3.2. Regarding the representativeness of the physical activity reported, 86% of respondents stated that the activities in which they had engaged over the previous 7 days were representative of their usual level of physical activities. Seventy-six percent of respondents reported that their physical activity has decreased since they received their diagnosis of PD, with 35.5% indicating that their levels of physical activity have *greatly decreased*, and 40.3% indicating that their levels of physical activity have *somewhat decreased.* Item descriptives, and corrected item-total correlations for the PASIPD are presented in Table 3.3.

Table 3.2

*Sample Descriptive Characteristics*

| Variable | Values |
|---|---|
| Gender (%) | |
| Male | 50.8 |
| Female | 49.2 |
| Years of age (mean ± SD) | |
| Male | 69.4 ± 8.2 |
| Female | 71.0 ± 7.5 |
| Level of Education (%) | |
| Grade 8 | 19.0 |
| High School | 23.8 |
| Some College | 14.3 |
| Completed College or University | 31.7 |
| Post-graduate Training | 11.1 |

Table 3.3

*PASIPD Total Score and Item Scores, Along With Corrected Item-total Correlations*

| Item | MET values† | Mean (SD) (hr/d) | Correlation With PASIPD Total Score |
|---|---|---|---|
| Home repairs | 4.00 | 0.13 (0.28) | 0.42** |
| Lawn and yard work | 4.00 | 0.21 (0.31) | 0.57** |
| Outdoor gardening | 4.00 | 0.27 (0.38) | 0.61** |
| Light housework | 1.50 | 0.74 (0.54) | 0.29* |
| Heavy housework | 4.00 | 0.22 (0.35) | 0.37* |
| Light sport and recreation | 3.00 | 0.43 (0.49) | 0.02 |
| Moderate sport and recreation | 4.00 | 0.49 (0.49) | 0.35** |
| Muscle strength & endurance training | 5.50 | 0.34 (0.45) | 0.09 |
| Care for another person | 1.50 | 0.19 (0.39) | 0.29* |
| Work for pay/volunteer | 2.50 | 0.22 (0.59) | 0.11 |
| Walking with assistance | 2.50 | 0.37 (0.48) | -0.07 |
| Strenuous sport and recreation | 8.00 | 0.17 (0.37) | 0.64** |
| PASIPD total score | - | 42.48 (37.77) | - |

** $p < 0.01$
* $p < 0.05$
† Moderate intensity activities require 3 to 6 METs

The average current physical activity rate within this sample was found to be 42.48 MET hr/day (*SD* = 37.77). A graph of the response distribution on the PASIPD total score is presented in Figure 3.1. Interestingly, close to 80% of the subjects obtained a PASIPD score of 60 MET hr/day or less, which is a third of the possible maximum score of 199.5 MET hr/d. This suggests that the measure is unlikely to suffer from a ceiling effect within this population.

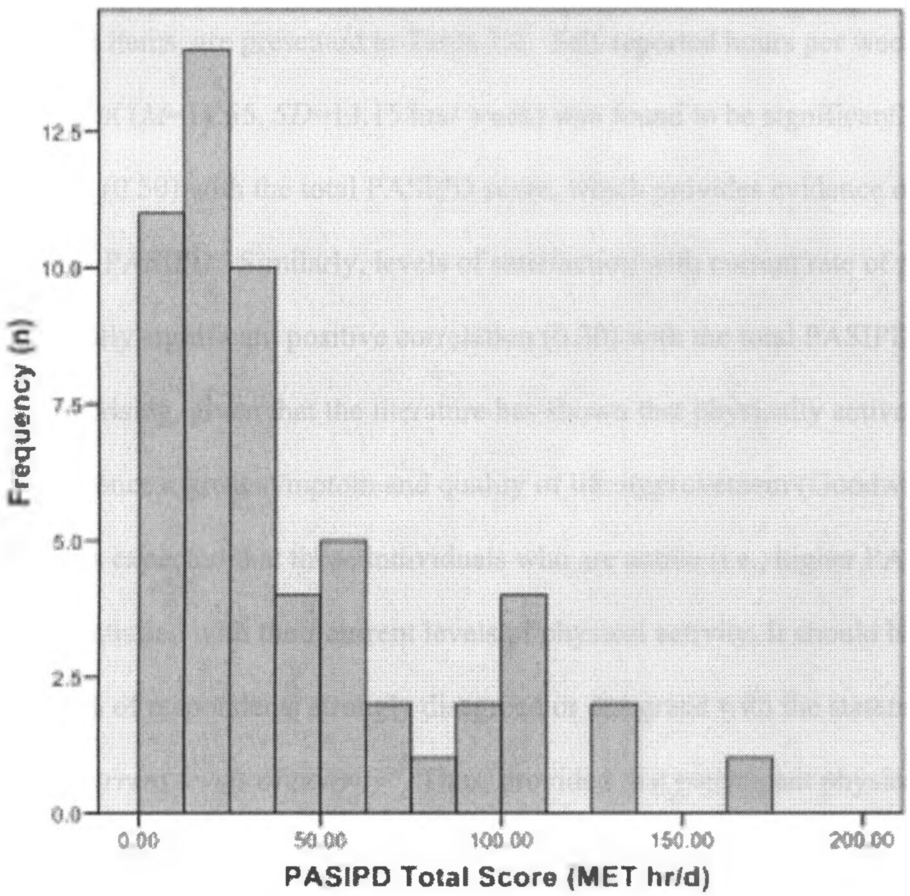


*Figure 3.1.* Total Score Distribution for the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD), among individuals with Parkinson's disease.

Pearson product-moment correlations between the PASIPD total score and selected self-report items, are presented in Table 3.4. Self-reported hours per week of physical engagement (*M*=11.65, *SD*=13.15 hrs/ week) was found to be significantly positively correlated (0.50) with the total PASIPD score, which provides evidence of face validity within the PASIPD. Similarly, levels of satisfaction with current rate of physical activity had a statistically significant positive correlation (0.30) with the total PASIPD score. This finding is not surprising, given that the literature has shown that physically active individuals with PD experience a great symptom and quality of life improvement (Goodwin et al., 2008), and thus it was expected that those individuals who are active (i.e., higher PASIPD score) would be more satisfied with their current levels of physical activity. It should be noted, however, that 58.3% of respondents strongly disagreed or disagreed with the statement *"I am satisfied with my current levels of activity"*. Thus, provided that participant physical capacity supports increased physical activity, there is a perceived need among individuals with PD for greater amounts of physical activity.

Table 3.4

*Additional Items Correlation Coefficients (Pearson's r)*

| Item | PASIPD Score |
|---|---|
| Extent to which Parkinson's has affected level of physical activity | -0.39** |
| Total number of hours per week spent in physical activity | 0.50** |
| Frequency of engagement in stationary activities | -0.30* |

* $p < 0.05$
** $p < 0.01$

*Qualitative Evaluation of Responses to Open-ended Questions*

Thematic analysis was conducted by first reading the data three times to become familiar with the material. A fourth reading of the data was conducted to identify the most common responses for each item. Once the main responses were identified and highlighted, a frequency count was produced, that was used to determine the proportion of individuals that endorsed these popular themes. The 5 most popular physical activities reported by respondents are the following: (a) *walking* (58.18% of respondents); (b) *grocery shopping or going to the mall* (52.72% of respondents); (c) *garden/yard work* (47.27% of respondents); (d) *housework* (41.81% of respondents); and (e) *formal exercise training*, including activities such as biking, fitness classes, swimming, or strength training (38.18% of respondents). Other activities that were fairly popular include physiotherapy, yoga, and stretching. It is important to note that responses to this item overlap, and individuals that engaged in formal exercise training tended to engage in more activities than the rest of participants. Activities in which this sample of individuals with PD would have liked to engage, but did not feel capable of performing, included: (a) *organized sports and exercise*, including biking, swimming, fitness classes or outdoor activities (40.39% of respondents); (b) *walking* (26.92% of respondents); and (c) *golfing* (13.46% of respondents). Other activities that are worth mentioning are dancing and gardening. The most commonly desired, but not accessible, activities are: (a) *swimming* or *water aerobics* (29.41% of respondents); and (b) *dancing* (11.76% of respondents). It is, however, important to note that a large proportion of individuals (41.18%) indicated that overall, access was not an issue. The major facilitators to engaging in physical activity include: (a) *improvement of PD-related symptoms*, such as balance, mobility, and gait (27.27% of respondents); (b) *social motivation*, including factors such as having an exercise partner (21.21% of respondents); and (c) *regularity or* *predictability of the exercise* (18.18% of respondents). In particular, some participants expressed the desire to attend fitness classes targeted specifically to individuals with PD. In addition, not surprisingly, the major barrier to physical activity was PD-related symptoms such as lack of balance, gait impairment, decreased mobility, tremors, lack of strength, and tiredness (59.18% of respondents). A few participants reported other issues worth exploring in future studies such as fear of falling, social anxiety related to PD symptoms (e.g., self-consciousness regarding tremor), poor weather, and transportation for those individuals living in rural areas.

**Discussion**

Understanding physical activity and the context in which it occurs is essential for the planning and execution of efficient and effective physical activity programs. The literature, however, provides little information with regards to current levels of physical activity, or the facilitators and barriers to engagement among individuals with PD. In the present study, PD was found to decrease individuals' physical activity levels. Specifically, the current physical activity rate within this sample was found to be *M*=42.48, *SD*=37.77 MET hr/d, which is almost three times higher than those individuals with physical disabilities over the age of 51 years (*M*=16.5, *SD*=13.40 MET hr/d) that Washburn et al. (2002) sampled to create the PASIPD. It is important to note however, that individuals with physical disabilities tend to be highly inactive (Warms, 2006), and the validation sample included individuals with conditions such as spinal cord injury, paraplegia, amputations, and muscular dystrophy (Washburn et al., 2002), which would produce significantly greater mobility impairment than that seen among the individuals with PD within the present sample.

The American College of Sports Medicine and the American Heart Association has suggested that seniors with chronic conditions that affect mobility, should engage in moderately intense activity (3 to 6 METs) at least 5 days per week for 30 minutes or in vigorous activity (> 6 METs) at least 3 days per week for 20 minutes, as well as in muscle strengthening exercises, in order to gain health benefits (Nelson et al., 2007). These recommendations are additional to engagement in routine activities of daily living of light-intensity (e.g., self care, cooking, casual walking or shopping) or moderate-intensity activities lasting less than 10 minutes in duration (e.g., walking around home or office, walking from the parking lot). To illustrate these recommendations in terms of PASIPD values, a score was calculated for a senior with limited mobility who engaged in: (a) daily living related walking 5 to 7 days for 2 to 4 hours per day; (b) light sport or recreational activities 5 to 7 days for less than an hour per day; (c) moderate sport or recreational activities 5 to 7 days for less than an hour per day; (d) muscle strength training for 5 to 7 days for less than an hour per day; and (e) light housework 5 to 7 days for 1 to 2 hours per day. The PASIPD score for such individual was 13.74 MET hr/d. Given that the PD sample obtained a PASIPD score mean of 42.48 ± 37.77 MET hr/d, and the self-reported average hours per week of physical activity was equivalent to an hour and a half of activity per day; it is evident that individuals with PD are meeting and considerably exceeding recommended levels of physical activity to gain cardiovascular health benefits. The fact, however, that the majority of participants are not satisfied with their current levels suggests that there is room for improvement in physical activity rates among individuals with PD. This low satisfaction is possibly due to a perceived lack of improvement in PD symptoms.

The thematic analysis illustrated that walking, grocery shopping or going to the mall, garden/yard work, housework, and formal exercise training were the most common activities undertaken by respondents. In addition, although participants expressed a desire to engage in high intensity activities such as organized sports, fitness classes, and golfing, they indicated that they felt unable to engage in these activities, due to their PD symptoms. Thus, while there is a motivation to engage in more challenging activities, this motivation is hindered by lack of self-efficacy or by a lack of access to activities with appropriate difficulty scaling. Participants indicated that improvement in PD symptoms, social interaction, and organizational structure of formal activities (particularly within those activities that are tailored to the needs of individuals with PD) would facilitate their engagement in physical activity. Even though individuals with PD have physical limitations that may restrict their full participation in traditional forms of physical activity, they seem to be eager to engage in more challenging and frequent activities, given the availability of "the right programs." This study, therefore, provides not only a snapshot of the current levels of physical activity of individuals with PD, but also provides information that is valuable to researchers, program planners, and health care providers to better serve the unique needs of the Parkinson's population.

Future studies should further explore how well self-rated ability predicts, or relates to, actual ability to perform physical activity. Emotional distress, such as tremor embarrassment and fear of falling, should be further examined as deterrents of physical activity engagement. In addition, research should establish physical activity guidelines regarding types, intensity, frequency, and duration of activities that would improve PD symptoms. Finally, the creation and validation of a physical activity measurement tool specific to the PD population will be a great addition to the literature. This tool would be widely used in research, physical activity program planning, execution, and evaluation, as well as by health practitioners.

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# Chapter 4: GENERAL DISCUSSION

Parkinson's disease is a neurodegenerative process with debilitating symptoms such as gait disturbance, decreased mobility, tremors, lack of balance (Olanow & Koller, 1998), depression, cognitive impairment (Chrischilles, Rubenstein, Voelker, Wallace, & Rodnitzky, 2002; Schrag, Jahanshahi, & Quinn, 2000), sleep disturbances (Karlsen, Larsen, Tandberg, & Maeland, 1999), and social limitations (Morimoto et al., 2003). Moreover, typical treatment (long-term antiparkinsonian medication) helps to control only some of the symptoms (Crizzle & Newhouse, 2006), while causing secondary effects such as hallucinations, daytime sleepiness, leg edema, involuntary muscle contractions, and abnormal and involuntary movement of the limbs (Lohle, Storch, & Reichmann, 2009). The proportion of Canadians who live with Parkinson's disease (PD) is expected to rise as the population ages, following decades of gradually increased longevity (Bioportal Canada, 2008). Furthermore, individuals with PD are five times more likely to live in a nursing home and stay longer than their matched peers, at a cost almost five times higher (Vossius, Nilsen, & Larsen, 2009). Thus, the financial demands of symptom management, coupled with an increased demand for long-term care, point to the societal significance of efficient and effective non-medical treatments for the individual living with PD.

Interestingly, the literature consistently shows that physical activity facilitates improvements in balance, mobility, gait, physical functioning, strength, and quality of life (Goodwin, Richards, Taylor, Taylor, & Campbell, 2008). Researchers, have not, however, conducted large-scale studies that explore current rates of engagement in physical activity and the context in which it occurs, among individuals with PD. The limited availability of population-appropriate physical activity measurement tools has likely contributed to the dearth of research in this area. Appropriate tools should take into consideration the types and intensity of activities that individuals with limited mobility (as is the case with PD) are able to perform, as well as their cognitive ability to recall and comprehend the scale (Wilcox, Ainsworth, Shumaker, Ockene, & Riekert, 2009). In absence of a physical activity scale validated and created for individuals with PD, the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD; Washburn, Zhu, McAuley, Frogley, & Figoni, 2002) is likely to be an appropriate scale to use, as it was designed and validated for individuals with limited physical mobility. In Chapter 2, we evaluated the PASIPD, in order to demonstrate the reliability, validity, and factor structure of this measure within a sample of individuals with PD. This study provided valuable information to researchers who are interested in finding an appropriate physical activity measure or developing a physical activity scale for individuals with PD. Also, it presented information that enhances the understanding of physical activity, and facilitators and barriers to engagement; which is essential for making informed decisions in future research, program planning, and health care delivery.

To evaluate the factor structure of the PASIPD, a principal components exploratory factor analysis was conducted, using multiple methods for identifying the appropriateness of the number of extracted factors. In addition, internal consistency was evaluated by obtaining the Cronbach's α value. Convergent validity was examined by obtaining Pearson product-moment correlations between the PASIPD total score mean and additional self-report items inquiring about the effect of Parkinson's disease on physical activity, satisfaction with physical activity levels, and self-reported hours per week of physical activity. Similarly, a quantitative descriptive analysis of the PASIPD was conducted (in Chapter 3) to assess current physical activity levels within individuals with PD. Common types of physical activities performed, facilitators, and barriers were identified through thematic analysis.

A three factor solution was found to be both mathematically defensible, and theoretically sound, with the following factors identified within the PASIPD: (1) *housework and home outdoor activities*; (2) *recreational and fitness activities*; and (3) *occupational activities*. These factors accounted for approximately 50% of the variance in the total solution, thus providing a reasonable reduced solution. Item 2 (*"walking with assistance"*) was problematic within all factor solutions, as it did not load substantively or uniquely on any of the factors. Additionally, Cronbach's α improved considerably upon removing this item from the variable list. A subsequent re-analysis of the factor solution suggests that the previously obtained three factor solution was still supported, and also suggested that the results of this analysis were consistent with the theoretical interpretations of the previous solution. As the wording of this item may be problematic, future iterations of the PASIPD used within a sample of individuals with PD should pay particular attention to this item within the measure, possibly re-writing it, or removing it from the measure altogether.

Convergent validity was supported through the demonstration of significant Pearson product-moment correlation values among items expected to correlate: (a) a negative correlation between the total PASIPD score and the extent to which the individual perceived Parkinson's disease to have affected his or her physical activity level; (b) a positive correlation between the total PASIPD score and the self-report estimate of total number of hours per week spent in physical activity; and (c) a negative correlation between the frequency of stationary activities and the total PASIPD score. Furthermore, the majority of participants reported being able to complete the survey without any assistance, which is indicative of the scale's comprehensibility within this population. The majority of participants also reported that the scale allowed them to properly describe their levels of physical activity. In conclusion, therefore, the measure was found to be internally consistent, valid, practical to implement via a mass-mailout to a sample of individuals with PD, comprehensible to participants, and was also found to have a theoretically defensible factor structure. It is likely that this measure would be useful in the surveillance of physical activity among individuals with PD, and would be useful for large scale surveys of physical activity within the greater PD population.

Subsequent quantitative descriptive analysis (i.e., Chapter 3) indicated that participants felt that PD decreased their physical activity levels, which corroborates the findings of Fertl et al. (1993), who conducted retrospective interviews with 32 individuals with PD. The current physical activity rate within this sample was found to have a mean PASIPD score of 42.48 ± 37.77MET hr/d, and self-reported physical activity was found to be (on average) equivalent to an hour and half per day of physical activity (including daily living activities). When these findings are compared to the recommended levels of physical activity given by the American College of Sports Medicine and the American Heart Association for seniors with limited mobility, it seems that individuals with PD are meeting (and considerably exceeding) these guidelines. Specifically, to gain health benefits, it is recommended to participate in moderately intense activity (3 to 6 METs) at least 5 days per week for 30 minutes or in vigorous activity (> 6 METs) at least 3 days per week for 20 minutes, and engage in muscle strength exercise, in addition to daily living activities (which are considered to be of light intensity; Nelson et al., 2007). These recommendations can be illustrated in terms of PASIPD values by examining the PASIPD score of a hypothetical individual that engages in: (a) daily-living-related-walking on 5 to 7 days of the week, for 2 to 4 hours per day; (b) light sport or recreational activities on 5 to 7 days of the week, for less than an hour per day; (c) moderate sport or recreational activities on 5 to 7 days of the week, for less than an hour per day; (d) muscle strength training on 5 to 7 days of the week, for less than an hour per day; and (e) light housework on 5 to 7 days of the week, for 1 to 2 hours per day. Such an individual is almost certainly meeting the recommended guidelines for physical activity, and would have a PASIPD score of 13.74 MET hr/d. The individuals with PD assessed within the present study are at least three times more active than such an individual, and are thus reporting more than enough physical activity, to gain cardiovascular health benefits. Room for improvement may, however, exist – individuals with PD reported being unsatisfied with their current levels of physical activity. These low levels of satisfaction are possibly due to their perceived lack of improvement in PD symptoms, which individuals may be attributing to 'low levels' of physical activity.

Similarly, thematic analysis identified walking, grocery shopping or going to the mall, garden/yard work, housework, and formal exercise training as the most common activities undertaken by respondents. Participants also expressed their motivation to attend organized fitness classes, or participate in high-intensity-level activities (e.g., golfing, biking, swimming, etc.), but noted that their  actual engagement is hindered, to a certain extent, by self-perceived lack of ability. Social interaction and organizational structure of formal activities (particularly within those activities that are tailored to the needs of individuals with PD) were reported as facilitators to physical activity engagement. Not surprisingly, PD-related symptoms were found to be the major barrier to engagement in physical activity. Thus, quantitative and qualitative analyses support the finding that PD-related symptoms are perceived to have a considerable effect on physical activity rates, but that individuals seem to be motivated to engage in more challenging physical activities, provided that adequate guidance is provided. Interestingly, the findings also suggest that individuals are managing to engage in substantially more than the minimally recommended amount of physical activity, per the recommendations of the American College of Sports Medicine, and the American Heart Association. This paradoxical finding should be investigated in future research, as it may suggest: (a) that individuals are over-reporting their levels of physical activity on specific items of the PASIPD; (b) that they are under-valuing the value of their current levels of physical activity (as demonstrated by the mismatch between their satisfaction with their physical activity and their actual levels of physical activity); or (c) that individuals with PD may require substantially greater levels of physical activity in order to achieve qualitatively obvious improvements to self-perceived wellness.

**4.1 Limitations of the Present Study**

The factor analysis findings should be examined with some caution as the sample size did not fulfill the suggested 10 participants per item for an optimal factor analysis (Nunnally, 1978), and Kaiser's sample adequacy criterion (the Kaiser-Meyer-Olkin score) only approximated the minimum value required for an adequate factor analysis. In addition, even though removal of item 2 did not distort the interpretability of the three factor model; it is possible that this item introduced bias to the overall scale. Finally, given that the PASIPD was developed (and originally validated) within a sample of individuals with various types of disabilities, such as vision impairment, hearing impairment, post-polio, paraplegia, cerebral palsy, spinal cord injury, amputations, and muscular dystrophy (Washburn et al., 2002), it is possible that unknown aspects of the physical activity construct within PD were not addressed. The recommended levels of physical activity to which the findings of the present study were compared to, were a result of a literature review (literature from 1991 to 2004) conducted by a panel of experts in public health, behavioral science, epidemiology, exercise science, medicine, and gerontology. It is important to note that the "health benefits" specified by these panels are not specific to PD, but pertain more specifically to cardiovascular health. It is possible (and is in fact likely, given the disparity between the levels of demonstrated physical activity, and the self-reported satisfaction with physical activity within the present sample) that substantively greater levels of physical activity are necessary in order to achieve significant relief from PD symptoms.

**4.2 Future Directions**

The PASIPD's factor structure should be examined with a larger sample of individuals with PD, and the questionnaire should be revised to include a different version of the *"walking with assistance"* item. Further examination of the PASIPD's criterion validity, using objectively scaled quantitative instruments such as accelerometers or pedometers, should be conducted within a sample of individuals with PD. Future scale development or upgrade should include alternative ways to be physically active, such as videogame systems (such as the Nintendo Wii) which have become popular among seniors for engagement in recreational physical activity (Yin-Leng, Amirrudin Bin, Meutia Latifah, & Thant Zin, 2009). Such activities may also be used as a source for validation information (i.e., through activity logs stored within the game console). Furthermore, more research should be conducted to understand current levels of physical activity and the context in which it occurs. Physical activity guidelines, regarding type, intensity, frequency, and duration of activities that result in PD symptom improvement, should be established to inform individuals with PD, health care providers, researchers, program planners, and policy makers. Future studies should also explore whether individuals with PD are as active as they can be, and how self-perceived ability predicts or relates to actual engagement. Emotional distress such as tremor embarrassment and fear of falling should be further examined as deterrents of physical activity engagement. Interventions that incorporate social support and organized fitness classes targeted to individuals with PD should be evaluated in regards to compliance and continuation rates.

**4.3 Conclusion**

The benefits of physical activity for individuals living with PD are well supported in the literature. A dearth of research however, exists in regards to current rates of physical activity and the context in which it occurs within the PD population. Limited availability of an adequate physical activity scale possibly have contributed to the lack of large scale studies within individuals with PD. In absence of a scale specific to individuals with PD, the PASIPD, a short scale that was designed to assess physical activity within individuals with limited mobility, was selected for validation and examination of physical activity within the PD population. The results of the present study suggest a theoretically sound three factor model: (1) *housework and home outdoor activities* (2) *recreational and fitness activities*; and (3) *occupational activities*. Convergent validity was also supported, as PASIPD scores correlated as expected with items tapping into PD's effect on physical activity, satisfaction of current levels of physical activity, self-reported hours per week of physical activity, and frequency of stationary activities. Parkinson's disease considerably decreases physical activity engagement. Current levels of physical activity however, seem to meet and exceed recommended levels. In general, individuals with PD are not satisfied with current levels of physical activity, and as a result, are motivated to engage in formal high intensity fitness classes. Future studies should examine the PASIPD's validity within a larger sample or develop a physical activity scale for individuals with PD. Researchers should evaluate further the context in which physical activity occurs within the PD population. Finally, further research and debate is needed to establish realistic recommended levels of physical activity, for the achievement and maintenance of patient-driven health outcomes within the PD population.

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Appendix A

Ethics Approval Forms

# LAWSON HEALTH RESEARCH INSTITUTE

## CLINICAL RESEARCH IMPACT COMMITTEE

RESEARCH OFFICE REVIEW NO.: R-09-213

PROJECT TITLE: Evaluation of Physical Activity Participation Among Individuals with Parkinson's Disease Using the Physical Activity Scale for Individuals with Physical Disabilities

PRINCIPAL INVESTIGATOR: Dr. A Johnson

DATE OF REVIEW BY CRIC: May 27, 2009

Health Sciences REB#: 16089E

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 Paiva, Room C210, Nurses Residence, South Street Campus.*

cc: Administration

Western

## Office of Research Ethics

The University of Western Ontario
Room 4180 Support Services Building, London, ON, Canada N6A 5C1
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

## Use of Human Subjects - Ethics Approval Notice

**Principal Investigator:** Dr. A.M. Johnson
**Review Number:** 16089E **Review Level:** Expedited
**Review Date:** April 08, 2009
**Protocol Title:** Evaluation of Physical Activity Participation Among Individuals with Parkinson's Disea Using the Physical Activity Scale for Individuals with Physical Disabilities
**Department and Institution:** Faculty of Health Sciences, University of Western Ontario
**Sponsor:**
**Ethics Approval Date:** April 28, 2009 **Expiry Date:** August 31, 2011
**Documents Reviewed and Approved:** UWO Protocol. Letter of Information
**Documents Received for Information:**

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Huma Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines: and the applicable laws regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Dru Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that tim you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) inv only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Joseph Gi

| Ethics Officer to Contact for Further Information | | | |
|---|---|---|---|
| ☐ Janice Sutherland | ☐ Elizabeth Wambolt | ☐ Grace Kelly | ☒ Denise Grafton |

*This is an official document. Please retain the original in your files.* cc: OR

Appendix B

Information Letter

**Title of Research**: Evaluation of Physical Activity Participation Among Individuals with Parkinson's Disease.

**Investigators**:

Andrew Johnson, PhD
Associate Professor
School of Health Studies

Shauna Burke, PhD
Assistant Professor
School of Health Studies

Mary Jenkins, MD, FRCPC
Assistant Professor
Clinical Neurological Sciences

Christopher Hyson, MD, RCPC
Assistant Professor
Clinical Neurological Sciences

Timothy Doherty, MD, PhD, FRCPC
Associate Professor
Clinical Neurological Sciences &
Physical Medicine and Rehabilitation

You are invited to participate in a research study that aims to assess levels of physical activity participation among individuals with Parkinson's disease, and to identify potential facilitators and barriers to this physical activity.

We are sending this survey to approximately 500 individuals with Parkinson's disease. Please take your time to make a decision, and discuss this proposal with your personal doctor, family members and friends as you feel inclined.

The attached survey is intended to assess your physical activity over a seven-day period, and should take approximately 25 minutes for you to complete. You may complete the questionnaire at your leisure, in your own home, and then return the questionnaire in the addressed stamped envelope included with this package. Your return of the completed questionnaire will be taken to indicate your consent to participation in this study.

Although there are no known risks or benefits associated with your participation in this research, your participation may increase our understanding of the types of physical activities engaged in by individuals with Parkinson's disease, and may allow us to improve access to these activities. Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time with no effect on your future medical care.

If you choose to participate, your completed questionnaire will be stored without any identifying information, except for a participant identification number. Please do not write your name on the questionnaire. Any electronic records created from this completed questionnaire will be similarly stripped of identifying information, and will be stored indefinitely in a location that is not accessible over the internet. All records (including any information that may be used to link your contact information with your questionnaire data) will be locked in a file cabinet within a locked and secure room. Only the study investigators will have access to your data. If the results of this study are published, your name will not be used and no information that discloses your identity will be released or published without your explicit consent to the disclosure.

If you have any questions about your rights as a research participant or the conduct of the study you may contact: Dr. David Hill, Scientific Director, Lawson Health Research Institute If you would like to obtain further information concerning the study itself, you may contact any of the co-investigators for this project, listed at the outset of this document.

Finally, if you would be willing to be contacted for participation in future studies within our laboratory, involving quantitative assessment of your gait (i.e., your walking) or your posture, please indicate this on the final page of the questionnaire. We will utilize the participant identification number listed at the top of your questionnaire, to identify you within our research database.

Completion and return of the questionnaire indicates your consent to participate in this study. This letter is yours to keep.

Thank you,

Dr. Andrew M. Johnson

Dr. Shauna Burke

Dr. Mary Jenkins

Dr. Christopher Hyson

Dr. Timothy Doherty