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Measuring Participation in Individuals with Parkinson Disease: Relationships with Disease Severity, Quality of Life, and Mobility

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Abstract

Purpose: Our aims were to: 1) describe participation in people with Parkinson disease (PD), 2) evaluate the relationship between quality of life and participation, and 3) determine which mobility measures predict participation.

Methods: Participants with idiopathic PD (n=62) were tested off medication for participation (Activity Card Sort), quality of life (PDQ-39), disease severity (MDS-UPDRS), and mobility (Berg Balance Scale, Five Time Sit to Stand (FTSTS) , Six Minute Walk, forward walking velocity, dual-task walking velocity, and Freezing of Gait Questionnaire (FOGQ)). Relationships of all variables to participation were examined using Pearson correlations. Subsequent regression analysis was employed to determine which mobility measures best predicted participation.

Results: Participants with PD retained, on average, 78.3% (SD = 15.6%) of total activities. Participation was negatively correlated with all PDQ-39 domains (*r* range -.36 to .-78, all $p < 0.005$) with the mobility domain having the strongest correlation. All mobility measures were significantly correlated with participation, with the final regression model including only FTSTS and FOGQ which combined explained 37% of the variance in participation.

Conclusions: Participation is highly related to mobility-related QOL and may be most impacted by ability to stand up from a chair and freezing of gait in those with PD.

Introduction

Parkinson Disease (PD) is a progressive, neurologic disorder associated with degeneration of the dopamine-producing cells in the substantia nigra [1]. The cardinal features of PD are rigidity, bradykinesia, tremor, and postural instability [2]. In an individual with PD, it is understood that these motor symptoms can disrupt daily functions, roles and activities [3]. These functions, roles and activities comprise the meaning of the term participation, which is defined by the International Classification of Functioning, Disability and Health (ICF) as the patient's involvement in life situations [4]. Engagement in social activities has been positively correlated with well-being [5]; participation in activities has been shown to contribute to the maintenance of function and quality of life in older adults [6]. Because of the association between activity engagement, quality of life, and well-being, it is essential to understand how participation in activities may or may not be affected in individuals with PD.

To our knowledge, participation in activities has not yet been described or quantified in individuals with PD, though several studies have examined level of physical activity. Previous studies have used activity monitors to determine amount of walking activity performed by individuals with PD [7-9]. Others have used qualitative methods to determine how PD has affected physical mobility and quality of life [10, 11]. However, it is unclear whether understanding aspects of an individual's physical activity may be associated with one's participation in life situations. Although participation in activities has not been described or quantified in PD, previous studies described, and occasionally quantified, participation in people with neurologic conditions in other populations [12- 14]. The Activity Card Sort (ACS) [15] has emerged as a unique tool for measuring participation in activities in older adults and individuals with a neurological condition [13, 16-22]. The ACS contains items from all domains of the ICF 'Activity & Participation' category [4].

The purposes of this study are to: 1) describe and quantify participation in activities and social participation in individuals with PD using the Activity Card Sort and 2) evaluate the relationship between participation in activities and quality of life in those with PD, and 3) determine which factors are most related to participation in activities. We hypothesized that activity engagement and social participation would be reduced in those with PD and would be negatively correlated with disease severity. Identification of factors that contribute to reduced participation in activities is important in order to facilitate the development of interventions to increase activity and social participation and thereby, potentially improve quality of life for people with PD.

Methods

Participants

Participants for this study were recruited using databases from the Washington University School of Medicine Movement Disorders Centre and from the Washington University Volunteers for Health, advertisements in the Greater St. Louis Chapter American Parkinson Disease Association newsletter, and word of mouth. The target population for this study was individuals of any age with a diagnosis of idiopathic PD (Hoehn & Yahr (H&Y) Stages 1-4). Via telephone interview, potential participants were excluded if found to have any of the following: 1) a serious medical problem, 2) evidence of abnormality other than PD-related changes on brain imaging (previously done for clinical evaluations-not part of this research), 3) history or evidence of neurological deficit other than PD that could interfere, such as previous stroke or muscle disease, 4) history or evidence of orthopedic or muscular problem, or 5) a diagnosis or evidence of dementia. Recruitment was done as part of a larger clinical trial and data were collected as part of the baseline evaluation for this larger trial. The recruitment goal for the larger study was 60 subjects. Each participant gave informed consent in

accordance with the policies and procedures of the Washington University School of Medicine's Human Research Protection Office.

Outcome Measures

The ACS is a collection of 89 pictured activity cards that are sorted by an individual in order to determine how one's participation in activities has been affected due to the onset of a certain condition. The pictured activities fall into one of four domains which are: 1) Instrumental Activity of Daily Living (IADL), 2) Low-Demand Leisure Activity (LDLA), 3) High-Demand Leisure Activity (HDLA), and 4) Social Activity. Participants then sort these cards into one of five categories: 1) Continued to Do Since Illness, 2) Do Less Since Illness, 3) Given up Due to Illness, 4) New Activity Since Illness, or 5) Not Done Prior to Illness, with PD being the illness to which the categories referred. Following completion, the examiner would use the ACS scoring sheet to determine the percentage of activities retained in IADL, LDLA, HDLA, and Social, as well as the total percentage of activities retained. Baum and Edwards previously established test-retest reliability of the ACS in a study of twenty community-residing older adults. The test-retest reliability coefficient was .89 with one week between testing [15]. Katz and colleagues studied the discriminative validity of the ACS using 5 groups (healthy adults, healthy older adults, people who have had a stroke, people with multiple sclerosis, and spouses and caregivers of people with Alzheimer's disease) and found significant differences between groups ($p < .0001$) for current activities performed and retained activity levels [13].

A variety of measures were used in the study to examine characteristics of disease severity and mobility in participants with PD. The full Movement Disorders Society Unified Parkinson Disease Rating Scale (MDS-UPDRS) was completed [23]. The Berg Balance Scale (BBS) is a well-established tool commonly used to measure balance and has been found to be both reliable and valid [24-26]. Interrater and intrarater reliability were measured when testing individuals with PD, the intraclass correlation

coefficients were 0.74 and 0.87, respectively [24]. The Five Times Sit to Stand test (FTSTS) has been shown to possess discriminative validity in that it was able to discriminate between individuals with and individuals without balance disorders [27]. Lord and colleagues found that strength explains a significant portion of the variance in performance of FTSTS [28] Test-retest reliability was found to be high (ICC = .89) for a subset of thirty older adults with a variety of health conditions; however, those with PD were excluded [28]. Forward walking and dual task walking velocities were recorded using the 5-metre, computerized GAITRite walkway (CIR Systems, Inc, Havertown, PA). The Six Minute Walk Test (6MWT) is a commonly used measure of walking capacity in individuals with PD [29-32]. The 6MWT has demonstrated high test-retest reliability (ICC = .96 [33] and ICC = .95 [34]) when examining those with PD.

Two questionnaires were used to assess each participant's quality of life and freezing of gait. Quality of life was measured using the Parkinson Disease Questionnaire-39 (PDQ-39), which has demonstrated good internal and test-retest reliability, as well as good construct validity [35-36] For the summary index score, high internal reliability was found with a Cronbach's α of 0.84 [37]. The Freezing of Gait Questionnaire [38] was issued to quantify freezing of gait. Giladi and colleagues found the FOGQ to be a reliable (r = 0.84) and valid tool as it was able to identify 85.9% of those who experience freezing [39].

Procedures

All of the aforementioned outcome measures were completed in the Locomotor Control Laboratory in the Program in Physical Therapy at Washington University School of Medicine. In order to avoid variability in response to anti-Parkinson medication, participants were tested OFF medication. For a participant to be considered OFF of medication, the participant must have reported a withdrawal of all anti-Parkinson medication for greater than or equal to 12 hours. All participants were assessed by the

same rater. The participants completed each outcome measure in the following order: 1) MDS-UPDRS III, 2) BBS, 3) Forward walking velocity (FWV) and dual task walking velocity (DTWV) on the GAITRite, 4) FTSTS, 5) 6MWT. Regarding forward walking, participants completed three trials at a self-determined 'normal' speed. Dual task walking involved three trials in which the participant walked forward at their 'normal' speed while naming as many words as possible that began with a certain letter of the alphabet. The first letter used was 'H', the second, 'L', and the third was 'T'. The three trials for both FWV and DTWV were averaged to determine the mean walking velocity for each condition. Following the completion of all mobility measures, the participants were instructed to take their usual dose of anti-Parkinson medication. The participants then completed the ACS, PDQ-39, and FOGQ, and MDS-UPDRS-I, II, IV (non-motor, activities of daily living, and motor complication subscales) [24].

Statistics

To determine the relationships between participation in activities, as assessed by the percentage of total retained activities on the ACS (ACS_{total}), and other measures, Pearson correlations were used. No corrections were made to account for the multiple relationships examined, as we considered this to be an exploratory analysis given that this is the first study to examine the ACS in individuals with PD. Those measures most related to ACS_{total} then were entered into a simultaneous regression analysis to determine which factors are most predictive of participation levels. All analyses were conducted with NCSS software [40].

Results

Of the 112 individuals meeting all eligibility criteria who were invited to participate, 62 agreed to take part in the study. Those who agreed to participate were not systematically different from those who opted not to participate. Evaluations of participants began October 1st, 2009 and ended on

December 31st, 2009. The final sample was 56% male with a mean age ± SD of 70.3 ± 8.9 years and an average H&Y stage ± SD of 2.5 ± 0.5 (range 1-4). Figure 1 displays the percentage of retained activities for each category of the ACS, including ACS_{total}. Regarding demographic and disease severity information, age was mildly but significantly correlated with participation (i.e. ACS_{total}), while gender and H&Y stage were not related to participation in activities (see Table 1). All sections of the PDQ-39 demonstrated significant correlations with ACS_{total} ranging from mild to strong with PDQ-Mobility having the strongest relationship with participation in activities (Table 1).

All mobility measures were significantly correlated with participation. Figure 2 shows scatter plots illustrating the relationships between each mobility measure and ACS_{total}. Many of the mobility measures were also highly correlated with one another (Table 2). As such, it was not appropriate to include all mobility measures in the regression analyses due to concerns about colinearity. The final regression model included only two mobility measures, FTSTS and FOGQ, which combined explained 37% of the variance in ACS_{total} (Table 3). It is worth noting that the BBS alone was able to explain 24% of the variance in ACS_{total} but was not included in the final regression because of its high correlations with the other mobility measures. Addition of the BBS, 6MWT, FWV, or DWV alone and in various combinations resulted in mild to severe colinearity and provided only minimal increases in the amount of variance explained.

Discussion

Restoration of physical function is often the focus of rehabilitation programmes, while participation in activities is often left unaddressed. It is not yet understood whether or not participation is reduced in those with PD, and as such, this study sought to characterize activity participation levels in those with PD using the ACS and to determine the factors to which activity engagement is related.

Individuals with PD demonstrated reductions in all categories of the ACS. Total percent of activities retained was significantly negatively correlated with disease severity as assessed by the MDS-UPDRS.

There was also a strong, negative correlation between overall QOL, as measured by the PDQ-39, and participation in activities. The mobility section of the PDQ-39 demonstrated an even stronger inverse relationship with the ACS. It has been previously established that mobility plays a significant role in QOL [41-44]; however, until now mobility-related QOL has not yet been examined in relation to participation in activities. This study shows that those with decreased QOL participate less in a wide range of activities with a strong specific relationship for mobility. While mobility is a term that encompasses many things, it is important to understand which aspects of mobility may affect activity engagement in individuals with PD.

Overall, FTSTS and FOGQ combined to account for 37% of the variance in participation in activities. While the other mobility measures were also significantly correlated with participation, they were also highly correlated with one another. FTSTS and FOGQ appear to be measuring two distinct and unrelated aspects of mobility, both of which may influence participation. The identification of mobility factors that influence activity engagement is important for rehabilitation professionals who must decide which of these modifiable factors to target during interventions. Our results suggest that interventions targeted at improving mobility, and in particular lower extremity strength (FTSTS) and freezing of gait, may lead to increased participation in high demand leisure activities in individuals with PD; however, future research is needed to confirm this hypothesis.

Comparison to Other Populations

When compared to the populations (multiple sclerosis, stroke, healthy elderly) studied by Katz and colleagues, the participants with PD in this study had a higher percentage of activities retained in all ACS categories, except IADL, exceeded only by healthy elderly [13]. It is important to note that an Israeli

version of the ACS was used in the study by Katz, whereas, in the current study, a US edition of the ACS was implemented [13].

Limitations and Future Directions

One possible explanation for the high percentage of activities retained in those with PD is that the participants had to be willing to travel into the community to take part in this study. As such, our sample may reflect those with PD who have retained higher levels of participation than the general PD population. The percentage of activities retained would likely be lower if those individuals with PD who were homebound were included. Future work could consider administering the ACS in the homes of individuals with PD to obtain a clearer picture of participation levels across the full spectrum of the disease.

Cognitive deficits, including dementia, are commonly seen in those stricken with PD [45]; however individuals with cognitive impairments or dementia were not included in this study. The authors identify the lack of a specific measure for cognitive function as a limitation to the present study. It is not yet understood how cognitive function may impact performance on the ACS in those with PD, and this would be an important concept requiring further research.

We also did not employ any correction for the multiple correlational relationships examined, given the exploratory nature of the study. However, we think such a correction would have had little impact on the results, as many of the correlations were highly significant ($p < 0.0001$).

Conclusion

Individuals with PD experience reduced participation in activities. Mobility measures explained a substantial portion of the variance in activity engagement, which suggests that mobility significantly

influences one's level of participation in activities. While physical therapists often focus on movement activities such as sit to stand, forward walking, turning or other tasks in those with PD, often left unaddressed is whether or not improvements in these tasks increase participation in activities. The ACS provides insight into the specific roles and activities one performs less or has given up due to the disease, and can facilitate an improved client-centered approach to rehabilitation. Future research is necessary to determine whether or not interventions targeted at improving mobility actually increase levels of participation in activities in those with PD.

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Declaration of Interest

This study was funded by a grant from the Parkinson's Disease Foundation. The authors have no commercial or financial interests related to this work. The study sponsors played no role in the study design, collection, analysis and interpretation of data, the writing of the manuscript, the final conclusions drawn, or the decision to submit the manuscript for publication.

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Table 1. Pearson Correlations with ACS_Total.

	Variable	Correlation	*p* Value
Demographics and Disease Severity	Gender	-0.08	0.512
	Age	-0.26	**0.041**
	H&Y	-0.18	0.167
	MDS-UPDRS-I	-0.29	**0.024**
	MDS-UPDRS-II	-0.72	**0.000**
	MDS-UPDRS-III	-0.41	**0.001**
	MDS-UPDRS-IV	-0.22	0.080
	MDS-UPDRS-Total	-0.60	**0.000**
PDQ-39	PDQ-Mobility	-0.75	**0.000**
	PDQ-ADL	-0.57	**0.000**
	PDQ-Emotional	-0.44	**0.000**
	PDQ-Stigma	-0.39	**0.002**
	PDQ-Social	-0.35	**0.005**
	PDQ-Cognitive	-0.32	**0.009**
	PDQ-Communication	-0.56	**0.000**
	PDQ-Bodily Discomfort	-0.33	**0.008**
	PDQ-Summary Index	-0.66	**0.000**

Table 2. Pearson Correlations Between Measures of Mobility

	BBS	FTSTS	6MWT	FOG-Q	DTWV	FWV
BBS	-	-0.16	0.79	-0.68	0.63	0.76
FTSTS		-	-0.30	-0.03	-0.27	-0.30
6MWT			-	-0.44	0.80	0.86
FOGQ				-	-0.35	-0.38
DTWV					-	0.85
FWV						-

Table 3. Final Regression Model

	B	SE B	**β**	**R^2 When I.V. Fit Alone**	**Partial R^2**
FTSTS	-0.0055	-0.4061	-0.005	0.16	0.21
FOG-Q	-0.0148	-0.4679	-0.011	0.21	0.26

Figure Legends

Figure 1. Percentage of activities retained in each of the four categories of the Activity Card Sort as well as overall percent retained (ACS_TOTAL). The four categories are instrumental activities of daily living (IADL), low demand leisure activities (LDLA), high demand leisure activities (HDLA), and social activities (SOC). Values are means ± SDs.

Figure 2. Scatter plots illustrating the relationships between each mobility measure and participation as assessed by the ACS. All mobility measures were significantly correlated with ACS_Total.

Figure 1

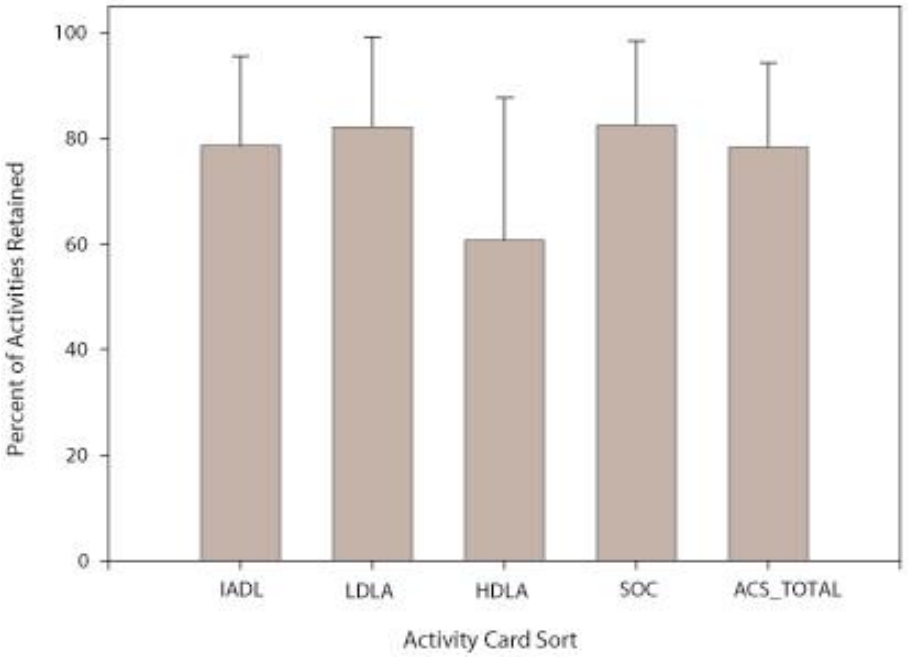
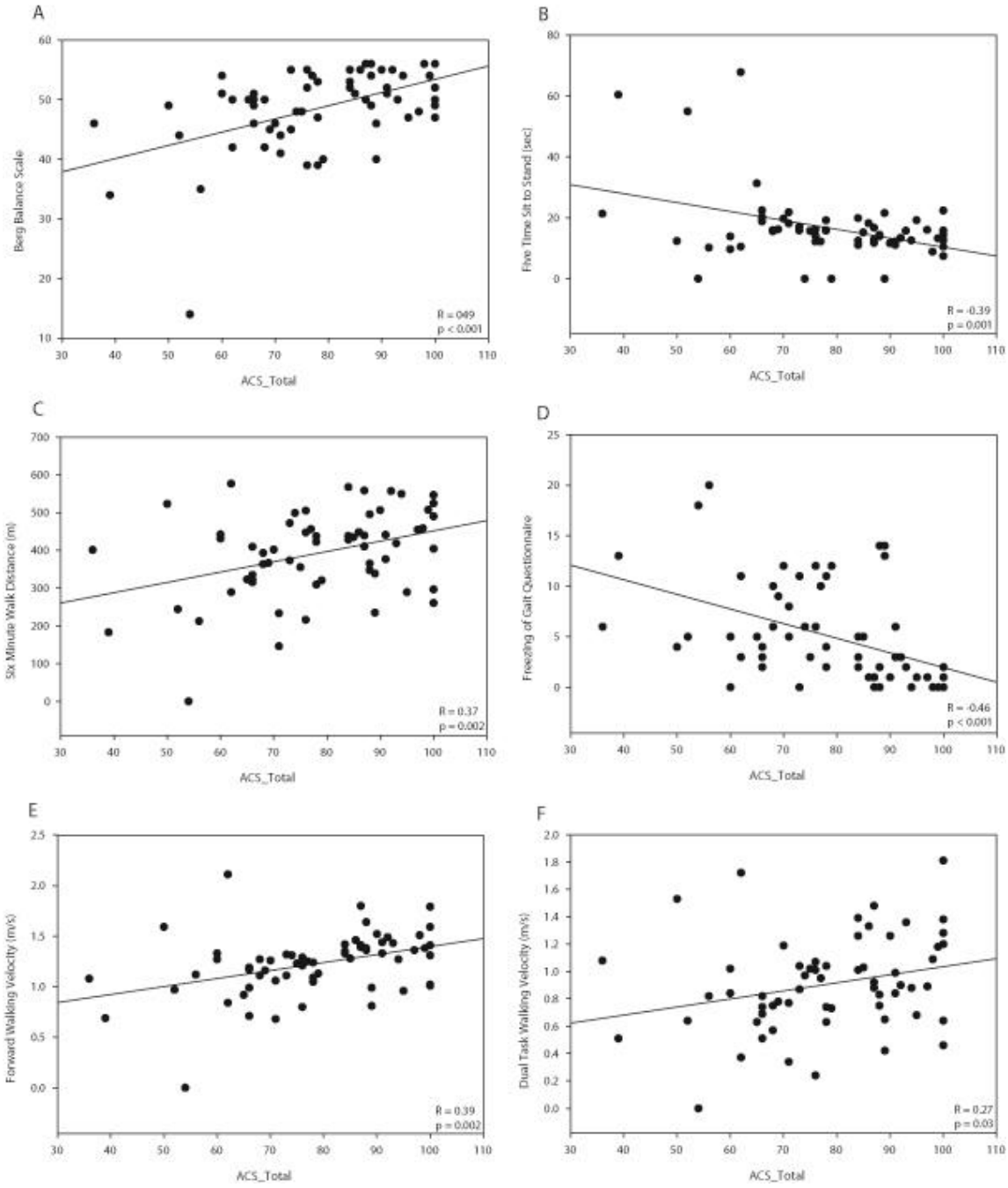

100
80
60
40
20
0
Percent of Activities Retained
IADL
LDLA
HDLA
SOC
ACS_TOTAL
Activity Card Sort

Figure 2


A
Berg Balance Scale
ACS_Total
R = 049
p < 0.001
B
Five Time Sit to Stand (sec)
ACS_Total
R = -0.39
p = 0.001
C
Six Minute Walk Distance (m)
ACS_Total
R = 0.37
p = 0.002
D
Freezing of Gait Questionnaire
ACS_Total
R = -0.46
p < 0.001
E
Forward Walking Velocity (m/s)
ACS_Total
R = 0.39
p = 0.002
F
Dual Task Walking Velocity (m/s)
ACS_Total
R = 0.27
p = 0.03