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Understanding physical activity in Veterans with Parkinson disease: A mixed-methods approach

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ABSTRACT

Introduction: Physical activity is critical in Parkinson disease (PD) management, but barriers and motivators of activity in Veterans with PD may be unique. We examined activity habits, including barriers and motivators, in this population.

Methods: Participants completed the Physical Activity Scale in the Elderly (PASE). Compliance with American Heart Association (AHA) recommendations was assessed. Veterans also completed the Exercise Perceptions Questionnaire (EPQ), assessing knowledge, barriers, and motivators of activity. Free-text barriers/motivators were analyzed by the overlapping clusters method.

Results: Seventy-five Veterans were recruited; mean age (standard deviation [SD]) was 70.5 (8.2) years and mean disease duration (SD) was 5.4 (5.2) years. Raw median PASE was 120.4 (interquartile range [IQR] 68.8–165.7); age-adjusted median PASE was 135.3. Only 9 Veterans (14.3%) were AHA-compliant. There were trends toward negative association between PASE and UPDRS-3 ($r = -0.24$, $p = 0.06$) and between PASE and PDQ-8 ($r = -0.23$, $p = 0.08$). Sixty-three subjects (84%) completed the EPQ; 27 (42.9%) preferred scheduled exercise, and only 33 (53.2%) reported that they preferred to exercise with others. Common themes of 46 free-text responses included desire to improve PD symptoms (n = 15, 32.6%) and social engagement (n = 12, 26.1%).

Conclusions: Self-reported activity in Veterans with PD is low, with less than 15% of subjects meeting recommended activity targets. Qualitative analysis of barriers and motivators revealed that although many Veterans enjoy the social aspects of group exercise, they may not feel comfortable in general exercise classes aimed at younger participants without chronic illnesses. These data will be useful in designing Veteran- and/or PD-specific interventions to increase activity levels.

1. Introduction

Monitoring and promoting physical activity is an integral component of Parkinson disease (PD) management, as noted by recent quality guidelines from the American Academy of Neurology [1]. Free-living daily physical activity, which encompasses both basic activity (e.g. household chores, walking) and dedicated exercise (e.g. sports, dance, weight-lifting), is defined as distinct from physical therapy, which is a goal-oriented, supervised rehabilitation program. The symptomatic benefits of exercise for persons with PD are well-described [2,3]; exercise may also have a neuroprotective benefit [4], manifesting as a slower rate of decline of both motor and non-motor symptoms over time [5]. Conversely, sedentary behavior is associated with worsening disability [6]. Thus, activity habits represent a potential modifiable lifestyle factor for the management of PD.

Despite efforts by specialty societies to encourage exercise, no PD-specific activity guidelines have been developed. In the absence of disease-specific targets, the American Heart Association recommendation of at least 75–150 min of moderate-to-vigorous physical activity (MVPA) [7] provides a useful proxy benchmark. Even in early disease, most PD patients do not meet these parameters [8] in the free-living condition, and activity levels decline further as the disease progresses [9]. Nevertheless, PD patients are able to achieve moderate- and high-intensity activity in targeted clinical interventions [3], which range from written prescriptions for in-office counseling [10] to virtual coaching [11] to dedicated, PD-specific exercise classes [12].

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One major obstacle to the implementation of effective exercise programs is incomplete understanding of the challenges faced by PD patients attempting to exercise. The barriers and motivators to exercise among people with PD may differ from those described in the general population [13] or in older adults without chronic disability [14]. In particular, both motor and non-motor symptoms may affect ability and willingness to exercise. This exploratory study characterizes the activity habits, barriers, and motivators of general activity and exercise in a group of US Veterans with PD, in order to better inform design of interventions to increase physical activity in this group of patients.

2. Methods

2.1. Subjects

The study was approved by the Institutional Review Board of the Corporal Michael J. Crescenz Veterans Affairs Medical Center (CMCVAMC) in Philadelphia, Pennsylvania. Subjects were recruited from the CMCVAMC Parkinson Disease Research, Education, and Clinical Center (PADRECC), one of six national centers providing comprehensive care to US military Veterans with PD and other movement disorders. Community-dwelling Veterans were recruited in consecutive fashion between January 2017 and April 2018 and provided informed consent. Inclusion criteria were a clinical diagnosis of PD by a movement disorders specialist, with Hoehn & Yahr (HY) stage ≤ 3 (i.e. mild-moderate disease). We excluded individuals with atypical parkinsonism, drug-induced parkinsonism, dementia, or severe medical comorbidities preventing exercise (e.g. New York Heart Association class 4 heart failure, severe chronic obstructive pulmonary disease).

2.2. Assessments

The primary assessment of activity was the Physical Activity Scale in the Elderly (PASE; New England Research Institute; Watertown MA) [15], a self-reported questionnaire querying the frequency, duration, and intensity of a variety of activities over the previous seven days. Household and leisure subscores can be calculated; there is also a "work" item which is not included in either subscore. This tool is well-validated against objective activity metrics [16] and has been used in other cohort studies of people with PD [8,17], enabling comparison between the Veteran population and others.

Veteran subjects also completed the Non-Motor Symptoms Questionnaire (NMSQ) [18], the Parkinson Disease Quality of life (PDQ-8) [19], and the Exercise Perceptions Questionnaire (EPQ) [20], which is subdivided into knowledge, barriers, and motivators subscales and also allows for "write-in" responses of barriers and motivators. Clinical and demographic features, including age, disease duration, disease stage, body mass index (BMI), Unified Parkinson Disease Rating Scale-part 3 (UPDRS-3) score indicating motor impairment, and recent (within 6 months) Montreal Cognitive Assessment (MoCA) [21] were extracted from the subject's clinical chart.

2.3. Data analysis

Our primary outcome measure was the PASE score, which ranges from 0 to 500, with higher scores indicating increased levels of physical activity. To minimize possible miscategorization of activity intensity, we audited activity descriptions provided by participants against the PASE Scoring Manual. We used responses to the intensity and frequency of moderate, vigorous, and strength-training activities to determine compliance with AHA guidelines as previously described [8]. Individuals who reported at least 150 min of moderate activity or 75 min of vigorous activity, together with at least 2 days of strength training, were coded as compliant with AHA guidelines. All other individuals were coded as non-compliant.

Data was analyzed using Stata/SE version 13.1 (StataCorp LP, College Station TX). Because questionnaire responses were not normally distributed, non-parametric tests were used. Because PASE declines with age, we adjusted raw scores using median regression, an established statistical technique used to adjust rank-ordered data for confounders [22]. We also examined the proportion of subjects who reported "often" (e.g. 5–7 days per week) sitting, walking, strength training, and participating in light, moderate, or vigorous sports. In partial correlations controlling for age and excluding missing data by pairwise deletion, we investigated relationships between PASE, NMSQ, PDQ-8, EPQ, BMI, and MoCA among Veterans. We also determined the proportion of subjects who were AHA compliant, in comparison to prior studies of AHA compliance among the PD population [8]. Lastly, we conducted an overlapping cluster analysis [23] of EPQ responses to determine other barriers and/or motivators influencing subjects' ability to maintain physical activity.

Table 1
Demographic characteristics of veteran responders and non-responders.

	Veterans Median (IQR) N = 75	Responders Median (IQR) N = 66	Non-Responders > Median (IQR) N = 9	p
Age, y	70 (69–76)	70 (69–74)	72 (68–76)	0.60
Disease Duration, y	4 (1–8)	4 (1.5–7.5)	6 (1–9)	0.85
BMI	26.5 (24.8–29.8)	26.5 (24.4–29.7)	27.9 (25.6–31.4)	0.34
MoCA	25 (23–27)	25 (23–27)	23 (21–24)	0.01
HY	2 (2–2)	2 (2–2)	2 (2–3)	0.09
UPDRS3	19 (12–28)	15 (11–23.5)	30 (18–33)	0.02

IQR = interquartile range; y = years; H&Y = Hoehn & Yahr stage; BMI = body mass index; UPDRS-3 = Unified Parkinson Disease Rating Scale, part 3; MoCA = Montreal Cognitive Assessment. P-values are for comparison by Wilcoxon rank-sum test.

3. Results

Demographics of Veterans are shown in Table 1. Seventy-six Veteran subjects were recruited; one withdrew prior to completing the questionnaires, leaving 75 active subjects. Sixty-six fully completed questionnaire packets have been returned, for a response rate of 88%. Compared to responders, non-responders had worse UPDRS-3 scores (median [interquartile range, IQR] 30 [18–33] for non-responders vs 15 [11–23.5] for responders, p = 0.02) and worse MoCA scores (median [IQR] 23 [20–23] for non-responders vs 25 [22–26] for responders, p = 0.01). Other clinical-demographic characteristics did not differ between responders and non-responders. Most subjects were overweight (BMI 25.0–29.9, n = 36, 48%) or obese (BMI ≥ 30.0, n = 18, 24%). Most subjects (n = 45, 60%) were HY stage 2, indicating bilateral disease without impairment of balance. The majority were Caucasian (n = 61, 81.3%) and male (n = 72, 96%), reflecting the PD patients of the CMCVAMC PADRECC as a whole. Forty-three (57.3%) reported access to gym equipment.

3.1. Activity levels in veteran PD patients

Raw median PASE (IQR) among Veterans was 120.4 (68.8–165.7); age-adjusted PASE was 135.3. Subscore analysis revealed that leisure PASE (median 39.0, IQR 17.0–76.1) was significantly lower than household PASE (median 80.0, IQR 25.0–116.0, p = 0.005) The majority of Veterans reported no (n = 45, 71.4%) or exclusively sedentary (n = 6, 9.5%) work/volunteer activities; only 9 (14.3%) reported at least 10 h of work/volunteering, of any intensity, over the past week.

The frequency breakdown of leisure activities is shown in Fig. 1; the

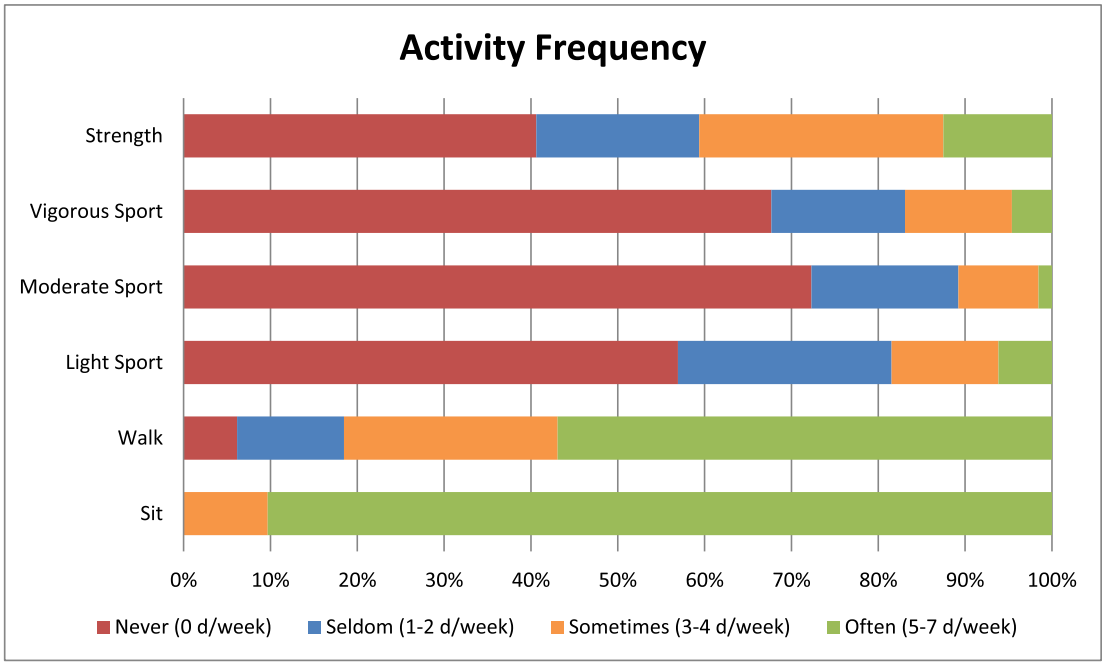

Fig. 1. Frequency of PASE-Leisure Activity, as a percentage of all responses. A detailed list of activity intensities can be found in the PASE scoring manual [New England Research Institute, Watertown MA]. Category examples given to the subjects are: Sit = reading, watching TV, doing handcraftsWalk = walking the dog, walking to work Light sport = bowling, golf with a cart, shuffleboard, fishingModerate sport = doubles tennis, ballroom dancing, hunting, ice skating, golf without a cart, softballVigorous sport = jogging, swimming, cycling, singles tennis, aerobic dance, skiingStrength = lifting weights, pushups, activities specifically to increase muscle strength.

proportion of subjects reporting "often" performing an activity (i.e. 5–7 days/week) declined significantly with increasing activity intensity ($\chi^2 = 253.3$, $p < 0.001$). Only 14.3% (n = 9) of Veteran respondents were compliant with AHA guidelines.

Median NMSQ (interquartile range [IQR]) was 11 (7.5–15.5); median PDQ-8 (IQR) was 7 (3–11.5); and median MoCA (IQR) was 25 (23–27). Controlling for age, there were trends toward a negative association between PASE and UPDRS-3 ($r = -0.24$, $p = 0.06$) and between PASE and PDQ8 ($r = -0.23$, $p = 0.08$). MoCA, NMSQ, disease duration, BMI, and access to a home or commercial gym were not associated with PASE or with AHA compliance.

3.2. Knowledge and attitudes about exercise in veterans with PD

Sixty-three subjects completed the EPQ (Table 2). Subjects had high levels of agreement that exercise was beneficial to motor (n = 63, 100%) and non-motor (n = 62, 98.4%) symptoms. However, 5 subjects (8.2%) disagreed that exercise was a potential disease-modifying therapy for PD. Higher levels of exercise knowledge were moderately associated with PASE ($r = 0.28$, $p = 0.03$); there was no association between PASE and self-reported exercise barriers or motivators (Table 2). The most common barriers were general health (44 agree or strongly agree, 71.0%) and aches/pains (40 agree or strongly agree, 63.5%). The most common motivators were feeling better after exercise (63 agree or strongly agree, 100%) and a desire to stay healthy (63 agree or strongly agree, 100%). Only 27 subjects (42.9%) indicated that they preferred to be in a scheduled exercise program, and only 33 (53.2%) subjects reported that they preferred to exercise with others.

Of those who completed the EPQ, 46 (73.0%) provided free-text responses on barriers and motivators of exercise. In overlapping cluster analysis of these responses, the most common cluster was a desire to improve PD symptoms (n = 15, 32.6%), followed by social engagement with family (n = 12, 26.1%). Common barriers included depression/apathy (n = 11, 23.9%) and other medical comorbidities (n = 8, 17.4%) such as arthritis or heart disease.

4. Discussion

In this study, we identified habits, barriers, and motivators of physical activity among US Veterans with mild-to-moderate Parkinson disease. We previously reported activity habits among PD subjects in the Parkinson Progression Markers Initiative (PPMI) [8], finding that activity levels in that cohort are similar to those of healthy controls. In comparison to the PD participants in the PPMI, however, Veterans with PD are more inactive and are less compliant with AHA exercise targets. Additionally, although Veterans and PPMI participants spent similar amounts of absolute time in dedicated leisure/exercise, there was a shift toward lower intensity sitting and walking behaviors among Veterans compared to higher intensity sports among PPMI participants. There are a number of possible explanations for this. Veterans were older than PPMI participants, and PASE is inversely correlated with age [15]; additionally, PPMI enrolled *de novo* participants, whereas most participants in the Veteran cohort had more advanced disease, as measured by both disease duration and Hoehn & Yahr stage. Activity intensity and frequency is known to decline with disease progression [24], and the differences seen here may be the result of the natural history of the disease. Additionally, PPMI subjects are highly motivated (e.g. willing to undergo serial assessments including phlebotomy, imaging, and lumbar punctures) and may be "over-exercisers" compared to others with PD.

Prior studies demonstrate that activity levels are correlated with disease duration and/or disease stage [24]; this study was relatively underpowered to detect an effect of Hoehn & Yahr stage on PASE, but there was a negative association of activity and motor burden as measured by the UPDRS-3. Though the cross-sectional study design limits assessment of causal pathways, other longitudinal studies indicate that those who start exercising after diagnosis decline less quickly than persistent non-exercisers [5]. Importantly, access to home or commercial gym equipment was not a predictor of activity level in our cohort. This may reflect the fact that access does not necessarily entail use; the majority of gym memberships in the United States are underused [25],

Table 2
Responses to exercise perceptions questionnaire, N (%).

	Statement	Strongly Agree	Agree	Disagree	Strongly Disagree
Knowledge	My PADRECC providers have told me about the importance of exercise in PD	50 (79.4)	12 (19.0)	1 (1.6)	0 (0)
	Exercise can improve my motor symptoms of PD (tremor, walking, stiffness)	46 (73.0)	17 (27.0)	0 (0)	0 (0)
	Exercise can improve my non-motor symptoms of PD (Mood, sleep, memory)	34 (54.0)	28 (44.4)	1 (1.6)	0 (0)
	Exercise can slow down the progression of PD	28 (44.4)	28 (44.4)	2 (3.2)	3 (4.8)
Barriers	I feel the same whether I am physically active or not	4 (6.3)	8 (12.7)	31 (49.2)	15 (23.8)
	I am concerned that I will hurt or strain myself if I am too physically active	2 (3.2)	13 (20.6)	34 (54.0)	14 (22.2)
	I sometimes get tightness in my chest when I exert myself.	2 (3.2)	16 (25.4)	23 (36.5)	21 (33.3)
	I have too little time for exercise.	2 (3.2)	5 (7.9)	32 (50.8)	23 (36.5)
	I do not have the stretch for exercise.	2 (3.2)	4 (6.3)	30 (47.6)	22 (34.9)
	If my health were better I would be more active	13 (20.6)	31 (49.2)	11 (17.5)	7 (11.1)
	I am not interested in exercise	3 (4.8)	5 (7.9)	24 (38.1)	27 (42.9)
	It is difficult to exercise when I ache.	5 (7.9)	35 (55.6)	17 (27.0)	6 (9.5)
	It is difficult to exercise if I feel depressed	10 (15.9)	18 (28.6)	15 (23.8)	14 (22.2)
	Lack of transportation limits my exercise options	1 (1.6)	7 (11.1)	31 (49.2)	24 (38.1)
	Bad weather prevents me from exercising	3 (4.8)	12 (19.0)	33 (52.4)	15 (23.8)
	I sometimes get short of breath when I exercise	4 (6.3)	24 (38.1)	21 (33.3)	14 (22.2)
	Fear of falling prevents me from exercising	3 (4.8)	9 (14.2)	32 (50.8)	16 (25.4)
Motivators	I prefer to be in a scheduled exercise program	10 (15.9)	17 (27.0)	29 (46.0)	7 (11.1)
	I feel better when I exercise	35 (55.6)	28 (44.4)	0 (0)	0 (0)
	Exercising gives me more energy	31 (49.2)	30 (47.6)	1 (1.6)	0 (0)
	Exercising gives me a sense of accomplishment	30 (47.6)	32 (50.7)	1 (1.6)	0 (0)
	Exercise keeps my mind active	28 (44.4)	33 (52.4)	1 (1.6)	0 (0)
	Exercise is good for my heart.	39 (61.9)	24 (38.1)	0 (0)	0 (0)
	Exercise helps my spirits	28 (44.4)	31 (49.2)	3 (4.8)	0 (0)
	I exercise to keep myself healthy.	28 (44.4)	33 (52.4)	0 (0)	0 (0)
	I want to exercise when I want, not when someone tells me	21 (33.3)	26 (41.7)	16 (25.4)	0 (0)
	I feel better when I am active	34 (54.0)	29 (46.0)	0 (0)	0 (0)
	I prefer to exercise with others	8 (12.7)	25 (39.7)	26 (41.3)	3 (4.8)

*row totals may not add to 100% due to missing data or rounding. PADRECC = Parkinson Disease Research Education and Clinical Center; PD = Parkinson disease.

and one prior study of gym use in PD demonstrated that even with a free membership, fewer than half of participants visited the gym at least weekly [26]. Additionally, the finding that expensive equipment or memberships are not required for adequate exercise has important implications for the promotion of health equity among people with PD, particularly for older adults living on a fixed income.

Although clinical variables were largely not correlated with activity levels, participants identified several barriers and motivators to exercise, some of which may be Veteran-specific and others which may be generalized to other groups with PD. Depression and apathy are well-documented barriers to physical activity, both in PD [27] and in other chronic diseases [28]. However, other common barriers [13,14], such as time constraints, weather, and lack of transportation, were not often reported by this cohort. This may be because this cohort, unlike many others, was elderly, mostly retired, and may enjoy additional flexibility compared to working-age patients. Additionally, scheduled exercise programs and group exercise were not preferred by this cohort, in contrast to studies of activity motivators among healthy adults as well as those with other chronic illnesses [28]. Qualitative analysis of free text responses demonstrated that Veterans with PD do enjoy the social aspects of exercise with family members, but they may not feel comfortable in a general exercise class with much younger participants or those without chronic illnesses. Targeted exercise programs may be better able to capture and retain these participants. Subjects also expressed a desire for exercise variety, vividly expressed by one participant who wrote, “I don't look forward to doing something that everyone has labeled exercise. I'd rather hear let's go for a hike.” This suggests that some individuals may be more adherent to active social activities, such as hiking or dance, rather than traditional “exercise.” This information can be used to help counsel Veterans on incorporating moderate-intensity activities more naturally into their daily lives.

Our study expands current knowledge about physical activity in PD by incorporating a detailed and well-validated Exercise Perceptions Questionnaire, along with qualitative analysis of disease-specific barriers and motivators. These findings can be used to design and improve exercise interventions targeted to individuals with PD, particularly Veterans. Nevertheless, some important limitations should be noted. The cohort was derived from a single center and was demographically homogeneous; results may not reflect activity levels among non-Veterans or in different geographic areas. The PASE, as a self-reported, retrospective questionnaire, may not capture true activity levels. However, the PASE has been validated against objective measures of energy expenditure [16,29]. We attempted to mitigate over-reporting of activity by auditing activity descriptions against the official scoring manual, though it remains possible that activities without a detailed description may have been miscategorized by participants. However, under-reporting of activity is as common as over-reporting [8], indicating that aggregate median scores are unlikely to change appreciably due to individual miscategorization. An ongoing extension of the current study incorporating accelerometry will more objectively determine the correlation between PASE self-report and actual step count. Lastly, this study excluded individuals with more advanced PD, who are at greatest risk of decline and are also most sedentary. Studies targeting this high-risk group are needed to better understand the impact of physical activity across the disease spectrum.

5. Conclusion

This study examining activity habits, barriers, and motivators among US Veterans with PD found that activity levels were low, with only one in seven subjects achieving AHA targets. Validation of this finding in other cohorts, as well as objective monitoring, will be important to fully understand the impact of exercise on PD symptoms and vice versa. Because exercise is a potential disease-modifying therapy in PD, the low levels of exercise identified in this study are a major area of concern; effective interventions to increase exercise are a crucial unmet need in the care of Veterans with PD. The identified barriers and motivators, particularly those related to social engagement, can be leveraged to increase activity levels, including pragmatic trials to evaluate the effectiveness of exercise modalities in a real-world, free-living setting.

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