

RESEARCH ARTICLE

Development of an Exercise-Specific Parkinson's Disease Questionnaire: The PDQ-Exercise

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ABSTRACT: Background: Exercise is now a significant and key component in the management of Parkinson's disease. However, no self-report, Parkinson's-specific measure of exercise currently exists.

Objective: To develop a patient-reported outcome measure (PROM) for use in studies and clinical trials that aim to assess the efficacy of exercise therapy for people with Parkinson's (PwP).

Methods: Participants were recruited via Parkinson's UK. To generate meaningful items, PwP participated in exploratory cognitive interviews. To pretest the items generated, PwP took part in two rounds of cognitive debrief interviews. Items were subsequently tested through an online survey that also included the eight-item Parkinson's Disease Questionnaire (PDQ-8) and Oxford Participation and Activities Questionnaire (Ox-PAQ).

Results: Twenty PwP were interviewed for item generation. Analyses identified issues related to adopting and maintaining exercise, resulting in the generation of 10 items. Fourteen PwP took part in subsequent cognitive

debrief interviews. Following the first 10 interviews, one item was removed, and minor adjustments were made to the wording of two items. Four final interviews verified that no further adjustments were required. Consequently, nine items were included in the validation survey, which was fully completed by 398 PwP. Inspection of floor and ceiling effects resulted in the removal of two further items. A principal component analysis identified a single seven-item factor explaining 61.6% of variance. Further analyses indicated that the measure demonstrates sound reliability and validity.

Conclusions: Results indicate that the PDQ-Exercise is an acceptable, reliable, and valid PROM. Further assessment of its psychometric properties is in progress. © 2021 The Authors. *Movement Disorders* published by Wiley Periodicals LLC on behalf of International Parkinson and Movement Disorder Society

Key Words: Parkinson's disease; exercise; patient-reported outcome measure; validity; reliability

Treatment for Parkinson's disease (PD) has traditionally depended largely on pharmacological intervention. However, exercise is now also recognized as a significant and key component in the management of the condition.^{1,2} Exercise in this context (or "exercise therapy"

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as it is sometimes referred to in the literature) embraces activities as diverse as Tai Chi,³ Nordic walking,⁴ endurance training,⁵ yoga,⁶ and various forms of dance such as Tango⁷ and Irish dancing.⁸

The relative merits of such activities are now well documented, and a number of recently published reviews that focus specifically on exercise and PD are available, which readers may wish to refer to.⁹⁻¹² Such reviews highlight a range of potential benefits from a variety of different activities. For example, Tango has been identified as a highly effective activity for the improvement of functional mobility, whereas intensive exercise can have a positive impact on muscle strength, cardiorespiratory fitness, balance, walking, and quality of life. There is also significant evidence that the benefits of exercise for PwP are demonstrable in both the short- and long term; moreover, although the majority of exercise programs are conducted outside the home, they also have the potential to be conducted within the home.

Patient-reported outcome measures (PROMs) have become increasingly central to Parkinson's research. Indeed, there are now published clinical trials that use PROM data as their primary outcome.^{13,14} However, trials¹⁵⁻¹⁹ and research studies²⁰⁻²² that focus on or incorporate an exercise component currently use established PROMs to evaluate their efficacy. Measures such as the disease-specific 39-item Parkinson's Disease Questionnaire (PDQ-39)²³ and the generic 36-item short-form (SF-36)²⁴ health survey are often completed by people with Parkinson's (PwP), and although their use is widely recommended,^{25,26} they were not designed to measure exercise-specific elements of PD management. Consequently, they may lack sensitivity to important outcomes associated with exercise interventions.

Despite the increasing prominence of exercise therapy in PD management, no self-report, Parkinson's-specific measure of exercise currently exists. A new measure, developed in line with current best practice as provided by the United States Food and Drug Administration (FDA)²⁷ and the European Medicines Agency (EMA),²⁸ is needed to accurately measure the efficacy of interventions and clinical trials that contain an exercise component. FDA and EMA guidelines place PwP at the heart of the development process, thus ensuring that PROMs measure areas of concern that are particularly relevant to that group.

Data reported here are part of a wider study that was undertaken to review the continued relevance and acceptability of the PDQ-39, the full results of which will be reported elsewhere. In particular, results presented here concern the development and validation of a PROM for use in studies and clinical trials that aim to assess the efficacy of exercise therapy for PwP.

Patients and Methods

The study comprises three phases: item generation interviews, pretesting, and a validation survey. Ethical approval for each phase was granted by the Medical Sciences Inter-Divisional Research Ethics Committee of the University of Oxford. All data were collected before the coronavirus pandemic.

Participants

Recruitment of PwP for all three phases of the study was undertaken via Parkinson's UK, which advertised each phase on its website inviting potential participants to take part.

Materials

Participants completed the following measures online during the study.

Item Generation Interviews

*Thirty-Nine-Item Parkinson's Disease Questionnaire (PDQ-39)*²³: The PDQ-39 comprises 39 items across 8 domains: mobility, activities of daily living, emotional well-being, stigma, social support, cognitions, communication, and bodily discomfort. The measure demonstrates excellent validity, reliability, and sensitivity to change.²⁹

Validation Survey

*PDQ-8*³⁰: The PDQ-8 is a short-form version of the PDQ-39, with one item from each of the eight domains of the parent measure. The measure generates a single-index score on a scale of 0 to 100.

*Oxford Participation and Activities Questionnaire (Ox-PAQ)*³¹: The Ox-PAQ is a 23-item measure of activity and participation across three domains: routine activities, emotional well-being, and social engagement. The measure demonstrates sound validity, reliability, and sensitivity to change.³²

Procedure

Item Generation Interviews

PwP participated in face-to-face cognitive interviews that were conducted in their own home. Participants completed the PDQ-39 on their laptop, personal computer, or other electronic device. On completion of the items, participants were asked whether aspects of their daily life were represented through the existing item content. Where identified, aspects of their daily life, which were not included through the existing PDQ-39 items, were explored further using prompts from the interviewer. To gain a deeper understanding of the relevance of exercise on daily living, participants were asked to describe the impact of exercise on living with Parkinson's where appropriate. Interviews were audio-recorded and were not time limited.

Pretesting

PwP took part in two rounds of cognitive interviews. In the presence of a researcher, participants completed newly generated items on an electronic device of their choice (personal computer, laptop, tablet, or cell phone) and gave verbal feedback on each of the items.

Validation Survey

PwP completed newly generated items alongside the PDQ-8 and Ox-PAQ electronically via Qualtrics³³ survey software.

Statistical Analysis

Item generation interviews were analyzed through a content analysis. Pretesting interview transcripts were

reviewed independently by D.M. and S.D., and adjustments were made accordingly. Validation survey data were checked for normality of distribution and presence of outliers before statistical analysis. Means and standard deviations (SDs) were calculated for demographic variables. Floor and ceiling effects were calculated for each newly generated item. The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy and Bartlett's test of sphericity were calculated to ensure that the use of principal component analysis (PCA) was acceptable. PCA was subsequently performed, alongside calculation of eigenvalues and explained variance, to confirm the factor structure of the newly generated items. Internal reliability was assessed through Cronbach's α and corrected item-total correlations (ITCs). Concurrent validity was determined through the calculation of Pearson correlations with the PDQ-8 and Ox-PAQ. Data were analyzed using SPSS version 25.³⁴

TABLE 1 Newly generated exercise items

Number	Item
1	Problems moving after exercise
2	Pressured to undertake exercise
3	Constrained by cost
4	Lacked motivation to exercise
5	Struggled to maintain exercise regime
6	Difficulty doing as much exercise as should
7	Amount of exercise never enough
8	Exercise regime not working
9	Lacked motivation to do things for enjoyment
10 ^a	Bothered by exercise regime

^aRemoved from further analysis after pretesting phase.

TABLE 2 Floor and ceiling effects for the newly generated nine exercise items

Number	Item	Floor (%)	Ceiling (%)
1	Problems moving after exercise	40.5	1.0
2 ^a	Pressured to undertake exercise	47.7	3.8
3 ^a	Constrained by cost	71.9	2.0
4	Lacked motivation to exercise	24.6	4.3
5	Struggled to maintain exercise regime	14.6	5.3
6	Difficulty doing as much exercise as should	13.3	7.8
7	Amount of exercise never enough	16.8	10.6
8	Exercise regime not working	25.9	5.3
9	Lacked motivation to do things for enjoyment	23.9	2.8

^aRemoved from further analysis after calculation of floor and ceiling effects.

Results

Item Generation Interviews

A total of 20 PwP were interviewed. The sample consisted of 10 men and 10 women, with a mean age of 68.7 years (range 57–78) and a mean disease duration of 7.9 years (range 2–23 years). Analyses identified specific issues relating to PwP undertaking and maintaining exercise as a means of managing PD. Consequently, based on interview data, the research team generated 10 items that were proposed to cover these issues (Table 1).

Pretesting

A total of 14 PwP were interviewed to review the 10 newly generated items. The sample consisted of 8 men and 6 women, with a mean age of 66.7 years (range 54–84) and a mean disease duration of 5.1 years (range <1–16 years). Following the first 10 interviews, one item (item 10), asking the extent to which PwP “felt bothered by your exercise regime,” was removed as the majority of participants experienced significant difficulty in answering it. Minor adjustments were made to the wording of two further items to make them easier for respondents to answer. Four final interviews were subsequently conducted to confirm these changes were appropriate and acceptable. These four interviews verified that no further adjustments were required. As a result of this phase of the study, nine items comprised the validation survey. The nine retained items are provided in Table 2.

Validation Survey

Three hundred and ninety-eight PwP (190 men, 208 women) fully completed the online survey. The mean age was 65.5 years (SD 8.6, range 40–90), with a mean disease duration of 5.7 years (SD 4.7, range <1–27). The

TABLE 3 Factor loadings, item-total correlations, and mean item scores for the seven retained exercise items

Number*	Item	Factor loading	Corrected ITC	Mean score
5	Struggled to maintain exercise regime	0.89	0.82	1.77
6	Difficulty doing as much exercise as should	0.88	0.81	1.89
8	Exercise regime not working	0.84	0.76	1.44
7	Amount of exercise never enough	0.79	0.70	1.92
4	Lacked motivation to exercise	0.77	0.68	1.39
9	Lacked motivation to do things for enjoyment	0.75	0.65	1.41
1	Problems moving after exercise	0.52	0.42	0.93

*Corresponds to original item numbers.

TABLE 4 PDQ-Exercise correlations with the PDQ-8 and the three domains of the Ox-PAQ

PDQ-8 (n = 391)	Ox-PAQ routine activities (n = 375)	Ox-PAQ emotional well-being (n = 383)	Ox-PAQ social engagement (n = 383)
0.64 ^a	0.69 ^a	0.57 ^a	0.57 ^a

^aCorrelation significant at the 0.01 level (2-tailed).

Abbreviations: PDQ-8; Eight-Item Parkinson's Disease Questionnaire; Ox-PAQ, Oxford Participation and Activities Questionnaire.

vast majority of participants were married (75.6%) and retired (78.6%).

Floor and ceiling effects for each of the nine retained items are presented in Table 2. Items 2 and 3 (in italics and highlighted) were removed from further analysis due to floor effects greater than 40%. A PCA of the remaining seven items was subsequently performed. Sampling adequacy was high (KMO = 0.892), and Bartlett's test of sphericity confirmed that the use of PCA was appropriate ($\chi^2 = 1595.84$, df 21, $P = 0.00$). PCA confirmed that the seven remaining items loaded onto a single factor with an eigenvalue of 4.31 explaining 61.60% of variance. Factor loadings ranged from 0.89 to 0.52 (full details are provided in Table 3). In terms of reliability, corrected ITCs for each item ranged from 0.82 to 0.42 (Table 3). Cronbach's α was high at 0.89. Validity, as assessed through Pearson correlations of the new exercise questionnaire with the PDQ-8 and Ox-PAQ, was sound, with correlations ranging from 0.57 to 0.69 (Table 4).

Discussion

A significant body of evidence now indicates that exercise is an effective component of PD management. The development and validation of a PROM to assess the efficacy of exercise interventions for PwP is therefore timely. The new measure has the potential to shed further light on the efficacy of exercise as a treatment for PwP. It may also identify specific interventions

and/or PD population groups for which exercise interventions will have the highest impact, levels of adherence, and compliance. Importantly, the development of the PDQ-Exercise involved input from PwP from the outset, in both the item generation process and the pretesting of newly generated items. As previously mentioned, this is central to current best practice guidelines provided by regulatory bodies such as the FDA and EMA.

Before the identification of the factor structure of PDQ-Exercise, floor and ceiling effects for each of the nine newly generated items were calculated, resulting in the removal of two items. Previous validation studies have incorporated a criterion of 40% for floor and ceiling effects, a principle adopted here.^{23,31} A subsequent PCA of the remaining seven items identified a single factor explaining 61.6% of variance. All factor loadings bar one were above 0.55 and therefore regarded as good, with a number above the level of 0.71 regarded as excellent.³⁵

The reliability of the PDQ-Exercise is demonstrated by ITCs that confirm individual item scores relate to the overall score. Items ranged between 0.42 and 0.82 and were thus significantly in excess of the 0.3 level regarded as adequate.³⁶ Additional evidence of reliability is provided by a Cronbach's α value of 0.89, indicating excellent internal consistency.

The validity of the new measure is established through the assessment of correlations with the PDQ-8 and the three domains of the Ox-PAQ. The Ox-PAQ domains of emotional well-being and social engagement

fall between 0.40 and 0.60 as typically observed in assessments of concurrent validity. The most similarly related domains, the PDQ-8 and the Ox-PAQ domain of routine activities, correlate with the PDQ-Exercise in excess of 0.60, thus representing a high degree of concurrent validity.³⁷

In terms of limitations, the authors acknowledge that the method of recruitment for the study was self-selecting in nature and that the participants may not therefore be fully representative of the Parkinson's population at large. In addition, not all PwP will have access to electronically administered measures or be computer literate, which may further limit the degree to which the sample is representative. Finally, it should be noted that the PDQ-Exercise has not been developed as a screening tool and is designed specifically for use at the group level.

In conclusion, results from the reported study indicate that the PDQ-Exercise is a valid and reliable measure that can be confidently used by researchers who wish to incorporate it in their research. Although validated in electronic format, previous postal surveys using the PDQ-39³⁸⁻³⁹ indicate that the PDQ-Exercise could legitimately be administered in paper-based format. Additional psychometric properties, such as test-retest reliability and sensitivity to change (thus allowing its use over time), are currently being assessed and will be reported in due course. Researchers who wish to use the PDQ-Exercise should request permission to do so via Oxford University Innovation (<https://innovation.ox.ac.uk/>) who hold the license for the questionnaire. ■

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