



Short communication

Test-retest reliability of the PDQ-Carer

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ABSTRACT

Introduction: The PDQ-Carer is a 29-item measure of health-related quality of life (QoL) for use with carers of people with Parkinson's (PwP). The measure produces a profile of scores across four domains. Previous validation data indicates that the measure possesses sound psychometric properties in terms of validity and internal consistency. An additional important attribute of any measure is test-retest reliability, i.e. the ability to provide stable results over time, presuming that there has been no change in the status of the construct being measured. To date, no assessment of the test-retest reliability of the PDQ-Carer has been undertaken.

Methods: Carers of PwP were recruited via Parkinson's UK. Participants completed the PDQ-Carer online on two occasions, two weeks apart. On second administration participants answered an additional question asking how much, if at all, their QoL had changed over the two week period. Subsequent analyses focused on those carers who reported no change in their QoL.

Results: At first administration 142 carers fully completed the PDQ-Carer and at second administration 104 participants with no missing data responded. Seventy four of these participants (71.2%) reported no change in QoL and thus went forward to the final analysis. Intraclass correlation coefficients for each domain were calculated as follows: Social and Personal Activities .97; Anxiety and Depression .95; Self-Care .96; Stress .95

Conclusion: Results indicate that the PDQ-Carer demonstrates sound test-retest reliability and can be confidently used by researchers who wish to incorporate it in studies of carers of PwP.

1. Introduction

The PDQ-Carer [1] is a 29-item measure of health-related quality of life (QoL) for use with carers of people with Parkinson's disease (PwP). The measure produces a profile of scores across four domains of health; Social and Personal Activities (12 items), Anxiety and Depression (6 items), Self-Care (5 items) and Stress (6 items). A summary index score can also be calculated for the measure [2], which allows users to derive a single score reflecting the overall impact of the caregiver role. The PDQ-Carer has been successfully administered in both postal and e-based surveys [3,4] and it has also been translated into a number of languages other than English [5].

A relatively recent review conducted by Page et al. [6] identified that current and widely used instruments assessing family carers of people with neurological conditions lack the full range of psychometric properties required to make a robust assessment of carer QoL. The purpose of the study reported here goes some way to ameliorate this in relation to the PDQ-Carer.

Previous validation data indicates that the PDQ-Carer possesses sound psychometric properties in terms of validity and internal consistency. An additional important attribute of any measure is test-retest reliability, i.e. the ability to provide stable results over time, presuming that there has been no change in the status of the construct being measured [7]. The objective of the study reported here is to assess the test-retest reliability of the PDQ-Carer.

2. Methods

Ethical approval was granted by the University of Oxford Medical Sciences Interdivisional Research Ethics Committee, reference number R62630/RE001.

Participants: Carers of PwP were recruited via Parkinson's UK (PUK), the national Parkinson's disease support organization in the United Kingdom. The study was advertised on the 'Take Part in Research' page of PUK's website where potential participants could access the participant information sheet, provide informed consent and

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click on a link to the survey.

Materials: The PDQ-Carer was administered via Qualtrics survey software [8]. Higher scores on the measure indicate inferior QoL. Additionally, participants were asked to provide demographic information including their age, gender, the length of time they had undertaken their caregiver role and the age of the PwP they cared for. Response options to all questions in the electronic survey were un-forced, i.e. respondents could omit any questions they did not want to answer. Participants could complete the survey on a device of their choice, e.g. laptop, tablet, personal computer or cell phone.

Procedure: Participants completed the PDQ-Carer online on two occasions, two weeks apart. On second administration participants answered an additional question asking how much, or otherwise, their QoL had changed over the two week period; ‘much better’, ‘a little better’, ‘the same’, ‘a little worse’, ‘much worse’. Subsequent analyses focused on those carers who reported no change in their QoL.

Statistical analysis: Data was checked for normality of distribution and presence of outliers prior to statistical analysis. Means and standard deviations were calculated for demographic variables and the four PDQ-Carer domains. Test-retest reliability was calculated using the intra-class correlation coefficient (ICC). Data were analyzed using SPSS Version 27. As analyses involved the assessment of psychometric properties, participants with missing data were excluded.

3. Results

At first administration 142 carers fully completed the PDQ-Carer and at second administration 104 participants with no missing data responded. Of these, 19 were male and 84 were female. One participant preferred not to indicate their gender. Further demographic information is provided in Table 1.

Seventy four of the 104 participants (71.2%) reported no change in QoL and thus went forward to the final analysis. Intraclass correlation coefficients for each domain of the PDQ-Carer were calculated as follows: Social and Personal Activities .97; Anxiety and Depression .95; Self-Care .96; Stress .95. Further details can be viewed in Table 2.

4. Discussion

This short communication has detailed a survey of carers of PwP that aimed to further explore the psychometric properties of the PDQ-carer. Specifically, data reported focuses on the test-retest reliability of the measure. Test-retest reliability is regarded as a key characteristic of psychometrically sound questionnaires [9,10]. However, in their review of instruments measuring the disease-specific quality of life of family carers of people with neurodegenerative diseases, Page et al. [6] concluded that few measures demonstrate adequate psychometric characteristics, one such characteristic being test-retest reliability. This study has aimed to address this in relation to the PDQ-Carer.

The study incorporated the commonly endorsed two-week test-retest interval [11]. Subsequent analysis of data provided intraclass correlation coefficients that fall between .95 and .97 for the four PDQ-Carer domains, indicating excellent test-retest reliability. All correlations are significantly above the widely regarded acceptable level of .70 [12].

In terms of limitations, it is recognized that not all carers of PwP will have access to the electronic devices used in this study, or be competent in their use. In this respect the sample reported may not be entirely representative of the PD carer population. Additionally, the sample size is relatively small, although adequate for the analyses conducted. Finally, the authors acknowledge that the data presented does not include analysis of sensitivity to change which would provide a more complete set of psychometric characteristics. Exploration of the sensitivity to change of the PDQ-Carer will be undertaken in due course.

In conclusion, results from the reported study demonstrate that the PDQ-Carer possesses sound test-retest reliability. This, in conjunction with previously reported psychometric properties [1,2,5], indicates that

Table 1

Sample characteristics.

	Mean (years)	Standard deviation	Range (years)
Age of carer	64.23	10.58	30–82
Length of time as carer	7.18	6.32	<1–40
Age of PwP being cared for	69.72	8.79	39–88

Table 2

Mean PDQ-Carer domain scores at first and second administration with resultant intraclass correlation coefficients.

PDQ-Carer Domain	Mean T1	Mean T2	Intraclass Correlation Coefficient
Social and Personal Activities	38.23 (26.72)	39.44 (26.80)	.97
Anxiety and Depression	43.13 (24.01)	43.92 (24.55)	.95
Self-Care	23.11 (23.70)	24.73 (25.45)	.96
Stress	42.40 (23.54)	42.62 (23.75)	.95

(standard deviation).

the measure can be used confidently by researchers who wish to incorporate it in studies of carers of PwP. Those who wish to do so should request permission via Oxford University Innovation (<https://innovation.ox.ac.uk/>) who hold the license for the questionnaire.

Author contributions

Conception and design of the study: DM, CJ, Acquisition of data: SD, LK, Analysis and interpretation of data: DM, SD, Drafting the article: DM, Revising article critically for important intellectual content: DM, SD, LK, CJ, All authors have approved the final article

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Data statement

Data from the reported study are available from the corresponding author on reasonable request.

Declaration of competing interest

All authors have conducted consultancy work for Oxford University Outcomes who manage the license for the PDQ-Carer.

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References

- [1] C. Jenkinson, S. Dummett, L. Kelly, M. Peters, J. Dawson, D. Morley, R. Fitzpatrick, The development and validation of a quality of life measure for the carers of people with Parkinson's disease (The PDQ-Carer), *Park. Relat. Disord.* 18 (2012) 483–487.
- [2] D. Morley, S. Dummett, L. Kelly, M. Peters, J. Dawson, R. Fitzpatrick, C. Jenkinson, The PDQ-Carer: development and validation of a summary index score, *Park. Relat. Disord.* 19 (2013) 448–449.

- [3] R. Ferrer-Cascales, M.J. Cabañero-Martínez, M. Sánchez-SanSegundo, N. Congost-Maestre, C. Jenkinson, Spanish version of the Parkinson's disease questionnaire-carer (PDQ-Carer), *Health Qual. Life Outcome* 14 (2016) 154.
- [4] L. Prado, R. Hadley, D. Rose, Taking time: a mixed methods study of Parkinson's disease caregiver participation in Activities in relation to their wellbeing, *Parkinsons Dis* (2020), 7370810.
- [5] C. Jenkinson, R. Fitzpatrick, V. Peto, S. Dummert, L. Kelly, D. Morley, *The Parkinson's Disease Questionnaires: User Manual*, fifth ed., Health Services Research Unit, Oxford, 2022.
- [6] T.E. Page, N. Farina, A. Brown, S. Daley, A. Bowling, T. Basset, G. Livingston, M. Knapp, J. Murray, S. Banerjee, Instruments measuring the disease-specific quality of life of family carers of people with neurodegenerative diseases: a systematic review, *BMJ Open* 7 (2017), e013611.
- [7] A. Bowling, *Research Methods in Health: Investigating Health and Health Services*, fourth ed., Open University Press, 2014.
- [8] Qualtrics, Copyright Year: 2019, 2005. Provo, Utah, USA.
- [9] C.B. Terwee, S.D. Bot, M.R. De Boer, D.A. van der Windt, D. L. Knol, J. Dekker, L. M. Bouter, H.C. de Vet, Quality criteria were proposed for measurement properties of health status questionnaires, *J. Clin. Epidemiol.* 60 (2007) 34–42.
- [10] G. Vilagut, Test-retest reliability, in: A.C. Michalos (Ed.), *Encyclopedia of Quality of Life and Well-Being Research*, Springer, Dordrecht, 2014, pp. 6622–6625.
- [11] D. Streiner, G. Norman, J. Cairney, *Health Measurement Scales, A Practical Guide to Their Development and Use*, fifth ed., Oxford University Press, Oxford, 2015.
- [12] J.C. Nunnally, I. Bernstein, *Psychometric Theory*, third ed., McGraw, New York, 1994.