

# Measuring the impact of Parkinson's disease with the Parkinson's Disease Quality of Life questionnaire

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## Abstract

**Objectives:** to assess the validity of the Parkinson's Disease Quality of Life (PDQL) questionnaire, a patient-specific multi-dimensional quality of life measure, in a community-based sample of patients with Parkinson's disease (PD) using standardized measures of disease severity, depressive symptomatology and cognitive function.

**Design:** a group of 194 patients with probable PD were randomly selected from a community-based register and were invited to self-complete the 37-item PDQL. Disease severity was measured by the disease-specific Webster scale, cognition by the CAMCOG neuropsychological test and depressive symptomatology by the self-report 15-item GDS-15 geriatric depression scale.

**Results:** a total of 136 patients returned completed PDQL questionnaires. Significant differences ( $P < 0.05$ ) emerged between the pooled PDQL score of patients grouped on the basis of disease severity. Depressive symptoms and cognition were also associated with poorer perceived quality of life as measured by the PDQL.

**Conclusions:** the results of this study are indicative of the validity of the PDQL as an important additional measurement which reflects the impact of PD from the patient perspective. It shows poorer quality of life to be associated with increasing age, disease severity, more severe depressive symptomatology and impaired cognitive functioning. However, the responsiveness of this instrument in the evaluation of care in PD remains to be determined.

**Keywords:** age, Parkinson's disease, quality of life, rating scales

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## Introduction

Traditional morbidity and mortality evaluations of health care are increasingly being supplemented by health-related quality of life measurements. Considerable controversy exists as to exactly what constitutes 'quality of life', how it can be measured and how it should be distinguished from health-related quality of life or health status. The measurement properties of health-related quality of life instruments need to be carefully considered before such outcome measures can usefully guide clinical decisions.

The reliability, responsiveness and validity of quality of life instruments need to be clearly demonstrated. 'Validity' is the property that an instrument has in measuring what it is intended to measure. 'Face validity' can be gauged by a judgement of how well the instrument is targeted to the right problem areas that determine quality of life for the population under study. 'Construct validity' reflects the logical relationships that

should exist between scores on the instrument when given to patients with differing disease severity (discriminant validity) and the degree of correlation between scores on the new instrument and existing validated measures covering similar domains (convergent validity).

Most health-related multi-dimensional quality of life measures have largely ignored the subjective values and preferences of patients, who are probably the best people to define what they feel constitutes a good quality of life. There are several generic health-related quality of life measures, such as the Functional Limitations Profile [1], Nottingham health profile [2] and the short form-36 (SF-36) [3], which provide useful information on subjective patient perceptions of well-being. However, these generic measures either fail to include items that are likely to be highly relevant to patients with specific diseases or include items that patients may feel are irrelevant to them. The main disadvantage of the Functional Limitations Profile is its length and the lack of a 'pain' dimension. The

Nottingham health profile suffers from floor effects (where respondents score at the extreme end of the questionnaire and are unlikely to improve or deteriorate on subsequent testing) and the use of closed choice questions and limited responsiveness [4]. The SF-36 is heavily biased towards physical function and its responsiveness has not been reported. Some of the items in the SF-36 are of doubtful relevance to elderly patients and this can result in high levels of missing data [5–7].

Most evaluations of health-related quality of life in Parkinson’s disease (PD) using generic measures have been biased towards the impact of the physical manifestations of the disease on quality of life. However, recently a patient-specific quality of life measure, the Parkinson’s Disease Quality of Life measure (PDQL) has been developed in Holland [8]. The PDQL is a self-administered measure which contains 37 items contained in four sub-scales: parkinsonian symptoms, systemic symptoms, social functioning and emotional functioning. An overall score can be derived, with a higher score indicating better perceived quality of life. The PDQL was developed from the existing literature, disease-specific measures and a series of open interviews with patients with PD. Those items to which the patients attached most importance and those mentioned most often were included in the PDQL. The convergent validity of the PDQL has been previously established [8] by the demonstration of a significant degree of correlation between scores on the domains of the PDQL with six of the seven corresponding sub-scales of the MOS-24 generic quality of life measure [9].

Here, we investigate the discriminant validity of an anglicised version of the PDQL in a community-based sample of patients with PD by comparison with a disease-specific measure for disease severity in PD and single domain measures of mood and cognitive function. This questionnaire was translated into English by the original authors who applied standardized guidelines for cross-cultural adaptations of health-related quality of life measures [10, 11].

## Methods

A total of 194 patients meeting the clinical diagnostic criteria for PD [12] were drawn from a community-based Parkinson’s syndrome register in a geographically defined area of North Wales and were mailed the self-report PDQL (for items, sub-scales and scoring system, see Appendices 1 and 2). Patients with known dementia were excluded from the study. The severity of PD was measured by the Webster scale, where scores 0–10 indicate early illness, 11–20 moderate disability and 21–30 severe or advanced disease [13]. Depressive symptomatology was measured by the self-report 15-item GDS-15 geriatric depression scale [14]

and cognition was measured by the CAMCOG [15]. These assessments had been completed over a 3-month period before the mailing of the PDQL as part of a continuing epidemiological study of parkinsonism in North Wales. The data were entered, verified and analysed using SPSS version 6.

## Results

A total of 136 (70%) patients returned fully completed questionnaires. Out of the original 194 patients, seven had left the area and were untraceable, 10 were too ill at the time to participate and six returned incomplete questionnaires. A total of 35 patients (18%) did not reply. The demographic and disease-specific details of the 136 patients who replied are shown in Table 1. No significant differences in terms of age, sex, disease duration or disease severity were found between patients who did and those who did not reply to the questionnaire. Around 55% of patients indicated they had some assistance from a carer to complete the PDQL.

Descriptive statistics (mean; standard deviations; confidence intervals) for the four sub-scales of the PDQL together with the internal consistency reliability coefficients are presented in Table 2. The internal reliability assessed using Cronbach’s  $\alpha$  statistic had values for the PDQL greater than the standard 0.7 [16]. In view of the association between self-reported health status and age, the sample was further sub-divided into those aged less than 75 years ( $n = 78$ ) and those aged 75 years or more ( $n = 58$ ) and a parametric analysis was

Table 1. Mean and median scores and range for age, sex, disease duration, Webster rating, GDS-15 score and CAMCOG score ( $n = 136$ ; 47% female)

	Mean (SD)	Median	Range
Age (years)	72.4 (9.02)	73	46–90
Duration of disease (years)	7.9 (6.7)	6	1–40
Webster score	15.6 (5.0)	15	2–30
GDS-15	5.4 (2.9)	5	0–14
CAMCOG	80.1 (13.3)	82	32–102

Table 2. Mean values, confidence intervals (CI) for the PDQL and its four sub-scales, together with the Cronbach’s  $\alpha$  internal consistency reliability coefficients

	Mean (SD)	95% CI	Internal consistency
Total PDQL	111.8 (30.7)	107–117	0.95
Parkinsonian symptoms	39.8 (10.0)	37.9–41.5	0.87
Systemic symptoms	21.3 (5.7)	20.3–22.3	0.77
Emotional functioning	29.1 (8.5)	27.6–30.5	0.87
Social functioning	19.0 (8.0)	17.6–20.4	0.85

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Table 3. Mean values and confidence intervals (CI) for the PDQL and its four sub-scales by age

	Age group (years)				<i>P</i> < 0.05 <sup>a</sup>
	<75 ( <i>n</i> = 78)		≥75 ( <i>n</i> = 58)		
	Mean (SD)	CI	Mean (SD)	CI	
Total PDQL	116.4 (32.3)	109–124	103.9 (28.4)	96.4–111	0.021
Parkinsonian symptoms	44.4 (12.1)	41.7–47.1	39.5 (11.0)	36.6–42.4	0.016
Systemic symptoms	22.3 (6.3)	20.9–23.7	19.6 (5.2)	18.3–21	0.011
Emotional functioning	29.1 (8.6)	27.2–31.1	28.5 (8.6)	26.3–30.8	0.69 <sup>b</sup>
Social functioning	20.5 (8.4)	18.6–22.4	16.1 (7.3)	14.2–18.1	0.002

<sup>a</sup>Parametric *t*-tests.

<sup>b</sup>Not significant.

Table 4. Pooled scores for the PDQL and its four sub-scales in patients grouped according to disease severity on Webster scale

Webster stage	Value (and SD), by PDQL sub-scale				
	Total	Parkinsonism score	Systemic symptoms	Functioning emotional	Functioning social
I	130.3 (32.4)	50.2 (10.8)	24.7 (5.9)	31.5 (9.0)	23.7 (9.1)
II	110 (29.8)	42.2 (11.5)	20.9 (5.8)	29.1 (8.5)	18.8 (7.5)
III	95.8 (27.5)	36.4 (10.4)	19.2 (5.4)	26.2 (8.3)	14.1 (7.6)
<i>P</i> <sup>a</sup>	0.0007	0.0002	0.003	NS	0.0003

<sup>a</sup>One-way ANOVA.

NS, not significant.

Table 5. Results of *t*-tests between PDQL sub-scales according to Webster disease severity category

Webster stage	Value, by PDQL sub-scale				
	Total	Parkinsonism score	Systemic symptoms	Functioning emotional	Functioning social
I and II	0.01	0.004	0.006	0.23 <sup>a</sup>	0.011
II and III	0.02	0.02	0.19 <sup>a</sup>	0.13 <sup>a</sup>	0.006
I and III	0.001	0.0001	0.001	0.04	0.0001

<sup>a</sup>Not significant at *P* < 0.05.

employed between the two groups (Table 3). In three of the sub-scales (parkinsonian symptoms; systemic symptoms; social functioning), those aged 75 years or more had significantly poorer reported quality of life than the group younger than 75 years (*P* < 0.05). The sub-scale of emotional functioning was found not to be significantly different between the two groups (*P* > 0.05).

The overall severity of disease in this study as measured by the Webster scale is reflected in the sub-scale scores of the PDQL. A one-way analysis of variance test for all the sub-scales, apart from emotional functioning, indicated significant trends in the data when patients were grouped by disease severity on the Webster scale (Table 4). In nearly all the sub-scales of

the PDQL there were significant differences between the PDQL scores (*P* < 0.05) when grouped by disease severity (Table 5). The relationship between PDQL score and the variables of mood, cognition and disease severity was explored by a multiple regression analysis (Table 6). The significant values presented in this table are the independent variables that make a contribution to the prediction of the dependent variables (total PDQL score; PD symptoms; systemic symptoms; social functioning; emotional functioning). Disease severity scores, impaired cognitive functioning and worsening depression were significantly associated with the parkinsonism symptoms and the systemic functioning sub-scales of the PDQL. The total PDQL score and the score in the social functioning sub-scale significantly

Table 6. Multiple regression analysis indicating independent variables that make a significant contribution to prediction of dependent variables

	Independent variables		
	GDS-15	CAMCOG	Webster
Total PDQL	0.008	NS	0.00001
Parkinsonian symptoms	0.01	0.04	0.00001
Systemic functioning	0.03	0.04	0.003
Social functioning	0.03	NS	0.00001
Emotional functioning	0.01	NS	NS

NS, not significant at  $P < 0.05$ .

affected the total PDQL score and social functioning sub-scales. Higher levels of depressive symptoms were significantly associated with lower scores on the emotional functioning sub-scale of the PDQL.

## Discussion

Despite the proliferation of quality of life instruments in the past few years, disease-specific quality of life measures for PD patients have until recently been unavailable. Ideally, disease-specific instruments (such as the PDQL) should, in clinical practice and research, have the power to discriminate, predict and evaluate [17]. Before the development and validation of the PDQL, only one other PD-specific quality of life measure had been available [18]. The advantage of these two disease-specific instruments over generic measures of quality of life is that they focus on the most distressing symptoms reported by patients.

Poorer quality of life of PD patients in this study as measured by the PDQL was found to be significantly associated with increasing age. There were also significant associations with increased disease severity, greater depressive symptomatology and more impaired cognitive function. Depression and cognitive problems are common in PD and are associated with both disease progression and severity of motor disturbance [19–22]. A possible confounding variable in this study is the use of self-report measures in patients with cognitive impairment. Although many PD patients will have depressive and cognitive impairments, it is still likely that, in the absence of severe dementia, patients can still make reliable self-reports of their experience of PD [23].

Our findings indicate that the PDQL is likely to have convergent validity, since generic measures of mood and cognitive function correlated significantly with conceptually-related sub-scales of the PDQL. The PDQL also appears to have discriminative validity as evidenced by its ability to define groups of PD patients with differing degrees of disease severity. The emotional sub-scale of the PDQL was not associated with disease severity as measured by the Webster scale: the

Webster scale does not measure emotional function, but is heavily biased towards physical function. An independent and validated measure of mood and distress, the GDS-15, was significantly associated with all sub-scales of the PDQL including the emotional sub-scale. However, the responsiveness of the PDQL to disease progression and health care interventions will require further evaluation in hospital and community settings.

## Key points

- There are limitations with rating scales used to measure health-related quality of life.
- The Parkinson's Disease Quality of Life (PDQL) questionnaire is a new quality of life measure specifically designed for patients with Parkinson's disease. It is easy to administer.
- The PDQL consists of 37 items, covering four sub-scales—parkinsonian and systemic symptoms and social and emotional functioning. It provides an overall score: the higher the score, the better the quality of life.
- In a survey of patients living at home, we have used an anglicized version of the PDQL. Our findings indicate that the scale has good internal validity.
- In parkinsonism, lower health-related quality of life (lower PDQL score) is related to older age, depression, cognitive impairment and severity of disease.

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Received 5 July 1997; accepted in revised form 24 April 1998

Appendix 1. The modified Parkinson's Disease Quality of Life questionnaire

This questionnaire has 37 questions, which will help us to know how you are feeling. Please do not leave out any questions, it is important that they are all answered. Place a tick ✓ in the box that you feel shows how much of a problem each one has been for you *in the past 3 months*

How often in the last 3 months have you had trouble with	All the time	Most of the time	Some of the time	A little of the time	Never
1. Stiffness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Feeling generally unwell?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Feeling that you are no longer able to do your hobbies?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Being tense?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Feeling insecure of yourself due to your physical limitations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Shaking of your hand(s)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Feeling worn out or having no energy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Difficulties in doing sport or leisure activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Clumsiness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Feeling embarrassed about your illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Shuffling when you walk?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Having to postpone or cancel social activities because of your illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. A feeling of extreme exhaustion?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Difficulties turning around while walking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Being afraid of possible progressing of the illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Difficulties writing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Being less able to go on holiday than before your illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Feeling insecure of yourself around others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Difficulties getting a good night's rest?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. 'On/off' periods?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Difficulty in accepting your illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Difficulties talking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Difficulties signing your name in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Difficulties walking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Drooling?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Feeling depressed or discouraged?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Difficulty with sitting still (for long periods)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Often needing to urinate and/or wetting yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Difficulties with transport?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Sudden extreme movements?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Difficulties concentrating?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Difficulties getting up (from a chair)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Constipation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Difficulties with your memory?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Difficulties turning around in bed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. That your illness inhibits your sex life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Feeling worried about (the possible consequences of) an operation in connection with your illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you need any help to complete this questionnaire?	Yes <input type="checkbox"/>	No <input type="checkbox"/>			
If yes, who?	Partner/spouse <input type="checkbox"/>	Friend/neighbour <input type="checkbox"/>	Family member <input type="checkbox"/>	Nurse <input type="checkbox"/>	Other (please specify) <input type="checkbox"/>

Appendix 2. Scoring of the Parkinson's Disease Quality of Life questionnaire: the questionnaire consists of 37 items, which provide an overall total score, and can be combined to give four sub-scales

Sub-scale	Item numbers
Parkinsonian symptoms (14 items)	1, 4, 6, 11, 14, 16, 20, 22, 25, 27, 30, 32, 35
Systemic symptoms (7 items)	2, 7, 13, 19, 24, 28, 33
Social functioning items (7 items)	3, 8, 12, 17, 23, 29, 37
Emotional functioning (9 items)	5, 10, 15, 18, 21, 26, 31, 34, 37

The responses to the items are scored for the total score and the sub-scales. Higher scores are indicative of better quality of life.