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The Parkinson's Disease Questionnaire (PDQ-39): development and validation of a Parkinson's disease summary index score

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Abstract

Objectives: to briefly outline the development and validation of the Parkinson's Disease Questionnaire (PDQ-39) and then to provide evidence for the use of the measure as either a profile of health status scores or a single index figure.
Design: the PDQ-39 was administered in two surveys: a postal survey of patients registered with local branches of the Parkinson's Disease Society of Great Britain ($n = 405$) and a survey of patients attending neurology clinics for treatment for Parkinson's disease ($n = 146$). Data from the eight dimensions of the PDQ-39 were factor-analysed. This produced a single factor on the data from both surveys.
Outcome measures: the eight dimensions of the PDQ-39 and the new single index score—the Parkinson's disease summary index (PDSI), together with clinical assessments (the Columbia rating scale and the Hoehn and Yahr staging score).
Results: in the postal survey 227 patients returned questionnaires (58.2%). All 146 patients approached in the clinic sample agreed to take part. Higher-order principal-components factor analysis was undertaken on the eight dimensions of the PDQ-39 and produced one factor on both datasets. Consequently it was decided that the scores of the eight domains could be summed to produce a single index figure. The psychometric properties of this index were explored using reliability tests and tests of construct validity. The newly derived single index was found to be both internally reliable and valid.
Discussion: data from the PDQ-39 can be presented either in profile form or as a single index figure. The profile should be of value in studies aimed at determining the impact of treatment regimes upon particular aspects of functioning and well-being in patients with Parkinson's disease, while the PDSI will provide a summary score of the impact of the illness on functioning and well-being and will be of use in the evaluation of the overall effect of different treatments. Furthermore, the PDSI reduces the number of statistical comparisons and hence the role of chance when exploring data from the PDQ-39.

Keywords: *health status, Parkinson's disease, Parkinson's Disease Questionnaire, summary score*

Introduction

In previous publications we documented the initial development and validation work for the Parkinson's Disease Questionnaire (PDQ-39) [1, 2]. Whilst a large number of clinical measures have been designed to characterize the impact of Parkinson's disease upon patients [3] there has been, until now, no systematic attempt to develop a disease-specific measure which is completed by patients themselves. The inclusion of

Table 1. The Parkinson's Disease Questionnaire (PDQ-39): scales and number of items in each

Dimension	No. of items
Mobility	10
Activities of daily living	6
Emotional well-being	6
Stigma	4
Social support	3
Cognitions	4
Communication	3
Bodily discomfort	3

health status measures, completed by patients, has been advocated as central to the evaluation of treatment regimes and surveillance of disease progression [4].

Whilst studies of Parkinson's disease including such measures are rare, there have been a few surveys reporting the use of the Sickness Impact Profile and Nottingham Health Profile in this patient group [5, 6]. However, although such generic measures can provide important information on the impact of illness upon areas of daily living and functioning regarded as universally important [7], they can also overlook important specific aspects of well-being that are adversely influenced by certain illnesses. Consequently, there is both a need for generic measures and disease-specific questionnaires.

The PDQ-39 was developed on the basis of interviews with Parkinson's disease patients and a number of large-scale surveys. It contains eight dimensions (see Table 1). Items for inclusion in the measure were generated from in-depth interviews with people diagnosed as having the disease. This led to the development of a 65-item questionnaire. This was included in a large-scale postal survey of Parkinson's disease patients. The data gained from this survey were then statistically analysed, resulting in a questionnaire containing 39 items and eight dimensions. The resulting multi-dimensional measure proved to have good internal and test-retest reliability, as well as good face and construct validity [1, 2]. Such profile measures can be of use in gaining a picture of the impact of the disease in specific areas of functioning and well-being, but interpretation can sometimes be hindered by the potential complexity of the data. Statistical analysis and interpretation become increasingly problematic as the number of dimensions multiplies.

The number of dimensions on a health status measure reduces the number of statistical comparisons and, consequently, the role of chance in testing hypotheses relating to health outcomes. Furthermore, interpretation of data from a number of dimensions can prove difficult if one wishes to gain an insight into the overall impact of ill health as measured by a questionnaire [8]. Summary scores can prove helpful in providing a guide as to the overall impact of ill health as measured on questionnaires which provide a profile of scores. Consequently statistical procedures have been employed by, for example, the developers of the Short Form Health Survey (SF-36), a multi-dimensional generic health profile, to reduce the number of dimensions. Recent work by Ware *et al.* [9] has outlined a method of reducing the number of dimensions of that instrument by using higher-order factor analysis, which involves factor analysing the dimension scores of a measure rather than the individual questions. This procedure is used here to create an overall single index figure [Parkinson's disease summary index (PDSI)] from the eight dimension scores gained from the PDQ-39.

The reliability and validity of both the profile scores and the overall index are assessed and compared with data gained from existing clinical measures of health, the Hoehn and Yahr scale [10] and the Columbia rating scale [11].

Methods

The PDQ-39 was administered in two surveys. The methods employed have been reported in full in previous publications [1, 2]. The first was a postal survey in which the PDQ-39 was sent to a sample of 405 people with Parkinson's disease who had been identified from membership of local branches of the Parkinson's Disease Society from five areas of England. The second survey was undertaken in a neurology clinic and permitted comparison of results gained on PDQ-39 with established clinical measures (the Hoehn and Yahr index and the Columbia rating scale). Subsequently, 146 Parkinson's disease patients participated in the clinic-based study.

Two of the investigators (R.G. and N.H.) examined the patients in the clinic and rated them on the Hoehn and Yahr scale and the Columbia rating scale. The Hoehn and Yahr scale has five stages for rating the severity of Parkinson's disease, whilst the Columbia scale consists of 25 items, scored from 0 to 4, addressing the signs and symptoms of Parkinsonism from which a summary score, with a range from 0 to 100, is obtained.

Results

Results from the postal survey of people with Parkinson's disease (study 1) and the clinic survey of Parkinson's disease patients (study 2) are reported below. PDQ-39 dimension scores and PDSI are coded on a scale of 0 (perfect health as assessed by the measure) to 100 (worse health as assessed by the measure).

Table 2. Means (standard deviations in parentheses) and 95% confidence intervals (CIs) on the dimensions of the Parkinson's Disease Questionnaire (PDQ-39) completed by patients in the postal survey (n = 201 minimum) and at clinic (n = 137 minimum)

	Postal survey		Clinic sample	
PDQ-39 scale	Mean (SD)	95% CI	Mean (SD)	95% CI
Mobility	66.59 (28.25)	62.8-70.4	41.71 (31.62)	36.4-47.0
ADL	55.82 (28.23)	52.1-59.6	40.40 (28.02)	35.8-45.0
Emotions	43.25 (23.88)	40.1-46.4	31.90 (22.13)	28.3-35.5
Stigma	34.67 (29.00)	30.8-38.5	30.86 (26.26)	26.2-35.2
Social	24.25 (24.08)	20.9-27.6	13.69 (20.05)	10.3-17.1
Cognitions	47.41 (23.08)	44.4-50.4	33.36 (22.91)	29.6-37.2
Communication	37.09 (24.35)	33.9-40.3	25.69 (22.95)	21.9-29.5
Body pain	52.18 (24.04)	49.0-55.4	40.79 (28.14)	36.1-45.4

ADL, activities of daily living.

Study 1

The postal survey was sent to 405 individuals who were registered with five branches of the Parkinson's Disease Society. Fifteen people were subsequently removed from the denominator as they could not be traced, were deceased or did not have Parkinson's disease. A total of 227 questionnaires were returned, yielding a response rate of 58.2%. The mean age of this sample was 70.30 years (SD 8.97; range 40.9-87.7); 57.4% were male, 42.6% female. The mean number of years since diagnosis was 8.6 (range <1-32) years. Completion of questions was high with only one dimension having more than 5% missing data (for the social support dimension 11.5% of questionnaires had insufficient data to permit calculation of the dimension score).

Descriptive statistics for the PDQ-39 is reported in Table 2. The eight dimensions were then subjected to higher-order principal-component factor analysis. One factor with an eigenvalue of in excess of 1 was produced which accounted for 51.1% of the variance (see Table 3). Each dimension of the PDQ-39 loaded on this factor (eigenvalue = 4.1). Consequently, all eight dimensions of the PDQ-39 were summed to create a single index figure. Internal reliability was assessed using Cronbach's α and a value of 0.84 was gained for the summary score, indicating high levels of internal reliability. The mean of the single index figure, referred to here as the PDSI was 44.63 (SD 17.62, min = 5.83, max = 87.19; 95% confidence interval 42.1-47.2; n = 184).

Table 3. Factor analysis of Parkinson's Disease Questionnaire (PDQ-39) dimensions (separate analysis of data from the postal survey and clinic sample)

	Factor loadings	
Dimension	Postal survey	Clinic sample
Mobility	0.76404	0.80558
ADL	0.75891	0.79596
Emotions	0.76307	0.80797
Stigma	0.69736	0.70343
Social	0.63362	0.69838
Cognitions	0.75811	0.71051
Communication	0.71458	0.75518
Bodily pain	0.61076	0.73992
% of variance explained by factor	51.1%	56.8%
Eigenvalue	4.1	4.5

ADL, activities of daily living.

Study 2

The analysis of the postal survey data was verified by undertaking an identical set of analyses on data gained from the clinic survey. This permitted verification of the factor analysis and internal reliability of the summary score. Furthermore, this data set permitted comparison with clinical assessments of disease severity in the form of the Hoehn and Yahr staging scale and the Columbia score.

Consecutive Parkinson's disease patients attending the neurology outpatient departments of hospitals in Oxford, Aylesbury, Newbury and Reading between September 1994 and January 1995 were invited to take part in the study. Two patients attending were not invited to take part because of uncertain diagnosis, whilst one was excluded because of very severe co-morbidity. Subsequently, 146 patients were recruited in the clinic-based study, with an average age of 66.09 years (SD 9.02; range 42.0-85.2); 59.6% were male, 40.4% female. The mean number of years since diagnosis was 6.73 (range <1 – 30) years. Completion of questions was high, with only one dimension having more than 5% missing data (for the social support dimension 6.1% of questionnaires had insufficient data to permit calculation of the dimension score).

Table 2 summarizes the data gained from eight dimensions of the PDQ-39. Table 3 provides the results from the principal-components factor analysis. One

Table 4. Correlation's between scores for the Parkinson's Disease Questionnaire (PDQ-39) domains against the Hoehn and Yahr and Columbia scales

PDQ-39 scale	Minimum value: Hoehn and Yahr (n = 131)	Minimum value: Columbia (n = 131)
Mobility	0.63**	0.54**
ADL	0.58**	0.56**
Emotions	0.27*	0.22**
Stigma	0.31**	0.29**
Social	0.16	0.08
Cognitions	0.40**	0.35**
Communication	0.45**	0.42**
Body pain	0.32**	0.19*

ADL, activities of daily living.
Spearman correlation: **P < 0.001, *P < 0.05.

factor with an eigenvalue in excess of 1 was produced which accounted for 56.8% of the variance. Each dimension of the PDQ-39 loaded on this factor (eigenvalue = 4.5) and all eight dimensions of the PDQ-39 were summed to create a single index figure. Internal reliability was assessed using Cronbach's α and a value of 0.89 was gained for the summary score, indicating high levels of internal reliability. The mean of the summary score PDSI was 31.62 (SD 19.03; min 0.78, max 85.88; 95% confidence interval 28.3-34.9; n = 128).

Patients in the clinic study were assessed on two clinical scales of dysfunction: the Hoehn and Yahr scale and the Columbia scale. The eight dimensions of the PDQ-39 were correlated with these scales (see Table 4). Correlations were highest for dimensions measuring physical aspects of health status (i.e. mobility and activities of daily living on the PDQ-39). The PDSI was significantly correlated with the Columbia score (r = 0.43, P< 0.001, n = 122) and the Hoehn and Yahr staging score (r = 0.51, P<0.001, n = 127).

Kruskal-Wallis tests undertaken on the data for all dimensions of the PDQ-39 indicated significant trends across the categories of the Hoehn and Yahr scale on all but one of the dimensions of the measures as well as on the PDSI (Table 5).

Discussion

This study has provided evidence for the creation of a summary index of health status based on the eight dimensions of the PDQ-39. Higher-order factor analyses on two separate data sets support the derivation of the PDSI. This provides substantial evidence that the disease has an overall effect on health and well-being, at least in terms of the eight dimensions measured by the PDQ-39. Reliability of the summary measure was assessed using Cronbach's α and found to be high, indicating that the index created by summing the eight dimensions is internally consistent and reproducible.

The construct validity of the measure was assessed by comparing the results of the PDSI with clinical assessments of ill health. Significant and high correlations were found between the PDSI and both the Columbia score and the Hoehn and Yahr staging score. Furthermore, a Kruskal-Wallis test supported these findings, with a linear trend for increased PDSI scores with greater clinically assessed Hoehn and Yahr scores.

Data from the PDQ-39 can be presented in profile form as well as summarized in the PDSI. The dimensions of the PDQ are similar to those reported

Table 5. Mean scores (standard deviations in parentheses) on the dimensions of the Parkinson's Disease Questionnaire (PDQ-39) and the Parkinson's disease summary index (PDSI) broken down by Hoehn and Yahr staging score

Dimension	Minimum value by stage: I (n = 37)	II (n = 57)	III (n = 21)	IV and V (n = 21)[a]
PDQ-39 scale				
Mobility*	15.69 (21.13)	39.04 (25.81)	49.77 (28.67)	77.40 (19.64)
ADL*	18.69 (17.78)	38.80 (26.69)	49.81 (21.76)	67.36 (20.62)
Emotions**	22.30 (18.59)	34.29 (23.23)	33.90 (23.65)	38.72 (19.75)
Stigma*	19.09 (19.98)	32.50 (27.68)	29.55 (23.87)	45.38 (26.26)
Social	10.71 (19.34)	13.98 (20.73)	14.29 (21.91)	17.86 (18.12)
Cognitions*	20.14 (15.39)	34.06 (24.20)	37.20 (19.41)	47.40 (22.79)
Communication*	13.19 (18.51)	23.36 (21.56)	34.09 (21.96)	40.97 (21.41)
Body pain*	28.60 (24.96)	39.97 (26.43)	41.67 (28.64)	58.68 (26.75)
PDSI*	18.39 (14.37) (n = 33)	31.60 (17.00) (n = 56)	36.53 (19.64) (n = 20)	48.59 (15.07) (n = 18)

ADL, activities of daily living.
[a] Summed due to small numbers in stages 4 and 5.
Kruskal-Wallis test: *P < 0.001, **P < 0.01.

in a recent paper presenting a Dutch Parkinson's disease questionnaire [12]. This provides further evidence for the appropriateness of the dimensions included in the PDQ-39. The impact of treatment on specific dimensions of well-being and functioning can be evaluated with the profile scores, whilst the overall impact of the disease on well-being and functioning, as measured by the PDQ, can be assessed using the PDSI. Such an index has the potential for use in the evaluation of different treatments for Parkinson's patients as interpretation of a single figure can often be less complex than that of a profile of scores. Furthermore, the adoption of a single index measure of outcome can reduce the number of statistical comparisons and consequently reduce the role of chance in testing hypotheses about health outcomes.

Copies of the PDQ are available from C.J. A user manual is in preparation and will be available in 1997.

Key points

- The Parkinson's Disease Questionnaire (PDQ-39) is a disease-specific measure of subjective health status.
- The PDQ-39 produces a profile of scores indicating the impact of Parkinson's disease in eight important areas of health status.
- A new summary measure, the Parkinson's disease summary index (PDSI), has been developed from the PDQ-39 and provides an indication of the global impact of Parkinson's disease on health status.
- The PDSI is shown to have high levels of reliability and validity.
- The PDSI will be useful in the evaluation of treatment regimes providing an economical and robust measure of the impact of the disease.

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