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PDQ-39: a review of the development, validation and application of a Parkinson's disease quality of life questionnaire and its associated measures

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Abstract Parkinson's disease is a common degenerative neurological condition. A number of general instruments exist to measure quality of life, but these were not designed to address areas salient to a specific disease. This contribution reviews the development and validation of the PDQ-39, a short 39-item quality of life questionnaire for Parkinson's disease. PDQ-39 data can be presented either in profile form or as a single index. This report also reviews the development and validation of a briefer measure (PDQ-8) derived from the PDQ-39, and of two summary indices (PDQ-39*SI* and PDQ-8*SI*).

Key words Quality of life · Parkinson's Disease · PDQ-39 · PDQ-8

Introduction

Parkinson's disease (PD) is a degenerative neurological condition with a prevalence of just over 1/1000 and increasing in incidence at older ages [1]. Problems associated with PD include walking, washing and dressing, a loss of dexterity, speech difficulties, fatigue, social and emotional problems. Few studies have attempted systematically to evaluate the impact of the illness upon individuals. In part this is due to the lack of a suitable measure of health status designed to evaluate the impact of the disease from the individual's perspective.

A large number of disease-specific clinical instruments exist to characterise the impact of the disease [2]. These instruments, which are completed by clinicians, emphasise the rating of neurological signs such as tremor, rigidity, bradykinesia and instability of posture. Whilst such instruments are valuable in clinical studies, they do not provide a complete picture of the impact of the disease. Most importantly they fail to address the impact of the illness upon subjectively assessed quality of life of patients [3].

A variety of general instruments exist to measure broader aspects of health problems that are identified by clinical scales [4, 5]. These instruments are variously referred to as health status, functional status, quality of life or health-related quality of life measures, and there is no agreed definition. For simplicity we use the term quality of life throughout this paper. However, while such instruments have been applied to patients with PD [6], it is increasingly recognised that such general measures may not address areas salient to specific diseases. Instruments which contain items specific to a particular disease are more likely to be relevant to areas that clinicians may wish to monitor and are more likely to be responsive because their content is of particular importance to patients [7, 8].

This paper summarises the process of development and validation of the PDQ-39, a quality of life instrument for Parkinson's disease [9, 10], and of subsequent measures and indices which have been derived from it [11, 12]. We review the different stages which were used in order to develop and test the PDQ-39, PDQ-39*SI*, PDQ-8 and PDQ-8*SI*.

Development of the PDQ-39 [9]

Item generation

Exploratory in-depth interviews were conducted with 20 persons with PD attending a neurology outpatients' clinic.

People were asked to describe the areas of their lives which had been adversely affected by their PD. This generated a large number of possible questionnaire items which could be included in the final questionnaire. These items were scrutinised for ambiguity and repetition. A 65-item questionnaire was developed and applied in a pilot study to test basic acceptability and comprehension. Each question asked about the influence of PD on a specific area of life over the past month, and for each question there was a range of five possible answers: never, occasionally, sometimes, often and always.

Item reduction and scale generation

All members with PD from eight local branches of the Parkinson's Disease Society (PDS) were surveyed by post using the 65-item questionnaire. A total of 359 persons (82.0%) responded. In this first postal survey sample the mean age was 71.4 years (range 42.2–89.4; 57.4% males, 42.6% females). The mean number of years since diagnosis was 9.4 (range < 1–40 years). Data from the 65-items were analysed to determine the underlying dimensions and to allow for removal of any redundant items for the final shorter questionnaire. Factor analysis (varimax rotation) produced ten factors with eigenvalues greater than 1 which explained 68% of variance. Two factors with eigenvalues less than 1.2 were subsequently removed because they did not produce meaningful scales and explained only 4.5% of variance. Fifteen items with a factor loading less than < 0.5 were removed. Seven additional items were removed from two factors with the largest number of items because their content was deemed to overlap with other items. Internal consistency reliability of each dimension was assessed using Cronbach's α statistic [13], where values above 0.5 are acceptable [14], although ideally scores should be in excess of 0.7 [15]. Internal consistency was found to be good for all dimensions of the PDQ-39.

The result was the PDQ-39 (Table 1), a questionnaire with 39 items covering eight discrete dimensions. The scores from each dimension are computed into a scale ranging from 0 (best, i.e. no problem at all) to 100 (worst, i.e. maximum level of problem).

Table 1 PDQ-39 dimensions and number of items in each

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

Validation of the PDQ-39

The measurement properties of the PDQ-39, reliability, validity and sensitivity to change, were assessed by using data from a second postal survey and an outpatient clinic sample [9, 10, 16].

For the second postal survey all members with PD from five different PDS branches were posted a booklet containing the PDQ-39, the SF-36 [4], a general quality of life measure, and questions about the severity of their PD symptoms. In addition, a second copy of the PDQ-39 was included in a sealed envelope. Respondents were asked to complete the second copy 3–6 days after the first and to report any important changes in their health during that time. In this survey 227 persons (57.6%) responded, and 167 of these completed the second copy of the PDQ-39 within 3–6 days and reported no important health changes. The mean age was 70.3 years (range 40.9–87.7; 57.4% males, 42.6% females). The mean number of years since diagnosis was 8.6 (range < 1–32 years).

In the clinic sample 146 consecutive PD neurology outpatients in Aylesbury, Newbury, Oxford and Reading were surveyed with the PDQ-39 and the SF-36 and clinically assessed using the Hoehn and Yahr Index and the Columbia Rating Scale. Two patients were not included due to uncertain diagnosis and one due to severe co-morbidity. At 4 months 136 patients (93.2%) were again surveyed and assessed. The mean age was 66.1 years (range 42–85; 59.6% males, 40.4% females). The mean number of years since diagnosis was 6.7 (range < 1–30 years).

Reliability

The two sets of PDQ-39 data from the second postal survey were available to examine the internal consistency reliability of the eight PDQ-39 dimensions. Cronbach's α was satisfactory for all scales on both occasions, with the exception of social support (0.66) at time 1, which was only slightly below Nunnally's criterion [15]. Test-retest reliability was calculated from the 167 respondents who completed both assessments. Correlation coefficients between scale scores at time 1 and time 2 were all significant ($P < 0.001$), and analysis by t test to evaluate changes in the distribution of scores between the two assessments produced no significant differences ($P < 0.05$).

Validity

Content validity was addressed by using patient-generated issues from the initial interviews. Construct validity was examined by means of correlations of scale scores with relevant SF-36 scores and with respondents' assessment of the severity of their PD symptoms. Mobility (PDQ-39) was correlated with physical function (SF-36; $r = –0.80$,

$P < 0.001$); activities of daily living (ADL; PDQ-39) with role limitations due to physical problems (SF-36; $r = -0.36$, $P < 0.001$); emotional well-being (PDQ-39) with mental health (SF-36; $r = -0.71$, $P < 0.001$); social support (PDQ-39) with social function (SF-36; $r = -0.34$, $P < 0.001$), and bodily discomfort (PDQ-39) with pain (SF-36; $r = -0.66$, $P < 0.001$) (negative correlations due to different directions of scoring PDQ-39 and SF-36 scales). Symptom scales for tremor, stiffness and slowness were calculated from the respondents' self-assessment of severity. A consistent pattern of worse scores on all PDQ-39 scales was obtained from patients with more severe symptoms. Differences in scale scores between individuals with varying severity of symptoms was significant ($P < 0.05$, Kruskal-Wallis analysis of variance test) except for communication with tremor, and social support with all three symptoms. Validity of the PDQ-39 was also examined in terms of agreement with clinical assessment. Patients in the clinic sample were assessed using the Hoehn and Yahr Index and the Columbia Rating Scale. These two measures were highly correlated with each other ($r = 0.81$, $P < 0.001$, $n = 140$). Significant correlations were found between both clinical scales and the PDQ-39 dimensions ($P < 0.05$) for all dimensions except social support. The highest correlations were with the physical aspects (mobility: Hoehn and Yahr Index, $r = 0.63$, $P < 0.001$; Col. $r = 0.54$, $P < 0.001$ and ADL, $r = 0.58$, $P < 0.001$; Col. $r = 0.56$, $P < 0.001$). Lower correlations were found with other PDQ-39 dimensions which assess aspects of well-being not captured by the clinical measures which focus on physical ability and symptoms. However, the overall severity of the disease as measured by the Hoehn and Yahr Index is reflected in all dimensions of the PDQ-39. This trend was significant across the categories of the Hoehn and Yahr Index (Kruskal-Wallis test, $P < 0.001$) for all dimensions except social support.

Sensitivity to change

Sensitivity to change in a quality of life instrument is particularly important in view of potential applications in clinical trials. This was tested on data from the clinic sample in terms of whether changes in PDQ-39 scores over a 4-month period were significant and consistent with patients' retrospective judgements of change, and changes on the SF-36, and in clinical assessment. In response to a transitional question: "Overall, has there been any change in the effects of your PD on your everyday life since you completed the previous questionnaire?" 11 persons (8.4%) replied a little or much better, 70 (53%) the same, and 51 (38.6%) a little or much worse. The PDQ-39 standardised response means for mobility (0.55) and ADL (0.43) were found to have significantly changed for the worse ($P < 0.01$) among those who described themselves as worse after 4 months. This suggests a reasonable response for these two dimensions [17]. In the overall sample of patients, retrospective judgement of change was significantly correlated with change scores for mobility and ADL. Change scores were examined in relation to patterns of change in the SF-36 physical and mental summary scores [18, 19]. Correlations were significant for five PDQ-39 scales (mobility, ADL, emotional well-being, stigma and social support). No significant correlations were found between changes in PDQ-39 scores and changes in the two clinical assessment scores.

Development of the PDQ-39*SI* (summary index score)

It has been suggested that the reduction in the number of dimensions on a quality of life instrument reduces the number of statistical comparisons and consequently reduces the role of chance in testing hypotheses relating to health outcomes. Furthermore, multi-dimensional data can be complicated to interpret. Summary scores can prove helpful in providing an insight into the overall impact of illness as measured by questionnaires which provide a profile of scores. Consequently, statistical procedures have been developed to derive useful summary scores [20]. Higher order factor analysis, which involves factor analysis of dimension scores rather than of individual questions, was used to create an overall single index score (PDQ-39*SI*) from the eight dimension scores gained from the PDQ-39 [11]. This analysis was initially undertaken on data from the second postal survey of PDS members. Higher order factor analysis produced one factor which accounted for 51.1% of the variance. Each dimension of the PDQ-39 loaded on this factor (eigenvalue = 4.1). Consequently, the PDQ-39*SI* was created by summing all eight of the PDQ-39 dimensions and standardising the score on a scale of 0–100. In this sample the PDQ-39*SI* was 44.63 ± 17.62 and gained a Cronbach's α score of 0.84, indicating high levels of internal reliability.

This analysis was then verified using an identical set of analyses on the clinic sample data. One factor resulted which accounted for 56.8% of the variance. Each dimension of the PDQ-39 loaded on this factor (eigenvalue = 4.5) and all eight of the PDQ-39 were summed to create a PDQ-39*SI*. With this sample the PDQ-39*SI* was 31.62 ± 19.03 and gained a Cronbach's α score of 0.89, again indicating high levels of internal reliability.

In this sample construct validity could be assessed by comparing the results of the PDQ-39*SI* with clinical assessments. The PDQ-39*SI* was significantly correlated with the Columbia score ($r = 0.43$, $P < 0.001$) and with the Hoehn and Yahr Index ($r = 0.51$, $P < 0.001$). In addition, the trend in worse scores on the PDQ-39*SI* across the categories of the Hoehn and Yahr Index was found to be significant (Kruskal-Wallis test).

Development of the PDQ-8 and PDQ-8*SI* (summary index score)

Success in creating the PDQ-39*SI* led to our search for an even briefer tool which could be used to provide the index alone (i.e. not designed to provide eight dimension scores) [12]. Data from the two postal surveys of PDS members was pooled. First, the most highly correlated item from each PDQ-39 dimension was selected to derive the following, shorter, eight-item questionnaire, referred to as the PDQ-8: "Due to having Parkinson's disease, how often during the last month have you ...

- Had difficulty getting around in public?
- Had difficulty dressing yourself?
- Felt depressed?
- Had problems with your close personal relationships?
- Had problems with concentration?
- Felt unable to communicate with people properly?
- Had painful muscle cramps or spasms?
- Felt embarrassed in public due to having PD?"

Using the same procedure described above, two summary scores were derived; first, the PDQ-39*SI* by summing the eight PDQ-39 dimensions, and second the PDQ-8*SI* by summing the eight items from the PDQ-8. These methods produced very similar and highly correlated results (r = 0.96, $p < 0.001$, n = 459). The mean score for the PDQ-39*SI* was 44.71 ± 18.36, and the mean score for the PDQ-8*SI* was 47.25 ± 18.36. In addition, a PDQ-8*SI* was derived from the clinic sample data, which produced very similar results to the PDQ-39*SI* when compared to the clinical assessments scores. Thus, the PDQ-8 seems to be a useful tool in studies where a short measure providing an overall index of self-perceived health in PD is required. Furthermore, it has been suggested that the potential exists for this type of short instrument to be of use in the clinical interview. The COOP Chart, a short nine-item measure has been found to be simple to administer, easy to interpret [21, 22], and could dramatically influence physician-patient communication [23].

Conclusion

Instruments are needed that complement existing forms of clinical scales by providing assessments of the impact of PD from the point of view of the patient. Generic quality of life instruments do not address the specific issues associated with PD, such as the disturbance of concentration, difficulties with communication, unusual bodily symptoms, feeling of social embarrassment and related social costs. The PDQ-39 is a well-validated, disease-specific, quality of life questionnaire for PD. It has been shown to be highly reliable in terms of internal consistency and test-retest results. Content validity was addressed by developing the items from interviews with patients rather than relying on the literature of clinical scales in this field. The questionnaire has construct validity in that scales scores are significantly associated with those scales of the SF-36 that measure related experience, and with assessment by clinicians. There is a consistent trend of poorer PDQ-39 scores associated with more severe symptoms of PD.

Four months is a short time in which to expect substantial changes to occur in PD, especially as there had been no systematic intervention. It is difficult to distinguish between no real underlying change and a lack of responsiveness in the measuring instrument. We found changes in five of the PDQ-39 scales which were significantly related to either patients' transitional judgements or to changes they reported via the SF-36. By contrast, none of the changes in the PDQ-39 were significantly related to changes in clinical scores. This supports the contention that the PDQ-39 and clinical scales are designed to assess different aspects of PD. The PDQ-39 appears to be sensitive to changes which matter to patients but are not the primary focus of clinicians' assessment, which concentrates on impairment and physical function. This would make the PDQ-39 an important addition to outcome measurement in clinical trials.

PDQ-39 data can be presented as a health profile, providing a fuller picture of the wide range of issues which affect quality of life with PD. The data can also be presented as a single index in which the overall impact of PD is being assessed. A single summary index can be derived from the PDQ-39 data. Alternatively, if the single index is all that is required, the summary index can be derived from the PDQ-8.

The PDQ-39 and its derivative measures have been translated and validated in many languages and is rapidly becoming the quality of life questionnaire of choice for PD disease research. For more information please contact the authors.

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