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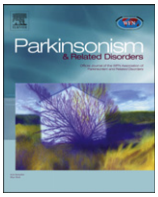

The development and validation of a quality of life measure for the carers of people with Parkinson's disease (the PDQ-Carer)

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ABSTRACT

Background: Parkinson's disease (PD) can have substantial effects not only on the quality of life of those diagnosedwith the condition but also upon the informal carers who provide support and assistance to them. However, to date no well-validated carer specific quality of life measure has been developed for carers of people with PD.
Objective: This paper documents the development and validation of a PD specific carer quality of life scale.
Methods: In depth interviews were undertaken with carers of people with PD. The interviews were transcribed and analysed thematically to derive a pool of potential items for the questionnaire. A pilot survey was used to refine the initial version of the questionnaire. A developmental survey was undertaken and the results analysed to produce the final 29-item measure. A validation survey was then undertaken to assess the construct validity and reliability of the measure.
Results: Survey results suggest a 29-item questionnaire tapping four dimensions of quality of life (Social and Personal Activities, Anxiety and Depression, Self care, and Strain). Internal consistency reliability was found to be high for all domains. Data completeness was high. Construct validity (assessed by correlations with a generic measure of quality of life) confirmed prior hypotheses.
Conclusion: The 29-item Parkinson Disease Questionnaire for Carers (PDQ-Carer) is a short, meaningful quality of life instrument, which taps areas of specific salience and concern to PD carers.

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1. Introduction

Parkinson's disease (PD) is a degenerative neurological condition characterised by slowness of movement, rigidity, tremor of the limbs whilst at rest and problems of posture. As the disease progresses patients may experience cognitive disorders, such as poor memory, problems of visuo-spatial functioning, slowness in motor tasks and psychological responses. Evidence suggests that PD has substantial effects on the functioning and well-being of those with the diagnosis [1–7]. However, to date the impact of the disease on informal carers has been less well documented. Informal carers include family members, typically partners, and close friends. Such carers can be an important source of help and support to people with long term conditions, such as PD, although their contributions are often overlooked by formal health care organisations [8]. Current literature highlights effects on such informal carers through interchangeably utilising the terms 'caregiver strain' and 'caregiver burden' [9,10]. The concepts of caregiver strain and burden have not been well defined in the literature, but suggest a direct measure of the duty of caring. This is in contrast to the concept of quality of life (QoL), which assesses a far broader spectrum relating to an individual's overall well-being.

To date, few studies have measured QoL in carers of people with Parkinson's disease. The few surveys that have been undertaken have been small scale and utilised generic quality of life measures [11,12]. Indeed this limited data on caregiver QoL in PD is likely, in part, to be a function of the limited tools for its assessment. To date one PD carer specific scale has been developed, the scale of Quality of Life of Care-Givers (SQLC) [13]. However, it has been rarely used, and the methods by which the measure was developed are not well documented, and the administration and scoring system have been subject to criticism due to their complexity [8]. Furthermore, the instrument was originally developed in Russia and no formally validated English language version of the measure exists.

This paper reports the development and validation of a questionnaire for use with carers of people with PD. The procedure to

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develop the carer measure replicates those used to develop the 39 item Parkinson's Disease Questionnaire (PDQ-39), which is the most widely used and validated disease specific patient reported outcome (PRO) measure in PD [14–17], and is consistent with recommendations for best practice [18]. A three-stage strategy was used in order to develop and test the questionnaire.

1.1. *Stage one -item generation*

Exploratory in-depth interviews were carried out with carers of people with Parkinson's disease in order to generate a large number of candidate questionnaire items. A questionnaire was developed and items were evaluated in cognitive testing and a pilot survey to assess acceptability and comprehension. The purpose of this aspect of the development was to ensure the instrument reflected the particular concerns of carers of people with PD.

1.2. *Stage two -item reduction and scale generation*

A developmental postal survey was conducted using the questionnaire generated in stage one in order to refine the number of items in the questionnaire and to assess the domains being measured by the instrument, using appropriate psychometric methods.

1.3. *Stage three -testing reliability and validity*

A further postal survey was conducted with an independent sample (referred to here as the validation survey) using the questionnaire generated at stage two, in order to test the reliability and construct validity of the new carer questionnaire generated at Stage two.

2. Methods

2.1. *Stage one - item generation*

In-depth semi-structured interviews with 21 carers who were members of Parkinson's UK were digitally recorded, and transcribed. The sample size for this stage of the study was determined by the point at which no new significant themes appeared to emerge from the interviews. Carers were asked to describe the areas of their lives that had been influenced by their caring role. A list of aspects of life adversely affected by their role was extracted from the transcribed interviews. Two researchers drafted questions on the basis of these interviews. A larger focus group of researchers then discussed the interviews and the proposed items. The selected set of preliminary items were then discussed by two further researchers, and scrutinised for repetition and ambiguity. The resulting questionnaire was presented to three carers in the context of cognitive interviews. Minor amendments were made at this stage. The resulting 44-item questionnaire was mailed, in a pilot survey, to 63 carers, who had volunteered, via local branches, to take part in the study. Participants were asked to indicate how long it had taken them to complete the questionnaire, and to identify any questions they found unclear or difficult to answer. Furthermore, respondents were asked if the questionnaire omitted areas of importance to them. Their responses and comments could be indicated on the questionnaire itself or made directly to a member of the research team via telephone. A response rate of 54 (85.7%) questionnaires was achieved. Minor amendments were made to two questions on the measure and one item was split into two separate questions.

The preliminary questionnaire created in this stage contained 45 items. Questions asked about the influence of caring on specific areas of life over the past four weeks. To each question respondents could select one answer from the range - Never (0); Occasionally (1); Sometimes (2); Often (3); Always (4).

2.2. *Stage two - item reduction and scale generation, (inc development survey)*

The 45 item questionnaire was administered, by postal survey, directly to carers. Local branches of Parkinson's UK in different areas of England were approached for help in recruiting a sample and fifteen branches agreed to take part. Each branch was requested to indicate how many questionnaires they required for carers of people on their lists who had PD. Reminder letters were sent approximately four weeks after the original mailing. Statistical and psychometric procedures were used on the dataset gained from this Development Survey to create the final 29-item short form measure.

2.3. *Stage three - testing reliability and validity, (inc validation survey)*

The validity and reliability of this 29-item questionnaire were assessed in a further postal survey of carers of people with PD. A sample of people with PD was identified from membership of local branches of Parkinson's UK from 26 areas which had not included in the first postal survey, and were requested to complete a copy of the Parkinson's Disease Questionnaire (PDQ-39) and to pass on the relevant questionnaires to their nominated carer. Questions were asked about the influence of caring on specific areas of life over the past four weeks. To each question respondents could select one answer from the range - Never (0); Occasionally (1); Sometimes (2); Often (3); Always (4).

The Validation Survey contained not only the 29-item Parkinson's Disease Questionnaire for Carers (PDQ-Carer) but also the SF-36 Health Survey Questionnaire (SF-36) [19–21]. The SF-36 Health Survey is a self-administered generic health status instrument which has been extensively validated throughout the world in a wide variety of populations. Correlations of the PDQ-Carer dimensions with specific scales of SF-36 were examined to determine the construct validity of the new measure.

3. Statistical analysis

Descriptive analyses on demographic data were performed. Decision rules for item reduction were non response greater than 10%, high floor or ceiling effects (greater than 40% selecting one of the two most extreme options (i.e. 'never', or 'always')); item loading in factor analysis less than 0.40, and items that did not load on any meaningful factor.

Exploratory factor analysis was used to identify potential subscales within the questionnaire. An orthogonal solution was sought and hence varimax rotation was chosen. This approach is likely to provide the most parsimonious solution. Items most strongly interrelated tend to gain high loadings on a single factor suggesting the items are assessing the same underlying concept. Those factors with an eigenvalue of greater than unity were retained in the analysis. Internal consistency reliability was assessed with the Cronbach's alpha statistic [22].

Construct validity was explored by correlating (Spearman rho) dimensions tapping similar constructs of the PDQ-Carer with those of the SF-36.

4. Results

4.1. *Item reduction and scale generation*

The forty-five item questionnaire, developed in Stage one of Methods (above), was mailed to 228 individuals. A response rate of 160 (70.0%) was achieved. The mean age of the sample was 67.41 years (range 33–89 years)); 73.7% were female and 26.3% male. The vast majority of respondents were spouses or partners of the person for whom they provided care ($n = 155$, 96.9%). The mean number of years that respondents reported being a carer was 6.96 (SD 5.77; range of 1 year–27 years), and the mean age of those with PD was 70.57 years (SD 8.05, range 41–89). The mean length of time to complete the 45-item questionnaire was 11 min (SD 5.41; range 2–30 min). Five items were found to be very highly correlated with other items on the questionnaire and were removed. Eight items were removed because of floor effects. A factor analysis was performed on the remaining 32 items. Three items were removed as they were not found to load on any meaningful factors. The final 29 items were than factor analysed and four domains were identified accounting for 60.12% of the variance:

4.2. *Social and personal activities*

(12 items) addresses to what extent caring has adversely affected relationships with friends, the ability to maintain pastimes and hobbies, the frequency and ease with which other family

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