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

Crispin Jenkinson*, Sarah Dummett, Laura Kelly, Michele Peters, Jill Dawson, David Morley, Ray Fitzpatrick

University of Oxford, Department of Public Health, Old Road Campus, Headington, Oxford OX3 7LF, United Kingdom

ARTICLE INFO

Article history:
Received 21 November 2011
Received in revised form
10 January 2012
Accepted 11 January 2012

Keywords:
Carers
Quality of life
Parkinsons disease questionnaire for carers
PDQ-Carer

ABSTRACT

Background: Parkinson’s disease (PD) can have substantial effects not only on the quality of life of those diagnosed with 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.

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
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 carers in 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) items reflecting 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
members can be seen and limitations on outings and holidays/breaks.

4.3. Anxiety and depression

(6 items) addresses to what extent caring has adversely affected mental health and well-being, causing anxiety, lack of energy and motivation, and depression.

4.4. Self-care

(5 items) addresses to what extent caring has adversely affected health, in terms of perceived physical well-being, and health behaviour, such as maintaining a good diet and paying less attention to ones own health.

4.5. Stress

(6 items) addresses to what extent caring has caused feelings of impatience and anger, together with feelings of being undervalued and weighed down by responsibilities.

The correlations of items to their corrected scale totals and the internal consistency reliability of scales found in the development survey is shown in Table 1. All the scales have excellent internal consistency reliability by the standard for group comparisons (7).

Each scale is transformed to have a range from 0 (best, i.e. no problem at all) through to 100 (worst, i.e. maximum level of problem) with each scale being calculated as follows: scale score = the total of the raw scores of each item in the scale divided by the maximum possible raw score of all the items in the scale multiplied by 100. Scores in the range > 60–100 for each dimension suggest seriously compromised aspects of quality of life, with respondents indicating problems often or most of the time. The scale scores of male and female respondents in the developmental postal survey are shown in Table 2, together with the number of respondents gaining scale scores in the range > 60–100.

4.6. Evaluating construct validity

A Validation Survey was conducted (Stage three in Methods, above) in order to test the construct validity of the scales of the 29-item questionnaire (PDQ-Carer) created on the basis of the Developmental Survey, and to confirm the internal consistency of the hypothesised dimensions of the measure. The questionnaire was sent to 387 individuals registered as members of local branches of Parkinson’s UK. A total of 236 carer questionnaires were returned, a response rate of 60.9%. The large majority indicated they were a spouse/partner (n = 219, 92.4% of those who responded to the question) of the person for whom they provided care. The mean age of the sample was 68.2 years (SD 9.49; range 25–89 years); 63.5% females, 21.3% males. The mean number of years respondents reported being a carer was 8.1 (range 6 months–51 years). The mean age of those PD respondents receiving care was 71.5 years (SD 7.71; range 44–87 years). The PDQ-Index was calculated, and indicated a wide variety of effects of PD on self reported health status (score range 2.92–88.80), with a median score of 38.23, and 10% of respondents scoring in excess of 60 on the PDQ-Index [17].

Construct validity was examined by means of correlations of scales for PDQ-Carer with relevant scales for SF-36, Personal and Social Activities (PDQ-Carer) was correlated with the Social Functioning domains of the SF-36 (rho = –0.60, p < 0.001, n = 234). Anxiety and Depression (PDQ-Carer) was correlated with the Mental Health Index of the SF-36 (r = –0.70, p < 0.001, n = 228). Self Care (PDQ-Carer) was correlated with the Role Physical (rho = –0.52, p < 0.001, n = 233) and Role Emotional (rho = –0.62, p < 0.001, n = 233) domains of the SF-36. Carer Strain (PDQ-Carer) was found to be highly correlated with the Energy/Vitality dimension of the SF-36 (rho = –0.62, p < 0.001, n = 232). Correlations between SF-36 and PDQ-Carer measures are negative due to the inverse scoring algorithms of the instruments (i.e. the ‘best’ score on domains of the SF-36 is 100, whilst 0 on the PDQ-Carer and worst scores are 0 and 100 respectively). Descriptive statistics for both the PDQ-Carer and the SF-36 are reported in Table 3.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Item to total correlations and internal reliability consistency (Cronbach’s alpha) of scales generated from the first main postal survey of carers of people with PD.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scale (in bold) and items</td>
<td>Item to total correlation</td>
</tr>
<tr>
<td>Personal and Social Activities (n = 151)</td>
<td>0.77</td>
</tr>
<tr>
<td>Felt prevented from pursuing hobbies and other interests?</td>
<td>0.67</td>
</tr>
<tr>
<td>Felt that relationships with friends have been affected?</td>
<td>0.67</td>
</tr>
<tr>
<td>Felt more withdrawn because of your caring role?</td>
<td>0.80</td>
</tr>
<tr>
<td>Been limited in what you can do socially?</td>
<td>0.62</td>
</tr>
<tr>
<td>Felt workload around the house has increased significantly?</td>
<td>0.67</td>
</tr>
<tr>
<td>Found it difficult to see friends and family?</td>
<td>0.67</td>
</tr>
<tr>
<td>Difficult to leave the person you care for alone for more than 1 h?</td>
<td>0.74</td>
</tr>
<tr>
<td>Felt that you cannot do things on the spur of the moment?</td>
<td>0.70</td>
</tr>
<tr>
<td>Found it difficult to be involved in regular activities which require commitment, e.g. volunteering, being on a committee etc?</td>
<td>0.70</td>
</tr>
<tr>
<td>Felt unable to go on holiday?</td>
<td>0.66</td>
</tr>
<tr>
<td>Felt responsible that Parkinson’s disease medication was available and taken at appropriate times?</td>
<td>0.49</td>
</tr>
<tr>
<td>Had to limit outings because you worry that, when taking the person you care for out, they won’t be able to cope?</td>
<td>0.72</td>
</tr>
<tr>
<td>Anxiety and Depression (n = 158)</td>
<td>0.69</td>
</tr>
<tr>
<td>Felt anxious because of the responsibility of caring?</td>
<td>0.69</td>
</tr>
<tr>
<td>Felt worried about your own physical health?</td>
<td>0.69</td>
</tr>
<tr>
<td>Felt worried about the future?</td>
<td>0.59</td>
</tr>
<tr>
<td>Lacked the energy and motivation to do the things you enjoy?</td>
<td>0.69</td>
</tr>
<tr>
<td>Felt depressed?</td>
<td>0.70</td>
</tr>
<tr>
<td>Felt worried about what would happen if you were unwell?</td>
<td>0.71</td>
</tr>
<tr>
<td>Self care (n = 157)</td>
<td>0.69</td>
</tr>
<tr>
<td>Found it difficult to get out, for example, to do the shopping</td>
<td>0.69</td>
</tr>
<tr>
<td>Found the demands of caring physically difficult?</td>
<td>0.67</td>
</tr>
<tr>
<td>Taken less care with your diet?</td>
<td>0.56</td>
</tr>
<tr>
<td>Felt your physical health has been affected by your caring role?</td>
<td>0.73</td>
</tr>
<tr>
<td>Paid less attention to your own health (e.g. put off visiting a doctor)?</td>
<td>0.73</td>
</tr>
<tr>
<td>Strain (n = 156)</td>
<td>0.50</td>
</tr>
<tr>
<td>Found you could not sleep through the night?</td>
<td>0.54</td>
</tr>
<tr>
<td>Thought that your caring role was taken for granted by others?</td>
<td>0.54</td>
</tr>
<tr>
<td>Felt impatient with the person you care for?</td>
<td>0.66</td>
</tr>
<tr>
<td>Felt exhausted?</td>
<td>0.73</td>
</tr>
<tr>
<td>Felt less in control of your temper than before you became a carer?</td>
<td>0.66</td>
</tr>
<tr>
<td>Felt that you are responsible for everything at home?</td>
<td>0.60</td>
</tr>
</tbody>
</table>

Note: summary item content. See appendix 1 for the full content of items.
Table 2
Descriptive statistics for the dimensions of the PDQ-Carer from results of the developmental survey.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Men (Mean, SD)</th>
<th>Women (Mean, SD)</th>
<th>Total (Mean, SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal and Social Activities</td>
<td>38.94 (21.10)</td>
<td>40.98 (24.57)</td>
<td>40.47 (23.69)</td>
</tr>
<tr>
<td>n (range of scores)</td>
<td>39</td>
<td>(0–89.58)</td>
<td>(0–89.58)</td>
</tr>
<tr>
<td>n (% high scores)</td>
<td>8 (20.5%)</td>
<td>34 (29.31%)</td>
<td>42 (27.01%)</td>
</tr>
<tr>
<td>Anxiety and Depression</td>
<td>42.56 (21.85)</td>
<td>44.76 (22.98)</td>
<td>44.17 (22.64)</td>
</tr>
<tr>
<td>n (range of scores)</td>
<td>42</td>
<td>(0–95.83)</td>
<td>(0–95.83)</td>
</tr>
<tr>
<td>n (% high scores)</td>
<td>10 (23.81%)</td>
<td>30 (25.86%)</td>
<td>40 (25.81%)</td>
</tr>
<tr>
<td>Self care</td>
<td>25.00 (19.55)</td>
<td>31.28 (24.79)</td>
<td>29.68 (22.67)</td>
</tr>
<tr>
<td>n (range of scores)</td>
<td>40</td>
<td>(0–90.00)</td>
<td>(0–90.00)</td>
</tr>
<tr>
<td>n (% high scores)</td>
<td>2 (5.0%)</td>
<td>15 (12.82%)</td>
<td>16 (10.20%)</td>
</tr>
<tr>
<td>Strain</td>
<td>42.78 (20.50)</td>
<td>48.12 (22.62)</td>
<td>47.62 (22.41)</td>
</tr>
<tr>
<td>n (range of scores)</td>
<td>42</td>
<td>(0–90.00)</td>
<td>(0–90.00)</td>
</tr>
<tr>
<td>n (% high scores)</td>
<td>11 (26.83%)</td>
<td>39 (33.91%)</td>
<td>50 (32.05%)</td>
</tr>
</tbody>
</table>

Each scale has a range from 0 (best level of self reported health measured on the instrument) through to 100 (poorest level of self reported health measured on the instrument).

Internal consistency of scales was again assessed and found to be high with alpha coefficients of 0.94 for the Personal and Social Activities Scale, 0.90 for the Anxiety and Depression Scale and 0.85 for both the Self Care and Strain scales.

5. Discussion

Informal caregivers of people with Parkinson’s disease face numerous responsibilities that stem from the need to provide support and assistance to a person with a progressively disabling disease. The effects of Parkinson’s disease range from physical functioning to cognitive and mental well-being. The demands of caring can have substantial effects on the lives of those charged with this responsibility. Furthermore, poor caregiver health has been linked to poorer outcomes for the people with PD for whom they care [23].

To date, however, no disease specific carer instrument has been available which directly addresses the issues and concerns of this particular group. Typically, the impacts of caring have been evaluated in the rather narrower notion of ‘carer strain’ or ‘burden’ [24–27], with a smaller number of studies using generic quality of life instruments, such as the SF-36 [28].

The 29-item questionnaire developed in this study has been shown to have good psychometric properties both in terms of internal consistency reliability and construct validity. Content validity has been addressed by developing items on the basis of in-depth interviews with carers rather than relying on existing literature. The content of the questionnaire addresses experiences of great importance to individuals who care for people Parkinson’s disease.

The questionnaire has construct validity in that scale scores are significantly associated, as predicted, with those scales of SF-36 that measure related experiences.

The questionnaire was developed in order to be sufficiently short and simple in format that it would be feasible for use in a wide range of health care applications. It is intended that the measure be used not only in studies evaluating interventions directed specifically at carers for people with PD, but also in trials of PD treatments where improved patient quality of life may lead to improved quality of life for carers. Furthermore, the possibility that this measure may be relevant to other groups of carers could be explored in focus groups and in-depth interviews with those caring for people with other neurological conditions. A list of the items included in the PDQ-Carer can be found in Appendix 1. To obtain a copy of the questionnaire please contact CJ.

Acknowledgements

This study was funded by The European Federation of Neurological Associations (EFNA). We are particularly grateful for the support and assistance of the past president of EFNA, Mary Baker MBE. We also wish to thank Parkinson’s UK and its members and the local branches which participated in this research.
Appendix One

Items of the PDQ-Carer

Personal and Social Activities

1. Been prevented from pursuing hobbies and other interests?
2. Felt that relationships with friends have been affected?
3. Felt more withdrawn because of your caring role?
4. Been limited in what you can do socially?
5. Felt that your workload around the house has increased significantly?
6. Found it difficult to see friends and family?
7. Felt it difficult to leave the person you care for alone for more than one hour?
8. Felt that you cannot do things on the spur of the moment?
9. Felt unable to go on holiday or take short breaks?
10. Found it difficult to involve in regular activities which require commitment, e.g., volunteering work, regularly meeting friends?
11. Felt worried about what would happen if you were unwell?
12. Felt worried about the future?
13. Felt worried about your own physical health?
14. Felt worried about what would happen if you were unwell?
15. Felt that your workload around the house has increased significantly?
16. Felt that you cannot do things on the spur of the moment?
17. Felt unable to go on holiday or take short breaks?
18. Felt responsible for Parkinson's disease medication being available and taken at appropriate times?
19. Felt that your physical health has been affected by your caring role?
20. Taken less care with your diet?
21. Felt anxious because of the responsibility of caring?
22. Felt worried about your own physical health?
23. Felt worried about the future?
24. Felt you lacked the energy and motivation to do the things you enjoy?
25. Felt depressed?
26. Felt impatient with the person you care for?
27. Felt exhausted?
28. Felt less in control of your temper than before you became a carer?
29. Felt that you are responsible for everything at home?

Response categories, for each item, are: Never/Occasionally/Sometimes/Often/Always. The questionnaire is copyright (c) Health Services Research Unit, University of Oxford, 2011.

References