Short communication

The PDQ-Carer: Development and validation of a summary index score

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A B S T R A C T

Introduction: The PDQ-Carer is a 29 item measure of health related quality of life for use with carers of people with Parkinson's disease. The original development of the instrument identified four domains. This study examined the possibility that the four domains could reasonably be summed to provide a single summary index score.

Methods: The PDQ-Carer was administered in a postal survey of patients and carers registered with local branches of Parkinson's UK. Data from the four domains of the PDQ-Carer was subjected to higher order factor analysis. Reliability and validity of the summary index were assessed.

Results: A total of 236 carer questionnaires were returned, a response rate of 61%. The mean age of the sample was 68.2 years (SD 9.49; range 25–89 years); 63.5% females, 21.3% males. Higher order principle components factor analysis produced one factor, accounting for 85.5% of the variance. The newly derived single index was found to be both internally reliable (alpha = 0.94) and valid through correlations with the eight domains of the SF-36 (all p < 0.001).

Discussion: The analyses undertaken here indicate that data from the PDQ-Carer can be presented in summary form. The index will provide an overall indication of the impact of caring. Furthermore, the single index reduces the number of statistical comparisons, and hence the role of chance, when exploring data from the PDQ-Carer.

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1. Introduction

A number of widely used outcome measures now incorporate summary index scores as an additional means of reporting respondent data. The generic SF-36 [1] and disease specific PDQ-39 [2] are just two such examples. The benefits of summary scores have been suggested as twofold. Firstly, a reduction in the number of domains on a measure reduces the number of statistical comparisons and consequently decreases the role of chance in testing hypotheses relating to health outcomes [3]. Secondly, interpretation of data over a number of domains can be problematic if attempting to gain insight into the overall impact of a health condition or role (i.e. caregiving) as measured by a questionnaire [4]. Summary scores can therefore be useful in gaining insight into the overall impact of the subject of investigation when assessed using measures that give a profile of scores via domains. The statistical procedure of higher order factor analysis has subsequently been employed to reduce the number of domains on instruments such as the SF-36 [3] and PDQ-39 [5].

The PDQ-Carer [6] is a recently validated 29 item measure of health related quality of life (QoL) for use with carers of people with Parkinson’s disease. The original development of the instrument identified four domains; Social and Personal Activities, Anxiety and Depression, Self-Care and Stress. The aim of this study was to examine the possibility that the four domains could be summed to also provide a single summary index score.

2. Methods

Ethical approval for the study was granted by the Central University Research Ethics Committee and the Medical Sciences Interdivisional Research Ethics Committee of the University of Oxford.

2.1. Participants

Caregivers of people with Parkinson’s were invited to take part in a postal survey as part of a wider study, the results of which are reported elsewhere [6,7]. All participants were recruited via local branches of the support charity Parkinson’s UK and provided informed written consent.

2.2. Measures

Participants completed two instruments; the PDQ-Carer [6] and the SF-36 [1]. The PDQ-Carer is a 29 item instrument answered on a 5-point Likert scale. The questionnaire contains four domains (Social and Personal Activities, Anxiety and Depression, Self-Care and Stress) and has been shown to have good psychometric properties both in terms of internal consistency reliability and construct validity [6]. Raw scores for each domain are transformed to have a range from 0 to 100 with lower scores indicating superior QoL. The SF-36 is a 36 item instrument containing 8
Table 1
Descriptive statistics for the domains of PDQ-Carer:

<table>
<thead>
<tr>
<th>PDQ-Carer domain</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal &amp; Social Activities</td>
<td>46.15</td>
<td>26.73</td>
</tr>
<tr>
<td>Anxiety &amp; Depression</td>
<td>46.44</td>
<td>24.93</td>
</tr>
<tr>
<td>Self-Care</td>
<td>32.57</td>
<td>24.72</td>
</tr>
<tr>
<td>Strain</td>
<td>44.74</td>
<td>24.04</td>
</tr>
</tbody>
</table>

Table 2
Correlations between the PDQ-Carer-SI and the domains of the SF-36.

<table>
<thead>
<tr>
<th>SF-36 domain</th>
<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Functioning</td>
<td>−0.38</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Role Physical</td>
<td>−0.49</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Role Emotional</td>
<td>−0.61</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>−0.68</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Mental Health</td>
<td>−0.66</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Energy/Vitality</td>
<td>−0.67</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Pain</td>
<td>−0.48</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>General Health Perception</td>
<td>−0.51</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

domains (Physical Functioning, Role Physical, Role Emotional, Social Functioning, Mental Health, Energy/Vitality, Pain and General Health Perception) that has been extensively used and shown to have excellent psychometric properties [8,9]. Higher scores indicate superior health status. Reminder letters were sent four weeks after the original mailing.

2.3. Statistical analysis

Data were checked for presence of outliers and normality of distribution prior to statistical analysis. Data from the four domains of the PDQ-Carer was subjected to higher order principal components analysis. Reliability was assessed via Cronbach’s alpha [10] and validity through calculation of Pearson correlation coefficients with the eight domains of the SF-36. Data were analysed using SPSS Version 20.

3. Results

A total of 236 carer questionnaires were returned, a response rate of 61%. 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 length of time in the caregiving role was 8.1 years (SD 7.46). Descriptive statistics for the PDQ-Carer are reported in Table 1.

The four domains of the PDQ-Carer were subsequently subjected to higher order factor analysis. One factor with an eigenvalue in excess of one was identified, accounting for 85.5% of the variance (extraction method principal component analysis). Each domain of the PDQ-Carer loaded on this one factor which had an eigenvalue of 3.50. Consequently, all four domains of the PDQ-Carer were summed to create a summary index score. The mean of the summary index figure was 42.05 (S.D. = 23.10, min = 0.00, max = 94.80). Cronbach’s alpha value was calculated as 0.94. Correlations with the domains of the SF-36 are presented in Table 2. All are highly statistically significant (p < 0.001).

4. Discussion

The results reported provide evidence for the creation of a summary index of caregiver QoL based on the four domains of the PDQ-Carer. Higher order factor analysis supports the derivation of the PDQ-Carer Summary Index (PDQ-Carer-SI). This summary index provides strong evidence that caring for people with Parkinson’s has an overall effect on caregiver QoL, at least in terms of the four domains measured by the PDQ-Carer. Reliability of the summary measure was assessed using Cronbach’s alpha which was found to be high, indicating that the index created by summing the four domains is internally consistent and reproducible. Validity is supported by the highly significant correlations with the SF-36. The PDQ-Carer-SI therefore suggests that the impact of caregiving affects most aspects of QoL measured by the eight domains of the SF-36.

In conclusion, data from the PDQ-Carer can be presented in profile form as well as summarised in the PDQ-Carer-SI. Thus, the impact of caregiving on specific domains of QoL can be evaluated with the profile scores, whilst the overall impact of the caregiving role can be assessed using the PDQ-Carer-SI. Such an index has the potential for use in studies evaluating interventions directed specifically at carers for people with PD and also in trials of PD treatments where improved patient QoL may lead to improved QoL for carers, 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 and QoL outcomes.

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References