Does self-reported well-being of patients with Parkinson's disease influence caregiver strain and quality of life?

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Abstract
Background: The impact of Parkinson's disease (PD) on the quality of life of both patients and their carers has not been well documented.

Objective: This study describes the health status of both PD patients and caregivers as measured on a generic measure of health status (SF-12), and then explores to what extent patient self-reported health, as measured on the disease-specific Parkinson's Disease Questionnaire (PDQ-39), is associated with carer strain and self-reported quality of life.

Methods: A postal survey was carried out of both patients and caregivers through local branches of Parkinson's UK. Questionnaire packs were sent to those on the database with a diagnosis of PD. The patient was asked to give the carer questionnaire to their main caregiver, if they had one.

Results: Results from the SF-12 suggests that PD has substantial adverse effects on both the physical and mental well-being of patients when compared with population norms. While carer physical health was not found to be substantially different from that of the general population, emotional health was lower than that of the general population. Furthermore, results suggest that the self-reported health status of PD patients is associated with higher levels of caregiver strain and poorer emotional health.

Conclusion: PD impacts on both the well being of both patients and caregivers; the data provide evidence that the health status of the patient, in particular their physical health, has a significant impact on the well-being of their caregiver.

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1. Introduction

The impact of Parkinson's Disease (PD) on the individual with PD is wide-ranging, with postural and gait problems reducing mobility or rigidity in the face affecting social interaction. There may also be cognitive effects including dementia in the later stages. Not surprisingly, PD may widely impact on health-related quality of life in terms of role function and emotional and social well-being [1,2].

Due to the problems associated with PD, individuals affected by the disease often need a caregiver. Usually it is a family member who becomes the caregiver. The role of the caregiver becomes progressively important as the disease progresses. Therefore it is

not only the impact of PD on patients that is of importance, but also the impact on caregivers. The impact on caregivers has been assessed in terms of quality of life, burden, strain or distress. Quality of life is lower in PD caregivers than in the general population [3,4] and they are more likely to report mood disorders [4]. Caregivers, in particular spouse caregivers, have more severe depression and higher reports of tiredness, sadness and lower life satisfaction than healthy elderly controls [5], and they report experiencing considerable burden in terms of health, depression and social life [6], psychological distress [7] and strain from their caregiving role [8]. Younger spouse caregivers are at greater risk for negative consequences from their caring role, even in the early stages of disease, than older spouse caregivers [8].

Previous studies have assessed associations between patient and caregiver variables, particularly with the aim of identifying which patient variables are associated with differences in caregiver well-being. Significant correlations have been found between caregiver quality of life and increasing disease severity [3,4], disease duration [4], patient disability [3] and patient depression [4]. Caregiver burden correlates significantly with increasing patient disability.
and symptoms of PD (in particular mental health problems and falls), patients’ depression and disease-specific quality of life scores [6].

The measurement of functioning and well-being from the perspective of the patient has, over the last few decades, become central to the assessment of health and the evaluation of treatment regimes. There has been an enormous growth in the application of measures designed to assess quality of life in a vast array of medical specialties. A number of measures have been used in PD [9,10]. However, to date, there has been limited research evaluating patient quality of life and its association with carer strain and well-being. Some small scale studies have explored this issue, mostly in clinical samples, and have suggested that predictors of carer quality of life, based on regression analysis, were patient gender, disease duration, patient quality of life and patient activities of daily living (ADL) [11] and possible predictors of caregivers’ burden were patients’ mood and quality of life [3]. One relatively small scale clinic survey suggested that patient reported quality of life, as measured on the Parkinson’s Impact Scale, was associated with carer reported well being as measured on the same instrument [12]. The purpose of this paper is, therefore, to explore the relationship of patient quality of life with carer burden and well-being in a large scale community survey:

- firstly, it documents the health status of both PD patients and caregivers as measured on a generic measure of health status, the SF–12 Health Survey. Data gained from both patients and caregivers is compared with normative data.
- secondly, the paper explores to what extent patient self-reported health, as measured on the disease-specific Parkinson’s Disease Questionnaire (PDQ-39), is associated with carer strain (Carer Strain Index) and self-reported quality of life.

2. Methodology

A postal survey was carried out with patients and caregivers from October 2008 to January 2009. PD patients were recruited through local branches of Parkinson’s UK (formerly the Parkinson’s Disease Society). Twenty-seven local branches participated with an average of 73 members (range 20–150). For reasons of data protection, the branches were not able to make address lists available to the research team and local branches thus mailed out pre-packed questionnaires to their members. Members of Parkinson’s UK are mostly people with PD and therefore the caregiver questionnaire was sent alongside the patient questionnaire. The patient was asked to give the caregiver questionnaire to their main carer, if they had one. For the purpose of this study, ‘carer’ was defined as ‘a family member or friend who provides unpaid care (such as help with dressing and feeding or help with housework) to the patient’. Additionally, the questionnaire packs included covering letters and information sheets for patients and caregivers respectively, as well as two return envelopes (one for the patient questionnaire and one for carer questionnaire). All the questionnaires were numbered. The patient and caregiver questionnaire in each pack had the same number which allowed matching the returned patient and caregiver questionnaires. A reminder/thank you note was sent two weeks after the initial mail out of the questionnaires. Ethical approval for the study was obtained through the University of Oxford Ethics Committee.

2.1 Sample

Members of local branches of the PDS were recruited from the nine geographical regions of England covered by the society (East Midlands, East England, Greater London, North-East, North–West, South–East, South–West, West Midlands and Yorkshire and Humber). The mean number of questionnaires sent by geographical region was n = 222 (range from 110 in North-East of England to 325 in the South–West). The total number of questionnaires mailed out was 1999.

2.2 Questionnaires

Patients and caregivers both completed two different measures to assess health status. The patient questionnaire included a generic health status measure and a disease-specific measure, whilst the caregiver questionnaire included the same generic health status measure as for patients, and a measure to assess caregiver strain. The generic measure of health status was the 12 item Short Form Health Survey (SF-12v2), whilst disease-specific aspects of health status was assessed by the 39-item Parkinson’s Disease Questionnaire (PDQ-39). Caregiver strain was assessed on the Caregiver Strain Index (CSI).

2.2.1. 12 item short form health survey (SF-12v2)

The SF-12v2 is a short form 12-item questionnaire which asks respondents to report on aspects of their daily lives over the past four weeks [13]. The questionnaire yields two scores - the Physical Component Summary (PCS) and the Mental Component Summary (MCS). Both of these scores are generated using norm-based methods and are standardised, to results from the general working age population, to have a mean of 50 and standard deviation (SD) of 10. Higher scores mean better quality of life. The items for the SF-12v2 were derived from a longer form ‘parent’ measure - the 36-item Short Form Health Survey (SF-36v2) [14,15]. The 12 items selected from the SF-36v2 reproduced 90% of the variance in the overall Physical and Mental Health components of the SF-36v2 [16]. Consequently, the SF-12v2 was chosen over the parent measure as it provides summary measures of physical and mental health which are more robust [16], and does so with considerable economy. Furthermore, short form health survey measures have been used previously in both PD patients and caregivers.

2.2.2. Caregiver strain index (CSI)

The Caregiver Strain Index (CSI) was selected to assess carer burden [17]. Stress on the caregiver is an important aspect in the assessment of serious illness upon family functioning and well-being. The CSI asks carers whether aspects of their lives, such as sleep, finances and normal routine have been affected by their carer role, and whether the carer has placed a substantial burden on him or her. The CSI was chosen as it is one of relatively few carer measures available, and is appropriate, without modification, for the carers of PD patients. The version of the CSI used here includes the original thirteen items but with an amended response set with three response categories to each question (‘never’, ‘sometimes’, ‘always’) [18]. A higher score on the CSI means a higher burden (with scores calculated on the range 0–26).

2.2.3. Parkinson’s disease questionnaire (PDQ-39)

The disease-specific measure used for patients was the thirty nine item Parkinson’s Disease Questionnaire (PDQ-39). The instrument was developed on the basis of in-depth interviewing of patients with PD, and covers areas and issues of direct importance to their quality of life [19–21]. Substantial evidence exists suggesting that it is both highly reliable and valid [9,10]. It is the most widely used disease-specific patient reported outcome measure in PD [22]. The 39 items cover eight dimensions including mobility (10 items), social support (4 items), stigma (4 items), social support (3 items), cognitions (4 items), communication (3 items) and bodily discomfort (3 items) [23]. Items are scored on a 5-point Likert-type scale (never, occasionally, sometimes, often and always or cannot do at all). Data can be presented either as domain scores or as a global single index score [21]. Scores for each of the eight dimensions and the single index score range from 0 (best, i.e. no problem at all) to 100 (worst, i.e. maximum level of problem). The multi-dimensional PDQ-39 was selected as it permitted exploration as to what aspects of patient reported health, as measured on the eight dimensions of the PDQ, are most likely to affect carer burden and mental health.

2.3 Analysis

All questionnaires were double entered and verified. Any discrepancies found between the first and second sets of data entry were corrected before data analysis commenced. Data analysis was conducted in SPSS version 18. Standard descriptive tests, Pearson’s correlations and regression analysis were used. No data imputation algorithms were employed for missing data. To account for multiple comparisons only statistical tests reaching a significance level of p < 0.001 or better are reported as statistically significant. 95% confidence intervals around mean scores is reported.

3. Results

A total of 901 (567 men and 320 women) patients and 704 (213 men and 539 women) caregivers were included in the study. In 197 (20.7%) cases, only the patient questionnaire was returned, in 51 (5.4%) cases it was only the caregiver questionnaire and in 704 (73.9%) cases both patient and caregiver questionnaires were returned. The mean age of patients in the study was 74 years (range 28–97 years), whilst the mean age of carers was 67 years (range 20–89 years). The majority of caregivers (n = 672) lived in the same household as the patient and 670 were the spouse of the patient. The majority of patients had been diagnosed more than 5 years prior to the survey, and the majority of caregivers had been a caregiver for more than 5 years (Table 1).
PCS and MCS scores were calculated for patients and caregivers. These summary scores require all SF-12 data for a respondent to be available and cannot be calculated if any item is missing. No data imputation algorithms were employed. Consequently summary scores could be calculated for 672 (74.58%) of patients and 626 (82.91%) of caregivers. The patients’ mean score on the PCS was 31.69 (SD 9.58, 95% CI 30.00–33.38; n = 672) and on the MCS was 55.31 (SD 9.58, 95% CI 53.24–57.38; n = 672). Caregiver scores were 46.23 (SD 11.78, 95% CI 43.36–49.09; n = 626) and 44.02 (SD 11.03, 95% CI 41.96–46.09; n = 626) respectively. While both the physical and mental health of patients is below that of published scores from the general population [15], this is true of only the mental health of carers [24,25]. To highlight the extent to which these scores are lower, Table 2 shows age adjusted scores for the two summary scores, with results for patients and caregivers aged 55–65 years compared with those gained in a general population survey. The physical health of patients shows the most severe adverse effects, with the mean score falling in the lowest 10% of scores from a population sample [15]. The physical health of caregivers is, however, comparable to that of the general population.

However, the mental health of caregivers is found to be substantially compromised, with the mean on the MCS for carers placing them in the lowest 22% of scores from the general population sample [15]. Caregiver MCS scores were found to be modestly correlated with years spent as a caregiver (r = −0.11 p < 0.01, n = 622) and hours spent caring per week (r = −0.22, p < 0.001, n = 599).

The mean Caregiver Strain Index (CSI) score was 11.89 (SD 6.39, 95% CI = 11.4–12.4; n = 571) on a score range from 0 to 26. No floor or ceiling effects were demonstrated, with only 1.1% gaining zero scores and 0.5% gaining maximum scores. CSI scores were significantly correlated with caregiver MCS (rho = −0.53, p < 0.001, n = 570).
n = 508) and carer PCS (rho = −0.23, p < 0.001, n = 508). CSI scores were found to be moderately correlated with patient PCS (rho = −0.33, p < 0.001, n = 420) and MCS (rho = −0.41, p < 0.001, n = 420). The negative correlations are a factor of the scoring algorithms where higher scores on the CSI indicate greater caregiver strain, whilst higher scores on the PCS and MCS indicate better levels of self-reported health. Patient PCS was moderately correlated to caregiver PCS (rho = 0.17, p < 0.001, n = 473) and patient MCS to caregiver MCS (rho = 0.36, p < 0.001, n = 473).

However, no evidence was found of an association between the physical health of patients, as measured on the PCS, and the emotional health of caregivers as measured with the MCS, or vice versa. CSI scores were found to be correlated with years since diagnosis (rho = 0.21, p < 0.001, n = 530), years spent as a carer (rho = 0.32, p < 0.001, n = 568) and hours spent caring per week (rho = 0.55, p < 0.001, n = 550).

Results on the Parkinson’s Disease Questionnaire are reported in Table 3. The PDQ Single Index was highly correlated with patient scores on the SF-12v2 PCS (rho = −0.49, p < 0.001, n = 524) and MCS (rho = −0.64, p < 0.001, n = 524). The PD Index was found to be highly associated with caregiver burden as measured on the CSI (rho = 0.56, p < 0.001, n = 422) and caregiver scores on the MCS (rho = −0.32, p < 0.001, n = 460). However, scores on the PD Index were not found to be associated with physical functioning of carers as measured on the PDQ. PDQ-39 Single Index scores were found to be correlated with years since diagnosis (rho = 0.34, p < 0.001, n = 648), years spent as a carer (rho = 0.34, p < 0.001, n = 519) and hours spent caring per week (rho = 0.47, p < 0.001, n = 501). Linear regressions were undertaken to determine what patient factors, as reported on the eight dimensions of the PDQ, are most likely to affect carer burden and mental health. The regressions included the eight dimensions of the PDQ as independent variables with the CSI score and carer MCS scores as dependent variables, controlling for duration of disease, years spent as a carer, reported hours spent caring per week and gender of both carer and patient. An adjusted R2 of 0.46 was achieved with the main predictors in the model for the CSI score as the dependent variable being Mobility and Social Support as measured on the PDQ-39 (see Table 4). However, an adjusted R2 of only 0.14 was gained in the regression using the MCS as the dependent variable. The only significant patient self-reported factors were Mobility and Social Support, once again controlling for duration of disease, years spent as a caregiver, reported hours spent caring per week and gender of both caregiver and patient.

4. Discussion

This paper assesses the potential impact of patient quality of life upon caregivers strain and well-being in Parkinson’s disease. Previous research [3,6,11] in this area has been relatively small scale and predominantly based on clinic samples. Furthermore, previous research has mainly only focussed on associations between clinical patient variables and caregiver quality of life. Two small scale studies have found significant associations between caregiver burden and patient disease-specific quality of life [6,11]. However only the PDQ-8 [11] or PDQ-39 summary scores [6] were used in the analysis. This paper is based on a large scale survey of patients with PD and their caregivers and examines the association between different dimensions of patient generic and disease-specific quality of life and caregiver well-being.

The evidence reported on the SF-12v2 suggests that PD has substantial adverse effects on both the physical and mental well-being of patients when compared with population norms. On the other hand, carer physical health was not found to be substantially different from that of the general population, although emotional health, as measured on the MCS score of the SF-12v2 appears lower than that of the general population [24,25]. The evidence suggests that the self-reported health status of PD patients is associated with caregiver strain and emotional health. Previous research has suggested a link between caregiver assessed strain and well-being and patient disease severity and disability, presence of key symptoms

**Table 3**

Descriptive statistics for the PDQ-39 for patients included in the study.

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Mean (SD), n</th>
<th>95% CI</th>
<th>Median</th>
<th>75 per-centile</th>
<th>% floor</th>
<th>% ceiling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>60.75 (28.72), 787</td>
<td>58.7–62.8</td>
<td>37.50</td>
<td>65.00</td>
<td>87.50</td>
<td>1.4</td>
</tr>
<tr>
<td>Activities of Daily Living</td>
<td>51.40 (28.18), 848</td>
<td>49.5–53.3</td>
<td>29.17</td>
<td>50.00</td>
<td>75.00</td>
<td>2.1</td>
</tr>
<tr>
<td>Stigma</td>
<td>28.87 (25.79), 865</td>
<td>27.1–30.6</td>
<td>6.25</td>
<td>25.00</td>
<td>43.75</td>
<td>18.7</td>
</tr>
<tr>
<td>Emotional Well-Being</td>
<td>36.41 (22.89), 823</td>
<td>34.8–38.0</td>
<td>16.67</td>
<td>33.33</td>
<td>50.00</td>
<td>3.0</td>
</tr>
<tr>
<td>Social Support</td>
<td>21.80 (22.74), 837</td>
<td>20.3–23.3</td>
<td>0</td>
<td>12.50</td>
<td>37.50</td>
<td>35.0</td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td>45.42 (24.79), 864</td>
<td>43.8–47.1</td>
<td>25.00</td>
<td>43.75</td>
<td>62.50</td>
<td>2.7</td>
</tr>
<tr>
<td>Communication</td>
<td>36.45 (26.29), 854</td>
<td>34.7–38.2</td>
<td>16.67</td>
<td>33.33</td>
<td>58.33</td>
<td>2.7</td>
</tr>
<tr>
<td>Bodily Discomfort</td>
<td>48.81 (25.42), 847</td>
<td>47.1–50.5</td>
<td>25.00</td>
<td>50.00</td>
<td>66.67</td>
<td>3.5</td>
</tr>
<tr>
<td>PDQ-index</td>
<td>41.00 (18.42), 651</td>
<td>39.6–42.4</td>
<td>27.24</td>
<td>40.21</td>
<td>53.39</td>
<td>0.3</td>
</tr>
</tbody>
</table>

**Table 4**

Regression model for CSI score with the 8 PDQ-39 dimensions as independent variables controlling for duration of disease, years spent as a caregiver, reported hours of caring and gender (patients and caregivers).

<table>
<thead>
<tr>
<th>Model</th>
<th>Unstandardized coefficients</th>
<th>Standardised coefficients</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td>4.0</td>
<td>1.2</td>
<td>3.4</td>
<td>0.001</td>
</tr>
<tr>
<td>PDQ-39</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activities of daily living</td>
<td>0.05</td>
<td>0.01</td>
<td>0.21</td>
<td>3.80</td>
</tr>
<tr>
<td>Stigma</td>
<td>0.01</td>
<td>0.01</td>
<td>0.04</td>
<td>0.60</td>
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<td>0.01</td>
<td>0.05</td>
<td>1.11</td>
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<tr>
<td>Social support</td>
<td>0.04</td>
<td>0.01</td>
<td>0.15</td>
<td>3.28</td>
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<tr>
<td>Cognitive impairment</td>
<td>0.01</td>
<td>0.01</td>
<td>0.04</td>
<td>0.70</td>
</tr>
<tr>
<td>Communication</td>
<td>0.02</td>
<td>0.01</td>
<td>0.08</td>
<td>1.53</td>
</tr>
<tr>
<td>Bodily discomfort</td>
<td>0.01</td>
<td>0.01</td>
<td>0.03</td>
<td>0.76</td>
</tr>
<tr>
<td>Years since diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3–4</td>
<td>0.09</td>
<td>1.08</td>
<td>0.01</td>
<td>0.08</td>
</tr>
<tr>
<td>5–10</td>
<td>0.14</td>
<td>1.05</td>
<td>0.09</td>
<td>0.09</td>
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<tr>
<td>Over 10</td>
<td>0.38</td>
<td>1.11</td>
<td>0.03</td>
<td>0.34</td>
</tr>
<tr>
<td>Years as a carer</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3–4</td>
<td>0.29</td>
<td>0.98</td>
<td>0.02</td>
<td>0.30</td>
</tr>
<tr>
<td>5–10</td>
<td>1.97</td>
<td>0.99</td>
<td>0.15</td>
<td>2.00</td>
</tr>
<tr>
<td>Over 10</td>
<td>0.79</td>
<td>1.12</td>
<td>0.52</td>
<td>0.71</td>
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<tr>
<td>Hours spent caring per week</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>20–34</td>
<td>2.70</td>
<td>0.68</td>
<td>0.16</td>
<td>4.00</td>
</tr>
<tr>
<td>35–70</td>
<td>4.13</td>
<td>0.67</td>
<td>0.26</td>
<td>6.15</td>
</tr>
<tr>
<td>Over 70</td>
<td>4.09</td>
<td>0.75</td>
<td>0.30</td>
<td>6.30</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
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<td>0.89</td>
<td>0.02</td>
<td>0.23</td>
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<tr>
<td>Carer</td>
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<td>0.89</td>
<td>0.15</td>
<td>2.40</td>
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</table>
[4,6]. This is supported here by evidence gained from a disease-specific patient-reported measure.

In order to explore the impacts of disease-specific aspects of patient health status on caregiver strain and emotional health two regressions were undertaken modelling the eight dimensions of the PDQ-39 on CSI and MCS scores. The results clearly indicate that patient limitations in physical mobility and problems with social support are strongly associated with increased caregiver strain. Thus it would appear that limitations in physical functioning cause demands on both the patient and carer, and it is highly likely that this has adverse effects on aspects of their relationship.

A similar result was observed for the MCS score for caregivers, although the strength of the relationships was weaker. Thus, patient disease-specific self-reported health status does not appear to be a potentially strong predictor of caregiver emotional well-being per se. However, it does appear to be a potentially strong determinant of the level of strain experienced by caregivers, and this in turn may account for the compromised emotional health of caregivers.

One potential limitation of the study relates to the proportion of complete patient-carer dyads included in the final analyses. However, the strength of association would tend to suggest that, at least for those patients and carer dyads where data is available, the impact of patient self-reported health clearly has an impact of caregiver strain and, consequently, quality of life. Furthermore, the findings are in line with previous results, gained from a smaller clinic sample, which have suggested a link between patient and carer self-reported health and well-being [12]. As such we have no reason to believe a systematic bias has influenced the results reported here.

This study set out to explore the association of patient reported quality of life with carer strain and well-being. The results of this study suggest that increasing disease severity, as reported by the patient, impacts on carer burden, and this in turn has an impact on the self-reported quality of life of carers. Consequently, treatment regimes that are found to have beneficial effects upon the self-reported physical functioning of patients may also lead to improvements in carer strain and well-being.

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References