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Quality of life in patients with PD and their caregiving spouses: A view from both sides

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ABSTRACT

Objective: In contrast to the wealth of studies on quality of life (QoL) in patients with Parkinson's disease, the number of reports on QoL in caregivers, especially partners as primary caregivers, is fairly limited. In this report we wanted to investigate if patients and caregiving partners are able to reliably estimate each other's present and former QoL.
Methods: We used a visual analogue scale in order to obtain the patients' and their partners' scores of present and former QoL. Moreover we studied correlations of these mutual estimates with demographic variables and measures of patient dependency.
Results: As expected both patients and partners considered their QoL as decreased when compared to former QoL. Interestingly both patients and partners were able to reliably estimate each other's QoL. Patients judged their own former QoL and that of their partner as lower as did their partners. All QoL measures were significantly correlated to measures of mental state and patient dependency. There was a negative correlation with increasing age but not with disease duration.
Conclusion: These results indicate the validity of using proxy information by a caregiving partner in estimations of QoL.

1. Introduction

Quality of life (QoL) has become an increasingly important parameter in clinical practice, as well as in the evaluation of the efficacy of interventions in patients suffering from Parkinson's disease (PD). Multiple studies, using a variety of approaches and methods, have shown that PD is invariably associated with a reduction of QoL in patients suffering from this relentlessly progressive neurodegenerative disorder [1–4]. A number of factors contribute significantly to this reduction, including demographic, clinical and/or social variables [5]. Demographic factors influencing QoL include the age of the patients at the time of evaluation, the age at disease onset and the educational level [6–13]. The clinical determinants of QoL can be divided into motor and non-motor features [14,15]. Although the severity of motor dysfunction, as illustrated by higher scores on motor scales, or the presence of motor fluctuations or gait disorders, is an important denominator of QoL, multiple reports have stressed an even greater impact of non-motor symptoms, among which the presence of depression stands out as a major determinant of QoL [1,4,6,8,10,13,16–30]. The impact of social factors is less well studied, but some reports have indicated an impact of civil status or work-related factors [13].

Multiple QoL scales have been used to estimate QoL in patients with PD. Some QoL scales were specifically evaluated for the PD population. The most familiar is the Parkinson's Disease Questionnaire (PDQ-39) or its short form (PDQ-8) [3,31–35]. Disease specific scales have the benefit of evaluating different items important for the disease under study, which allows the evaluation of specific subdomains and eventually longitudinal evaluation. However, these scales do not allow comparison of QoL between patient groups with different diseases or between patient groups and normal controls. For such evaluations non-specific questionnaires and scales have remained useful instruments. The Sickness Impact Profile (SIP) and the 36 item Short-Form Health Survey (SF-36) are well known examples of scales that were frequently used to study PD [3,31–34]. The EuroQoL scale (EQ-5D) is especially interesting as it is relatively short, it includes an evaluation with a linear visual analogue scale (VAS) and, similar to the SIP and SF-36, normative values were reported as a means of comparison to a healthy control population [3,7,23,35–39]. The VAS has frequently been used in

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other studies considering the quality of life in Parkinson's disease [3,7,23,35–39]. It was shown that positive effects of a treatment intervention on mood and QoL of PD patients can be demonstrated even by solely using a VAS [37].

In contrast to the growing body of literature on QoL of patients, the QoL of the caregiver has been studied less frequently. The primary caregiver is usually the cornerstone of care for PD patients, especially in the advanced stages of the disease [36,40]. The primary caregiver is usually the person spending most time with the patient and is considered to have a good insight into the patient's needs. Moreover, the primary caregiver generally serves as an interface between the professionals involved in the treatment of the patient, which requires an involvement of the primary caregiver in making decisions about the patient's care. A lack of support for the primary caregiver can therefore lead to a reduced quality of care for the patient and less ability of the caregiver to cope with the increasing demands of an advancing disease, leading to earlier institutionalization of patients [36,41–43]. The caregiver's needs will vary across the different stages of the disease. In the early stages, the burden for the caregiver will be largely influenced by a lack of information about the disease and the uncertainty about the evolution of the disorder. In later stages their ability to care for the patient will be dominated by an increasing dependence of the patient on the environment, combined with a deterioration of communicative possibilities [43]. In addition, a decrease of social activities, increased personal stress and eventual financial problems may add to a reduced QoL [41,42]. In their study, Martinez-Martin et al. [41] found a significant correlation of caregiver burden with the functional status of the patient. In addition, they emphasized a correlation between the QoL of the patient and that of the caregiver, which is extremely relevant, taking into account the progressive nature of the disorder [41].

Most frequently, the primary caregiver of the PD patient is the partner. Therefore, a crucial question is whether patients and their partners are able to reliably estimate each other's QoL. Such estimations are determined by multifactorial issues such as empathy, expectations, beliefs about disease and health, and estimates of former QoL. The quality of communication and care will depend in part on mutual estimation of each other's needs and feelings about QoL. In addition, the caregiver's impression will gain importance when the disease progresses and the patient's ability to adequately respond to QoL questionnaires diminishes. The aim of this study was to investigate the perception of patients and partners of their own as well as of each other's present and former quality of life and to explore a possible correlation of these estimates with measures of disease burden.

2. Methodology

2.1. Patients

Forty-nine ambulatory and non-demented PD patients were consecutively included in this study. All patients were recruited on an outpatient basis in the University Hospital Ghent at the occasion of one of their regular follow-up consultations. No restrictions on age, gender, or disease stage were made before inclusion. The single most important inclusion criterion was that they had a reliable partner within a stable relationship that had lasted for at least 5 years, who was also the patient's primary caregiver.

Patients or partners with a diagnosis of dementia, as based on DSM-IV criteria and eventually clinical screening during the consultation, were excluded from this study. This screening is in our institution performed using MMSE testing or MOCA [44,45]. The patients included in this study were thus non-demented and all had reliable, non-demented partners.

2.2. Methods

All patients and their partners filled in a questionnaire consisting of three sections. This questionnaire was presented as an interview that was taken by one of the authors. The interviewer was the same in all patients and partners.

Section 1 contained general and demographic questions such as age, age at diagnosis, marital status and professional status.

Section 2 of the questionnaire was evaluated using a VAS. Patients were asked to give an estimation of their own current QoL (*PDbyPD*) as well as of that of the partner (*PARTbyPD*). The same questions were asked to the partners (*PDbyPART* and *PARTbyPART*, respectively). For each question asked, a 10 cm line was presented to the subjects, indicating 0 at the left and 10 at the right. The patients were asked to indicate perceived quality of life with 0 meaning having no quality of life at all and 10 indicating an optimal quality of life. It was specifically asked to consider for the estimation of current quality of life the recent period of about two weeks in order to avoid interference with factors at the time of the interview. Patients and partners were not allowed to see or discuss each other's responses.

The same methodology was used for Section 3, in which patients and partners were asked to indicate on a VAS their estimations of their own and each other's QoL before the onset of disease (*fPDbyPD*, *fPARTbyPART*, *fPDbyPART* and *fPARTbyPD*).

We selected a linear *Visual Analogue Scale* over dedicated and disease-specific questionnaires for two reasons: on the one hand, it allows direct comparison with healthy people, in this case the partner [31–33]. On the other hand, the VAS is practicable for PD patients as it avoids writing, which may be severely impaired in PD patients.

Apart from the aforementioned questionnaire, part 1 of the *UPDRS* (mental state, behaviour and mood) and the *Schwab and England score* (SE) were also taken as measures of cognitive burden and dependence, respectively.

The study was approved by the Medical Ethics Committee of the Ghent University Hospital.

2.3. Statistical analysis

The scores on the VAS were determined by measuring in mm the distances on the 10 cm lines indicated by patients and partners as a measure of their QoL. The differences between groups in the ratings of QoL were calculated using Student's *t*-test using a cut-off *p*-value of 0.05 as indicating a significant difference. We tested the differences within patients (*PDbyPD vs fPDbyPD*) and within partners (*PARTbyPART vs fPARTbyPART*), as well as the differences between both (*PDbyPD vs PDbyPART*, *PARTbyPD vs PARTbyPART*). The differences between patients and partners in the estimation of mutual former QoL were tested similarly.

In order to determine whether there are significant correlations between different quality of life scores, Pearson correlations were calculated, using again a cut-off value of 0.05.

Correlation analysis was also used to calculate the impact of SE and *UPDRS* Part 1 on estimations of quality of life.

3. Results

The mean age of the patients ($n = 50$) was 65.0 years (range: 43–81 years) and the mean age at onset of disease was 57.3 years. Therefore, the mean duration of the disease was 7.7 years. Seventy percent of the included patients ($n = 34$) were males and 30% ($n = 15$) were females.