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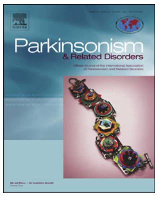

Burden and health-related quality of life among caregivers of Brazilian Parkinson's disease patients

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ABSTRACT

Purpose: To analyze the main determinants of burden and health-related quality-of-life (HRQoL) in caregivers of Brazilian Parkinson's disease (PD) patients.

Methods: Caregivers answered Hospital Anxiety and Depression Scale (HADS), Zarit caregiver burden interview (ZCBI) and EQ-5D, a generic measure of HRQoL. Patients were assessed with Hoehn and Yahr (H&Y) staging; Scales for Outcomes in Parkinson's disease (SCOPA) Motor, Cognition, Psychosocial and Sleep scales; Non-Motor Symptoms Scale; HADS; Clinical Impression of Severity Index; EQ-5D and Parkinson's Psychosis Rating Scale.

Results: 50 Caregiver-patient dyads were assessed. Caregivers were significantly younger (55.7 vs. 65.4 years), $p < 0.0001$. Eighty-eight per cent of caregivers were females, and 78% were spouses. The proportion of caregivers who scored ≥11 points in the HADS-anxiety or HADS-depression subscales was 12% and 14% respectively. ZCBI mean score was 20.2 (SD 12.8), and significantly worsened as severity of disease, based on H&Y, increased (H&Y 1–2: 16.4, H&Y 3–5: 24.6; $p = 0.02$). Caregiver's EQ-5D Index and visual analog scale mean scores were 0.7 (SD: 0.26) and 76.3 (SD: 16.2) respectively. Weak to moderate association ($r = -0.27$ to -0.39) between EQ-5D Index and ZBCI mean scores was observed in caregivers. Patient outcomes (sleep disorders and behavioral-psychotic symptoms) and caregiver outcomes (mood, time of caregiving) were independent predictors of caregiver burden (adjusted $R^2 = 0.55$; $p < 0.0001$) in the multivariate regression analysis. Caregiver's mood status was a significant determinant of caregiver's HRQoL, as measured by the EQ-5D Index (adjusted $R^2 = 0.28$; $p = 0.006$).

Conclusions: Patients' psychiatric and sleep disorders and caregiver's mood significantly influenced burden and HRQoL in Brazilian PD caregivers.

1. Introduction

Parkinson's disease (PD) is a chronic neurodegenerative disorder causing motor and non-motor disorders that result in progressive disability [1]. The disease has a considerable impact on many areas of the psychosocial functioning of patients including cognition, mood, social function, psychological status, communication, and occupational functioning [2]. As a consequence, PD importantly decreases the quality of life of patients and their caregivers [3].

Health status of PD patients, the intensity of direct care, the help and support that caregivers obtain from family and society influence their perceived level of burden and their social participation [4]. Indeed, caring PD patients has been deemed a task that becomes increasingly complex and demanding as the severity of the disease progresses [4]. Caregivers are at high risk of burn-out when social support network is scarce. Emotional exhaustion is an important dimension of burnout syndrome, and in close relationship with other types of mental illness such as depression and anxiety disorders [5].

Nevertheless, little is known about the long term psychosocial consequences of caregiving PD patients in South American countries. In order to expand our knowledge of caregivers in different cultures, Brazilian caregivers of PD patients were assessed. Because of the population aging process, the prevalence of PD in Brazil is expected to increase accordingly. Caregiver burden can be perceived differently depending on the society and culture in which caregivers live. The aim of this study was to assess the prevalence of

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mood disorders and the burden severity in PD caregivers, and analyze the main determinants of burden, and health-related quality of life (HRQoL) in PD caregivers. It was hypothesized that the HRQoL and the degree of burden in Brazilian caregivers are related with: 1) PD overall severity and several specific aspects such as patients' disability, psychiatric and sleep disorders; 2) caregiver's factors such as that their perceived health status and mood.

2. Subjects and methods

2.1. Design

Unicenter, observational, cross-sectional study.

2.2. Patients and caregivers

Fifty PD patients and their primary caregivers were consecutively recruited at the outpatient Neurology Clinic of the Sarah Hospital in Brasilia DF, between January and September 2008, and included in the study.

2.3. Definition and inclusion criteria

Patients with diagnosis of PD by a neurologist with competence in movement disorders and based on the United Kingdom Parkinson's Disease Society Brain Bank Criteria, with age >40 years at onset of disease were included [6].

Designation of primary caregiver was done as per Martinez–Martin's definition [3]: "Any relative or person who is not a professional caregiver or member of a social support network, usually living with the patient and directly involved in caring the patient or directly affected by the patient's health problem".

Spouses (wife or husband), children (son or daughter), parents and other close relatives were the main categories inside the group of caregivers. For the purpose of this study, professional and paid caregivers were excluded, whereas informal caregivers were eligible only if they were living with the patients or in close contact with them.

The study protocol was approved by the institutional review board and informed consent was obtained from all the patients and caregivers before their participation in the study.

2.4. Assessments

Sociodemographic data of caregivers (age, sex, educational level, duration of caregiving, relationship to care-recipient) and PD patients was prospectively collected through a questionnaire.

Assessment of PD patients included neurologist-based evaluations, and patient and caregivers self-assessments.

Neurologist-based assessments included the Hoehn and Yahr staging (H&Y) [7], the Clinical Impression of Severity Index for Parkinson's disease (CISI-PD) [8], the Scales for Outcomes in Parkinson's disease-Motor (SCOPA-Motor) [9], SCOPA-Cognition [10], the Parkinson's psychosis rating scale (PPRS) [11] and the Non-Motor Symptoms Scale (NMSS) [12]. PD self-assessment included the SCOPA-Sleep Scale (PDSS) [13], the SCOPA-Psychosocial [14], the Hospital Anxiety and Depression Scale (HADS) [15] and the EQ-5D [16].

Caregivers completed the HADS [15], the Zarit caregiver burden interview (ZCBI) [17] and the EQ-5D [16].

CISI-PD is a neurologist-based global score that represents a subjective estimation of PD severity. The scale is based on evaluation of four domains: motor signs, disability, motor complications, and cognitive impairment [8]. Global evaluation of the domains is combined to provide the CISI-PD global score, which runs from 0 (normal) to 24 (severe).

The SCOPA-Motor [9] contains 21 items that are grouped in three sections: motor impairment, activities of daily living (ADL), and motor complications. All items score in a scoring range from 0 (normal) to 3 (severe). Total score ranges from 0 to 75 points and the higher the score, the greater the severity.

The SCOPA-Cognition [10] has four domains: memory, attention, executive functions and visuo-spatial functions. The scale consists of 10 items with a maximum score of 43, and higher scores reflect a better cognitive performance.

The PPRS was used to assess the severity of levodopa-induced psychotic symptoms in PD patients [11]. The scale consists of six items: hallucinations, delusions, paranoid ideation, vivid dreams/nightmares, confusion and sexual ideation. Each individual item is rated from 1 (no symptoms) to 4 (extreme symptoms), and total score ranges from 6 to 24 points.

The NMSS [12] consists of 30 items that are grouped in nine domains: Cardiovascular, Sleep/fatigue, Mood/apathy, Perceptual problems/hallucinations, Attention/memory, Gastrointestinal tract, Urinary function, Sexual function, and Miscellaneous. Score for each specific item is based on a multiple of severity (from 0 to 3) and frequency scores (from 1 to 4). The theoretical maximum total score is 360 points.

The SCOPA-Sleep [13] assesses night-time sleep problems and daytime sleepiness in the past month. The night-time sleep subscale has 5 items, scored from 0 (not at all) to 3 (a lot), and global score range from 0 to 15. The daytime sleepiness subscale is composed of 6 items with response options ranging from 0 (never) to 3 (often), with a range score between 0 and 18.

The SCOPA-Psychosocial evaluates psychosocial functioning during the past month. It consists of 11 items scoring on a scale from 0 (not at all) to 3 (very much) [14]. The summary index is calculated as a percentage on the maximum possible score (33 points). The higher the summary index, the worse the patient's quality of life.

In this study, the HADS was used to assess anxiety and depression in both, caregivers and PD patients [15]. The HADS consists of 7 items for assessment of anxiety (HADS-anxiety subscale) and 7 for depression (HADS-depression subscale), with each item scored from 0 (no problem) to 3 (severe problem). Scores on individual items can be summed to calculate scores for anxiety (HADS-anxiety) and for depression (HADS-depression). The maximum score for each subscale is 21, and scores $\geq$11 points (cut-off value) for subscales are indicative of mood disturbance.

The EQ-5D, a generic measure, addresses health status through three main components: 1) a descriptive, composed of five items (mobility, self care, usual activities, pain and anxiety, and depression), scoring from 1 (no problems or symptoms) to 3 (serious problems or symptoms); 2) change in health status in the preceding 12 months (one question); and 3) a visual analog scale (EQ-VAS) for evaluating current health status (from 0, worse imaginable, to 100, best imaginable). Score profiles for the descriptive part can be converted (time trade-off technique) into a HRQoL preference index (EQ-5D Index) ranging from 0 (death) to 1 (perfect health) [16].

The ZCBI evaluates burden of caregivers and has 22 items. In addition, the presence of two dimensions has been observed using confirmatory factor analysis: Personal Strain dimension such as personal stress from care, consisting of 12 items; and Role Strain dimension, including social role limitations from caregiving, consisting of 6 items. The ZCBI total score, Personal Strain and Role Strain scores range from 0 to 88, 0 to 48 and 0 to 24, respectively. Higher scores indicate higher burden [17].

The applied scales were cross-culturally adapted versions to Brazilian setting and have been previously tested [18].

2.5. Data analysis

Chi-squared, Mann–Whitney and Kruskal–Wallis test were used for comparison between PD patients and caregivers. Significance level was established at 0.05. Spearman rank correlation coefficient (rS) was used to determine the association between patient assessments and caregiver measures. A moderate correlation between PD assessments and caregiver's burden and HRQoL was hypothesized ($rS = 0.30–0.50$) [19].

In spite of the relatively small size, multiple regression analyses were performed trying to obtain orientation about factors potentially influencing caregiver's burden and HRQoL. ZCBI and EQ-5D index were considered the dependent variables and the following independent variables were considered: 1) Patient-related variables: age, sex, motor disability as measured by the SCOPA-Motor ADL subscale, SCOPA-Cognition, PPRS, nocturnal sleep as measured by SCOPA-Sleep, and HADS-depression or anxiety subscales; and 2) Caregiver-related variables: age, duration of caregiving, and HADS-anxiety or HADS-depression subscales. Significant variables were tested for collinearity to prevent overparametrization of the prediction model, and those with correlation higher than 0.60 were excluded from analysis. Furthermore, a multicollinearity analysis was performed, and condition index and eigen values were analyzed. The highest condition index observed was 11.86, far away from the maximum limit of 20.

Statistical Package for the Social Science 16.0 for Windows (SPSS, Chicago, IL) was used for data analysis.

3. Results

The 28.5% (20) of the 70 PD patients admitted at the Outpatient Neurology clinic did not have a caregiver, and were excluded from the study; then, the final sample was composed by fifty patient/caregiver dyads. Demographic characteristics of PD patients and their caregivers are shown in Table 1. All caregivers were close relatives of the patients, and most of them cared PD patients on a permanent basis, with a mean duration of caregiving of 6.5 ± 4.1 years.

Functional evaluation of PD patients and their caregivers are shown in Table 2. Median H&Y was 3 (inter-quartile range: 2–3). Fifty-four per cent of patients were in H&Y stage $\leq$2; about 46% had H&Y stage $\geq$3; one patient was in H&Y stage 5. Duration of the disease, as reported by patients was 8.7 ± 4.9 years (range: 2–25).