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Caregiver strain in Parkinson's disease: National Parkinson Foundation Quality Initiative Study

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ABSTRACT

Background: National Parkinson Foundation Quality Improvement Initiatives (NPF-QII) is the first large scale data-driven initiative in Parkinson's disease (PD) aimed at identifying variables predicting best care models and outcomes.
Objective: To determine what measures of PD disability, demographics, and patient quality of life are associated with caregiver strain among caregivers of patients with PD.
Methods: All PD patients at 18 participating sites are eligible for enrollment into the NPF-QII registry. Dataset includes multidimensional measures of disease severity, health care utilization, PD quality of life questionnaire-39 (PDQ-39) and multidimensional caregiver strain inventory (MCSI). A univariate as well as an adjusted analysis was performed to examine the relationship between caregiver strain and variables of PD disability.
Results: The single best factor associated with high caregiver strain was the PDQ-39 total score (c-statistic of continuous variable $= 0.792$, $p < 0.001$) followed by the PDQ-mobility subscore ($c = 0.776$, $p < 0.001$). PDQ-39 ≥ 47 was the optimal cut off associated with a high caregiver strain with a sensitivity = 83% and specificity = 64%. A multiple logistic regression model with stepwise selection showed that in addition to PDQ-39 ≥ 47 (OR and 95% confidence interval = 5.1 (3.2, 8.2), the following subject characteristics were associated with high caregiver strain: (model $p < 0.001$, $c = 0.838$): Hoehn and Yahr stage >3 (2.0 (1.3, 3.1)), presence of concomitant medications such as antidepressants (2.1 (1.5, 3.1)) and antipsychotics (2.5 (1.5, 4.2)), social worker visits (1.6 (1.2, 2.1)), male gender (2.3 (1.5, 3.5)), and decreased verbal fluency (0.95 (0.92, 0.98)).
Conclusions: There is a high prevalence of caregiver strain in PD. PDQ-39 total score has the strongest association with high levels of caregiver strain. These results could guide clinicians in the assessment of caregivers at risk.

1. Introduction

Parkinson's disease (PD) is a progressive neurodegenerative disease associated with the loss of patient autonomy, which may also impact the caregiver's quality of life. Spouses and other family members often become informal caregivers and experience an increase in caregiver strain as a result of the disease progression and increasing scope of PD disability [1]. Patient care becomes the caregiver's main or almost sole activity leading to caregiver strain [2]. While there is extensive research on caregiver burden and strain affiliated with other chronic conditions, such as Alzheimer's disease [3–5], data on the factors associated with PD caregiver strain are limited [6–8].

Published literature in PD points to an association between caregiver strain and disease severity, including such factors as the presence of neuropsychiatric symptoms, especially depression, visual hallucinations and cognitive impairment [1,2,6,8]. Advancing motor symptoms such as motor fluctuations and dyskinesias, while increasing PD disability, have a lesser impact on the patient's health-related quality of life (HRQoL) and caregiver strain when compared to nonmotor symptoms [9–13].

This study sought to identify the variables of PD disability associated with caregiver strain among caregivers of patients with PD, to examine the relationship between caregiver strain and the

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patient quality of life (QoL), and to evaluate multivariate relationships that may identify higher levels of caregiver strain. This study also investigates the relationships between sub-domains of the PDQ-39 and MCSI and determines if there are univariate as well as multivariate associations between patient's disease-related QoL and caregiver strain.

2. Patients and methods

2.1. Study design and participants

Data was obtained from the National Parkinson Foundation's Quality Improvement Registry (NPF-QII); NPF-QII study protocol and design have been previously reported [14]. The data coordinating center is located at the University of Florida's McKnight Brain Institute, Department of Neurology, Gainesville FL, USA. Briefly, NPF-QII is a multicenter, nationwide, observational prospective longitudinal study conducted at 18 NPF Centers of Excellence (COE). QII is the first large-scale, prospective data-driven quality improvement initiative aimed at establishing criteria predictive of improvement of quality and efficiency of care, which ultimately will guide decisions regarding PD health care. The registry was launched in 2010. All patients diagnosed with PD at participating NPF sites were encouraged to be enrolled in the registry. Registry data is collected during a routine clinical office visit. The diagnosis of PD was confirmed by movement disorders experts at each Center based on the UK Parkinson's Disease Society Brain Bank Clinical Diagnosis [14]. The registry consists of a structured questionnaire covering sociodemographic factors, PD diagnosis and staging, presence of long-term motor complications, presence of comorbid conditions, categorical data on concomitant medications including classes of PD medications, antidepressants, cognitive enhancers, stimulants, antipsychotic and use of allied health care. The use of medications and other treatments is assessed in a dichotomous way (yes/no) with the data collected prior to the visit and capturing changes if such were made post visit. The registry includes a brief objective assessment of PD motor disability as measured by the timed up and go test (TUG), and a limited cognitive evaluation consisting of immediate and delayed five word recall and verbal fluency test. Patient quality of life is assessed with the Parkinson's disease questionnaire-39 (PDQ-39), and caregiver strain with the Multidimensional Caregiver Strain Index (MCSI). The registry is updated annually. The content of the registry was developed by the QII Steering Committee with the objective to capture major variables of PD disability within 15 min without interruption of the regular flow of patient care. The research coordinators were formally trained to collect the registry data. The study was approved by the institutional review boards and all participating centers. All patients and caregivers signed an informed consent.

This study analyzed cross-sectional data from baseline visits. MCSI data is collected only from non-professional (not financially compensated) caregivers. A non-professional caregiver is broadly defined as any person providing routine patient care, usually one who lives with the patient and is in some way directly involved in the patient's care or directly affected by the patient's health problems.

2.2. Measures

MCSI is a self-administered questionnaire, which spans 6 dimensions of caregiver strain including domains of physical, social, interpersonal, and financial strain, time constraints and elder demanding/manipulative behavior [28]. Each item is scored from 0 (never) to 4 (a great deal) with a total score range of 0–72. There are no validated caregiver strain scales in PD. MCSI was chosen based on expert recommendations as the most appropriate scale for this population [14]. For this study, MCSI was categorized as mild (less than 20), moderate (20–29), and severe strain (30 and higher). These cut-off points were based on data by Carter J. et al. (unpublished data) who examined thresholds for need: see e-appendix.

PDQ-39 is a 39-item validated disease specific self-administered scale completed by the PD patient, a widely used quality of life (QoL) scale in patients with PD. It spans 39 items aggregated into eight dimensions which include mobility, activities of daily living, emotional well being, stigma, social support, cognition, communication and bodily discomfort. A single index score for the PDQ-39 is calculated out of the eight subscores. The range is 0–100 with higher scores indicating higher level of health related QoL impairment [15,16].

2.3. Data analysis

As raw data was not available to determine reliability of the categories of MSCI, the category scores were used to measure reliability of MSCI total using Cronbach's alpha. Univariate comparisons of demographic caregiver strain by MCSI categories were made using Chi-square for categorical variables and Kruskal–Wallis tests for continuous variables. To determine the optimal threshold of total PDQ or PDQ subscores in relationship caregiver strain, a random sample of 33% was taken, and a receiver operating curve (ROC) analysis was used. The optimal threshold was based on Youden's index, the maximum sum of sensitivity and specificity [17,18]. The threshold was then used in the remaining 66% of the sample to independently estimate sensitivity, specificity, positive predictive value (PPV) and negative predictive values (NPV). Spearman's correlation coefficients were used to estimate the association between MCSI categories and PDQ total and subscores. Separate multiple logistic regression models were fit to determine predictability of PDQ thresholds on severe (vs. all others) and moderate (vs. no) caregiver burden, adjusting for social worker or mental health visits, and further adjusting for covariates of demographics and disease severity. Separate models were used as not to impose proportional odds on any relationships detected. All analyses were run in SASv9.2 (Cary, NC) at a two-sided type I error rate of 5%.

3. Results

At the time of this analysis, there were 4,132 PD patients included in the NPF QII registry. The mean age (±standard deviation (SD)) of PD patients was 68.4 ± 9.6, and ranged from 16 to 94; 66% were male; mean duration of disease was 7.9 (±6) years, with a maximum of 49 years. 3988 (96%) patients indicated having a non-professional caregiver, 2476 (59%) caregivers completed MCSI. Cronbach's alpha for the total MSCI was 0.855 and did not increase with the removal of any subscale. Median (MCSI) total was 11 (interquartile range) IQR $= (4, 21)$, range $= [0, 65]$. Analysis was restricted to the PD cohort that had corresponding MSCI data. 1773 (71.6%) of caregivers reported mild caregiver strain ($\text{MCSI} < 20$), of those 240 (9.6%) had $\text{MCSI} = 0$; 427 (17.3%) had moderate caregiver strain (MCSI 21–29); and 276 (11.2%) had severe caregiver strain ($\text{MCSI} \geq 30$). Descriptive characteristics of the cohort divided by levels of caregiver strain are presented in Table 1.

Caregiver strain was associated with disease duration and severity (H&Y stage greater than 3). Other patient characteristics that were associated with the higher levels of strain included the inability to stand unaided, not living at home, motor fluctuations, and higher frequency of falls.

Similarly, lower levels of verbal fluency, immediate and delayed 5 word recall, and longer TUG were associated with higher levels of strain.

Medication use was commensurate with findings of severity, such that caregiver strain was higher for patients on levodopa, COMT inhibitors, cognitive enhancers, stimulants, and antipsychotics, was less among caregiver of patients on dopamine agonists, and monoamine oxidase-B inhibitors.

Additionally, antidepressant use and utilization of social and mental health workers within the year was also more common among those with higher caregiver strain.

A total of 2257 (91%) of caregivers were spouse/partner, 9.4% other relatives and 0.5% other nonpaid caregivers. Spouse/partners were less likely to report higher levels of strain than other relatives ($p = 0.005$). Unfortunately, data collection did not include caregiver gender, but caregivers of male patients were more likely to report higher levels of strain ($p < 0.001$).

Excluding those caregivers who reported no caregiver strain (MCSI total $= 0$), the average percentage of the total MCSI from each domain is presented in Table 2. Caregivers with mild levels of strain were more stressed by time and social aspects of care, whereas those with moderate to severe levels of strain were most affected by the physical, financial, and elder demanding/manipulative aspects of care (all $p < 0.001$), even after accounting for the score range disparities of each domain.

3.1. PDQ-39 correlates of MCSI

A random sample of 826 (33%) was designated as a test sample using an ROC analysis to find an optimal cut off for PDQ-39 in determining caregiver strain ($\text{MCSI} > 30$). The total PDQ-39 was the single best factor associated with a high caregiver strain (c-statistic $= 0.792$, $p < 0.001$) (Fig. 1). Using Youden's index [17,18], a