

# Neuropsychiatric Features, Health-Related Quality of Life, and Caregiver Burden in Parkinson's Disease

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## Abstract

**Aim:** Parkinson's disease (PD) is a progressive neurodegenerative disease and significantly impacts patients and their caregivers. The current study aims at recognizing its neuropsychiatric symptoms, its impact on the health-related quality of life (HRQOL) of the patients, and the caregiver burden in a middle- to-low-income country. **Methods:** We conducted a cross-sectional survey of 73 idiopathic Parkinson's disease (IPD) patients and their caregivers from January 2021 to June 2021. Neuropsychiatric Inventory (NPI-12) and Parkinson's disease questionnaire (PDQ-39) were used to assess patients' symptoms and HRQOL, respectively. We used the Zarit caregiver burden interview (ZBI) and Hamilton depression scale (Ham-D) for the caregiver's burden assessment. **Results:** Of the 73 patients, 43 (59%) were men, and 30 (41%) were women. Their mean age was 60.25 years ( $\pm 11.1$ ), and the mean duration of PD was 6.4 years ( $\pm 3.4$ ). Eighty-six percent of the patients reported having one or more neuropsychiatric symptoms. HRQOL, as indicated by PDQ-39, correlated most significantly with H and Y staging ( $r = 0.680$ ,  $P < 0.001$ ) of the disease. Sixty-eight percent of the caregivers felt a disease burden, and 55% had depression. On regression analysis, NPI total score on caregiver burden ( $\beta = 0.883$ ,  $P < 0.001$ , confidence interval [CI] of 1.087 to 1.400,) and H and Y staging on depression ( $\beta = 0.772$ ,  $P < 0.001$ , [CI] of 0.629 to 0.934) were having the most decisive impact. **Conclusion:** Our study showed the presence of frequent neuropsychiatric symptoms in PD patients. It has a detrimental effect on the quality of life of patients and results in a significant increase in caregiver burden and depression among them.

**Keywords:** Caregiver burden, movement disorders, neuropsychiatric symptoms, Parkinson's disease, quality of life

## INTRODUCTION

Parkinson's disease (PD) first description can be seen in "An Essay on the Shaking Palsy" by British Surgeon James Parkinson in 1817.<sup>[1]</sup> It is a progressive neurodegenerative disorder affecting patients mainly after the fifth decade of life. Pathologically, it is characterized by the loss of dopaminergic neurons in the substantia nigra. Traditionally, tremors, bradykinesia, rigidity, and postural instability are described as cardinal manifestations of PD. However, it is now widely recognized as a complex disorder with various clinical features, including non-motor and neuropsychiatric symptoms. Depression, anxiety, apathy, psychosis, hallucinations, sleep disturbances, agitation, and irritability are the prominent neuropsychiatric manifestations.<sup>[2]</sup> PD is often quite challenging to deal with all these manifestations, both for the patients and their caregivers.

With the disease's progressive nature, there is a progression of motor symptoms and the emergence and worsening of neuropsychiatric symptoms. This not only negatively impacts the patient but also their caregivers.<sup>[3]</sup> Most PD patients are taken care of at their homes, and most of the time, spouses, children, or friends are the informal caregivers. They provide support and assistance to patients in their medicine administration, fall surveillance, care coordination, and emotional support in a day-to-day routine. In addition to that, they have to bear the brunt of mood problems, psychosis, agitation, irritability, and sleep disturbances.

Moreover, they have to go through the tedious process of PD diagnosis to treatment and palliative care, accompanying the ailing patient. These everyday challenges faced by caregivers affect their physical, mental, and social well-being. The amount of these effects perceived by them can be defined as caregiver burden.

Most of the evidence of caregiver burden comes from high-income countries. However, people living in low- to middle-income countries have additional challenges due to insufficient healthcare facilities, lack of educational and social support, and limited capacity to spend money on healthcare. Additionally, there is insufficient time spent on the patients in the busy outpatient clinics due to limited healthcare staff. Most of the time, non-motor and psychiatric symptoms are ignored,

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further worsening the quality of life in PD patients. It is often challenging to address caregiver issues in this environment, and usually, their concerns remain unaddressed.

The current study aims to increase our understanding of caregiver burden in a middle- to low-income country concerning health-related quality of life and neuropsychiatric symptoms in PD patients.

## SUBJECTS AND METHODS

We conducted a cross-sectional survey of caregivers and patients with idiopathic PD attending a neurology specialist outpatient clinic at a tertiary hospital in South India between January 2021 and June 2021. The study design and concept were approved by the JIEC (JIPMER institutional ethics committee - JIP/IEC/2020/279). A diagnosis of PD was established as per the criteria laid by the Movement Disorder Society Clinical Diagnostic Criteria for PD. Patients taking antidepressants, benzodiazepines, and antipsychotics, and receiving deep brain stimulation were excluded from the study. A sample size of 73 was calculated based upon the assumption of an 80% prevalence of neuropsychiatric symptoms, absolute precision of 6%, and confidence estimate of 80%. Caregivers were selected based on the predefined criteria that include a person close to the patient who assists him in daily activities or provides emotional support. The caregiver is required to spend at least three hours a day for more than six months. A caregiver belonging to a professional group or network was excluded from the study. Patients or caregivers who were unable to fill out questionnaires were excluded. Patients' and caregivers' demographic details including age, sex, duration, comorbidities, clinical history, and examination findings were noted in a pre-test format.

Neuropsychiatric Inventory (NPI-12) was used to assess the patient's symptoms. It comprises 12 different categories covering four major neuropsychiatric domains, including psychosis, agitation, apathy, and mood. The NPI is based on the responses from an informed caregiver. Symptom frequency was rated 1 to 4, and severity was rated 1 to 3. A composite score is calculated as the product of frequency and severity, ranging from 1 to 12. A total NPI score (0-144) was calculated after summing up all the composite scores.<sup>[4]</sup>

HRQOL was measured by Parkinson's disease-specific PDQ-39 questionnaire. It is a patient-reported measure of health status and quality of life. It consists of 39 questions on eight domains, including mobility, daily living activities, emotional well-being, stigma, social support, cognition, communications, and bodily discomfort. The score of each question ranges from 0 to 4 based on the frequency of symptoms (0 = never, 1 = occasionally, 2 = sometimes, 3 = often, 4 = always). Each domain score is calculated as a percentage and can range from 0 to 100, in which zero is the best score, and 100 is the worst quality of life.<sup>[5]</sup>

Caregiver burden was calculated using Zarit's caregiver burden (ZBI) and Hamilton depression scale (Ham-D). ZBI is

a 22-item questionnaire for assessing caregiver stress related to patient disabilities. Each response is scored from 0 to 4, and the total ranges from 0 to 88, with a higher score, representing poor caregiver burden.<sup>[6]</sup> Ham-D is a 21-item scale that categorizes depression severity into mild, moderate, severe, and very severe depression.<sup>[7]</sup>

## Statistical analyses

Demographics were described using the mean, standard deviation (SD), frequency, and percentage. Correlation analysis was done by Spearman's rank correlation for ordinal variables. Multiple linear regression analyses were performed to evaluate the effect of independent variables on caregiver burden. A *P* value <0.05 was considered significant. Statistical analyses were performed using SPSS software version 28.0 (SPSS Inc., Chicago, IL, USA).

## RESULTS

In this study, we recruited 73 patients, 43 (59%) were men, and 30 (41%) were women. Their mean age ( $\pm$  SD) and mean duration of PD ( $\pm$  SD) were 60.25 (11.1) years and 6.4 (3.4) years, respectively. Sixteen patients (21.9%) had diabetes, 25 (34.2%) had hypertension, 9 (12.3%) had heart disease, and 8 (11%) had an abnormal lipid profile. The mean Hoehn and Yahr stage was  $2.23 \pm 1.04$ . 86% of the patients reported having one or more neuropsychiatric symptoms. The most common symptoms were sleep disturbance (50.7%), anxiety (32.9%), and depression (28.8%). We interviewed 145 caregivers for the 73 recruited patients. The mean age of the caregivers was  $46.2 \pm 14$  years. Most of the caregivers were spouses (54.8%) and daughters (32%). Eighty-eight percent of the caregivers live with the patient, and 35% had access to domestic help. We found that only 11% of the caregivers were formally educated about the disease. 68.5% of the caregiver felt a burden, and 54.8% agreed to some form of depression [Tables 1 and 2].

Using Spearman's correlation coefficient, we assessed patient demographics, H and Y stage, and NPI-12 correlation with the patient's quality of life scale PDQ-39. Because of the large number of comparisons used, we applied the Bonferroni correction. For this part of the analysis, a *P* value of less than 0.029 was considered significant. Higher PDQ-39 total score correlated most significantly with greater disease severity as indicated by the H and Y scale ( $r = 0.680$ ,  $P < 0.001$ ), NPI total score ( $r = 0.466$ ,  $P < 0.001$ ), disease duration ( $r = 0.331$ ,  $P < 0.001$ ), presence of hallucination ( $r = 0.547$ ,  $P < 0.001$ ), delusions ( $r = 0.445$ ,  $P = 0.016$ ), and agitation ( $r = -0.374$ ,  $P = 0.029$ ). All the subdomains of PDQ-39 strongly correlated with H and Y staging. Except for activities of daily living, all subdomains are also strongly correlated with hallucinations. A greater number of caregivers were associated with improved quality of life as determined by PDQ-39 score ( $r = -0.303$ ,  $P < 0.001$ ) [Table 3].

We performed multiple regression analysis with ZBI as a dependent factor and patient's age, duration of disease, number of caregivers, NPI domains, NPI total score, Hoehn and Yahr

**Table 1: Demographic, clinical, and neuropsychological variables of patients and caregivers**

	Mean (SD) or percentage
Patient Demographics	
Total patients	73
Patient age (years)	60.25 (11.1)
Male: Female	43 (59%):30 (41%)
Disease duration (years)	6.4 (3.4)
Hoehn and Yahr stage	2.23 (1.04)
Hypertension	34.2%
Diabetes	21.9%
Heart disease	12.3%
Dyslipidemia	11%
Neuropsychiatric symptoms	86%
Delusions	9.6%
Hallucinations	22%
Agitation	15.1%
Depression	28.8%
Anxiety	32.9%
Elation	2.8%
Apathy	20.5%
Disinhibition	5.5%
Irritability	8.2%
Aberrant motor behavior	2.7%
Sleep disturbances	50.7%
Appetite and eating disorders	23.3%
NPI Score	41 (11.5)
Caregivers	
Number of caregivers	145
Age	46.2 (14.4)
Relationship of primary caregivers	
Spouse	54.8%
Daughter	32%
Son	11.8%
Others	1.4%
Caregivers living with patient	88%
Domestic help	35%
Caregivers education and support group	11%
Caregiver's HAM-D	
No depression	33 (45.2)
Mild depression	20 (27.4)
Moderate depression	10 (13.7)
Severe depression	10 (13.7)
Caregiver's ZBI	
No burden	23 (31.5)
Mild-to-moderate burden	37 (50.7)
Moderate-to-severe burden	12 (16.4)
Severe burden	1 (1.4)

stage, and PDQ-39 as independent factors. Overall NPI total score was the best predictor of caregiver burden (beta = 0.883,  $P < 0.001$ , confidence interval [CI] of 1.087 to 1.400) followed by Hoehn and Yahr stage (beta = 0.711,  $P < 0.001$ , CI of 8.345 to 13.450) and PDQ-39 total score (beta = 0.676,  $P < 0.001$ , CI of 0.28 to 0.47). Among neuropsychiatric symptoms, hallucinations were the most significant predictor of caregiver burden (beta = 0.690,  $P < 0.001$ , confidence interval [CI] of

2.048 to 3.402). It was followed by delusion (beta = 0.690,  $P < 0.001$ , CI of 2.048 to 3.402) and agitation (beta = 0.493,  $P < 0.001$ , CI of 1.886 to 4.597). Other variables correlating significantly with caregiver burden were the higher age of the patient, longer duration of the disease, and all neuropsychiatric symptoms except apathy. More than two caregivers were significantly associated with a decreased caregiver burden (beta = -0.506,  $P < 0.001$ , CI of -22.8 to -9.7) [Table 4].

HAM-D was also used as a dependent variable for multiple regression analysis with independent variables the same as mentioned for ZBI. Hoehn and Yahr's stage was the most significant predictor of depression among caregivers (beta = 0.772,  $P < 0.001$  [CI of 0.629 to 0.934]). NPI total score, hallucinations, delusions, agitation, depression, anxiety, irritability, sleep problems, age, duration of disease, and PDQ-39 were other variables strongly associated with depression among caregivers. More than two caregivers were strongly associated with decreased depression scores (beta = -4.330,  $P < 0.001$ , [CI of -1.417 to -0.523] [Table 5].

## DISCUSSION

This study is one of the few clinical studies done in middle to low-income countries investigating HRQOL and neuropsychiatric symptoms in PD patients and its direct comparison with caregiver burden.

Out of 73 patients recruited, 86% reported having one or more neuropsychiatric symptoms. Sleep disturbances were the most common neuropsychiatric complaints. Frequent awakening in the night and early morning were the most common complaints. This finding is consistent with previous studies demonstrating that up to 80% of PD patients can have sleep disturbances.<sup>[8,9]</sup> Anxiety and depression were the subsequent most common symptoms, in line with previous studies.<sup>[10]</sup>

In our study, a higher PDQ-39 score indicates that poor patient quality of life is most strongly associated with H and Y staging, duration of disease, and NPI score, in line with previous studies. However, in the NPI-12 domain, we found that hallucinations were most consistently associated with poor quality of life. In the previous studies, depression, anxiety, and apathy were reported as the most significant factor impacting a patient's quality of life.<sup>[3,11]</sup> This heterogeneity of our result could be due to longer disease duration in our patients, leading to more psychotic symptoms and thus, impacting the quality of life. Previously it has been shown that HRQOL in PD is worse than in many chronic conditions.<sup>[12,13]</sup>

In this study, 87% of the caregivers were female, slightly higher than previously reported. In middle- to low-income countries, caregiving is considered the primary job of wives and daughters due to various socio-economic reasons. However, this is in line with previous studies in that most of the caregivers were female.<sup>[14,15]</sup> Additionally, only 11% of the caregivers in our study were formally educated about the disease, depicting the scarcity of healthcare facilities in developing nations. Social

**Table 2: Neuropsychiatric manifestations as per NPI scores**

NPI Domains	Severity			Frequency (%)
	Mild n (%)	Moderate n (%)	Severe n (%)	
Delusions	5 (6.85)	1 (1.36)	1 (1.36)	9.6%
Hallucinations	12 (16.43)	3 (4.10)	1 (1.36)	22%
Agitation	8 (10.95)	4 (5.47)	0	15.1%
Depression	15 (20.54)	3 (4.10)	3 (4.10)	28.8%
Anxiety	14 (19.17)	7 (9.58)	3 (4.10)	32.9%
Elation	2 (2.73)	0	0	2.8%
Apathy	10 (13.69)	3 (4.10)	2 (2.73)	20.5%
Disinhibition	4 (5.47)	0	0	5.5%
Irritability	4 (5.47)	1 (1.36)	1 (1.36)	8.2%
Aberrant motor behavior	1 (1.36)	0	1 (1.36)	2.7%
Sleep disturbances	24 (32.87)	10 (13.69)	3 (4.10)	50.7%
Appetite and eating disorders	12 (16.43)	4 (5.47)	1 (1.36)	23.3%

**Table 3: Spearman correlation coefficients of the PDQ-39 summary score, and subscores with the clinical and neuropsychological variables**

	Mobility	Activities of daily living	Emotional well being	Stigma	Social support	Cognition	Communication	Bodily discomfort	Total PDQ-39 score
Patient age	0.339**	0.137	0.097	0.198	0.263*	0.209	0.097	0.278*	0.282*
Disease duration	0.265*	0.109	0.339**	0.248*	0.114	0.349**	0.155	0.390**	0.331**
H and Y stage	0.600**	0.477**	0.430**	0.359**	0.398**	0.544**	0.421**	0.658**	0.680**
No. of caregivers	-0.275*	-0.177	-0.254*	-0.137	-0.093	-0.398**	-0.040	-0.399**	-0.303**
Delusions	0.284*	0.211	0.346**	0.098	0.382**	0.359**	0.293*	0.561**	0.445**
Hallucinations	0.383**	0.219	0.388**	0.245*	0.409**	0.544**	0.456**	0.514**	0.547**
Agitation	0.294*	0.253*	0.341**	0.131	0.218	0.356**	0.172	0.394**	0.374**
Depression	0.173	0.091	0.308**	0.128	0.040	0.044	-0.026	0.261*	0.169
Anxiety	0.046	-0.050	0.209	0.023	0.024	-0.005	-0.010	0.155	0.061
Elation	-0.054	0.189	0.146	-0.055	0.019	0.114	-0.112	0.153	0.073
Apathy	0.098	-0.045	-0.059	-0.067	-0.200	-0.104	-0.094	-0.149	-0.110
Disinhibition	0.129	0.091	-0.032	0.080	-0.022	0.096	0.119	0.146	0.110
Irritability	0.189	0.094	-0.069	0.162	-0.049	0.264*	0.158	0.066	0.141
Aberrant motor behavior	0.066	0.063	0.026	0.126	0.311**	0.213	0.206	0.294*	0.233*
Sleep disturbances	-0.034	0.083	0.093	-0.085	0.138	0.129	-0.026	-0.025	0.048
Appetite and eating disorders	0.056	0.110	0.104	-0.001	0.012	0.197	0.030	0.039	0.093
NPI total score	0.416**	0.299*	0.495**	0.259*	0.242*	0.433**	0.179	0.413**	0.466**

\*\*Correlation is significant at the 0.01 level (2-tailed). \*Correlation is significant at the 0.029 level (2-tailed).

groups were virtually absent in part because of the ongoing pandemic caused by SARS-COV-2 and poor resources. Thus, almost the entire disease burden is borne by caregivers with a limited understanding of the disease. This, in part, is reflected in our study results showing that 68% of the patients experience caregiver burden; among them, 17% perceived moderate to severe burden. Previous studies had shown considerable variation in the prevalence of caregiver burden. Studies done in high-income countries had shown less caregiver burden than studies in low- to middle-income countries. A study done in Australia reported no caregiver burden, whereas done in the UK has shown 40% felt a caregiver burden.<sup>[14,15]</sup> NPI total score and its subdomain of psychosis impact the caregivers the most. We also found that poorer HRQOL of patients as assessed by PDQ-39 significantly affects the caregiver burden. Other

significant factors associated with worse caregiver burden were the disease's H and Y scale, and duration. In a previous study; with PD progression, caregivers had to spend more time with the patient, and their burden increased and significantly impacted their health.<sup>[12]</sup> In middle- to low-income countries, a joint family is a common way of living where many related people live under the same roof. This, in part, is reflected in our study, where 43.8% of the PD patients had more than two caregivers.

Our result showed that more caregiver number was associated with decreased perception of caregiver burden. Thus, the caregiving of a patient with a chronic illness like Parkinson's requires a joint effort of family members, society, and healthcare infrastructure to provide optimum care.<sup>[16]</sup>



**Table 4: Multiple regression analysis of dependent variable ZBI**

Domain score	Standardized Coefficients		t	Sig.	95.0% Confidence Interval for B	
	Beta				Lower Bound	Upper Bound
Patient age	0.388		3.547	<0.001	0.245	0.875
Disease duration	0.434		4.064	<0.001	0.985	2.882
H and Y stage	0.711		8.513	<0.001	8.345	13.450
No. of caregivers	-0.506		-4.944	<0.001	-22.835	-9.710
Delusions	0.533		5.308	<0.001	2.184	4.812
Hallucinations	0.690		8.030	<0.001	2.048	3.402
Agitation	0.493		4.768	<0.001	1.886	4.597
Depression	0.209		1.804	0.046	-0.116	2.306
Anxiety	0.332		2.967	0.004	0.592	3.019
Elation	0.255		2.224	0.029	0.604	11.072
Apathy	-0.015		-0.129	0.898	-1.219	1.071
Disinhibition	0.337		3.012	0.004	0.966	4.750
Irritability	0.318		2.823	0.006	0.782	4.548
Aberrant motor behavior	0.288		2.502	0.015	0.879	7.803
Sleep disturbances	0.410		3.783	<0.001	0.920	2.969
Appetite and eating disorders	0.394		3.609	<0.001	0.913	3.168
NPI total score	0.883		15.864	<0.001	1.087	1.400
PDQ-39 total score	0.676		7.726	<0.001	0.28	0.47

**Table 5: Multiple regression analysis of dependent variable Ham-D**

Domain score	Standardized Coefficients		t	Sig.	95.0% Confidence Interval for B	
	Beta				Lower Bound	Upper Bound
Patient age	0.306		2.707	0.008	0.008	0.051
Disease duration	0.325		2.895	0.005	0.030	0.161
H and Y stage	0.772		10.234	<0.001	0.629	0.934
No. of caregivers	-0.457		-4.330	<0.001	-1.417	-0.523
Delusions	0.499		4.854	<0.001	0.127	0.305
Hallucinations	0.721		8.773	<0.001	0.145	0.231
Agitation	0.540		5.404	<0.001	1.003	2.176
Depression	0.250		2.179	0.033	0.049	1.115
Anxiety	0.432		2.967	0.004	0.692	2.024
Elation	0.156		1.321	0.191	-0.510	2.510
Apathy	0.296		-2.614	0.011	1.362	0.183
Disinhibition	0.337		3.012	0.004	0.966	4.750
Irritability	0.318		2.823	0.006	0.782	4.548
Motor irritability	0.157		1.341	0.184	-0.494	2.522
Sleep disturbances	0.195		1.675	0.048	-0.078	0.900
Appetite and eating disorders	0.147		1.250	0.216	-0.218	0.949
NPI total score	0.604		6.386	<0.001	0.039	0.074
PDQ-39 total score	0.661		7.422	<0.001	0.039	0.068

Depression was reported by 55% of the caregivers, and 18% fell in the moderate to severe category. Previously, depression in caregivers had been reported in the range of 28 to 44%.<sup>[10,17,18]</sup> A significant relationship was found between caregiver depression and H and Y stage, NPI total score, and psychotic symptoms in patients. This aligns with one study where psychiatry symptoms, falls, and disability was most closely associated with caregiver depression.<sup>[10]</sup> However, most of the studies on this subject highlighted anxiety and depression as the most significant factor.<sup>[16,19,20]</sup>

During the study, we found that many patients and their caregivers require urgent intervention due to the non-diagnosis of neuropsychiatric symptoms. According to a previous study, in more than 50% of outpatient department consultations, non-motor symptoms were not identified by neurologists.<sup>[21]</sup> This number became much higher if we included general practitioners. To provide holistic care to the patient, we must use HRQOL evaluations to assess multiple dimensions of the patient and aid in the overall understanding of the patient. For example, the PDQ-39 questionnaire covered eight dimensions

of patient care and provided a comprehensive assessment of patient status, raising concerns that may otherwise go unnoticed.

This study has several strengths and limitations. The major strength was excluding the patient from taking antipsychotics, antidepressants, and anxiolytics. These drugs can lead to improvement in symptoms in some of the patients leading to a lesser NPI-12 score. Additionally, the study has an appropriate sample size for assessing neuropsychiatric symptoms, as most of the studies from middle to low-income countries lack suitable sample sizes.<sup>[22,23]</sup> Furthermore, the study focuses on caregivers considering their detailed demographics, caregiver burden, and depression. A major limitation of our study is that it is a single-center, cross-sectional study, and thus, the generalization of results is limited. Also, we did not examine the impact of cognitive symptoms on caregiver burden, which in previous studies significantly impacted it. Another possible limitation is the use of only scales to assess patients and caregivers; impulse control disorders may not be captured in NPI-12. A detailed psychological examination will be more appropriate. Our study only included the patients that can attend the clinic which may have led to exclusion of patients with severe disease.

In conclusion, this study showed the presence of frequent neuropsychiatric symptoms in PD patients. It has a detrimental effect on the quality of life of patients and results in a significant increase in caregiver burden and leads to depression among them. Since caregivers are an integral part of ensuring the patients' quality of life, our efforts to address these issues should go beyond medical treatment. Apart from the motor symptoms, there is an unmet need to address these issues to provide holistic care to patients and their caregivers, especially in low-resource settings.

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### Conflicts of interest

There are no conflicts of interest.

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