

Caregiver Burden for Patients Diagnosed with Parkinson's Disease: A Cross-sectional Study from Southern India

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ABSTRACT

Introduction: Parkinson's Disease (PD) is a progressive neurodegenerative disorder where the individual over time needs more and more assistance from their caregivers to carry on their life and that causes increasing burden on the caregiver. The burden for the caregiver is affecting them physically, mentally and also on a socioeconomic level.

Aim: To examine the factors related to caregiver burden in caregivers of Parkinson's patients.

Materials and Methods: This was a cross-sectional study conducted in Parkinson's clinic of a Tertiary Care Hospital of Kochi, on 100 Parkinsonism patients and their respective caregivers. Patients were assessed using the Unified PD Rating Scale (UPDRS), Hoehn and Yahr Scale (H&Y) and Mini-Mental State Examination (MMSE). Caregivers were assessed using Zerit's Caregiver Burden inventory (CBI). Semi structured questionnaire was administered for socio-demographic details.

Non parametric tests were done to examine the correlation among various variables.

Results: Among the patients and caregivers, mean age was 70.65 ± 7.30 and 67.31 ± 8.56 , respectively. Among the patient's majority were males ($n=74$) while among caregivers, majority were females ($n=73$). Mean duration of disease was 6.79 ± 2.68 years, mean caregiver burden score was 65.05 ± 21.79 , mean UPDRS score was 21.89 ± 8.74 and had significant positive correlation with caregiver burden. Mean MMSE score was 17.19 ± 4.91 . The disease duration and UPDRS score had a significant positive correlation with caregiver burden score. MMSE score had significant negative correlation with caregiver burden score.

Conclusion: This study concludes that a patient's Parkinsonism related disability accounts for majority of caregiver burden. An early identification of factors contributing to stress in caregivers will help to avoid its persistency leading to a better insight in the caregiving role and thus in-patient care.

Keywords: Caregiver distress, Elderly, Movement disorder

INTRODUCTION

The Parkinson's disease is the second most common neurodegenerative disease which affects 1-2% of the population over 65 years of age [1]. The motor and nonmotor symptoms of Parkinson can have a profound impact on the patients and family members taking up the role of a caregiver [2]. Patients with chronic debilitating disease gradually become increasingly dependent on a caregiver for assistance in activities of daily life [3]. A study suggested that responsibilities of caregivers keep on increasing till a point where caregiving becomes their main or only activity [4].

Formal caregivers are paid helpers while friends while family members constitute the unpaid caregivers. According to a study by Kasuya RT et al., informal caregiving is the act of providing assistance to an individual with whom the caregiver has a personal relationship [5]. Stable main caregiver is "any person who, without being a professional or belonging to a social support network, usually lives with the patient and, in some way, is directly implicated in the patient's care or is directly affected by the patient's health problem [4]. Caregivers become the intrinsic part of patient's life and play a useful role in the medical treatment process [6].

Existing literature suggests that caregiver's sense of burden affects the patient's functionality and adjustment to PD [7]. McFall S and Miller BH identified three factors that predict nursing home placement within a 2-year period- advanced age, race and ADL impairment [8]. Sanders-Dewey NE et al., suggested that the study of caregiving factors in the disease, which typically causes a combination of physical and cognitive deficits, has received little attention [9]. Several studies have shown that functional status of the patient, depressive symptoms, duration since onset of PD and other health related issues have a role in determining caregiver burden [10-12].

Some researchers suggest that communication, cognitive and other less obvious problems associated with the disease progression create the most strain on family caregivers [13,14]. While some other studies implicate sleep fragmentation, cramping or nocturnal pain and motor difficulties with caregiver distress [15].

There is still lack of clarity about the exact determining factors in caregiver burden but it is sure that the progressive debilitating nature of Parkinsonism puts further expectations on the informal caregiver. Understanding the nature and mediators of caregiver burden would allow the clinicians to more effectively treat caregivers and maintain them in the vital role of caring for patients with Parkinsonism. The aim of this study was to assess if informal caregivers of Parkinson's patients experience a significant amount of burden. The secondary objective was to assess if disease progression would be associated with greater caregiver burden.

MATERIALS AND METHODS

This cross-sectional study was conducted in the Parkinson's clinic of Amrita Institute of Medicine, Kochi, Kerala which includes a neurologist, neurosurgeon, psychiatrist and psychologist. The study had been given approval by the AIMS Ethics Committee (IRB-AIMS-2017-112).

The sample size as calculated based on a previous study with type 1 error of 0.05 and power of 80% had been 65 subjects, but it was decided to enrol a larger sample [16]. Convenience sampling method was used and 100 Parkinson's patient and their 100 caregivers over a period of 24 months from September 2017 to August 2019 were included in the study, after taking written informed consent. After the treating neurologist had confirmed the diagnosis of PD the patients were administered the assessment about disease severity and then the identified primary informal caregivers were administered measures of caregiver burden.

The following instruments were used:

Semi structured proforma: A semi-structured proforma, with certain predefined questions and option to ask for additional details, was created for collecting the sociodemographic details of the patient and caregiver also about the clinical variables of the PD of the patients.

Zarit Burden Inventory (ZBI): It is a 22-item questionnaire with responses ranging from 1 to 4 (1-little or no burden, 2-mild to moderate burden, 3-moderate to severe burden, 4-severe burden) and a total score range of 0 to 88 [17]. For statistical analysis purpose, categories 2 and 3 were grouped together. Each caregiver completed the ZBI in around 10 minutes.

Mini-Mental Status Examination (MMSE): It is a 30-point structured clinician-rated interview scale incorporating pencil and paper tasks for assessing nine items, memory, orientation, attention, verbal fluency, normal aphasia, receptive aphasia plus receptive apraxia, alexia, agraphia and constructional apraxia [18].

Unified Parkinson's Disease Rating Scale (UPDRS): It is accepted mostly for use in clinical research and drug trials that follow the longitudinal course of PD [19]. It is divided into four parts or scales: (1) mentation, behaviour, and mood; (2) Activities of daily living; (3) motor; and (4) complications of therapy. It is used to quantify all motor and behavioural features of PD. A total score from 0 which means no disability to maximum of 199 which indicates total disability.

Modified Hoehn and Yahr Staging Scale: As the fifth part of the original UPDRS, the modified Hoehn and Yahr (H&Y) Staging Scale estimates disease staging [20]:

0-No evidence of disease.

1.0-Unilateral disease only.

1.5-Unilateral disease plus axial involvement.

2.0-Bilateral mild disease without impaired balance.

2.5-Mild bilateral disease with recovery on pull test.

3.0-Mild-to-moderate bilateral disease with some postural instability but physically independent

4.0-Severe disease, but still able to walk or stand unassisted.

5.0-Wheelchair bound or bedridden unless aided

STATISTICAL ANALYSIS

Analysis was done using Statistical Package for Social Sciences (SPSS) version 13 software. Distribution of the patient and caregivers with respect to sociodemographic factors and clinical variables was generated. Association with gender, of both the patient and the caregiver, and ZBI scores was examined. MMSE scores of the patients and ZBI scores of their respective caregivers were analysed to examine the association. Pearson correlation between severity of PD and ZBI score in caregivers was computed and its statistical significance was tested. Pearson correlation coefficient was also computed between the duration of Parkinson disease and ZBI scores. A p value less than 0.05 was considered statistically significant.

RESULTS

The sociodemographic and clinical features have been shown in [Table/Fig-1]. Out of 100 patients, 74 were males, the mean age was 70.65 ± 7.30 years with a range from 46 to 89. Of the 100 caregivers, 73 were females and the mean age of caregivers was 67.31 ± 8.56 years with a range from 42 to 88. Sixty three of the patients had education up to high school only which was almost similar to caregivers where 66 had highest education qualification up to high school. Most of the patients ($n=81$) were not formally employed, similarly 79 caregivers were not employed but most were homemakers. Majority of patients ($n=80$) belonged to upper lower socioeconomic status, as per the modified Kuppuswamy classification. Most of the caregivers ($n=83$) were spouses of the

Variable		Patient N=100	Caregiver N=100
Age in years (\pm SD)		70.65 ± 7.30	67.31 ± 8.56
Gender	Male	74	27
	Female	26	73
Highest educational qualification	Graduation	12	9
	Middle school	25	25
	High school	63	66
Occupation	Unemployed	81	79
	Employed	19	21
Socioeconomic status	Upper middle	10	10
	Lower middle	10	10
	Upper lower	80	80
Relation to patient	Spouse		83
	Son/Daughter		3
	Others		14
Duration of Parkinson's disease in years		6.79 ± 2.68	
Presence of psychiatric co-morbidity	Yes	72	
	No	28	

[Table/Fig-1]: Distribution of socio-demographic variables of patients and caregivers.

patients. The mean duration of PD was found to be 6.79 ± 2.68 years with a range from 1 to 15 years. Majority of the patients ($n=72$) were having psychiatric comorbidity of which were depressive disorders.

In the [Table/Fig-2] which showed distribution of caregiver burden as per gender. Out of 100 caregivers, 73 reported to have "severe" caregiver burden. The mean caregiver burden score was 65.05 ± 21.79 . Gender of the caregiver was analysed with caregiver burden and was found 74% ($n=54$) of females and 70.4% ($n=19$) of males had "severe" caregiver burden. The mean caregiver burden for those with psychiatric comorbidity ($n=72$) was 66.33 ± 18.97 and for those without ($n=28$) it was 50.54 ± 24.65 .

Caregiver gender	Caregiver burden			
	MILD Grade 1 (0-20)	MODERATE Grade 2 (21-60)	SEVERE Grade 3 (61-88)	Mean score \pm SD
Females: n (%)	4 (5.5)	15 (20.5)	54 (74)	65.39 ± 21.41
Males: n (%)	4 (14.8)	4 (14.8)	19 (70.4)	64.11 ± 23.17
Total (n=100)	8	19	73	65.05 ± 21.79

[Table/Fig-2]: Grading of severity of caregiver burden as per the gender of caregiver.

The distribution of cognitive impairment to the grading of caregiver burden is shown in [Table/Fig-3]. The mean MMSE score was 17.19 ± 4.91 . Forty six patients had severe cognitive impairment. The distribution of caregiver burden as per stage of PD is shown in [Table/Fig-4]. The mean UPDRS score was 21.89 ± 8.74 . Majority (46%) of the patients were at stage four Parkinson Disease, as per the modified H&Y staging scale.

MMSE grade	Caregiver burden grade			Total (n=100)
	Grade 1 N (%)	Grade 2 N (%)	Grade 3 N (%)	
24-30	4 (13.7)	9 (31)	16 (55.17)	29
19-23	1 (4)	3 (12)	21 (84)	25
0-18	3 (6.52)	7 (15.2)	36 (78.26)	46
Mean MMSE score	22.83 ± 3.43	18.59 ± 3.42	15.81 ± 4.86	17.19 ± 4.91

[Table/Fig-3]: Distribution of patient's cognitive impairment as per MMSE score to the grading of caregiver burden scores.

In the [Table/Fig-5] which shows the correlation of clinical variables with caregiver burden these were the findings. Association between patient's age and caregiver burden was done and was found to be

Stage of Parkinson's disease (UPDRS)	Caregiver burden			Total (n)
	Grade 1 N (%)	Grade 2 N (%)	Grade 3 N (%)	
Stage 1	2 (7.14)	6 (21.42)	20 (71.42)	28
Stage 1.5	1 (14.2)	2 (28.5)	4 (57.14)	7
Stage 2	1 (25)	1 (25)	2 (50)	4
Stage 2.5	1 (20)	1 (20)	3 (60)	5
Stage 3	1 (20)	1 (20)	3 (60)	5
Stage 4	6 (13.04)	10 (21.73)	30 (65.21)	46
Stage 5	0 (0)	0 (0)	5 (100)	5
Mean UPDRS score	17.17±5.67	20.47±6.91	22.47±9.2	21.89±8.74

[Table/Fig-4]: Caregiver burden distribution as per stage of Parkinson's disease.

Variables	Caregiver burden	
	r-value	p-value
Age of the patient	0.247	0.013
Age of the caregiver	0.252	0.011
Duration of Parkinson's disease	0.117	0.247
Severity of the Parkinson's disease	0.501	0.001
UPDRS score	0.469	0.001
MMSE score	-0.179	0.02

[Table/Fig-5]: Pearson correlation of clinical variables with Caregiver burden.
p-value <0.05 statistically significant

statistically significant suggesting higher the patient's age, more is the caregiver burden ($r=0.247$, $p<0.013$). Similarly, age of caregiver was analysed with caregiver burden and was found to have statistical significance ($r=0.252$, $p<0.011$). The association between duration of the disease and caregiver burden was not statistically significant ($p<0.247$) but they showed a positive correlation ($r=0.117$). The association of gender of caregiver and caregiver burden was found non-significant ($p<0.074$). The severity of the disease was correlated with caregiver burden and was found to have statistical significance ($p<0.001$) and showed significant positive correlation ($r=0.501$). MMSE scores and caregiver burden were analysed and was found to have statistical significance ($p<0.02$) and a negative correlation ($r=-0.179$).

DISCUSSION

This cross-sectional study highlights the significant effect that the physical and cognitive impairments, commonly seen in Parkinson's patients, have on the persons providing care to Parkinson's patients. Despite the high prevalence of disability in Parkinsonism patients and difficulties of caregiver burden reported in conditions with similar multifocal deficits such as Alzheimer's dementia [11,21-23], this study probably represents one of the first to elaborate this burden for caregivers of patients with PD in our region.

In this study, majority of the caregivers were women as it has been in another study conducted in the past [24]. In the Asian-Indian cultures, family members take up the care of other family members as it is a cultural expectation [25]. In this study, majority of the patients were males and hence, majority of the caregivers were their wives. Caregiving is traditionally seen as being the responsibility of wives, daughters or female members in the family [26]. In Indian culture, caregiving by female members is expected, in study, it was found that they perceived high levels caregiver burden. In a study by Shin H et al., they had suggested that caregiver burden is quantitatively similar but qualitatively different among different family members in the family [27]. A study by Hooker K et al., found that women were solely responsibly for caregiving, yet they felt guilty about not giving enough and were found to be even feeling responsible for the patient's condition [28]. Another study reported that initial differences in subjective burden between wives and

husbands were present during initial assessment but were no longer present at the time of two year follow-up [29]. In a study by Yang Z et al., it was similar to present study about female member predominantly the daughter being the caregiver and that study also had found that caregiver self-efficacy and social support for the caregiver have significant effect on caregiver burden [30]. Gender is only one facet of the intense complex caregiving process. According to stress paradigm by Lazarus R and Folkman S perceived stressors and resources influence caregiver burden [31]. In present study, majority of caregiver belong to upper lower socioeconomic status which was similar to the study by Yang Z et al., [30].

While a significant relationship exists between measures of functioning of the patient (UPDRS staging) and caregiver burden, a significant association also exist between basic cognitive functioning as assessed by MMSE and caregiver burden [32]. This was the finding in the present study also which showed an inverse correlation between both. This is similar to another study done by Prizer LP et al., they have opined that the patients who have more cognitive impairment need more care and this results in more depressive and anxiety symptoms in caregivers [33].

The study done by Cifu DX et al., did not find age as an additional risk factor [3]. This was contrary to the present study where the age of the patient and caregiver had significant positive association probably as with increasing age patients would need more support. Further with increasing age the caregiver would find it harder to give the sort of care which these patients require. A study by Shin H et al., also suggested that with age the caregiver burden increases which supports our findings [27].

Among the patient related variables, various disease specific variables are significant predictors of caregiver burden. Since PD is a movement disorder with characteristic motor difficulties that lead to significant disability, it is understandable that motor experiences which measure symptom severity and functional impairment as in UPDRS score were found to be the strongest predictors of the caregiver burden showing positive correlation. This is in keeping with what was suggested by an earlier work [7].

In a recent study, it was found that with patients with an early middle stage of disease non-motor symptoms predict caregiver strain more than motor symptoms [32]. In another study done by Carter JH et al., 380 caregivers were assessed using family caregiving inventory and was found to have caregiver burden across all stages of PD and accumulated significantly as the disease progressed [34]. In study done by Happe S and Berger K, 106 caregivers were assessed using CBI and suggested that caregiver burden was associated with sleep disturbances, severity of the disease, male gender, bad sleep in patients and frequency of caregiving [15]. Contrary to this, in the present study, there were no gender differences in caregiver burden but this study supports the notion that caregiver burden increases with severity of the disease. In another study, 41 caregivers were assessed using Zarit CBI. Activities of daily living and perceived social support were the significant predictors of the caregiver burden [35]. Another study showing similar results with 80 caregivers and using Zarit CBI suggests that severity and disability of PD and caregiver burden have positive association [4]. A study done by Prizer LP et al., found that patients who did not have a caregiver had poorer quality of life and poorer medication adherence also [33]. A study done by Smith ER et al., had found that they could account for the caregiver mental health fully by the extent of caregiver burden which highlights the importance of dealing with reducing caregiver burden [36]. The study shows that caregiver burden in patients suffering from Parkinson's disease is correlating to age of the caregiver, severity of the PD. Also, as the UPDRS score increases caregiver burden increases significantly and as MMSE score of patient reduces the caregiver burden increases significantly.

Limitation(s)

This study had 5% stage 5 patients as they were selected from Neurology clinic and most of the stage 5 patients become almost fully restricted to their homes. We believed that scales exploring the objective and subjective burden of the disease such as CBI could be useful for evaluation of the caregiver strain. In a large study which looked at 819 elderly individuals with disability they had found most caregivers had felt caring for them burdensome and this contributed to the increase of psychiatric comorbidity in the caregiver. Also, this emotional strain on the caregivers was an independent risk factor for patient mortality [37].

CONCLUSION(S)

This current study indicated that patients of Parkinson's motor and cognitive symptoms severity accounts significantly for the caregiver burden while certain other sociodemographic and clinical factors to some extent were associated. Caregiver burden is not related to one specific key factor but rather is a cumulative effect of varied factors adding up together. Results of this study may have practical implications for elderly patients and their caregivers. Identifying caregivers at risk of psychosocial burden may lead to reduction in caregiver stress and thereby improving the support given to the patients ultimately delaying the institutionalisation. Still, further research is needed with larger sample size and including other caregivers than spouses to have results that can be more generalised.

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AUTHOR DECLARATION:

- Financial or Other Competing Interests: None
- Was Ethics Committee Approval obtained for this study? Yes
- Was informed consent obtained from the subjects involved in the study? Yes
- For any images presented appropriate consent has been obtained from the subjects. NA

PLAGIARISM CHECKING METHODS: [Jain H et al.]

- Plagiarism X-checker: Aug 08, 2020
- Manual Googling: Oct 14, 2020
- iThenticate Software: Dec 12, 2020 (25%)

ETYMOLOGY: Author Origin

Date of Submission: Aug 03, 2020
Date of Peer Review: Sep 21, 2020
Date of Acceptance: Oct 26, 2020
Date of Publishing: Dec 15, 2020