

**ROLE STRAIN AND BURDEN AMONG CAREGIVERS OF  
PARKINSON'S DISEASE**<sup>1</sup>Salma Suresh and <sup>2</sup>Kanmani J.<sup>1</sup>MSc Nursing, Amrita College of Nursing, Amrita Vishwa Vidyapeetham, India.<sup>2</sup>Professor, Amrita College of Nursing, Amrita Vishwa Vidyapeetham, India.

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Vidyapeetham, India.**ABSTRACT**

**Objective:** Parkinson's disease is a progressive neurodegenerative disorder with the major burden of informal care on the spouse and other family members. Objectives of the study were to identify the role strain and burden, find correlation between role strain and burden and find association between role strain and burden with selected variables

among caregivers of patients with Parkinson's disease. **Materials and Methods:** A quantitative research approach with descriptive design was chosen. 85 subjects who were caregivers of patients with Parkinson's disease were selected using non-probability convenience sampling technique and the data were collected using Modified Caregiver Strain Index (MCSI) and Zarit Burden Interview (ZBI). **Results:** Among 85 subjects, 67 (78.8%) were spouses. Clinical data revealed 39 (45.9%) patients were in stage 3 of their illness and more than half i.e. 52 (61.2%) patients had disease onset within 5 years. Majority of 75 subjects (88.2%) belong to mild category of MCSI and 81 (95.3%) subjects had minimal burden. A moderately positive correlation between role strain and burden was found. The disability of disease was significantly associated with role strain and burden. Also there was a significant association between burden and clinical variables including urinary problems, disease severity, and medication carbidopa -levodopa at  $p > .05$  level of significance. **Conclusion:** The study findings revealed the fact that role strain and burden were correlated and the relatively low role strain and burden among the caregivers of patients with Parkinson's disease can be attributed to less severity and duration of disease.

**KEYWORDS:** Parkinson's disease, caregiver, role strain, burden

## INTRODUCTION

Parkinson's disease is a disorder of the central nervous system that causes a loss of cells in the part of the brain that controls movement. The Centre for Disease control rated complications from Parkinson's disease as the 14th leading cause of death in the United States. Worldwide, it is estimated that four to six million people suffer from the condition. In India incidence of PD is 1% among adults aged 65 years or older and 5% among aged more than 80 years. India has about 7 million people living with PD.<sup>[1]</sup> The disease often begins insidiously, often unilaterally, with only few apparent symptoms. Because the onset is insidious and the population affected is elderly, symptoms are frequently disregarded as normal consequences of aging process.<sup>[2]</sup> People with Parkinson's disease experience a range of symptoms, including tremor (shaking), rigidity (stiffness), slowness of movement, and problems with balance and coordination. They may also have memory problems, depression, and sleep complaint. With progression PD patients often need a family member or friend as a caregiver. Finally, the demands of caring can lead to restriction of other areas of the carer's life including work, social, and recreational function, reducing their quality of life which may lead to caregiver strain and care giver burden.

## MATERIALS AND METHODS

A quantitative non –experimental descriptive design was chosen for the study. 85 caregivers of patients with Parkinson's disease attending Parkinson's clinic of Amrita Institute of Medical Sciences, Kochi were selected using non probability convenience sampling technique. Caregivers of patients with Parkinson's disease who are registered in Parkinson's clinic and those who were immediate caregivers were included whereas caregivers of patients with Parkinson's disease those who are in stage one of Hoehn and Yahr scale,<sup>[2]</sup> also who were not willing to participate in the study were excluded. Data were collected using The Modified Caregiver Strain Index (MCSI), a standardized tool used to quickly screen for caregiver strain with long-term family caregivers. It includes 13-questions which measures strain related to care provision. There was at least one item for each of the following major domains: Financial, Physical, Psychological, Social, and Personal. Scoring was 2 points for each 'yes' and 1 point for each 'sometimes' response. The higher the score, the higher the level of caregiver strain and is scored as mild strain 0-8, moderate strain 9-16 and severe strain 17-26. Also Zarit *et al.*; caregiver burden was also used. It was also a standardized scale consisting of 21 items to rate overall level of burden in caring for your spouse/relative on a five point likert scale. It was a 22 negatively stated statements each on a 5 point likert

scale and was scored as no or minimal burden: 0 to 20, Mild to moderate burden: 21 to 40, Moderate to severe burden: 41-60 and Severe burden: 61 to 88. A written informed consent was obtained from the subjects and the questionnaire which included the demographic and clinical variables were collected by interview method and followed by self administered questionnaire of MCSI and ZBI.

## RESULTS

The analysis of data from the study is presented under the following headings:

**Section I:** Distribution of subjects according to their demographic and clinical variables.

**Table 1: Distribution of subjects based on demographic variables.(n=85)**

Variable	Frequency	Percentage (%)
<b>Age</b>		
<50 years	17	20
51-60 years	35	41.2
61-70 years	29	34.1
>70 years	4	4.7
<b>Gender</b>		
Male	32	37.6
Female	53	62.4
<b>Marital status</b>		
Married	83	97.6
un married	2	2.4
<b>Employment status</b>		
Employed	30	35.3
Unemployed	33	38.3
Retired	22	25.9
<b>Relationship to patient</b>		
Spouse	67	78.8
Daughter/son	18	21.2
<b>Co morbidities of caregiver</b>		
Diabetes	26	30.6
Hypertension	23	27.1
Cholesterol	15	17.6
Others	9	10.6
<b>Years of care giving</b>		
1 year	10	11.8
1-5 year	52	61.2
5-10 year	17	20
>10 year	6	7.1

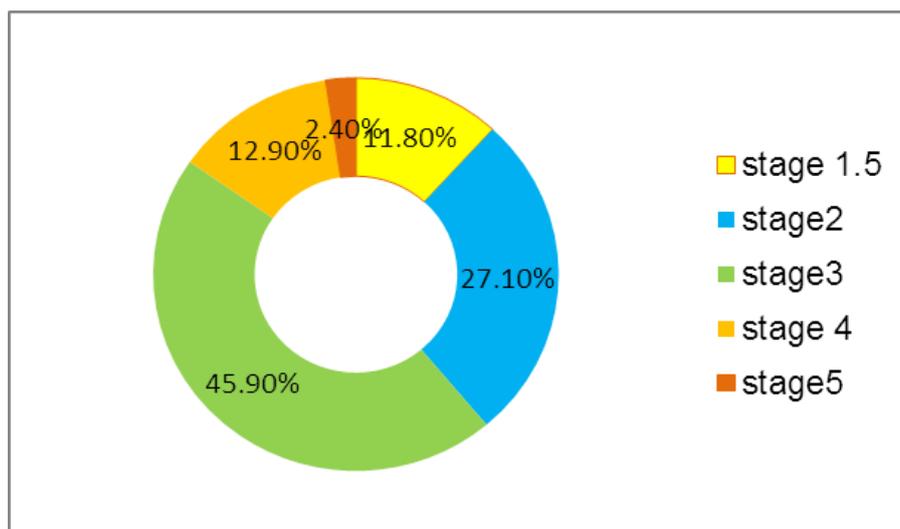
The data presented in table 1 shows 83 (97.6%) of subjects were married.. The employment status data reveals 33 (38.3%) subjects were unemployed. 67 (78.8%) subjects as spouses of

the patient. Regarding the co morbidities of caregiver diabetes ranks first among 26 (30.6) subjects. With regard to years of care giving, 52 (61.2%) were having between 1-5 years of care giving.

**Table 2: Distribution of subjects based on clinical variables. (n=85)**

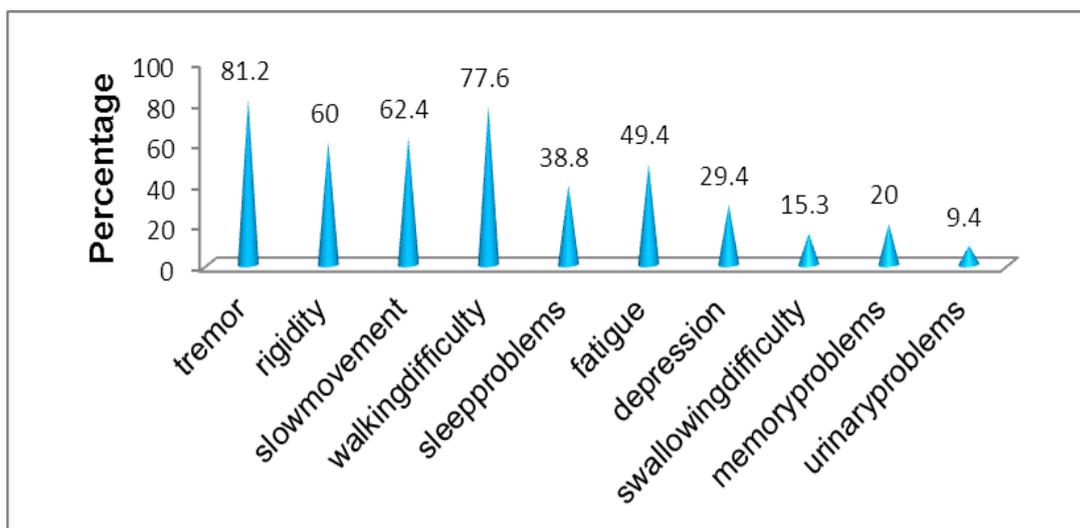
Variable	Frequency	Percentage (%)
<b>Age</b>		
<50 years	6	7.1
51-60 years	39	45.9
61-70 years	32	37.6
>70 years	8	9.4
<b>Duration of disease</b>		
<1 year	10	11.8
1-5 year	52	61.2
5-10 year	17	20
>10 year	6	7.1
<b>Co morbidities of patient</b>		
Diabetes	17	20.6
Hypertension	33	38.8
Cholesterol	19	22.4
Others	12	14.17
<b>Barthel Index score</b>		
0-50	3	3.5
50-75	8	9.4
>75	74	87
<b>Medications</b>		
Carbidopa-levodopa	80	94
Dopamine agonist	31	63.5
COMT inhibitors	7	8.2

The data presented in table 2 shows majority of subjects numbering 39 (45.9%) belong to age group of 51-60 years. Most of subjects numbering 53 (62.4%) had disease duration between 1-5 years. Among the co morbidities, hypertension was common among 33 subjects (38.8%). Majority of the subjects totalling 80 (94.1%) were on treatment with carbidopa-levodopa. According to Hoen and Yahr stage of Parkinson disease 39 subjects (45.9%) belong to stage 3. With regard to Barthel index score majority of 74 (87.1%) subjects belong to the category of mild score.



**Figure 1: Doughnut diagram showing distribution of patients with Parkinson's disease based on stage of disease**

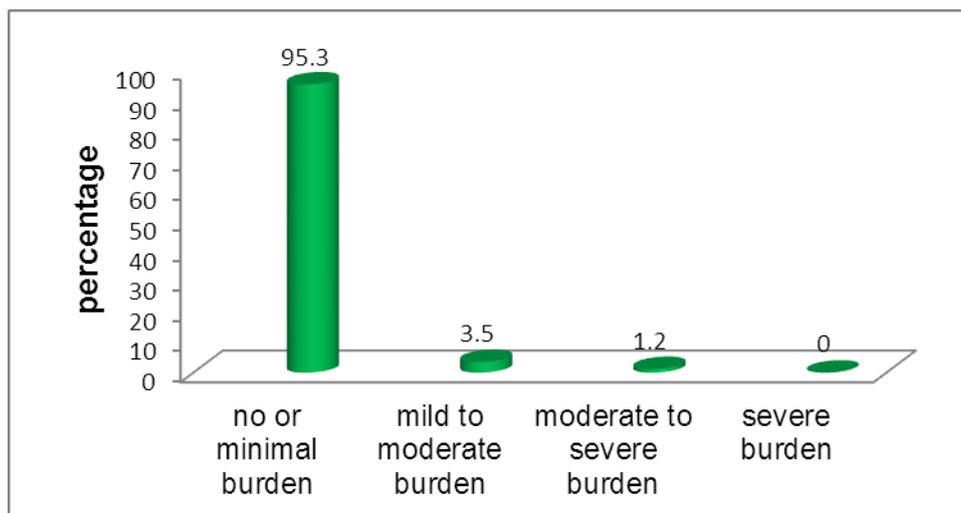
The data presented in fig.1 reveals that 39 (45.9%) subjects belong to stage 3 of disease, 23 (27.1%) of the subjects belong to stage 2 category, 11(12.9%) belong to stage 4, 10 (11.8%) subjects belong to stage 1.5 category and 2(2.4%) belong to stage 5 category.



**Figure2: Cone diagram showing clinical manifestations of Parkinson's disease.**

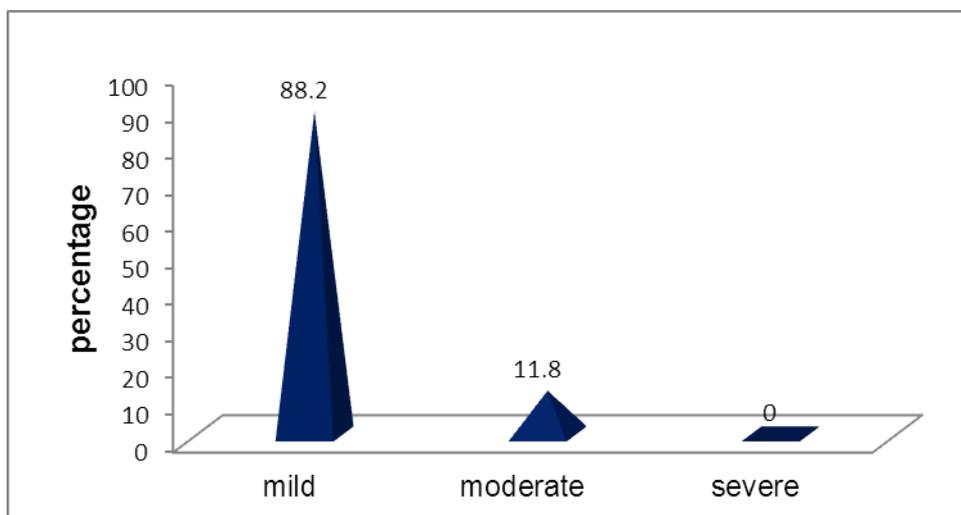
The data presented, in the fig.2, show majority of the subjects numbering 69 (81.2%) had tremor followed by walking difficulty among 66 (77.6%) subjects, slow movement among 53 (62.4%) subjects, rigidity among 51(60%) subjects, fatigue among 42 subjects (49.4%), sleep problems in 33 subjects (38.8%), depression with 25 subjects (29.4%), memory problems among 17 (20%) subjects and urinary problems among eight(9.4%) subjects.

## Section II: Role strain and burden among caregivers of patients with Parkinson disease.



**Figure3: Cylindrical diagram on distribution of Zarit burden interview score among caregivers of patients with Parkinson disease.**

The data presented in fig 3 shows majority of 81 subjects (95.3%) had no or minimal burden, 3 subjects (3.5%) had mild to moderate burden and 1 subject (1.2%) had moderate to severe burden.



**Figure 4: Pyramidal diagram on distribution of subjects based on Modified care giver strain index score among caregivers of patients with Parkinson disease.**

The data presented in fig 4 shows majority of 75 subjects (88.2%) belong to mild category of MCSI, 10 subjects (11.8%) belonging to moderate category of MCSI.

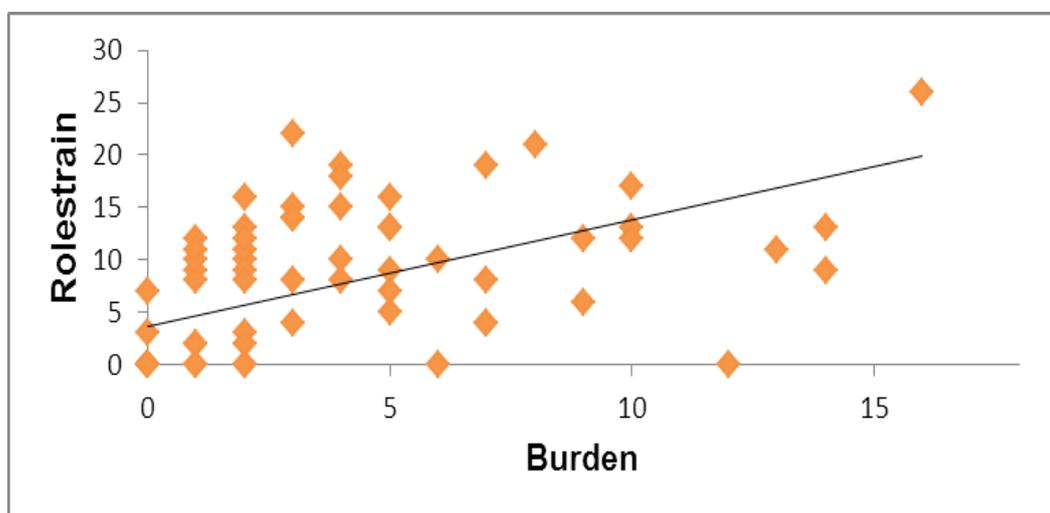
**Section III:** Correlation between roles train and burden among caregivers of patients with Parkinson disease.

**Table 3: Correlation between role strain and burden. (n=85).**

SL NO	Variable	Correlation coefficient	P value
1.	Role strain with Burden	.528	0.000

\*significant  $p < 0.01$

Table 3 represents the correlation between the role strain with burden among the caregivers of patients with Parkinson's disease. The data in the table shows that is a significant moderately positive correlation between role strain and burden among the caregivers of patients with Parkinson's disease. It is computed by Karl Pearson correlation coefficient.



**Figure 5: Scatter diagram on correlation between role strain and burden.**

The data presented in fig 9 show that there is correlation between role strain and burden.

**Section IV:** Association between role strain and burden with selected variables among caregivers of patients with Parkinson's disease.

**Table 4: Association between Burden and clinical variables of patients with Parkinson's disease. (n=85)**

Clinical variable	Category	Mild	Moderate	Severe	df	X <sup>2</sup>	p
Urinary problems	yes	6(75%)	2(2.5%)	0	2	1.999	.043 <sup>s</sup>
	no	75(97.4%)	1(1.3%)	1(1.3%)			
Carbidopa-levodopa	yes	79(7.5%)	1(1.3%)		2	10.761	.016 <sup>s</sup>
	no	3(60%)	2(40%)	0			
Hoen and yahr stage	1.5	10(100%)	0	0	8	17.2	.005 <sup>s</sup>

	2	22(95.7%)	0	1(4.3%)			
	3	39(100%)	0	0			
	4	9(81.8%)	2(18.2%)	0			
	5	1(50%)	1(50%)	0			
<b>Barthel index</b>	0-50	0	3(100%)	<b>0</b>	4	25.4	.000 <sup>s</sup>
	50-75	8(100%)	0	0			
	75 and above	73(98.6%)	0	1(1.4%)			

Table 4 represents the association between burden with selected Clinical variables among the caregivers of patients with Parkinson's disease. It is computed by chi square. The data show burden is associated with urinary problems with  $X^2=1.999, p<.05$ , indicating that burden is higher among caregivers of patients with Parkinson's disease having urinary problems. The data also reveal that burden is associated with medication carbidopa-levodopa with  $X^2=10.768, p<.05$ , indicating that burden is higher among the caregivers of patients with Parkinson's disease who are on medication carbidopa-levodopa. Also the burden is associated with Hoen and Yahr stage of Parkinson's disease  $X^2=17.279, p<.05$ , indicating that burden is increased with increase in stage of disease. The burden was associated with Barthel index score with  $X^2=25.446, p<.05$ , indicating that the burden is higher among the caregivers of patients with Parkinson's disease having a decreased score of barthel index.

**Table 5: Association between role strain and Barthel Index. n=85**

clinicalvariable	category	mild	Moderate	df	X <sup>2</sup>	P value
<b>Barthel index</b>	0-50	2(66.7%)	1(33.3%)	2	7.402	.023 <sup>s</sup>
	50-75	5(62.5%)	3(37.5%)			
	75 and above	68(91.9%)	6(8.1%)			

S: significant

Table 5 represents the association between the role strain and Barthel Index of patient. It is computed by chi square. The data show the role strain was associated with Barthel index score with  $X^2=7.402, p<.05$ , indicating that role strain is higher among the caregivers of patients with Parkinson's disease having a decreased score of barthel index.

## DISCUSSION

**The first objective of the study was to identify role strain among caregivers of patients with Parkinson's disease.**

75 subjects (88.2%) belong to mild category of MCSI and 10 subjects (11.8%) belong to moderate category of MCSI. The findings of the present study was supported by a cross-

sectional study conducted by Carter J H, Stewart B.J., Archbol.D, Inoue.I, Jaglin, Lannon.J et al <sup>[3]</sup> during the year 2004 in USA on experience of spouses care giving for their spouse with Parkinson's disease (PD) among 380 spouse caregivers revealed that specific types and amounts of role strain accumulated as the disease progressed, ( $p < 0.05$ ). The negative changes in lifestyle plus decreases in predictability in caregivers' lives increased significantly in late-stage disease ( $p < 0.05$ ). The depression was significantly higher by stage 4/5. Mutuality, the positive quality of the relationship as perceived by the care giving spouse, declined beginning at stage 2. Thus the above study findings indicate that caregiver strain was experienced across all stages of PD and accumulates significantly as the disease progresses.

In the present study the relatively low amount of strain may be probably due to less severity of disease (45% in stage 3) and due to 61.2% of them had disease onset within 5-10 years.

**The second objective of the study was to identify burden among caregivers of patients with Parkinson's disease.**

In this present study the burden was assessed using a standardized questionnaire named Zarit Burden Inventory and was categorized as mild, moderate, severe burden. Regarding burden 81 subjects (95.3%) had no or minimal burden. 3 subjects (3.5%) had mild to moderate burden and 1 subject (1.2%) had moderate to severe burden. The findings were similar found in a cross-sectional study conducted by Dotchin.C, Paddick.SM, Longdon.AR, Kisoli.A, Gray.W.K, Dewhurst.F et al <sup>[4]</sup>; during the year 2014, on the comparison of caregiver burden in older persons and persons with Parkinson's disease or dementia in Tanzania among 25 PD patients using Zarit Burden Inventory. The findings revealed that Median ZBI was 30.5 for PD. Disease duration and disease type were identified as univariate predictor of ZBI score. The study concluded that people with more advanced PD had higher caregiver burden.

Present study findings of relatively low amount of burden (median:5) may be due to the nature of caregivers and patients as majority of patients (45.9%) belong to stage 3 of Hoen and Yahr stage of disease which demands less assistance from caregivers and had disease onset within only 5-10 years without long disease duration.

**The third objective of the study was to find correlation between role strain and burden among caregivers of patients with Parkinson disease.**

In the present study, as expected correlation was found between role strain and burden among caregivers of patients with Parkinson's disease.

In comparison to the present study findings a cross sectional study was conducted by Gracia.S, Fernandez. F.<sup>[6]</sup> during the year 2014 on factors contributing to caregiver stress and burden in Parkinson's disease in Spain among 121 non-demented patients with PD and their Caregivers found a high correlation between ZCBI and CSI. Also the activities of daily living had the strongest influence on ZCBI and CSI. The study concluded that Disability and mood of patients with PD were the main factors contributing to burden and stress.

Also in line with the review findings the present study supports activities of daily living had the strongest influence on ZCBI and CSI as Barthel index (activity of daily living) is associated with role strain and burden at the level of significance  $p \leq 0.05$ .

The findings supports ZCBI and CSI Were correlated. The weakly positive correlation can be due to fairly low role strain and burden which in turn may be due sample characteristics of less severity and disease duration.

**The fourth objective of the study was to find association between role strain and burden with selected variables.**

In the present study the role strain was not associated with demographic variables of caregiver which included age, sex, education, employment, years of care giving at the level of significance  $\leq 0.05$ . With regard to clinical variables the role strain not was associated with symptoms, medications, and Hoen and Yahr at the level of significance  $\leq 0.05$  stage. But there was association with Barthel index (activity of daily living score) at the level of significance  $\leq 0.05$ .

The above mentioned study by Gracia.S, supports the present study findings as barthel index was found to be associated with CSI.

The present study findings were contradictory to cross sectional study conducted by Oguh.O. M. Kwasny. B. Stell.T. Simuni <sup>[7]</sup> during the year 2012 in Chicago on Predictors of Caregiver burden in Parkinson's disease among 2476 care givers of Parkinson's which

revealed that among them 276 had modified care give strain index  $\geq 30$ . The predictor of caregiver burden were PDQ-39 total score, Hoehn and Yahr stage  $>3$ , presence of concomitant medications such as antidepressants and antipsychotics, social worker visits, male gender and decreased verbal fluency. The study concluded that there was high prevalence of caregiver strain in PD.

In the present study the burden was found to not to be associated with demographic variables of caregiver which included age, sex, education, employment, years of care giving at the level of significance  $p \leq 0.05$ . With regard to clinical variables burden was not associated with symptoms except urinary problems, medications except carbidopa, at the level of significance  $p \leq 0.05$ . The burden was also associated with urinary problems, Hoen and Yahr stage, Barthel index and medication cabedopa at the level of significance  $p \leq 0.05$ .

The findings of the study were supported by cross-sectional descriptive study was conducted by Kim. K.S, Kim. B.J, Kim.K.H, Choe.M.A, Yi.M, Hah.Y.S, et al<sup>[8]</sup> during the year 2007, on Subjective and objective caregiver burden in Parkinson's disease among 76 primary caregivers of PD patients in Korea revealed older and spousal Caregivers of PD patients experienced high levels of burden also greater motor disability and higher Hoehn and Yahr grade were related to higher caregiver .The study concluded that Caring for PD patients is associated with a high level of caregiver burden.

Like the previous study, present study findings revealed Hoen and Yahr stage, Barthel index is associated with burden. The congruency with the present study findings in level of burden may be due to similarities in caregiver characteristics including the age and relationship to the care recipient. In both the studies most caregivers falls between 51-60 years and spouses represented the largest proportion with 67% and 47% respectively in the present study and in literature reviewed. But in contradiction to the findings in the present study the review shows that age was not associated with burden. And this may be due to the difference in the scores obtained for ZBI in both studies which were 35.4 and 6.8 in the previous study and in the present study respectively.

Another study, conducted by Cifu.DX, Crane.W, Brown.R on caregiver distress in parkinsonism, in 2006 in Richmond, among 49 caregivers found Caregiver burden was significantly negatively associated with activities of daily living and motoric difficulties as measured on the Unified Parkinson's Disease Rating Scale (UPDRS) also caregiver burden

was negatively associated with caregiver self-reported sleep and coping. The study suggests that the patients motor impairment, decreased ability to perform activities of daily living and decreased sleep time experienced by caregivers are associated with caregiver burden.

In comparison with the literature which has supported the present study findings as activity of daily living was found to be associated with burden which may be due to the similarity in caregiver variables of age and relationship as caregivers were predominantly wives with 82% and 78.8% in the previous study and present study respectively. However, other two aspects including sleep of caregiver and motoric disabilities of patient were not associated and this disparity may be due to the difference in the ability of coping which was high (mean score=4.6/6) in the previous study and in the present study it was not assessed.

According to Mosby which reports dystonia and orthostatic hypotension as side effects of carbidopa-levodopa which results in dependency on caregivers, can be attributed to its association with burden. The researcher could not find any studies supporting the association of urinary problems with burden.

Above all the fairly low care giver strain and burden may be can be attributed to less severity and duration of disease which shed light on the fact that those with increased severity and duration are either receiving inpatient care or are residing in community. This provides with the need to direct the activities of health professional in community.

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