

Caregiver Burden in Primary Caregiver Spouses of Elderly Patients with Dementia/Cognitive Impairment

Abhishek Shukla¹, Amita Shukla MS², Pankhuri Mishra³

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Abstract

Background and Objective: Patients with dementia and cognitive impairment require regular care. In the present study, we assess the burden of care among primary caregiver spouses of elderly patients with dementia/cognitive impairment.

Material and Method: A total of 50 elderly patients (>60 years) having a history of dementia/cognitive impairment for a minimum of two years who had spouses as their primary caregiver were enrolled in the study. Demographic and social profile of the patients and caregivers was noted. Severity of cognitive impairment was assessed using Mini Mental State Examination (MMSE). Burden assessment scale (BAS) was used to study the caregiver burden. Data was analyzed using Independent samples t-test and ANOVA.

Results: Mean age of patients was 74.52±5.94 years. Mean age of caregivers was 73.1±8.57 years. Majority of patients were males (64%), were from middle class (60%), lived in joint family (56%), were not able to perform their routine works (60%) and had mild cognitive impairment (56%). Mean BAS score was 68.22±10.57. No significant association of BAS scores was seen with different demographic and clinical characteristics except for severity of CI and duration of care.

Conclusion: There was a substantial caregiver burden on the primary caregiver spouses of elderly patients with dementia/cognitive impairment.

Keywords: Dementia; Cognitive impairment; Caregiver burden; Spouses; Primary caregivers.

Author's Affiliation: ¹HOD & Medical Director, ³HOD, Aastha Centre for Geriatric Medicine, Palliative Care Hospital, Hospice & Social Welfare Society, Lucknow 26006, Uttar Pradesh, India, ²HOD, Geriatric Medicine, Late Sri S.C. Trivedi Memorial Mother & Child Care Trust Hospital, Lucknow 226024, Uttar Pradesh, India.

Corresponding Author: Amita Shukla MS, HOD, Geriatric Medicine, Late Sri S C Trivedi Memorial Mother & Child Care Trust Hospital, Lucknow 226024, Uttar Pradesh, India.

E-mail: amitaobg@gmail.com

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INTRODUCTION

Dementia can be defined as a clinical syndrome characterized by a cluster of symptoms and signs manifested by "difficulties in memory, disturbances in language and other cognitive functions, changes in behavior, and impairments in activities of daily living".¹ Cognitive decline and dementia are common problems associated with ageing and Alzheimer's disease.^{2,3} Patients with

dementia and cognitive decline often require care. In the community, the burden of care of dementia patients is borne mainly by familial caregivers.⁴ Caregiving to a dementia patient is strenuous and very demanding. Caregivers to dementia have been known to have high burden of care.⁵ Caring for a patient with dementia is more stressful than caring for a person with a physical disability.⁶⁻⁸ Spouses play an important role as familial caregivers, especially to elderly. Role of spouses as caregivers to elderly patients with dementia places them an additional burden as they themselves are old, often have poor health. Moreover, their physical and psychological well being is also compromised.⁹ Hence, the present study was carried out to understand the burden of care and its association with duration and severity of dementia among elderly patients whose spouses play the role of primary caregivers.

MATERIAL AND METHOD

The present study was carried out at the Outpatient Dementia/Alzheimer Clinic of a specialized geriatric care facility in Lucknow, India after getting approval from the appropriate institutional authorities (Approval letter No. _____ dated _____) and receiving consent from the participating patients and their caregivers.

The inclusion criteria of the study was: (i) Spouse of an elderly patient (aged >60 years) with dementia; (ii) Index patient having a minimum two years history of dementia as per DSM-5 criteria; (iii) Acting as primary full-time caregiver with no other occupational commitment;. The exclusion criteria of the study was: (i) History of any psychiatric illness; (ii) medical/surgical illnesses requiring hospitalization during the entire caregiving period; (iii) Mental retardation or any other cognitive dysfunction; (iv) Presence of any other dementia/psychiatric illness in any other member of the family than the index elderly patient.

Primary caregiving for the purpose of the study was defined as “staying with the dementia patient for at least two years with continuous contact, and actively involved in his/her care”.

Sample size was determined on the basis of a previous article that found a correlation between severity of dementia and caregiver burden with “r” value 0.4210. In the present study we also expected a similar correlation. The sample size was calculated using the following formula: $n = [(z\alpha + z\beta)/C]^2 + 3$, where $z\alpha = 1.96$ at 95% confidence, $Z\beta = 0.8416$ at 80% power and $C = 0.5 * \ln[(1+r)/(1-r)]$ at a targeted

‘r’ value of 0.4, the value of C was derived as 0.4236. Thus the calculated sample size was 47. However, we targeted a sample size of 50.

METHOD

Spouses of dementia patients falling in the sampling frame were contacted during the Outpatient visit of the index patient and were invited to participate in the study. Those consenting to participate in the study were included in the assessment. Age and sex of index patient and caregiver was noted, details regarding socioeconomic status, family type and caregiver’s educational status was noted. The caregiver’s were also enquired regarding the ability of the index patient to perform all the routine works. Duration of caregiving was also noted and categorized as <5 years, 6-10 years and >10 years respectively.

Severity of dementia was assessed using Mini Mental State Examination (MMSE) scale.¹¹ The following criteria was used for the purpose of identification of cognitive status and its stratification:

MMSE Score	Cognitive Status
>26	No Impairment
21-26	Mild Impairment
13-20	Moderate Impairment
<13	Severe Impairment

Assessment of burden of care was done using Burden Assessment Schedule (BAS).¹² BAS is a 40-item schedule that covers burden of care on nine domains, viz., spouse related (5 items), physical and mental health (6 items), external support (5 items), caregiver’s routine (4 items), support of patient (3 items), taking responsibility (4 items), other relations (3 items), patient’s behavior (4 items) and caregiver’s strategy (4 items). Each item is scored on a three point Likert scale with scores ranging from 1 (“not at all”) to 3 (“very much”) showing the degree of caregiving burden. The total burden is assessed by summation of scores obtained on all the 40 items and could range from 40 to 120 with higher scores representing higher burden of severity.” It can be categorized into five categories, viz. <40 – No burden, 41-60 – Minimal burden, 61-80 – Moderate burden, 81-100 severe burden and 101-120 – very severe burden respectively.¹³

Data Analysis:

The data obtained from the patients was fed into computer using IBM SPSS Stats software version 21.0. Association of BAS scores with different sociodemographic factors, severity of dementia and duration of dementia was assessed using Independent samples 't'-test and ANOVA.

RESULTS

Age of index patients ranged from 62 to 82 years. Maximum patients (48%) were aged between 71-80 years. Mean age of patients was 74.52±5.94 years. Majority of patients (n=32; 64%) were males, came from middle class (60%), lived in a joint family (56%) and were not able to perform routine works (60%). Majority (56%) had mild dementia. There were 22 (44%) having moderate dementia. None of the patients had severe dementia (Table 1).

Table 1: Profile of Elderly Patients with Cognitive Impairment (n=50)

Characteristic	Number	Percentage
Age		
<70 Years	12	24
71-80 Years	24	48
>80 Years	14	28
Mean age±SD (Range) in years	74.52±5.94 (62-82)	
Sex		
Male	32	64
Female	18	36
Socioeconomic status		
Middle	30	60
Upper Middle	19	38
Upper	1	2
Family type		
Nuclear	22	44
Joint	28	56
Able to perform routine works		
	20	40
Severity of impairment		
Mild	28	56
Moderate	22	44

The age of caregivers ranged from 55 to 90 years with a mean age of 73.1±8.57 years. Maximum (46%) of caregivers were aged between 71 and 80 years and majority (64%) were females. Maximum caregivers were educated upto high school (30%) followed by intermediate (22%), illiterate (16%),

graduates (14%), primary (12%) and postgraduation or above (6%) respectively. Majority (62%) were rendering care for <5 years. Mean total caregiver burden scores (BAS Total) were 68.22±10.57. Mean domain scores for spouse related, physical and mental health, external support, caregiver's routine, support of patient, taking responsibility, other relations, patient's behaviour and caregiver's strategy were 8.92±3.68, 10.74±2.48, 10.58±3.15, 8.18±1.78, 7.08±1.75, 7.22±2.18, 9.02±1.20, 6.48±1.171 and 8.62±2.00 respectively. The severity of caregiver burden was minimal, moderate and severe in 11 (22%), 33 (66%) and 6 (12%) cases (Table 2).

Table 2: Caregiver Profile and Burden of Care (n=50)

Characteristic	Number	Percentage
Caregiver's Age		
≤70 Years	18	36.0
71-80 Years	23	46.0
>80 Years	9	18.0
Mean age ± SD (Range) in years	73.1±8.57 (55-90)	
Caregiver's sex		
Male	18	36.0
Female	32	64.0
Caregiver's Education		
Illiterate	8	16.0
Primary	6	12.0
High School	15	30.0
Intermediate	11	22.0
Graduation	7	14.0
Postgraduation or above	3	6.0
Duration of Care		
≤5 Years	31	62.0
6-10 Years	11	22.0
>10 Years	8	16.0
Caregiver Burden		
Total	Mean	SD
Total	68.22	10.57
Spouse related	8.92	3.68
Physical and Mental health	10.74	2.48
External support	10.58	3.15
Caregiver's routine	8.18	1.78
Support of patient	7.08	1.75
Taking responsibility	7.22	2.18
Other relations	9.02	1.20
Patient's behavior	6.48	1.71
Caregiver's strategy	8.62	2.00
Severity of Burden		
Minimal	11	22.0

Table to be cont....

Moderate	33	66.0
Severe	6	12.0

No statistically association of mean BAS (Total) scores was seen with patient's age, sex, socioeconomic status, family type and ability to perform routine works on their own. However, mean BAS scores were significantly higher among patients with moderate dementia (77.10 ± 5.38) as compared to that among patients with mild dementia (61.25 ± 8.18) ($p < 0.001$) (Table 3).

Table 3: Association of Caregiver Burden with Patient Profile and Severity of Cognitive Impairment

Characteristic	Number	Mean BAS \pm SD
Age		
<70 Years	12	68.08 \pm 10.92
71-80 Years	24	68.58 \pm 10.37
>80 Years	14	67.71 \pm 11.38
Statistical significance	F=0.030; p=0.970	
Sex		
Male	32	68.72 \pm 11.26
Female	18	67.33 \pm 9.47
Statistical significance	t=0.441; p=0.661	
Socioeconomic status		
Middle	30	69.33 \pm 10.34
Upper Middle	19	66.79 \pm 11.22
Upper	1	62
Statistical significance	F=0.503; p=0.608	
Family type		
Nuclear	22	67.23 \pm 10.36
Joint	28	69.00 \pm 10.86
Statistical significance	t=0.585; p=0.561	
Able to Perform Routine works		
Yes	20	67.90 \pm 10.27
No	30	68.43 \pm 10.93
Statistical significance	t=0.173; p=0.863	
Severity of Impairment		
Mild	28	61.25 \pm 8.18
Moderate	22	77.10 \pm 5.38
Statistical significance	t=7.891; p<0.001	

Caregiver burden scores did not show a significant association with caregiver's age and education but was found to increase significantly with increasing duration of care ($p=0.007$) (Table 4).

Table 4: Association of caregiver burden with caregiver profile

Characteristic	Number	Mean BAS Score \pm SD
Caregiver's Age		
\leq 70 Years	18	70.20 \pm 10.16
71-80 Years	23	67.30 \pm 9.71
>80 Years	9	67.47 \pm 12.44
Statistical significance	F=0.367; p=0.695	
Caregiver's Education		
Illiterate	8	63.50 \pm 12.92
Primary	6	73.50 \pm 8.12
High School	15	63.87 \pm 12.09
Intermediate	11	71.45 \pm 7.13
Graduation	7	72.43 \pm 5.56
Postgraduation or above	3	72.73 \pm 13.32
Statistical significance	F=1.691; p=0.157	
Duration of care		
\leq 5 Years	31	64.97 \pm 10.68
6-10 Years	11	70.91 \pm 7.42
>10 Years	8	77.13 \pm 8.10
Statistical significance	F=5.523; p=0.007	

DISCUSSION

In the present study, mean BAS score was 68.22 ± 10.57 . Majority of caregivers experienced moderate burden (66%). Caregiver burden was primarily determined by severity of dementia and duration of care. Mean caregiver burden scores in the present study are in close proximity with those reported by Pattanayak *et al.*¹⁴ who reported the mean BAS scores as 67.50 ± 13.98 . Interestingly, the profile of patients and caregivers in their study also matched substantially with the profile of patients in the present study in the present study, mean age of patients was 74.52 ± 5.94 years as compared to 71.75 ± 9.66 years in their study. In the present study, 64% of patients were males (64%) and 64% of caregivers were females, similarly in their study, 62.5% of patients were males and 56.25% of caregivers were females. However, MMSE scores in their study were 16.72 which were lower than that in the present study in which they were recorded as 20.54, thus despite having a higher cognitive decline, the burden of care in their study was comparable to ours. However, the present study differed from their study from the point of view that in the present study, all the caregivers were spouses of the index patients whereas in their study, this condition was not essential and

only half the caregivers were spouses of the index patients. Similar caregiver burden with a relatively less severe cognitive decline in the present study could be attributed to the fact that the caregivers were spouses of the patients, and had a mean age above 70 years whereas in their study, owing to a large proportion of caregivers being other familial members (47% sons and daughters) they had a relatively much younger age profile (mean age 53.94 years) that seems to influence the overall coping ability of the caregivers. In the present study, the caregivers themselves were ageing elderly individuals and hence their coping abilities and resilience against caregiver burden were compromised to some extent.

In the present study, we did not find a significant association of caregiver burden with patient and caregiver's socio-demographic characteristics, however, both severity as well as duration of care had a significant association with burden of care. Although some studies report an association between caregiver's age and caregiver burden¹⁵, however, it was not seen in our study as all the caregivers were in almost same life stage. Some other studies have shown the association of caregiver burden with socio-economic factors too.¹⁶ Occupational commitments in different life stages have an impact on caregiver's burden, however, in the present study, none of the caregiving spouses had any other occupational commitment, and hence effect of age was not dominant. The role of other socio-economic factors also seemed less effective as most of the patients were retired persons with no major familial responsibilities that seem to add to the caregiver burden in otherwise younger family members acting as caregivers. The association of caregiving burden with severity and duration of caregiving as seen in the present study has been documented in other studies too.^{10,17,18} The association of caregiver burden with duration of caregiving could also be attributed to the fact that with increasing duration of caregiving the spouses who also are in elderly age group tend to experience the physical and psychological stresses associated with ageing.

The present study had certain limitations, such as it did not study the psychological burden of caregiving, had limited covariates, however, it was one of the pioneering attempts to study the burden of care in elderly spouses who were playing the role of primary caregivers to dementia patients, thus exploring a rather unexplored area of geriatric health issues. With the changing social milieu and transformation of families into more nuclear forms,

the elder generation today has to live away from their dependents and here the spouses play the caregiving role to each other, the present study tries to explore the caregiving burden of elderly spouses in this changing social context. Further studies with inclusion of comparative group and incorporation of other possible factors that may have an influencing role are recommended.

CONCLUSION

The present study showed a predominantly moderate burden of care among elderly spouses who play the role of primary caregivers to their partners with dementia. Severity of dementia and duration of caregiving had a significant association with increasing burden of care.

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