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## Predictors of caregiver burden in caregivers of dementia patients

Md. Anowar Hossain, Ahsan Aziz Sarkar, Fatima Zohra, Md. Mamun Al Mujahid, Md. Shohedul Alam, Afroza Rahman Lopa

**Background:** Dementia patients need assistance and supervision in their daily life activities and this often places a major burden on their caregivers, thereby putting the caregivers at a great risk of mental and physical health problems. Identifying the severity and factors related to caregiver burden will facilitate the care of the dementia patients.

**Objectives:** To assess the proportion, severity and factors associated with caregiver burden in dementia patients.

**Methods:** It was a cross-sectional, observational study conducted in National Institute of Mental Health (NIMH), Dhaka in 2019. Eighty caregivers of dementia patients were enrolled in this study by convenient sampling technique. Following enrollment, sociodemographic and relevant data and Mini-Mental State Examination (MMSE) score of each patient and Zarit Burden Interview (ZBI-B) score of each caregiver was recorded.

**Results:** Overall, all of the 80 participants described different levels of burden; among them 35% reported mild to moderate, 51.2% reported moderate to severe and 13.8% reported severe burden. Caregivers with low family income ( $r=-.133$ ,  $p=0.238$ ) who were not living with the patients ( $t=-4.04$ ,  $p<0.001$ ), who had no provision of respite care ( $t=-3.32$ ,  $p=0.001$ ) and who spent more time on care-giving ( $B=0.244$ ,  $p=0.001$ ) reported higher and statistically significant burden. Finally, with deteriorating cognitive function of the dementia patient as measured by MMSE, caregiver burden had also increased ( $B=-1.22$ ,  $p=0.001$ ).

**Conclusions:** All caregivers experienced different levels of burden while providing care to their dementia relatives. Increased time spent in care-giving and more cognitive impairment greatly increased burden. Provision of respite care and adequate social support can reduce the burden perception of carers.

**Declaration of interest:** None

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**Keywords:** Caregiver burden; predictors; factors; dementia patients; tertiary care hospital.

### Introduction

Caregiver burden has been defined as “a multidimensional response to physical, psychological, emotional, social and financial stressors associated with the caregiving experience”.<sup>1</sup> Caregiving for persons with dementia is a global nursing issue, in part because of a worldwide

demographic shift to an aging population. In addition to cognitive features like memory, language, attention, problem solving deficits, etc. dementia patients can present with complaints of personality change, mood change, social withdrawal, perceptual change and neurological

features like seizure, pseudo-bulbar palsy, focal deficits, primitive reflexes, etc.<sup>2</sup> Both informal and formal caregivers provide support for dementia patients as the disease progresses and they provide ongoing assistance with activities of daily living or instrumental activities of daily living to the patient. Much of the care-giving responsibility fall on family caregivers, such as a spouse, although other family members (siblings and children) are increasingly assuming this role.<sup>3</sup>

Jones described two dimensions of caregiver burden, subjective and objective.<sup>4</sup> Subjective burden depends on the caregiver's appraisal of the situation related to the task and the client's disruptive behavior, whereas objective burden depends on caregivers' tasks that need to be done. The association between objective and subjective burdens are complex. Townsend described two contradictory hypotheses to explain carer experiences over time.<sup>5</sup> First hypothesis is 'wear and tear' analogy, whereby with increasing cognitive and functional decline of the patient, it leads to more and more negative outcomes for carers over time. Second hypothesis is adaptation based, whereby carers gradually adjust to the care demands and learn to cope with the stressors.

'Stress Process Model' developed by Pearlin,<sup>6</sup> proclaims six distinct groups of stressors that are involved in the development of carer burden outcomes. Age, gender, education, income or social class, kinship ties, gender of ill relative are the common sociodemographic variables that can modify caregiver burden. Illness related factors like symptomatic presentation, amount of care needed and type-diagnosis and course of dementia also affect burden perception. Caregivers' social and psychological resources along with their own health status also modify the perception of satisfaction or burden.<sup>7</sup>

Prevalence of dementia was estimated as 3.3% in Bangladesh<sup>8</sup> and with increasing life expectancy for both sexes, it poses as an important public health problem. This study was undertaken with the aim of identifying the risk and protective factors associated with perceived burden.

## Methods

It was a cross-sectional, observational study conducted at National Institute of Mental Health (NIMH), Dhaka in between January 2019 to March 2020. Research proposal was approved by Institutional Review Board (IRB), NIMH, Dhaka. By convenient sampling technique, 80

caregivers of dementia patients were enrolled in this study. Caregivers who got paid for their work, were excluded from the study.

Following enrollment, sociodemographic and relevant data like age, sex, education, income, marital status, residence, duration of caregiving, time spent in caregiving, provision of respite care, were collected by a semi-structured questionnaire. Bangla version of Mini-Mental State Examination (MMSE)<sup>9</sup> score of each dementia patient was also recorded to measure the severity of cognitive deficits. MMSE is a 30-point questionnaire used extensively in clinical and research settings for dementia screening and to evaluate severity and progression of cognitive impairment. It examines cognitive function in orientation, registration, attention, recall and language domains and usually takes 5-10 minutes to administer. Scores can be used to classify severe ( $\leq 9$  points), moderate (10–18 points) or mild (19–23 points) cognitive impairment.<sup>10</sup>

Caregiver burden was measured by Bangla version of Zarit Burden Interview (ZBI-B).<sup>11</sup> ZBI-B is a 22-item self-report inventory which examines burden associated with functional/behavioral impairments and the home care situation. The items are worded subjectively, focusing on the affective response of the caregiver. Each question is scored on a 5-point Likert scale ranging from never to nearly always present. Total scores range from 0 (low burden) to 88 (high burden). Scores are interpreted as, 0-20 little or no burden; 21-40 mild to moderate burden; 41-60 moderate to severe burden and 61-88 severe burden.

Data were collected by face-to-face interview and following collection data cleaning was performed, followed by editing, coding and entering into SPSS. Between group comparison was done by t-test and ANOVA. Association between continuous variables was seen by Pearson's correlation test. P values obtained from t-test, ANOVA, Pearson's correlation tests were considered significant, if  $p < 0.05$ .

## Results

Majority of the caregivers were females (65%), married (97.5%) and aged between 35-49 years (43.8%). Most of them (45%) were spouses of the dementia patients. Mean (SD) care-giving duration was  $4 \pm 2.2$  years and mean (SD) time spent each week in care-giving work was  $41.2 \pm 25.9$  hours. Most of the caregivers' family (42.5%) earned between 30-40000 BDT each month. Average number of family members was  $5.6 \pm 1.6$ . Table 1 shows the caregivers' characteristics.

**Table 1: Characteristics of the dementia patient caregivers attending NIMH (N=80)**

Characteristic	Frequency (n)	Percentage (%)
<b>Age group (year)</b>		
20-34	11	13.8
35-49	35	43.8
50-64	24	30
65-79	10	12.5
<b>Gender</b>		
Male	28	35
Female	52	65
<b>Marital status</b>		
Married	78	97.5
Unmarried	2	2.5
<b>Educational status</b>		
Illiterate	11	13.8
Primary	37	46.3
Secondary	16	20
Higher secondary	12	15
Graduate and higher	4	5
<b>Relation with the patient</b>		
Spouse	36	45
Daughter	18	22.5
Son	11	13.8
Other	15	18.8
<b>Living with the patient</b>		
Yes	78	97.5
No	2	2.5
<b>Respite care</b>		
Yes	69	86.2
No	11	13.8

Of the 80 dementia patients, 48.8% were males, and minimum and maximum age were 49 and 85 years, respectively with a mean (SD) of  $67.1 \pm 7.4$ . Only 16 (20%) of the dementia patients were less than 60 years and 52.5%

patients more than 65 years old. Mild cognitive impairment was present in 10% patients, moderate in 73.7% patients and severe in 16.3% patients as measured by MMSE. Zarit Burden Interview (ZBI-B) Bangla version was taken by each caregiver to estimate burden of care-giving. Minimum score on ZBI was 24 and maximum 77 with a mean (SD) of  $47.4 \pm 11.4$ . Mild to moderate caregiver burden was reported by 35% caregivers, moderate to severe burden by 51.2% and severe burden by 13.8%. T-tests showed unmarried caregivers, those not living with the patient and those without any provision of respite care, reported statistically significant higher caregiver burden (Table 2).

One-way ANOVA between independent variables of three or more levels like educational status ( $F=1.13$ ,  $p=0.342$ ), occupation ( $F=1.12$ ,  $p=0.149$ ) did not find any statistically significant differences in caregiver burden across various groups. Pearson's correlation test (Table 3) showed that time spent in care giving had moderately strong positive correlation ( $r=0.548$ ,  $p=0.001$ ) with caregiver burden. Cognitive impairment measured by MMSE showed moderately strong negative correlation ( $r=-0.419$ ,  $p=0.001$ ) with caregiver burden, meaning decreasing score on MMSE was related with increasing scoring pattern on ZBI-B or in another term, with increased cognitive impairment the caregiver burden had also increased. Age of the caregiver, monthly income, number of family members, duration of care-giving and age of the dementia patient had no statistically significant relationship with caregiver burden (Table 3).

Linear regression was conducted to estimate how changes of time spent in care-giving and MMSE score affect caregiver burden. Carers who spent more time on care-giving reported higher statistically significant burden ( $B=0.244$ ,  $p=0.001$ ). Also, with deteriorating cognitive function of the dementia patients as measured by MMSE, caregiver burden had increased ( $B=-1.22$ ,  $p=0.001$ ).

## Discussion

Rabin while conducting Bangla validation of ZBI scale found that 35% of the caregivers had little or no burden, 54% had mild to moderate burden, 10% had moderate to severe burden and 1% had severe burden.<sup>11</sup> After retesting, she found that 31.6% of the caregivers had little or no burden, 58.9% had mild to moderate burden, 9.5% had moderate to severe burden and none had severe burden.<sup>11</sup> Her study was conducted in the outpatient dementia clinic whereas present study enrolled both indoor and outdoor dementia patients' caregivers. This variation in selection

**Table 2: T-tests showing mean differences in ZBI-B scores of caregivers across various variables (N=80)**

Care-giving fact	Mean±SD	t	p value
<b>Caregivers' gender</b>			
Male	49.8±12	1.4	0.160
Female	46.1±11		
<b>Marital status</b>			
Married	47.1±11.4	-9.1	0.000
Unmarried	59		
<b>Living with the patient</b>			
Yes	46.6±10	-4.04	0.000
No	77		
<b>Provision of respite care</b>			
Yes	45.8±10.6	-3.32	0.001
No	57.4±11.4		
<b>Gender of dementia patient</b>			
Male	45.2±10.4	-1.68	0.096
Female	49.5±12		

might explain why burden was more in this sample. Age did not modify perceived burden and similar finding was reported by Jorm, where he found no consistent age-related trend in caregiver burden.<sup>12</sup> However, other studies found younger age linked to greater burden<sup>13</sup> where more secondary role strain and less mastery were described as the reasons behind it.<sup>14,15</sup>

Both male and female caregivers expressed similar level of burden and gender differences had little effect in modifying overall burden. Other studies found that gender of the carer has no effect in burden perception.<sup>16-18</sup> Few studies reported that female carers report greater burden in mild cognitive impairment and dementia sample.<sup>19</sup> The reason given was indirect effect for female sex via associations with primary subjective<sup>20</sup> and secondary stressors, such as more role strain, higher levels of neuroticism<sup>21</sup> and less mastery.<sup>15</sup> Educational status had no bearing on burden perception although a high number of years of formal education might increase caregiver burden.<sup>22</sup> Most of the caregivers here completed primary and SSC education, so this non-correlation could be explained in this way. Low-income caregivers experienced higher burden which is consistent with previous research

**Table 3: Pearson correlation test between quantitative variables and caregiver burden measured by ZBI-B (N=80)**

Variable	Caregiver burden	
	r value	p value
Age of the caregiver (yrs)	0.118	0.297
Monthly income (BDT)	-0.133	0.238
Number of family members	0.134	0.237
Duration of care-giving (yrs)	0.096	0.397
Time spent in care-giving (hrs/wk)	0.548	0.001
Age of the dementia patient (yrs)	0.198	0.079
MMSE score	-0.419	0.001

findings. The reason behind it could be that higher income had increased coping and problem-solving capacities of the carers.<sup>16,23</sup>

Caregivers living with the dementia patients reported lower burden. Possible reasons could be that non co-residing carers had to maintain multiple households, travel stress, etc. Other researchers published mixed evidence; some studies reported positive associations with co-residing, while others did not find such link.<sup>24</sup> Caregivers without provision of respite care reported higher burden than who had provision of respite care. Studies have shown that respite and day care use can lead to a reduction in burden.<sup>25,26</sup> In a review of 29 studies,<sup>26</sup> McNally et al. found however, that these effects are short term and that evidence of long-term effects has not been reported.

Relationship status (spouse, son, daughter, others) did not show any statistically significant difference in burden perception. Pinquart reported that spouses suffer more burden than adult children and children-in-laws.<sup>27</sup> However, he stated that overall evidence is inconclusive and burden is probably because of indirect effect through association with physical health of similar aged spouses.

Age of the dementia patients weakly modified that caregiver burden among caregivers of higher aged patients had higher burden. Few previous studies linked younger patient age to more burden,<sup>13,28</sup> but most studies emphasized that higher age and subsequent age-related decline in cognitive function in dementia causes more burden. Similarly, gender of the dementia patients had little bearing on burden perception with carers of female dementia patients described slightly higher burden than carers of male dementia patients. Few studies published that female sex is linked to more burden<sup>29</sup> whereas few other studies published that male patient sex is linked to more burden.<sup>13,30</sup> So, there is mixed evidence for effect of patient gender on burden perception.

For how long the carers are providing support or duration of care-giving had weak correlation with caregiver burden. Instead, time spent each week in care-giving had significant relation with burden where burden increased as the amount of nursing time increased. Schulz et al. reported time spent in caregiving is the single most consistent factor related to caregiver burden.<sup>24</sup> Level of support provided linked to burden is stronger for dementia than for non-dementia patients.<sup>24,31</sup> Other studies also reported that performing more nursing tasks is linked to burden, depression, anxiety<sup>32</sup> and time spent providing care correlates with burden.<sup>33</sup>

This study found that with increasing cognitive impairment of the dementia patient measured by MMSE, caregiver

burden had also increased ( $B=-1.22$ ,  $p=0.001$ ). Worse memory,<sup>34</sup> executive function,<sup>33</sup> and cognitive complaints are linked to burden<sup>35</sup> as evident from previous studies. Few studies reported that evidence is less conclusive or if associations reported, cognitive function association is weaker than for behavioral or functional impairment.<sup>31,36</sup> Few studies reported no evidence for cognitive deterioration and burden.<sup>37</sup>

This study had several limitations. The cross-sectional design limits the strength of the causal relationship. Another potential limitation is about generalization as study sample was taken conveniently. Real world population may also vary in their experience as data were collected from a tertiary care hospital.

## Conclusions

It can be concluded that all caregivers experience different levels of burden while giving care to their dementia relatives. The extent of physical, psychological, interpersonal and financial burdens increase as the time spent in care-giving increases. Also, cognitive impairment of dementia patients indicate greater burden. Provision of respite care can reduce burden perception of the carers.

**Md. Anwar Hossain**, Consultant, Psychiatry, Jessore General Hospital, Jessore, Bangladesh; **Ahsan Aziz Sarkar**, Assistant Registrar, Psychiatry, National Institute of Mental Health (NIMH), Dhaka, Bangladesh; **Fatima Zohra**, Assistant Professor, Uttara Adhunik Medical College, Dhaka, Bangladesh; **Md. Mamun Al Mujahid**, Assistant Professor, Psychiatry, TMSS Medical College, Bogura, Bangladesh; **Md. Shohedul Alam**, Consultant, Psychiatry, Islami Bank Medical College Hospital, Rajshahi, Bangladesh; **Afroza Rahman Lopa**, Medical Officer, NIMH, Dhaka, Bangladesh.

**Correspondence:** Md. Anwar Hossain, Consultant, Psychiatry, Jessore 250 Bed General Hospital, Jessore, Bangladesh.  
Email: anwar.bdj78@gmail.com

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