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### **Original Research Article**

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# Assessment of burden among caregivers of cognitively impaired elderly, residing in an urban area of North Karnataka: a cross sectional study

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#### **ABSTRACT**

**Background:** The population of elderly is on the rise with estimates of 8.8% in urban area. Increase in the number of nuclear families, specially in the urban areas the elderly have been experiencing multiple morbidities, predominantly dementia and the burden associated with the caregivers of such elderly is enormous. Thus the study was undertaken to assess the burden of the caregivers of cognitively impaired elderly, residing in an urban area.

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**Methods:** It was a Cross sectional study in an Urban Health Centre, field practice area, of JN Medical College, KLE University, Belagavi of North Karnataka from 1<sup>st</sup> January to 31<sup>st</sup> December 2012. Among the 783 elderly, >60 years, assessed for cognitive impairment using Mini Mental State Examination/Hindi Mini Mental State Examination for literate /illiterate respectively, 55 elderly were cognitively impaired (MMSE/HMSE score<25). Caregivers of these 55 elderly who were permanent residents of the field practice area (Residing for one year with demented elderly) were interviewed using Zarit Caregiver Burden Scale (ZBI) to assess for emotional, financial, social burnout.

Results: 22 (40.00%) Caregivers were males and 33 (60.00%) were females.

07(12.73%) had studied up to primary school, 15 (27.27%) up to high school, 24 (43.64%) up to Pre-university degree 01(1.81%) had completed diploma and 8(14.55%) caregivers were graduates. 16 (29.09%) of them had a ZBI scale score between 21 to 40 (mild to moderate burden), 38 (69.09%) scored between 41 to 60 (Moderate to severe burden) and 1 (1.82%) scored between 61-88 and experienced severe burden.

**Conclusions:** Majority 60.0% of the caregivers were women in the productive age group of 21-40 years. Had to take the dual responsibility of care-taking and working plus raising up their children. The caregivers of cognitively impaired elderly, majority of them experienced a lot of physical, emotional, psychological stress and strain. Maximum of the caregivers were over taxed with responsibilities and felt that all responsibility fell on one caregiver (dependence burden).

Keywords: Cognitively impaired elderly, Caregivers, Burden

#### INTRODUCTION

Ageing is a universal phenomenon and the population of elderly is on the rise, with current estimates of 8.8% in urban areas in developing areas. With the increase in the number of nuclear families especially in the urban areas the senior citizens have been experiencing lot of age

related morbidities predominant being Alzheimer's dementia and the burden associated with the caregivers of such patients is enormous.

#### **Objective**

To assess the burden of the caregivers of cognitively impaired elderly, residing in an urban area.

#### **METHODS**

It was a cross sectional study conducted from 1<sup>st</sup> January to 31<sup>st</sup> December 2012 in an Urban Health Centre, field practice area of Department of Community Medicine, of JN Medical College, KLE University, Belagavi of North Karnataka. 783 elderly aged 60 years and above were screened with mini mental state examination/Hindi mini mental scale examination and among the 783 elderly screened with MMSE/HMSE, 55 elderly had cognitive impairment (MMSE/HMSE score <25).<sup>2-6</sup>

Caregivers are relatives or friends who provide a wide range of unpaid care to dependent children, spouses, parents, siblings, other relatives, friends and/or neighbors. Caregiving includes:

- Practical assistance with basic activities of daily living (e.g. housekeeping, shopping, meal preparation)
- Personal care (e.g. help with monitoring medication, bathing)
- Physical help (e.g. assistance with movement, supervision, direct medical care)
- Emotional and social support (e.g. visiting transportation, talking about emotions)
- Finding and accessing services (e.g. housing, medical supports)
- Behavioral support (e.g. communicating effectively, managing challenging behaviors)
- Financial help (e.g. financial support, managing finances).

Caregivers who spent at least six hours with the elderly permanently residing with them were assessed for emotional, financial burden and burnout using Zarit caregiver burden scale.<sup>8</sup>

#### Inclusion criteria

Caregivers of >60 years age, cognitively impaired elderly, with MMSE/HMSE score <25, who were permanent residents of the field practice area, residing with the elderly for >1 year.

#### Data collection

After obtaining institutional ethical clearance, a predesigned, pretested questionnaire was used to assess the socio-demographic details of elderly were also assessed for cognitive impairment using mini mental state examination/ Hindi mini mental state examination (MMSE/HMSE) for literate/illiterate elderly respectively. MMSE includes domains that assess cognition with respect to orientation, registration, attention, recall and language and visio-spatial orientation. Total score for all the domains is 31. MMSE/HMSE scores of 25 and above are no cognitive impairment. Scores 20-24 are mild cognitive impairment and MMSE/HMSE Score <19 is

severe cognitive impairment. Among those demented elderly (n=55) their caregivers were interviewed. Caregivers of the 55 cognitively impaired elderly (MMSE/HMSE score <25) were interviewed using Zarit Caregiver Burden Scale to assess for emotional, financial, social burnout. The variables assessed in caregiver burden scale were the following domains as mentioned in (Table 1). Each variable was assessed as per scoring system 0= never, 1= once in a while, 2= sometimes, 3= nearly always, 4= always. A Total score of 0-20=No or minimal burden, scores 21-40=mild to moderate burden, score of 41-60= moderate to severe burden and a score of 61-88 would indicate severe burden.

#### RESULTS

Among the caregivers 22 (40.00%) of them were males and 33 (60.00%) were females. Majority of the caregivers 46 (83.64%) were among the productive age group of 31-40 years. The mean age±SD of the male caregivers was 39.7±6.6 years with median 39.5 years and the range was 30-56 years. The mean age±SD of the female caregivers was 33.6±8.0 years with median 34 years and the range was 23 to 62 years.

With respect to the relationship of cognitively impaired elderly with caregiver, 23 (41.83%) of the caregivers were daughters, 22 (40.00%) were sons, 09 (16.36%) were daughter in law, and 01 (1.81%) was a spouse of the demented elderly. 24 (43.63%) of the caregivers have a literacy status up to pre university grade, 15 (27.27%) up to high school grade, 08 (14.54%) were graduates, 07 (12.73%) had literacy level of primary school grade and 01 (1.81%) caregiver was a diploma graduate. As regards of the occupation of the caregivers, 23 (41.82%) were homemakers who spent majority of their time in taking care of the cognitively impaired elderly and doing their household activities. 20 (36.36%) of the caregivers were employed in private firms, and 12 (21.82%) were working in government set up. With respect to the variables in ZBI, a major portion 29 (52.72%) of caregivers felt that they were overtaxed with responsibilities and that they had no enough time for themselves. 39 (70.90%) of the caregivers were uncertain as to what to do to their relative. A vast majority 49 (89.09%) of caregivers experienced emotional and social burden. A major portion 32 (58.18%) of caregivers social life i.e. relationship with their family and friends was affected. Majority 23 (41.81%) of the caregivers felt that responsibility of caretaking fell on one caregiver. Of the total number of caregivers assessed by ZBI,

16 (29.09%) of the caregivers had a ZBI score of 21 to 40 (mild to moderate burden), 38 (69.09%) scored 41 to 60 (Moderate to severe burden) and 1 (1.82%) caregiver had a score of 61-88 and experienced severe burden.

Majority of the caregivers were women in the productive age group of 21-40 years. This study's findings reminds us of the multiple roles a woman has to play in her daily

routine: prepare food, get ready for work, get the children ready for school, look after the house, husband and the elderly at home including their medications and yet have are expected to have a smiling face and a positive attitude. These women had to take the dual responsibility of caretaking and working plus raising up their children. A nuclear family and a competitive lifestyle forces a working woman who is also playing a role of a caregiver to devote little time to the elderly and experience burden in various forms as compared to the women in the previous generations where non-working homebound

caregivers had more time for caregiving and lesser burden than today. Of the 55 Caregivers of demented elderly 38 (69.09%) of caregivers experienced moderate to severe burden, 16 (29.09%) experienced mild burden and 01 (1.81%) experienced severe burden (Figure 1). The caregivers of these demented elderly experienced a lot of physical, emotional, psychological stress and strain. Maximum of the caregivers were over taxed with responsibilities and felt that all responsibility fell on one caregiver (dependence burden).

Table 1: Variables assessed in caregiver burden scale.9

Zarit caregiver burden scale details	Variables assessed
General feeling	Overtaxed with responsibilities, No time for self, Lost control of your life.
Caring for elderly	Uncertain about what to do for their elderly, Wish to do more for your relative, Could do a better caring job.
How often does the caregiver feel	A sense of strain, Anger, Embarrassment, Uncomfortable to have friends around.
Caring for your relative negatively impacts	Your social life, your privacy your social life, your relationship with friends and family.
How often does one feel	The elderly is asking for excessive help requests, Fear regarding the future of their relative, Fear of not having enough money for caregiving, Discontinuing caregiving, wish to give the Responsibility to someone else.
How much does the spouse depend on	On caregiver for their caregiving.

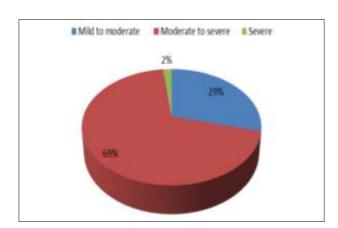


Figure 1: Zarit caregiver burden scale score.

#### **DISCUSSION**

Our study had 60% of the women caregivers similar to an international study by Lund, revealed that 61% were female caregivers. <sup>10</sup> In terms of schooling, most caregivers had high school and pre-university level of education, i.e. an average educational level which would fetch them a job of a very meager salary with lot of workload and hence are more likely to dedicate themselves to housework and care activities. Regarding

the caregivers' ages, the mean age±SD of the male caregivers was 39.7±6.6 years with median 39.5 years and the range was 30-56 years. The mean age±SD of the female caregivers was 33.6±8.0 years with median 34 years and the range was 23 to 62 years. The average burden was 69% of caregivers experienced moderate to severe burden (ZBI score 41-66), 29% experienced mild burden (ZBI score 21-40) and 2% experienced severe burden (ZBI score 61-88). International studies, which utilized the ZBI and addressed caregivers of older adults with dementia, found higher averages, such as the prospective study carried out in Spain. 11 It analyzed the ability of ZBI to identify exhaustion in 66 caregivers of older adults with dementia and risk factors of caregiver burden and found an average of 74.6 (severe burden). In a prospective study at a geriatric service in Ottawa, Canada, which evaluated 141 elderly individuals (76.6% with dementia), ZBI was used and found average scores of 31.3 (mild to moderate burden). 12

#### **CONCLUSION**

Increased caregiver burden is observed in morbidities like cognitive deficit caused by dementia. The more the decline in cognition more is demand for care, thus overloading the caregivers' responsibilities.

#### Recommendations

Responsibility of caregiving should be shared equally among all the household members to ease the burden on one caregiver. Establishing rehabilitative services such as old age homes, preventive geriatric clinics, geriatric clubs and easy accessibility of pension schemes to the elderly to prevent economic dependence is the need of the hour.

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Institutional Ethics Committee

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