



To study the caregiver burden in the caregiver's of dementia patients.

KEYWORDS

Caregiver stress, Dementia, Zarit Burden Interview

Dr Wilson Benny Paul

Assistant Professor, Dept of Geriatric Medicine,
Christian Medical College, Vellore, India

Dr T Murari

Assistant Professor, Department Of Internal Medicine,
Armed Forces Medical College, Pune, India

Dr Vivek Aggarwal

Assistant Professor, Department Of Internal Medicine,
Armed Forces Medical College, Pune, India

Dr Sandeep Kumar

Assistant Professor, Department Of Internal Medicine,
Armed Forces Medical College, Pune, India

Dr I V Nagesh

Assistant Professor, Department Of Internal Medicine, Armed Forces Medical College, Pune, India

ABSTRACT

With the rise in geriatric population there is rise in the patients with dementia also. Dementia is often degenerative and relentlessly progressive and required continuous monitoring, care and attention by the caregiver. Caregivers of the dementia patients are often ignored as maximum attention is taken by the patients. Care giving is a very stressful and demanding job and predisposes the caregiver to tremendous caregiver stress which in turn can lead to impairment in the health of the caregiver. Caregiver is often called as a hidden patient. In our study we have seen that more than 90% of the caregivers have moderate to severe caregiver stress as assessed by Zarit Burden Interview (ZBI) and almost 64% has associated comorbidities which can impair their health

Introduction: - Dementia is a common problem in the elderly with the prevalence increasing with the age approaching almost 20-40% in patients above 85 years of age (1). According to the statistics of National institute of aging the oldest old (> 80 years) is the fastest growing segment of population around the world including developing countries like India and China. Thus, the number of patients with dementia are likely to rise exponentially in the near future. The vast majority of cases of dementia are degenerative or vascular in nature and are usually relentlessly progressive with few therapeutic measures for treatment available, and requires continuous monitoring, care and support. Caregiving for a dementia patients is a continuous job without any respite and is often very stressful and tiring. Caregiver stress is very common and poorly studied in the developing countries like India. Most of the dementia patients are taken care by their family members. One survey revealed that persons with Alzheimer's disease required an average of 70 hours of care per week, with 62 of those hours provided by the primary caregiver (2). As per recent report of US Alzheimer's society it was noted that in 2014, more than 15 million family members and unpaid caregivers provided an estimated 17.9 billion hours of care to people with Alzheimer's disease and other dementias leading to contribution valued at more than \$217 billion (3). It has been seen that the caregivers of dementia patients has higher levels of stress than caring for patients with other disabilities or chronic illnesses(4). Caregiver is addressed as a hidden patients as he is predisposed to number of diseases due to stress of the caregiving. Numerous tools and questionnaires have been designed to quantify the caregiver stress. Zarit Burden Interview (ZBI) is the most widely referenced scale in studies of caregiver burden (5). ZBI is a 22 questions scoring index with a maximum score of 88. Each question has varying severity of stress ranging from grade 0-4. The scoring can be indexed and the caregiver burden can be assessed as no or minimal caregiver stress, mild stress, moderate stress or severe caregiver stress. It is important to identify the caregiver stress early as proper education of the caregiver and respite care can cause reduction in the caregiver stress which will be beneficial for the caregiver in a long run. In our study we planned to assess the caregiver stress with a validated ZBI in the caregivers of the diagnosed patients of dementia as per DSM IV attending the outpatient department (OPD).

Aim: To study the caregiver stress burden by ZBI in the primary caregivers the dementia patients across various forms of dementia

attending the OPD.

Objectives

- 1.To estimate the caregiver stress burden by ZBI.
- 2.To study the distribution of the caregiver burden across various dementias.
- 3.To assess the co-morbidities in the caregivers of the dementia patients

Study Design:- Cross sectional observational study done in the primary caregivers of the elderly population with dementia attending the OPD between May 2013 to Aug 2016.

Inclusion Criteria:-

- (a)Primary caregiver of the diagnosed patients with dementia as per HMSE score of ≤ 24 attending OPD
- (b) Caregiver is residing in the same house as the patient and is providing caregiving services including assistance in activities of daily living to the patient

Exclusion Criteria:-

- (a) Caregiver staying in the house other than the patient.
- (b) Caregiver providing only part time services

Duration of Study:- May 2014 to Aug 2016

Material and Methods

All the dementia patients attending the OPD along with their primary caregivers were taken into the study. The caregiver was screened for the existing co-morbidities and caregiver stress by a validated ZBI questionnaire which was administered by a trained health assistant as per the proforma. Probable cause of dementia was assessed as per the OPD follow up card of the dementia patient and with a detailed history, clinical examination, neuro-imaging and relevant investigations as available with the patient. All the caregivers underwent blood pressure monitoring and basic investigations including hemoglobin, urine routine examination, blood sugar fasting and post prandial and serum creatinine. Caregiver stress was classified as mild, moderate to severe and very severe stress depending upon ZBI score. All patients were educated about the coping up skills to overcome and reduce the caregiver stress and the associated co-morbidities were treated.

Results

Total 200 caregivers of the patients with diagnosed dementia with HMSE score ≤ 24 were taken from the OPD. The average age of the caregivers was 47.2 years with 54.5% females and 45.5% males. It was also noted that in 99.5% of the patients the primary caregiver was a family member. Spouse acted as a primary caregiver in 56% of the cases followed by son, daughter in law and daughter. Caregiver stress had a linear relation to the duration of dementia and presence of neuropsychiatry symptoms. The mean value of the caregiver stress as assessed by ZBI was 59.94 suggesting moderate to severe stress. The caregiver stress was much more in the caregivers of the patient's with dementia with lewy bodies (DLB) and dementia with vitamin B12 deficiency. The difference in the caregiver stress was statistically significant across various dementias with highest caregiver stress in patients with DLB. Spouse acted as a primary caregiver in 55% of the cases. It was also noted that caregiver stress was less if the caregiver was the spouse of the patients with a mean score of 57.33 as against the score of 63.40 when the caregiver is other than the spouse of the patient. Fifty six percent (112/200) of the caregivers were found to have raised blood pressure ($> 140/90$ mm of Hg) and 34 patients had diabetes and 15 impaired glucose tolerance. Sixty seven caregivers were already known case of hypertension on regular medicines whereas 45 patients were freshly diagnosed. Among the caregivers with diabetes 15 were freshly diagnosed and 19 were on regular medicines. Two patients had deranged renal function out of which one was a old diagnosed case of CKD. 64% of the caregivers were found to have some disease or the other and with 22.5% (55/200) newly diagnosed hypertension, diabetes and renal dysfunction out of which 5 patients had both diabetes and hypertension and one patient also had deranged renal parameters also.

Table 1. Profile of Caregiver's of Dementia patients

	n= 200	
Age in yrs	Mean	:47.2 \pm 6.2
ZBI score	Mean	:59.94 \pm 10.84
Diabetes mellitus		34 (17%)
Impaired Glucose Tolerance		15 (7.5%)
Hypertension		112 (56%)
Systolic blood pressure (mm of Hg)	Mean	: 157 \pm 13
Diastolic Blood pressure(mm of Hg)	Mean	: 99 \pm 13
Renal Dysfunction		2 (1%)
Renal Dysfunction		2 (1%)

Table 2:- Mean ZBI core in the caregivers of dementia patients across various dementias

Type of Dementia	Mean ZBI Score in the caregiver
All dementias	59.94 \pm 10.84
Alzheimer's Disease	56.35 \pm 10.06
Vascular dementia	58.53 \pm 10.87
Parkinson's related dementia	62.09 \pm 9.42
Dementia with Lewy bodies	73.94 \pm 4.49
Dementia with B12 deficiency	62.4 \pm 8.07

Table 3: Severity of caregiver stress in various types of dementia

ZBI Score	Number of Patients (n=200)
21-40 (mild caregiver stress)	9 (4.5%)
41-60 (moderate caregiver stress)	83 (42.5%)
> 60 (severe caregiver stress)	108 (54%)

Discussion

Caregivers have been described as "hidden patients" (4, 6). Family physicians should identify these caregivers through a detailed family and social history. Caregivers should be assessed for their level of perceived burden and for the presence of affective disorders such as depression and anxiety. In addition, family physicians should assist caregivers with coping strategies, counseling them about ways to

handle behavioral management issues that arise during the course of dementia. One study revealed that anxiety was present in 17.5 percent of caregivers, compared with 10.9 percent of subjects in a matched control group (7). This is also corroborated by increase use of psychotropic drugs in the caregivers. When compared with persons who are not in a care giving role, caregivers perceive their own health status to be lower (8). It has been shown that the immune functions in the caregivers is impaired with reduced cellular immunity than the controls and thus viral illnesses tends to last longer in these caregivers.(9). A landmark study of caregiver health revealed that elderly spousal caregivers who experienced caregiver strain had a mortality risk that was 63 percent higher than that in control subjects(10).In our study 62% of the caregiver was found to have one or more comorbidity. Psychological assessment of the caregiver was not done in our study hence anxiety and depression could not be commented upon. Majority of the caregivers were family members emphasizing good social support system in the study population. It was noticed that spouse acted as a caregiver in 57% of the cases. It was also noted that caregiver burden as assessed by ZBI was much less if the primary caregiver was spouse (57.33 vs 63.40). It was noted that in 55% of dementia patients, the primary caregiver was a female. This was in accordance with the Indian study done by Emmati and Bhatti where majority of the caregivers were women (wives, daughters, and daughters-in-law) in 70% of dementia cases (11). In our study noted that the majority of caregivers had moderate to severe caregiver stress as assessed by ZBI with a mean score of 59.94. Similar findings were seen in the study done by Pattnayak and Jena, where the caregivers had moderate to severe caregiver stress and the stress was more in patients with behavioural and psychiatric symptoms (12). In our study also the caregiver stress was maximum in patients with DLB where behavioral and psychiatric symptoms were prominent. The limitation of the study was that these caregivers were not assessed for presence of depression and anxiety and were not followed up to see the long term effects of the caregiving.

Conclusion

It was noted that more than 90% of the caregivers of the dementia patients had moderate to severe caregiver stress. Caregiver stress was maximum in the patients with DLB. Sixty four percent of the caregivers had associated co-morbidities out of which 22.5% were freshly diagnosed. Hypertension was the commonest co-morbidity followed by diabetes. The caregivers of dementia patients are the hidden patients who are often ignored. It is important to assess the health and caregiver stress of the caregiver also along with the patient of dementia. This will help to reduce the caregiver stress and early recognition and optimal management of physical and psychological abnormalities in the caregiver.

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