

CAREGIVER BURDEN AMONG CAREGIVERS OF DEMENTIA PATIENTS IN SOUTHERN INDIA

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Abstract

Background: Dementia is a disease which is more common among older people and contributes to a significant proportion of Years Lived with Disability. Care giving is associated with significant adverse impact on care giver physical and mental health. This care giver burden which was exceeding the capacity of care giver, put them more vulnerable to development of depression. **Materials and Methods:** The present study was conducted in Department of Neuroscience, Government Stanley medical college. In the present study 40 caregivers of cancer patients were included in the study. Assessment of Caregivers' burden was assessed using the Zarit Burden Interview (ZBI). **Result:** Age of the caregiver was analyzed and found that a majority were in 41-60 years age group. Among Dementia caregivers it was 45.0%. Among them, majority of the caregivers were female, married, belongs to nuclear family and urban population. According to Zarit Burden Interview scale, most of the caregivers were suffering from Caregiver burden. Among them, 70% had little burden, 12.5 % had mild Burden, 5% had moderate burden and 12.5% had severe burden. **Conclusion:** In caregivers, Caregiver Burden was higher among middle age caregivers, female, illiterate, low socio-economic status, nuclear family and urban population. These caregivers with Caregiver Burden were more prone for psychiatric comorbidities. The Psychiatric comorbidities has negative effects on quality of life of caregivers and also patients. To sustain this ever growing pool of caregivers, counselling centre to be suggested to set up in all Dementia care centres and appropriate interventions support group to be established so as to help the caregiver cope and deal with miserable multifaceted burden.

INTRODUCTION

India is one of the most populated countries in the world. Increased life expectancy (70.4 years in 2020) and access to quality healthcare has led to an increased geriatric population. It has been expected that the geriatric population would be around 20% of the country's total population. It is also expected that almost 15% of the global geriatric population would be from the Indian subcontinent.¹⁻³

Lee et al conducted a cross-sectional study to assess the prevalence of dementia at the state and national levels. In their study they had used the Harmonized Diagnostic Assessment of Dementia for the Longitudinal Aging Study in India (LASI-DAD). They have reported that almost 8.8 million Indians aged above 60 years had been diagnosed with dementia. They also observed that there was an uneven distribution in the prevalence of dementia across different states. They had suggested tailor

made interventions in the form of planning and support to face the increasing burden of dementia.⁴ Increasing prevalence of dementia has in turn increased the requirement of care givers and health professionals. Dementia patients need for care increases with increasing duration of disease. As the disease worsens, they rely on the primary care givers for carrying out their routine day to day activities.⁵⁻⁷ The care givers are in turn forced to make some compromises and sacrifices in their personal and professional life. These sacrifices in turn severely affect the social, psychological, and physical aspects of Quality of Life (QOL) of the primary caregivers.⁸⁻¹¹ Studies have shown that the prevalence of depression and its associated symptoms are increasing among the caregivers of dementia patients. The caregivers of dementia patients often lack support and social contact this leads to social isolation which in turn leads to depression. Despite the increasing magnitude of the caregiver burden

among caregivers of dementia patients, very few reports are available to quantify the experienced burden. The present study was undertaken to assess the level of caregiver burden amongst caregivers of dementia patients.

MATERIALS AND METHODS

The present study was conducted in Department of Neuroscience, Government Stanley medical college. It is a tertiary care institute where patients come northern part of Chennai, Thiruvallur District and southern districts of Andhra Pradesh. The present study included 40 Caregivers of patients satisfying ICD- 10 criteria. The present study was carried out for a period of 6 months. The study included consenting care givers aged between 20 to 85 yrs. Caregivers with the family history of psychiatric illness, history of Substance abuse and history of suicide attempt were excluded from the study.

Study Procedure

After obtaining informed consent from patients and their caregivers, socio-demographic details, family history details and a semi structured clinical profile of Caregivers were collected using a semi structured questionnaire. Assessment of Caregivers' burden by Zarit Burden Interview (ZBI).

The Zarit Burden Interview, is a caregiver self-report tool employed for assessment of caregiver burden. The original version has 29 items of questions which was evolved by Zarit in 1980. The revised version by Bedard contains 22 items. Each item on the interview is an expression in which the caregiver is asked to endorse using a 5 point scale. It is the instrument most commonly used in dementia care giving research and by clinicians in usual practice to measure the change over time resulting from interventions aimed at decreasing the burden.14-16

RESULTS

Socio-Demographic profile

In the present study majority of the caregivers were female (87.5%), while male constituted only 5 (12.5%) study participants. Majority (45%) of the caregivers were in the 4th and 5th decade of their life, 35% of the study participants were above 60 years. In the present study, participants aged less than 40 of age constituted 20% of the study population. Majority of the study participants were married (90%) while divorced and widowed participants each constituted 5% of the study population. Among the caregivers, 77.5% belonged to nuclear families, while those from joint family constituted 22.5% of the study participants. In this study, the caregivers from urban areas were 62.5% of the study population while 37.5% were from rural background. The details of educational background of the caregivers showed that 32.5% of the study population were illiterate. Study participants educated up to Middle school (40%), High/Hr sec school (22.5%) and Graduates (5%) were also in the study.

Care givers characteristics

Relationship of the caregivers was recorded in the present study. We observed that majority (52.5%) of the study participants were spouses of the dementia patients. Children of the dementia patients constituted 20% of the caregivers in the present study. Siblings and either daughter-in-law or son-in-law each constituted 5% and 20% of the study participants respectively. Majority of the caregivers had given care for less than a year (52.5%). In our study, we found that 7.5% of the study participants had given care between 5 to 10 years, while those who were care givers for 1 to 5 years constituted 40% of the study population.

Degree of care giver burden

In the present study we used the Zarit Burden Interview to assess the caregiver burden. We observed that Mild burden was experienced by 12.5% of the study participants. Moderate burden was observed in 5% of the caregivers of dementia patients. Severe burden was experienced by 12.5% of the study population. We had observed that 70% of the study participants reported to have experienced little or no burden.

Table 1: Socio-Demographic Characteristics of the study participants (n=40)

	Frequency (n=40)	Percentage
Gender		
Male	5	12.5
Female	35	87.5
Age of the caregiver		
≤ 40 Yrs	8	20
41-60 Yrs	18	45
Above 60 Yrs	4	35
Marital status of care givers		
Unmarried	0	0
Married	36	90
Divorced	2	5
Widowed	2	5
Type of family		
Nuclear family	31	77.5
Joint family	9	22.5
Locality		
Rural	15	37.5

Urban	25	62.5
Educational status of caregivers		
Illiterate	13	32.5
Middle school	16	40
High/Hr sec school	9	22.5
Graduates	2	5

Table 2: Care givers characteristics of the study participants (n=40)

	Frequency (n=40)	Percentage
Relationship to the patients		
Siblings	2	5
Spouse	21	52.5
Daughter/Son	8	20
Daughter/son -in-law	8	20
Others	1	2.5
Duration of care given		
5-10 years	3	7.5
1-5 years	16	40
less than 1 year	21	52.5

Table 3: Degree of burden in ZBI scale of care givers of Cancer patients

	Frequency (n=40)	Percentage
Zarit Burden Interview Scale		
Little/No burden	28	70
Mild burden	5	12.5
Moderate burden	2	5
Severe burden	5	12.5

DISCUSSION

Caregiver distress and burden are suggestive of prolonged poor physical and emotional health. Caregiver burden drastically affects the physical, mental and social parameters of the quality of life of both the patient as well as the caregiver. The present study was undertaken among 40 caregivers of dementia patients to assess the burden of caregiving. In the present study the burden encountered by the caregivers was assessed using the Zarit Burden Interview.

In the present study majority of the caregivers were female (87.5%), Majority (45%) of the caregivers were in the 4th and 5th decade of their life, Majority of the study participants were married (90%) Among the caregivers, 77.5% belonged to nuclear families, Anantharamu et al in their study have reported similar findings.^[17]

Our results showed that caregivers from urban areas were 62.5% of the study population. The details of educational background of the caregivers showed that majority of the study participants were educated up to Middle school (40%) Studies conducted by Anantharamu et al,^[17] and Rosdinom et al,^[18] have also reported that majority of the caregivers were settled in urban areas and educated.

The relationship status of the caregivers showed that majority of the study participants were spouses of the dementia patients while other care givers were immediate family members of the patients. Similar findings were reported by Srivastava et al,^[13] Anantharamu et al,^[17] and Pattanayak et al.^[18] Kim et al had described the role of families in the caregiving process as a result of strong cultural and traditional structure prevailing in the Asian countries.^[19,20]

Pattanayak et al in their study had reported moderate degree of burden among the caregivers of dementia patients.^[19] Srivastava et al,^[13] and Burns et al,^[21] had reported that caregivers experienced mild to moderate burden. These studies have also suggested that burden associated with care giving increases exponentially with the progression or worsening of the disease. Our results have shown that the care givers have experienced mild and moderate burden. Majority of the caregivers had not reported any burden, this could be attributed to the fact that majority of the caregivers had undertaken this role for less than 5 years. Longer follow-up studies could be useful in determining the role of progression of the disease with the increased caregiver burden.

CONCLUSION

Increasing incidence of dementia has in turn increased the need for caregiving. It is essential that the needs of the caregivers are met. It is empirical to ensure the burden of the caregivers be eased. This in turn leads to better quality of care provided and better quality of life of both the caregiver and the patient. Periodic screening, counselling and the creation of self-help groups would be instrumental in easing the burden encountered by the caregivers.

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