



## CAREGIVERS BURDEN AMONG CAREGIVERS OF DEMENTIA PATIENTS

Dr. D. Punithavathi

M.D. Psychiatry, Assistant Professor, Department of psychiatry Govt Villupuram Medical College Hospital, Villupuram.

Dr. D. Bhuvaneswaran\*

M.D. Psychiatry, Assistant Professor, Department of Psychiatry, Government Nagapatnam Medical College, Villupuram. \*Corresponding Author

## ABSTRACT

Caregivers burden among caregivers of dementia patients **Introduction** 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. **Aim Of The Study** To analyse the caregivers' burden in caregivers of people suffering from dementia. **Materials And Methods** The sample is drawn from female or male Caregivers of patients of dementia in the age group of 20-85 years attending the Outpatient Psychiatry department, Neuro medicine department at Government Stanley Hospital, Chennai. including not less than 40 Caregivers of patients with Dementia but consecutive sampling. Socio demographic details were obtained using semi-structured proforma. Assessment of caregiver burden in caregivers was done using Zarit Burden Interview. **Results:** Age of the caregiver was analysed 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 Socioeconomic 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 centers and appropriate interventions support group to be established so as to help the caregiver cope and deal with miserable multifaceted burden.

**KEYWORDS :** Dementia, Caregivers burden

## INTRODUCTION

Population ageing is an upcoming public health challenge, because of an increase in the number of older people in the global population. This is due to the direct consequence of declining ongoing global fertility transition and of declining mortality at older ages. Population ageing is expected to be among the noticeable prominent global demographic trends currently.

Population ageing has consequences on socioeconomic and health domains, including the increase in the elderly age dependent ratio. Older people especially who are in eighties and nineties have more prevalence of neuropsychiatric disorders. In them, many older people require assistance from other persons, even for basic activities of daily living. Dementia is a disease which is more common among older people and contributes to a significant proportion of Years Lived with Disability.

Non communicable diseases like dementia which are associated with significant disability do not get adequate support and care from health care services. It remains concealed problem due to widespread low public health awareness. These are not commonly met in primary care setting though they may be extensive in the community. People with dementia generally require high level of care, which are usually cared by the family members, those are called unpaid family or informal care givers. Most of the caregivers are women, and other family members. For dementia they have to give long term care, so it is associated with significant burden to the caregiver. 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. Dementia causes three types of symptoms: losses in cognitive capacity, difficulties in performing basic and instrumental activities of daily living and changes in mood or personality

and decline in interpersonal functioning. Dementia can be further divided into reversible and irreversible types. Reversible dementia can be caused by factors including depression, cerebrovascular disease, reactions to medications, normal pressure hydrocephalus, brain space occupying lesions, environmental toxins, nutritional deficiencies, infections, inflammatory illness and other metabolic disorders. Irreversible dementia may be caused by factors including Alzheimer's disease, vascular disease, parkinson's disease, head trauma & inheritable background. The other rare causes of dementia include renal failure, chronic excessive use of alcohol or other substances, hepatic failure, and cardiopulmonary disorder.

## MATERIALS AND METHODS

## Study Setting

The study was conducted at psychiatry/ neuromedicine/ outpatient department at government Stanley medical college hospital, Chennai. It is a tertiary care institute where patients come northern part of Chennai, Thiruvallur District and southern districts of Andhra Pradesh.

## Study population

The sample is drawn from female or male Caregivers of these patients of dementia attending the Outpatient Psychiatry department, Neuro medicine department department at Government Stanley Hospital, Chennai.

study, including not less than 40 Caregivers of patients with Dementia.

**Duration of study:** 6 months.

## Inclusion Criteria

1. Caregivers of patients satisfying ICD- 10 criteria for Caregivers of patients diagnosed to have dementia.
2. Participants to be willing to provide informed consent for

- the interview and assessment.
- 3. Patients willing to allow Caregivers to be assessed.
- 4. Caregivers aged from 20- 85 yrs were taken.

**Exclusion Criteria**

- 1. Those patients and caregivers who did not give their consent.
- 2. Refusal to allow spouse to be evaluated.
- 3. Caregivers with the history of Substance abuse and with the history of suicide attempt/ attempts or previous psychiatric symptoms and interventions.
- 4. Caregivers with the family history of psychiatric illness.

**Variables Studied**

Socio economic variables- Age, Sex, Religion, Family type, Marital status, Education, Occupation, Monthly income. Clinical variables- chronic illness, caregiver burden.

**Study Procedure**

- 1. After obtaining informed consent from patients and their caregivers attending the Psychiatry, Neuromedicine OPD, they will be interviewed and assessed using various scales. Data will be recorded for this purpose.
- 2. Information is obtained from caregivers.
- 3. Socio demographic and medical details will be obtained using semi structured questionnaire designed for this study.

**Instuments Used**

- 1. A semi structured pro-forma to collect the socio demographic details, family history details and a semi structured clinical profile of Caregivers.
- 2. Assessment of Caregivers' burden by Zarit Burden Interview ( ZBI).

**Zarit Burden Interview**

The Zarit Burden Interview, is a popular caregiver self report measure employed by many aging agencies. The original version has 29 items of questions which was evolved by Zarit in 1980. The revised version by Bedard in 2000 which contains 22 items. Each item on the interview is an expression in which the caregiver is asked to endorse using a 5 point scale. The response options range from 0(never) to 4(nearly always). The score range from 0 to 68. The score 0 to 21 indicates little or no burden, score 21-40 indicates mild to moderate burden., score 41-60 indicates moderate to severe burden and the score 61-68 indicates severe burden. 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. The scale has two factor model, one is personal strain and the other one is role strain. The reliability and validity of this scale was tested by Herbert, Bravo and Previlke in 2000, concluded that it has good internal consistency, reliability, with a cronbach's alpha coefficient of 0.92. They also concluded that the score on this scale were unrelated to age, sex, language, locale, marital status or employment status, indicating the measure is appropriate for use with a variety of population. Scores were also significantly positively associated with behavioural and psychological severity in the older adult patients and depression scores of the caregiver, as studied by Center for Epidemiological studies Depression Scale.83.

Gender	
Male	5(12.5%)
Female	35(87.5%)
Age of the caregiver	
≤ 40 Yrs	8(20.0%)
41-60 Yrs	18(45.0%)
Above 60 Yrs	14(35.0%)
Marital status of care givers	
Unmarried	0(0.0%)

Married	36(90.0%)
Divorced	2(5.0%)
Widowed	2(5.0%)

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(40.0%)
High/Hr sec school	9(22.5%)
Graduates	2(5.0%)

Relationship to the patients	
Siblings	2(5.0%)
Spouse	21(52.5%)
Daughter/Son	8(20.0%)
Daughter/son -in-law	8(20.0%)
Others	1(2.5%)
Duration of caregiver given	
5-10 years	3(7.50%)
1-5 years	16(40.0%)
less than 1 year	

Degree of burden in ZBI scale of care givers of Dementia patients	
Little/No burden	28(70.0%)
Mild burden	5(12.5%)
Moderate burden	2(5.0%)
Severe burden	5(12.5%)

**DISCUSSION:**

**Sociodemographic Factors**

**Caregivers At Increased Risk Of Psychiatric Comorbidities**

Caregivers who are

- 1. Predominantly younger age and female.
- 2. Low socio economic status and low level of education
- 3. Who live with the patient such as spouses rather than the children of the patient
- 4. Who report poor relationship status with the patient
- 5. Who are unmarried or in short term marriage duration
- 6. Who report high levels of unmet needs for supportive care
- 7. Who report co morbid illness or destructive behaviour
- 8. Who use avoidant coping
- 9. Who feel less prepared for care giving and confident in their abilities
- 10. Who are caring for patients that are older, or at a later disease stage and patient with poor physical functioning
- 11. Who have high care giving demand
- 12. Who report high intensity of care
- 13. Who report lower levels of social support .

Care giving also appears to reduce a person's chance of being employed, many caregivers are unable to work, need to take leave without pay, fewer working hours, are in low paid jobs, or work from home to manage the caregiver demands.

Age of the caregiver was analysed and found that a majority were in 41-60 years age group. Among Dementia caregivers it was 45.0%.87.5% of the caregivers were female.

Among the caregiver for Dementia patients 36(90.0%) got married The study revealed 77.5% of Caregivers were from nuclear family and 22.5% were joint family.

The analysis on educational status of caregiver shows that illiterates were high among Dementia caregivers(32.5%). Dementia caregivers (22.5%) of them studied High/ Higher secondary education and 40% of them studied middle school education.

A higher proportion (65.0%) of them were unemployed. The analysis of relationship of caregiver to Dementia patient shows that 52.5% were spouses and 20% were son/daughters. The duration of caregiving less than one year was 52.5% among caregivers of dementia patients. Duration of care giving 1-5 years and more than 5 years was 40% and 7.5% respectively. The status of chronic illness was analysed and it was found that 35% of caregivers of dementia patients had chronic illness.

In Zarit Burden Interview, most of the caregivers found to have caregiver burden. Severe, moderate and mild burden among caregiver was 5%, 25.0% and 15% among caregivers of dementia patients respectively.

### Limitation

The caregiver sample was taken only from the hospital based patients, so the sample may be an over representation of caregivers than from the general population. Individual differences in caregivers like their personality, attitudes, cultural beliefs and ethnicity were not taken into account. The sample size was small and it was not community based sample. The pre exposure coping strategies and other domains of caregivers were not taken into account.

### CONCLUSION

Dementia is a debilitating illness worldwide, which is having comparable levels of dependence to family members, especially the primary caregivers. The study was aimed at analysing the caregiver burden among caregivers of dementia patients. Caregiver Burden was higher among middle age caregivers, female, illiterate, low Socioeconomic status, nuclear family and urban population. More than half of the caregivers had chronic illness.

Most of the caregivers of dementia patients had caregiver burden. Among them, approximately three-fourth had little caregiver burden, one-third had more caregiver burden.

Caregiver burden has negative effects on quality of life of caregivers and also patients. It may lead to psychiatric comorbidities like anxiety, depression, Adjustment disorder and so on. So assistance, psycho education and early intervention from health care professionals is the key to improve the quality of life of caregivers and hence the patients' quality of life.

### REFERENCES:

1. World Health Organization: world health statistics 2014 p 42. Available from: [www.who.int/gho/publications/world\\_health\\_statistics/2014/en](http://www.who.int/gho/publications/world_health_statistics/2014/en)
2. World Health Organization. The global burden of disease: 2004 update [internet]. Update 2008 p 40. Available from: [www.who.int/healthinfo/global\\_burden\\_disease/2004\\_report\\_update/en/index.html](http://www.who.int/healthinfo/global_burden_disease/2004_report_update/en/index.html)
3. Kaplan & Sadock. Comprehensive Textbook of Psychiatry, 9th edition.
4. 10/66 Dementia Research Group Population-based studies: Incidence phase, centre for global mental health.
5. Le Navenec C, Vonhof T. One day at a time: how families manage the experience of dementia. Westport, CT: Auburn house: 1996, 25-44
6. Cummings JL. The neuropsychiatric inventory: assessing psychopathology in dementia patients. *Neurology*. 1997;48:s 10-6
7. Schulz, R, O'Brien A.T., Bookwala J., & Fleissner K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *The Gerontologist*, 35(6), 771-791.
8. Patterson, T., Semple, S., Shaw, W., Yu, E., He, Y., Zhang, M.Y., et al. 1998. The cultural context of caregiving: A comparison of Alzheimer's caregivers in Shanghai, China and San Diego, California. *Psychological Medicine*, 28, 1071-1084.
9. Georges J, Jansen J, Meyrieux A, Sadowska A, Selmes M (2008). Alzheimer's disease in real life- the dementia carers survey. *Int J Geriatr Psychiatry* 5:551.
10. Belle SH, Burgio L, Burns R, Coon D, Czaja SJ, Gallagher-Thompson D, et al. (2006). Enhancing the quality of life of dementia caregivers from different ethnic and racial groups: a randomized control trial. *Ann Intern Med* 145:727-738.
11. Haung CY, Sousa VD, Perng SJ, Hwang MY, Tsai CC, Huang MH, et al. (2009). Stressors, social support, depressive symptoms and general health status of Taiwanese caregivers of persons with stroke or Alzheimer's disease. *J Clin Nurs* 18:502-511.
12. Hanan El-Shinnawy, Tamer Goueli and Mohamed Nasr, mar 2012, Emotional involvement and burden in caregivers of patients with Alzheimer's disease, p 150-157.

13. Baker K. L, & Robertson, N. (2008), Coping with caring for someone with dementia; reviewing the literature about men. *Aging and mental health*, 12, 413-422
14. Verma R & Anand K. 2012. Gender differences in anxiety and depression among the caregivers of patients with dementia. *Advances in alzheimers' disease*, 1, 17-21
15. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues in Neurosci*. 2009;11(2):217-228