

Cross Sectional Study of Burden in Caregivers of Patients with Dementia

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Abstract

Background: dementia is a progressive illness consisting of cognitive decline in multiple domains. It affects the quality of life of the patient as well as of the caregiver. Mental health of the caregivers is important as it will improve the quality of care given to the patients with dementia. This study was done to assess the various factors affecting the distress in caregivers of dementia. Sociodemographic profile of the caregivers was assessed by semi structured proforma and burden was assessed using the Zarit burden scale. Associations was found by Chi square tests and Anova. Significant associations was found between gender of the caregiver and burden.

Keywords: dementia, caregiver, caregiver burden

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Introduction

“Dementia refers to a disease process marked by progressive cognitive impairment in clear consciousness.” It involves multiple cognitive domains and cognitive deficits that cause impairment in social and occupational functioning.

It is seen that worldwide at least 50 million people are living with dementia.¹

By 2030, 20% of the population will be older than 65 years.² With the growing age of the population, more and more number of people are living with chronic disease which might need extensive family and professional care.^{3,4,5}

In 75% of cases, care is provided by family⁶ and friends. The major proportion of those caregivers are spouses⁷ and children,⁸ who are females.⁹

Dementia Research Group studied the caregivers of people living with dementia in China, South-East Asia, India, the Caribbean, Latin America and Nigeria. It was found that the characteristic of the caregiver was found to be similar and the number of female¹⁰ caregivers were found to be higher, spouse and children as caregivers were mainly found to be associated with the caregiving, followed by 11% of daughters-in-law (But in India daughter in law as caregiver was 24%¹⁰).

Individuals with dementia requires high level of care by informal or family caregivers. Devoid of caregivers, people having dementia will have a poorer quality of life and will need to be admitted to hospitals more quickly, and thus national burden of health care will increase. However, this support comes at a cost of caregiver distress and poorer quality of life.

Certainly, the effect of dementia is extensive and consequent social – economic health burden on the individual, family and society is immense.¹¹

Due to rising elderly population and successive higher prevalence of chronic illnesses which include dementia leads to the increased need for patient care.

Care for management of dementia has been considered either as ‘formal’ or ‘informal’ care. Formal care involves activities taken place in hospitals, social/community care, long term residential or nursing home care. Informal care includes voluntary care by family members of the diseased or others, who have been hired to take care of the diseased.¹²

In India, a greater part of caregiving is informal care particularly by family members. While formal care is relatively easier to cost, costing informal care poses several challenges for example absenteeism, loss of job, stress, Psychological problems.

Archbold¹³ gave a concept of caregivers and care managers. Caregivers are the ones who provide care on hands, dressing, assisting with daily activities and care managers are the ones who arrange for others to provide such care, such as a nurse for personal care, an accountant for assistance with finances. Usually the spouses tend to be the caregivers and adult children and other relatives tend to be the care managers.¹³ It is found that caregivers are more stressed than the care managers.

Studies have found that caregivers¹⁴ of dementia tend to have higher levels^[15] of burden than caregivers¹⁶ of other illness.

Due to these factors there is increased demand for caregivers. It has been seen that caregivers has both positive and negative experiences associated with the care giving for people living with dementia.¹⁷

Positive experiences and outcomes related to care giving like improved outlook on life, feeling useful or competent has been seen. While negative outcomes related to care giving have enormous physiological, psychological effect on caregivers like increased stress, family conflicts, decreased¹⁸ Quality-of-life, increased incidence of depression and anxiety. Few studies also pointed out that caregivers experience more physical illness, poorer immunity and in some cases increased mortality.

It has been found in various studies that since dementia is a long-term disease, care giving for dementia is the most stressful as compare to caregiving for other types of illnesses. The increased stressfulness is likely due to the fact that dementia disrupts the lives of patients and their families not only so completely, but also for extended periods of time.¹⁹ Caregivers face various problems as they have to look after their own families needs, and have to balance caregiving with other demands, which includes career, child rearing and relationships.²⁰ Thus caregivers are at more risk for various health problems and stress.

The caregivers conditions depends on following-

- Dependency of the person with dementia on the care givers for their basic day to day activity
- The level of behavioral disturbance
- The judgment of burden by the caretaker, which includes the assessment of the physical and emotional impact, their psychological state, and resources.
- Psychological morbidity–stress can manifest as psychological morbidity, including depression and anxiety. A robust relationship between dementia caregiving and negative effects on psychological has been demonstrated in numerous studies. Rates of depression vary between 23% and 85% in developed countries, and of anxiety between 16% and 45%. In the developing countries, psychiatric morbidity range from 40%-75%.

- Due to their commitment to the patients caregiver often lack social contact and support thus feel socially alone or isolated.
- In a meta analysis done by Schulz R *et al.*,²¹ in 2008 on Physical and Mental Health Effects of Family Caregiving. Results showed that dementia family caregivers to be significantly more stressed than non dementia caregivers and to suffer more serious depressive symptoms and physical problems.

Study done by Gaugler *et al.*,²² in 2009 showed that following placement of patients in nursing home, the caregivers reported significant increase in Burden and depressive symptoms. Caregivers who are heavily burdened may opt for institutionalization of the relative as a role exit, which in fact is associated with increased feelings of burden and depression in some caregivers following placement, along with adjustment issues and even early mortality of the relatives with dementia.

In 2010, study by Miyamoto *et al.*, who conducted a cross sectional study among the formal caregivers of dementia, found that disruptive behaviours such as aggression and screaming were significantly correlated with higher burden.

In a study done by Chang HY *et al.*,²³ in 2010, on impact of mental health and caregiver burden on family caregivers' physical health. Results stated that high number of hours of daily caregiving was related to low emotional support and, poor mental health and increase in weight. Higher emotional support was related with better emotional well-being and less sickness. Higher physical help was related with more poor psychological well-being, a more prominent number of sickness indications and ongoing infections. Lesser the number of hours of caregiving, and utilization of functional, emotional and physical help were related with psychological well- being.

Aims And Objectives

- 1) to assess the sociodemographic profile of the caregivers
- 2) To assess burden in caregivers
- 3) To find the association between sociodemographic profile and burden

Materials And Methods

1. Setting

The study was conducted at Institute of Psychiatry and Human Behaviour, Goa. It is a tertiary care psychiatry hospital in the state of Goa, having inpatient and outpatient facilities. The study sample was drawn from the patients attending OPD. Consecutive patients were approached for consent. Those who consented, were interviewed along with their caregivers, and scales were administered both on the patient and the caregiver. Data was collected for 85 patients.

2. Type of Study and Sample

A cross sectional descriptive study, a total sample of 100 were considered for the study, however due to Covid-19 pandemic the OPD attendance of patients were significantly reduced during the time period of March 2020

- June 2020 and a sample of 85 patients and caregivers was collected

3. Criteria

Inclusion Criteria

- Diagnosed cases of dementia using ICD-10 criteria presenting with caregiver.
- Caregiver consenting to participate.

Exclusion Criteria

- Informed consent not available.
- Intellectually disabled.
- Diagnosed psychiatric illness in caregivers.

4. Methodology

- Patients with their caregiver who attended Institute of Psychiatry and Human Behaviour OPD constituted the sample of this study.
- Consent to participate in the study was taken both from the patient and their caregiver.
- Interview time for each patient and caregiver was approximately 1 hour.
- Each patient and caregiver were interviewed separately.
- Sociodemographic data of the caregiver was recorded by using semi structured pro forma.
- Caregivers were evaluated for their distress using Zarit burden interview scale.
- The scales were converted to Konkani for patients and caregivers who did not understand English. In order to do the same the instruments used were translated by a professional translator from English to Konkani. The scales were then back translated to English.

5. Tools

THE ZARIT BURDEN CAREGIVER^{24,25}: The ZARIT burden interview, a popular caregiver self-report measure used by many ageing agencies, originated as a 29 item questionnaire (Zarit, Reeves & Bach-Peterson, 1980). The revised version contains 22 items. Each item on the interview is a statement which the caregiver is asked to endorse using a 5 point scale. Response range from 0 (Never) to 4 (Nearly always). Study done by Herbert et al., in 2000, scores on the ZARIT burden inventory were unrelated to age, gender, locale, language, living situation, marital status or employment status, indicating the measure is appropriate for use with a variety of populations. Scores were also found to be significantly positively correlated (<0.001) with behavioural problems in the older adult patients and depression scores of the caregivers. Translations of the ZARIT burden inventory have been studied as well, including versions in Chinese, French, Japanese and Portuguese.

Scale used in this study included 22 questions each with a likert scale ranging from

0-4 : Total score of each 22 questions was taken and interpreted as follows

0-21 : little or no burden

21-40 : mild-moderate

41-60 : moderate-severe

61-88 : severe burde

6. Statistical Analysis

- Data was entered into Microsoft Excel (Windows 7, version 2007) and analyses were done using the Statistical Package for Social Sciences (SPSS) for windows software (version 22.0; SPSS Inc, Chicago).
- Descriptive statistics such as mean and standard deviation for continuous variables were determined. Association between variables was analysed by using Chi-Square test for categorical variables.
- Comparison of mean between quantitative variables were analysed using ANOVA (analysis of variance).
- Level of significance was set at <0.05

7. Ethics

The approval of the ethical committee of Goa Medical College was sought prior to the commencement of this study.

Caregivers were explained about the study in their local language. The aims and objectives were informed and their queries were addressed. They were informed that the information given by them would be used for study purposes only and they could withdraw from the study at any time if they wished so.

Informed written consent for the interview and assessment was taken from the patient and their caregiver. Each interview was carried out after informed written consent was obtained from them.

The data collected was sorted in a secure manner. The names of the patients and caregivers were kept confidential.

Patients were offered treatment at the Institute of Psychiatry and Human Behaviour (IPHB).

Results

TABLE 1: Caregivers sociodemographic profile

		N	%
AGE (years)	20-30	12	14.1
	31-40	31	36.5
	41-50	15	17.6
	51-60	9	10.6
	61-70	12	14.1
	>70	6	7.1
GENDER	FEMALE	31	36.5
	MALE	54	63.5
EDUCATION	NIL	7	8.2
	PRIMARY	6	7.1
	HIGH SCHOOL	52	61.2
	GRADUATE	20	23.5
OCCUPATION	EMPLOYED	62	72.9
	UNEMPLOYED	4	4.7
	HOMEMAKER	19	22.4
SOCIOECONOMIC STATUS	UPPER	2	2.4
	MIDDLE	54	63.5
	LOWER	29	34.1
MARITAL STATUS	MARRIED	83	97.6
	UNMARRIED	2	2.4
TYPE OF FAMILY	NUCLEAR	36	42.4
	EXTENDED	41	48.2
	JOINT	8	9.4

TABLE 2: Distribution of caregivers according to Zarit Burden

ZARIT BURDEN	N	PERCENT
None-little	6	7.1

Little – mild	49	57.6
Mild – moderate	26	30.6
Moderate – severe	4	4.7
Very severe	0	0

TABLE 3: Association between Caregivers Sex and ZARIT (N = 85)

GENDER	None	Little	Mild-Moderate
Female	2(6.5)	20(64.5)	9(29.0)
Male	4(7.4)	29(53.7)	21(38.9)
P Value	0.868	0.332	0.032*

Chi square test, P value = 0.013, significant

Association between caregiver sex and ZARIT shows that there was statistically significant association between caregiver sex and ZARIT ($p=0.013$)

Female caregivers experienced moderate-severe level of burden, where as male caregivers majoritarily experienced little to mild level of burden.

The difference in the proportion of level of burden in the male and females caregivers was found to be statistically significant.

Discussion

Caregiver's Profile

In the present study majority of the caregivers were in the age group of 31- 40 years, followed by 17.6% among 41-50%. Majority of them were males(63.5%) in contrast to Alzheimer's Association of the United States census in which females are the predominant caregivers.²⁶ 61.2% of caregivers were educated till high school, followed by 23.5%, who were graduates. Majority of the caregivers, 72.9% were employed and 22.4% were homemaker. Majority of them were from middle class (63.5%) and were married (97.6%). Distribution of to the Caregiver's type of family shows 48.25 were from extended family, followed by 42.4% from nuclear family.

Distribution of caregivers according to the relationship with patients shows that majority of the care givers were children (57.6%), followed by spouse (37.6%), similar to Schultz *et al.* and the 10/66 Dementia research group.^{27,28,29}

Distress profile

Distribution of Study Subjects according to the ZARIT Burden shows 57.6% had little burden, followed by 30.6% had mild burden.

Significant association was found between gender of the caregiver and Zarit.

Moderate level of distress was found in the age group of caregivers belonging to 20-30 years and 51-60 years, whereas mild level of distress was seen majoritarily in the age group caregivers belonging to 31-40 years., suggesting that as the age increases, the level of burden also increases.

Moderate level of distress was seen in female caregiver suggesting that gender could influence the perceived distress and majority of them were cohabiting with the patients, which is consistent with other studies such as by Heejung³⁰ *et al.* (2011), Livingston *et al.*³¹ (2005) and Pinquart *et al.*³² (2002)

Strengths And Limitations

Strenghts

1)first type of study in Goa to evaluate the burden in caregivers of dementia

LIMITATIONS

- 1) Small sample size, results cannot be generalized
- 2) Cross sectional study design, might be having inherent bias.

Conclusion

Sociodemographic profile of the caregivers was studied. Distress in caregivers was evaluated. Significant association was found between gender of the caregiver and the burden. Generally caregivers mental health is usually not given much attention to which if left unattended for a long time can lead to significant psychiatric morbidity in the caregiver. Which can further lead to compromised care for the patient with dementia. Hence assessment of caregiver burden and timely intervention can improve the quality of life of both the patient and caregiver.

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