

# Caregiver Burden and Depression among Dementia Caregivers

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**Abstract:** Dementia is one among the most feared disorders of the present time. As dementia produces a decline in the intellectual functioning of an individual it usually interferes with the personal activities of daily living. They become dependent on their family members who often play the role of caregivers. The care giving experiences often leads to multidimensional stressors like physical, psychological, emotional, social and financial depending on the status of the demented recipient. The present study investigated the possible gender differences and the relationship between caregiver burden and depression among dementia caregivers. The participants were 34 dementia caregivers aged between 30-70 years selected from Trichur district of Kerala using purposive sampling. They were administered The Zarit Burden Interview and the Hamilton Rating Scale for Depression. The data obtained were analysed using 't' test and coefficient of correlation. The results revealed significant gender differences with respect to caregiver burden and depression among the dementia caregivers. Significant positive correlation was obtained between caregiver burden and depression.

**Keywords:** Caregiver burden, Depression, Dementia caregivers.

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## I. INTRODUCTION

One among the most feared disorders of the present time, especially of geriatric life is dementia. It is a serious loss of cognitive ability in a previously unimpaired person, beyond what might be expected from normal aging. Dementia is the loss of mental functions such as thinking, memory, and reasoning that is severe enough to interfere with a person's daily functioning. Dementia is not a disease itself, but rather a group of symptoms that are caused by various diseases or conditions. Symptoms can also include changes in personality, mood, and behaviour. It is a general term to describe symptoms such as impairments to memory, communication and thinking. Dementia describes two or more types of symptom that are severe enough to affect daily activities.

As dementia produces a decline in the intellectual functioning of an individual it usually interferes with the personal activities of daily living. They are dependent on their caregiver, often family members. Dementia caregiver is a non-statutory person who could be a partner or any family member taking care of a relative suffering from dementia. *Caregiver burden* has been defined as the type of stress or strain that caregivers experience related to the problems and challenges they face as a result of the status of the care recipient. It is the state resulting from necessary caring tasks or restrictions that cause discomfort for the caregiver (Zarit, Reever, & Bach-Peterson, 1980). Caregiver burden has also been defined as the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member (Stucki & Mulvey, 2000). Caregiver burden threatens the physical, psychological, emotional and functional health of caregivers (Carretero, Garces, Rodenas, & Sanjose, 2009). Caregivers frequently suffer from depression, exhibit maladaptive coping strategies and express concern about their poor quality of life (Serrano-Aguilar, Lopez-Bastida & Yanes-Lopez, 2006., Papastavrou, Kalokerinou, Papacostas, Tsangari & Sourtzi, 2007., Molyneux, McCarthy, McEniff, Cryan & Conroy, 2008). They also report more physical and psychological symptoms, and use more frequent prescription medications and healthcare services than comparable non-caregivers (Brodsky & Green 2002, Serrano-Aguilar, Lopez-Bastida & Yanes-Lopez, 2006). Hirono, Kobayashi, and Mori (1998) assessed that 'the patients' functional and neuropsychiatric impairments were the main patient factors which increased the caregiver's burden. Marvardi, Mattioli, and Spazzafumo (2005) found that patients behavioural disturbances and disability were the major predictors of the time-dependent burden; the psychophysical burden was explained mainly by caregiver anxiety and depression.

Caregiver burden has been described as both observable and perceived. Objective burden is an observable, concrete, and tangible cost to the caregiver for taking care of the recipient. Subjective burden refers to the perceived costs, such as the extent to which the caregiver is bothered by performing these tasks and the positive or negative feelings experienced while giving care (Jones, 1996). The caregiver's perception of the burden, rather than the perception of other family members or healthcare providers, determines the impact on his or her life (Kasuya, Polgar-Bailey, & Takeuchi, 2000). The degree of caregiver burden may be made worse by a number of factors, and it can be reduced by other factors. It tends to worsen when

- The people involved are socially isolated,
- The person gives care lack of knowledge about the condition,
- The person giving care has limited interpersonal skills,
- There are long standing immature coping patterns,
- There is strain on the relationship ( before the condition started),
- There are guilt feelings (e.g. over a decision to institutionalize the person) and high expressed emotions.

But there are also protective factors that help reduce the likelihood of caregiver burden. These include

- Help from other family members,
- The ability to use problem-focused coping strategies,
- Availability of support from the community.

From the above, it is clear that dementia is a serious medical, social, and psychological problem which has become a horror for individuals as well as families. The problem of caring for the demented persons is assuming greater magnitudes. Actually, it is the caregiver who experiences the real problem and difficulties than the demented ones. In view of the above, the present study envisages to have an understanding of the extent of burden experienced by the persons providing care for the demented elderly and the consequent affective feelings they experience. The problem for the present study is stated as "Caregiver Burden and Depression among Dementia Caregivers".

## II. OBJECTIVES

The main objectives of the present study are

- To examine whether there is significant difference between the male and the female caregivers in their levels of caregiver burden.
- To examine whether there is significant difference between the male and the female dementia caregivers in their levels of depression.
- To examine the relationship between caregiver burden and depression among the dementia caregivers.

## III. METHOD

### **Participants**

The sample for the study consisted of 34 dementia caregivers belonging to the age range 30 to 70 years. The participants were chosen from individual households mainly using the addresses provided by institutions and hospitals providing treatment for the demented in Thrissur district, Kerala.

### **Inclusion Criteria**

1. Caregivers who cared for a family member with dementia and satisfied the definition of the primary caregiver.
2. Caregivers of non- institutionalised patients with possible diagnosis of Alzheimer's disease, vascular dementia or some other forms of irreversible, progressive dementia according to the DSM –IV-TR criteria, as ascertained by the treating medical practitioner or as per the medical records.
3. Caregivers who cared for a patient of either gender from the age of 60 years to 90 years residing within the study area.
4. Caregivers who have a minimum educational qualification of SSLC.

***Exclusion criteria***

1. Caregivers who cared for a relative with dementia due to Human Immunodeficiency Virus (HIV), considering the unique factors contributing to caregiver stress.
2. Caregivers who cared for a patient who had a major sensory impairment or physical disability prior to the onset of dementia or not due to dementia.
3. Caregivers who were illiterate.

**Tools**

Only questionnaire measures were used in the present research. In addition to the personal data sheet, well established measures having high reliabilities and demonstrated validities were used to obtain data regarding caregiver burden and depression of the participants. The details of the tools are given below.

***Personal data sheet***

A personal data sheet was used to collect data regarding the socio demographic characteristics of the subjects. The personal details regarding the caregiver's age, gender, educational qualification, type of family, income, employment status, relationship with the patient, length of care as well as patient's age, gender, diagnosis, duration of illness and treatment history.

***The Zarit Burden Interview***

The Zarit Burden Interview (ZBI) is one of the most commonly used measures of caregiver burden (Knight et al., 2000). It was initially developed and validated more than 25 years ago (Zarit et al., 1980), the ZBI has been used to measure strain associated with the care of individuals with dementia. The 22 items are assessed on a 5-point Likert scale, ranging from 0 = 'never' to 4 = 'nearly always'. Item scores are added up to give a total score ranging from 0 to 88, with higher scores indicating greater burden. The questions focus on major areas such as caregiver's health, psychological well-being, finances, social life and the relationship between the caregiver and the patient. The scale's 22 items are divided into two factors: personal strain and role strain (Zarit et al., 1985), and it has been found to demonstrate adequate concurrent and construct validity (Pratt et al., 1986), as well as high internal reliability (Bachner & Ayalon, 2010) and adequate internal consistency ( $\alpha = 0.89$  and  $\alpha = 0.77$ , respectively). The concurrent validity of responses was also established (Bédard et al., 2001).

***Hamilton Rating Scale for Depression (HAM-D or HRSD)***

This is one of the earliest scales to be developed for depression, and is a clinician rated scale aimed at assessing depression severity among patients. The original HAM-D included 21 items, but Hamilton pointed out that the last four items (diurnal variation, depersonalization/derealization, paranoid symptoms, and obsessive compulsive symptoms) should not be counted toward the total score because these symptoms are either uncommon or do not reflect depression severity (Hamilton, 1960). Therefore, the 17-item version of the HAM-D has become the standard for clinical trials. The total score is obtained by summing the score of each item, 0–4 (symptom is absent, mild, moderate, or severe) or 0–2 (absent, slight or trivial, clearly present). For the 17-item version, scores can range from 0 to 54. Cut-Off Scores - It is accepted by most clinicians that scores between 0 and 6 do not indicate the presence of depression, scores between 7 and 17 indicate mild depression, scores between 18 and 24 indicate moderate depression, and scores over 24 indicate severe depression.

A number of studies have shown the internal consistency of different versions of HAM-D to range widely from 0.48 to 0.92. Higher coefficient alpha values were reached with the use of a structured interview (Hamilton, 2000). All items showed adequate reliability when the scale was administered with interview guidelines (Moberg et al., 2001). A sufficiently high inter-rater reliability ( $>0.60$ ) was reported for most of the HAM-D items and the total score (0.57–0.73) in a study on inter-rater reliability in 21 psychiatric novices who had negligible previous experience with the HAM-D (Muller & Dragicevic, 2003).

## Procedure

The selected participants were contacted over telephone and were met individually. After getting their informed consent, the questionnaires were administered in the form of face to face interview. The collected data were analyzed using the statistical techniques of 't' test and Pearson's correlation coefficient.

## IV. RESULTS AND DISCUSSION

**Table 1: The mean and the standard deviation of the scores obtained by the male and female caregivers in caregiver burden and the corresponding 't' value**

Variable	Mean		Standard deviation		t
	Male (N=16)	Female (N=18)	Male (N=16)	Female (N=18)	
Caregiver burden	42.13	50.17	6.18	7.79	3.30**

\*\* Significant at the .01 level

Table 1 shows the mean and the standard deviation of the scores obtained by the male and the female caregivers in caregiver burden and the obtained t- value. The obtained 't' value clearly shows that there is significant difference between the two groups of caregivers in caregiver burden. The female caregivers have got higher mean burden score than the male caregivers. Our society is changing—while care giving has traditionally been considered as women's activity (Baker & Robertson, 2008), the number of male caregivers is rapidly increasing. In fact, men over 65 years in the UK soon outnumber women as caregivers (Hirst, 2001). Women and men may approach their care giving differently. Whereas men seem to consider it more as a task, women may take it more comprehensively (Russell, 2001; Calasanti & King, 2007).

A review of 93 articles on gender differences in care giving studies (Baker & Robertson, 2008) reports that most studies conclude that women experience more distress and use more services than men. However, in respect to worrying and stress, studies have had contradictory findings. Furthermore, several studies have reported no gender differences (Baker, Robertson, & Connelly, 2010). There is lack of knowledge on gender differences of continuous care giving affecting distress and wellbeing of dementia caregivers. Therefore, caregiver burden of male and female caregivers of patients with dementia was made in this study. In our culture the women are considered as caregivers and men as bread winners. It is considered as their duty to care for the family. In Kerala most dementia patients live with their children. The burden of caring for the family as well as for their demented relative is most often shouldered by the women folks usually the wife or the daughter - in - law. Also most women have to spare time to meet their children's and family needs and in attending to other house hold chores along with the caring for their relative. This could be the reason for the women to experience more caregiver burden than the men. Fitting, Rabins, Lucas, and Eastham (1986) have reported female caregivers to be more distressed than male caregivers. Maria Pöysti et al. (2012) reported that male caregivers of dementia experienced lower burden than female caregivers despite care recipients' more severe disease. Thus, the results of the present study are consistent with the existing findings in this regard.

**Table 2: The mean and the standard deviation of the scores obtained by the male and female caregivers in depression and the corresponding 't' value**

Variable	Mean		Standard deviation		t
	Male (N=16)	Female (N=18)	Male (N=16)	Female (N=18)	
Depression	10.81	12.94	1.97	3.07	2.4*

\*Significant at the .05 level

The results in Table 2 show the mean and the standard deviation of the scores obtained by the male and the female caregivers in depression and the obtained t- value. The obtained 't' value clearly shows that there is significant difference between the two groups of caregivers in depression. The female caregivers have got significantly higher mean score than the male caregivers in depression. Verma and Anand (2012) have reported in their study that female dementia caregivers had higher levels of anxiety and depression than the male dementia caregivers. Depression is found to be higher among females than among males in the general population also. Thus, the present finding is in agreement with existing findings with respect to depression.

The quality of life and well-being of the caregiver must be at an optimum level in order to provide the best care. Compared to other disease states, dementia caregivers experience greater dependency, provide more extensive assistance and care for a longer time period. With disease progression, caregivers often experience increased emotional stress, depression, health impairments, and financial loss. Gender is an important contextual factor that influences the stress response, coping and access to resources. Beyond positing that differences exist in caregivers, there is a dearth of current research that explores the role of gender in these processes. A mixed methods cross-sectional research design was used to assess the role of gender in dementia caregiver risks, experiences and challenges by Lippa, Bowen, Robertson-James, Nunez and Gonzalez (2014). The quantitative component that includes self-administration of a questionnaire in clinical and community samples were used. They used questionnaire to assess six risk domains: depression, burden, behaviors, support network, safety, and management strategies. The qualitative component included an analysis of a gender activity and discussion in dementia caregiver support groups. Their study results indicated a trend toward significant gender differences in the risk domains of management strategies, behaviours, and support network.

#### ***Correlation between caregiver burden and depression***

The coefficient of correlation obtained between caregiver burden and depression in the dementia caregivers is given in Table 3. The results indicate that there is high positive correlation between these two variables. This indicates that caregiver burden is significantly related to depression among the caregivers. The greater the burden experienced, the higher the depression.

**Table 3: The coefficient of correlation between caregiver burden and depression (N=34)**

Variables	Depression
Caregiver burden	.621**

\*\*Significant at the 0.01level.

Caregivers of dementia patients are often called invisible patients. The effects of being a caregiver though sometimes positive are generally negative, with high rate of burden and psychological morbidity as well as social isolation, physical ill-health and financial hardship. Caregivers face many obstacles as they balance care giving with other demands, like child rearing, career and relationship, this increase the risk for burden, stress and depression and other health complications. A robust relationship between dementia care giving and negative effects on psychological health has been demonstrated in numerous studies (Campbell et al., 2008; Cooper, Katona, Orrell, & Livingston, 2006; Gaugler, Roth, Halely, & Mittelman, 2008).

## **V. CONCLUSIONS**

It can be concluded from this study that there is gender difference with respect to caregiver burden and depression among the dementia caregivers. The female caregivers have reported to experience higher level of caregiver burden as well as depression. A high positive relationship between caregiver burden and depression was also found.

#### **Implications of the study**

The following implications of this study have been enumerated:

1. The findings provide baseline information about the experience and psychological status of caregivers providing care for their relatives with dementia.
2. The study helps in understanding the factors affecting of the caregivers psychological well-being. This would help health care professionals to meet the needs of the caregiver population.

3. Psychological interventions has to be developed to reduce caregiver burden and depression. Interventions increase caregiver knowledge, improves mood and reduces stress.
4. Comprehensive management of the patients with dementia like building a partnership between health professionals and family caregivers such as referral to dementia associations or Alzheimer's Associations can be made.
5. Guidance and counselling classes or workshops for the dementia caregivers will help them cope better with the stress of care giving burden.
6. The results of this study would provide evidences to establish public policies and programmes that are targeted to meet the long-term needs of dementia caregivers.

### Limitations of the study

Despite all attempts to design the study to be scientific, methodical and foolproof, the following limitations have been enumerated:

1. The participants comprised predominantly of caregivers who had initiated some contact with a clinic or hospital; therefore, the sample may be an over representation of caregivers willing to seek some kind of professional help.
2. Individual differences based on caregiver personality, attitudes, cultural believes, and values were not fully taken into account.
3. The sample was of limited size and was chosen from a limited geographical area, narrowing the scope for wider generalizations.

In the light of the above, the following suggestions are made for further research in the area of dementia caregiver burden. Future directions may incorporate larger samples, more stringent longitudinal study design and more number of psychosocial variables. Research may also explore the patient- caregiver relationship. Females are often over-represented in care giving research and are accounted for almost three- quarters of care giving population. Hence, further studies may also need to consider the higher levels of emotional stress found in females before being exposed to the care giving situation. In addition, baseline levels of caregiver well-being or depression should be assessed, requiring prospective research designs, including a measure that looks retrospectively at life. Future researches may also include greater geographical areas and larger number of samples.

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