

## Significance of Burden and Competence of Caregiving among Elderly Patients of Dementia

*Tripti Singh \* Kamayani Mathur\*\**

### Abstract

*Elderly people face lot of problems which are age specific, along with it Dementia makes them completely dependent upon others even for the trivial tasks of daily routine. Dementia is a general term for a decline in mental ability severe enough to interfere with daily life, generally seen among the elderly people. Therefore the caregiver's role and responsibility becomes very crucial for the elderly patients of Dementia. A caregiver or carer is an unpaid or paid member of a person's social network who helps them with activities of daily living. The aim of the present research was to study the role of caregivers and their feeling of burden and competence in the task of caregiving. A total sample of 53 caregivers of elderly patients of dementia were selected by purposive sampling method. The sample was further divided as per gender, age and type of caregivers. Zarit Burden Interview Scale (Zarit 1980) and Sense of Competence Questionnaire (Vernooij-Dassen, Persoon, & Felling (1996) were selected as tools. The collected data was statistically analysed by using Student's 't' test. The findings showed a significant difference between the gender of caregivers. This was indicative of the feminine sense of caregiving as natural than in males. The significant difference in the findings of age criteria has clearly indicated that young age caregivers felt more burden than middle age caregivers. Similarly the findings in case of type of caregivers were significant as to show that spouses have unconditional desire to provide a loving and caring environment to the patient. Children also take the responsibility of caregiving wholeheartedly but tend to feel some burden at some point of time. Others are generally distant relatives therefore they feel more burden. Competence in the caregivers is seen more in males than females, children and other relatives of young age than middle age ones, and spouses have less competence levels as they are elderly people themselves. More research is necessary in this field.*

**Keywords:** *Burden, Caregivers, Competence, Dementia*

### About Authors:

*\*M Phil Student, \*\*Supervisor, Professor & Head, Department of Psychology, School of Psychology, Philosophy & Education, Gujarat University, Ahmedabad, Gujarat*

### Introduction

Old age brings complications and dependency for tasks accomplishments. Dementia among elderlies makes it more difficult making them completely dependent upon others even for the trivial tasks of daily routine. Therefore elderly people need lot of support and care. Dementia is a general term for a decline in mental ability severe enough to interfere with daily life, generally seen among the elderly people. An example is memory loss.

Most common type of Dementia is Alzheimer. While symptoms of dementia can vary greatly, at least two of the following core mental functions must be significantly impaired to be considered dementia:

- Memory
- Communication and language
- Ability to focus and pay attention
- Reasoning and judgment
- Visual perception

Caregiving is most commonly used to address impairments related to old age, disability, a disease, or a mental disorder. Caring for someone with dementia is difficult because the person declines in many ways. Care usually goes on for several years, and caregivers have to make many changes in their own lifestyle to provide this care. The Dementia India Report 2010 explains that care giving for dementia is long-term and the needs for care increase with time. Caregiving becomes a difficult task when people with dementia become restless or aggressive. Thus caregivers also reported that they themselves had feelings of anger, depression, and fatigue. Caregiving has all the features of a chronic stress experience: It creates physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, has the capacity to create secondary stress in multiple life domains such as work and family relationships, and frequently requires high levels of vigilance.

### **Burden**

Caregiving of elderly patients of dementia is felt like a burden by the caregivers resulting in stressful experience and further deteriorating physical as well as mental health. Braithwaite (1990) proposed that caregiving burden is very much subjective phenomenon and that the carer's perception of their situation is the most reliable predictor of the impact of caregiving. Caregiving burden may be at its most acute when caregiving does not follow its desired path when it does not make things better; and when it accompanies losses rather than gains in the well-being of the dependent. Recently it has been recognized that caregiver characteristics (such as gender, availability of social support, relationship to patient) may play a major role in determining how burdensome they find their roles. A review of gerontological research in India indicates the paucity of studies on caregiver burden.

### **According to Schoenmakers Birgitte, Buntinx Frank, Delepeleire (2010): Dementia caregivers suffer most care burden**

Dementia caregivers suffer a considerable care burden. More than in comparable groups of caregivers or peers, they are confronted with feelings of depression and decreased physical health. Although many studies are set up to determine the link between the stressors in dementia care-giving and the impact on the family caregiver, the results remained inconclusive. Others, depression in caregivers remains the main cause of a premature or acute ending of home care.

### **Competence**

The competence of caregiver is well reflected through his or her understanding of how the person with Dementia feels, and would not dismiss a person's worries. They will always listen to them and show them that they are there for them. A competent caregiver would always respect the age of the patient and would stay in the moment rather than thinking too much about what the future may or may not hold. Maintaining their own sense of humour. It is important to look beyond the words or behaviours a caregiver can see to the feelings that the person might be trying to express. Strong emotions of the patient may also be caused by unmet needs. Carers should try to work out what these needs are and meet them where possible.

Ensure people have time to do the activities they enjoy and that gives them a purpose in life. If a person makes a mistake, try to be as supportive as possible. Help people to maintain existing social relationships and form new ones. This can be done by facilitating joint activities with friends and family, joining hobby groups and encouraging conversation. A competent caregiver is able to take care his or her own self in a better way. The role of a caregiver is tedious as well as of utmost importance in case of elderly patients of Dementia.

**Rosalia J. M. et al (2016) - Feelings of competence in the caretaking process.**

Studied an urgent need for psychosocial interventions that effectively support dementia caregivers in daily life. The Experience Sampling Methodology (ESM) offers the possibility to provide a more dynamic view of caregiver functioning. ESM-derived feedback may help to redirect caregivers' behavior towards situations that elicit positive emotions and to increase their feelings of competence in the caretaking process.

**Objective of the present study**

As with Dementia patient in most of the world, they face extreme deterioration in their cognitive skills and memory. As per the estimates of the World Health Organization, aging population is increasing in developing countries and dementia is going to become epidemic among elderly in the coming decades. Prevalence rates (PRs) from different regions of India differ widely. There were only few studies that explored the problems around the Dementia patients and issues related to caregiving to elderly patients of Dementia. Nevertheless, the information from those few studies illustrated various aspects of the extreme marginalized situation of these people and their caregivers' well being and mental health. **The present paper is depicted to study the effect of Caregivers' Burden and Competence among elderly patients of dementia.**

**Hypotheses**

- There will be significant mean difference between burden and competence scores of caregivers' gender (male and female) of elderly patients of Dementia.
- There will be significant mean difference between burden and competence scores of the types of caregivers (spouse, children and other) of elderly patients of Dementia.

**Methodology**

Sample: The total sample comprised of 60 caregivers of elderly patients of Dementia from the various hospitals and clinics in Ahmedabad, Gujarat were approached and finally 53 gave their consent and became the part of this study as to give the required details. Since the study was of the elderly patients therefore their age group considered was above 65 years. To constitute the sample purposive sampling technique was employed. The efforts were made to select the sample as representative as possible in terms of gender, age and types of caregivers for the elderly patient of Dementia. Proper rapport was established with the caregivers and were informed about the confidentiality of their details.

**Variables:****Independent Variables:**

- Gender: Male and Female
- Type of caregivers: Spouse, Children and Other (siblings, cousins, relatives etc)

**Dependent Variables:**

- The scores of Zarit Burden Interview
- The scores of Sense of Competence

**Research Measures:****Inclusion Criteria:**

- Only clinically diagnosed patients of Dementia by the Neurologists were considered.
- Gender of Caregivers of Dementia patients
- Type of Caregivers of Dementia patients that includes spouse, children, siblings, cousins, relatives
- Elderly patients of Dementia between 65 years to 75 years

**Exclusion Criteria:**

- Younger patients of Dementia who were below 60 years
- Effect of the death of the spouse on caregiving of the elderly patient of Dementia

- Any other complications involved in Dementia patients were not taken

#### Tools:

1) A personal information data sheet was used to get the data for demographic characteristics of the respondents.

#### 2) Zarit Burden Interview (ZBI) by Zarit (1980):

To assess the quality of burden during the process of caregiving for the elderly patient of Dementia, Zarit Burden Interview (ZBI) was used. This Inventory was constructed by Zarit (1980). This test consists of 22 items and can be used in clinical or community setting and was developed to measure subjective burden among caregivers of adults with dementia. The reliability coefficient by Cronbach's alpha = 0.83 and 0.89. A test-retest reliability of 0.71 was obtained. It has good construct validity. Spearman's rho correlations include: 0.32 with activities of daily living, 0.32 with social life restrictions, 0.41 with the Brief Symptoms Inventory, 0.71 with the global index of burden, and -0.57 with the quality of relationship between the caregiver and the recipient.

#### 3) Sense of Competence Questionnaire, (SCQ) by Vernooij-Dassen, Persoon, & Felling (1996):

Sense of Competence Questionnaire, SCQ, Vernooij-Dassen, Persoon, & Felling (1996) - A 27 item instrument measuring a caregiver's feelings of being capable to care for a person with Dementia. The inventory has yield satisfactory reliability and validity indices - satisfaction with the care recipient: Cronbach's a

= 0.83 and range of item-total correlations: 0.50–0.68; satisfaction with one's own performance as a caregiver: Cronbach's a = 0.83 and range of item-total correlations: 0.16–0.70; consequences of involvement in care for the personal life of the caregiver: Cronbach's a = 0.85 and range of item total correlations: 0.50–0.76. The validity of the scales has come out to be  $r_s = 0.40, 0.80$  respectively.

#### Data Collection and Procedure:

The samples of elderly dementia patients' caregivers were identified in the specific areas of Ahmedabad. Written permission was sought from the incharge officers / Superintendents of the hospitals from where the data was to be collected. Rapport was established by the researcher and she explained the objective of the present research study to them. Before beginning the data collection rapport was established and consent was taken on the ensurance that the data and name shall be kept confidential and shall be used for the purpose of the said study. All those who have shown willingness to participate in the research study were given proper instruction for the test and accordingly tests were administered. The collected raw data were scored as per the scoring key given in the test manual. The raw data was statistically analysed using student's t-test.

#### Results

The results of the present study of the research study are presented below:

**Table: 1(a) Showing mean, SD and "t" value of Score of burden for male and female partners or spouses of elderly patients of dementia :**

Group	N	Mean	SD	"t" - value	Table value	Level of Significance
Male partners	06	44.83	2.48	2.86	2.23	0.05
Female partners	06	40.67	2.56			

\*\* Significant at .01 level, \* significant at .05 level and NS Not significant

As can be seen from above table the two groups under study differ significantly in relation to burden. According to scoring pattern, higher score indicated higher burden. Thus from the

result it could be said that male partners group show more burden than female partners as caregivers of elderly patients of dementia.

**Table: 1(b) Showing mean, SD and “t” value of Score of burden for male and female children of elderly patients of dementia :**

Group	N	Mean	SD	“t” - value	Table value	Level of Significance
Male children	14	54.07	5.48	2.93	2.81	0.01
Female children	11	42.79	11.82			

\*\* Significant at .01 level, \* significant at .05 level and NS Not significant

As can be seen from above table that the two groups under study differ significantly in relation to burden. According to scoring pattern, higher score indicated higher burden. Thus from

the result it could be said that, male children group show more burden than female children of elderly patients of dementia.

**Table: 1(c) : Showing mean, SD and “t” value of Score of burden for male and female others of elderly patients of dementia :**

Group	N	Mean	SD	“t” - value	Table value	Level of Significance
Male others	09	53.11	8.45	1.41	2.14	N.S.
Female others	07	45.56	12.06			

\*\* Significant at .01 level, \* significant at .05 level and NS Not significant

As can be seen from above table that the two groups under study does not differ significantly in relation to burden.

**Table: 2(a) Showing mean, SD and “t” value of Score of competence for male and female partners or spouses of elderly patients of dementia :**

Group	N	Mean	SD	“t” - value	Table value	Level of Significance
Male partners	06	99.83	5.79	1.87	2.23	N.S.
Female partners	06	93.67	5.62			

\*\* Significant at .01 level, \* significant at .05 level and NS Not significant



As can be seen from above table that the two groups under study does not differ significantly in relation to competence.

**Table: 1(b) Showing mean, SD and “t” value of Score of burden for male and female children of elderly patients of dementia :**

Group	N	Mean	SD	“t” - value	Table value	Level of Significance
Male Children	14	92.14	11.93	4.03	2.81	0.01
Female Children	11	67.86	16.94			

\*\* Significant at .01 level, \* significant at .05 level and NS Not significant

As can be seen from above table that the two groups under study differ significantly in relation to competence. According to scoring pattern, higher score indicated higher

competence. Thus from the result it could be said that, male children group show more competence than female children of elderly patients of dementia as caregivers.

**Table: 2(c) Showing mean, SD and “t” value of Score of competence for male and female others of elderly patients of dementia :**

Group	N	Mean	SD	“t” - value	Table value	Level of Significance
Male others	09	100.33	13.74	4.78	2.98	0.01
Female others	07	63.67	16.28			

\*\* Significant at .01 level, \* significant at .05 level and NS Not significant

As can be seen from above table that the two groups under study differ significantly in relation to competence. According to scoring pattern, higher score indicated higher competence. Thus from the result it could be said that, male others group show more competence than female others group of elderly patients of dementia.

## Discussion

Caregiving was a global concept which was traditionally allotted to women. Women due to their maternal instincts accepted caregiving naturally and thus felt less burdensome in the task. Elderly Dementia patients are very much

dependent upon their caregivers. They need lot of support and acceptance from their caregivers. The present study supports the concept of females feeling lesser burden of caregiving than males as there was significant difference between males and females in the criterion of spouses and children. The results showed no significant difference in case of others. The closeness of the relationship results in feeling less burden while providing care to elderly dementia patients.

The present study also focuses on the competence issue of caregivers while caregiving the elderly patients of Dementia. If the caregivers are competent they would be able to

manage the tediousness of the task as well as would be able to take care of themselves. Here the males showed better competence than females in the criterion of children and others, as per the results that there was significant difference in scores. Except in case of spouses, the results showed no significant difference in their scores. Since the spouses are also elderlies, therefore their competence level was low. Males are known to have sufficient skills and abilities to act effectively in a situation and are more decisive in critical circumstances.

Overall a family is a basic unit having single minded, unconditional desire to provide a loving, caring home. Thus caregiving happens as a natural phenomenon. Although elderly dementia care was crucial as to feeling of burden and competence to manage. Thus making caregiving an utmost important task and to provide better understanding of caregivers' issues.

### Conclusions

There is need for the social acceptance and understanding of elderly dementia patients. They go through lot of emotional turmoil and stress. That makes caregiving very crucial as the caregivers also have lot of issues which has adverse effect upon their mental and physical health. Therefore it is important for all family members to contribute and show empathy for caregivers as well as the elderly patients of dementia.

### Limitations

As with the other studies, the present study too has its own limitations. Due to time constraints, the data has been collected from Ahmedabad city only. Further studies can be done and conducted in the other cities and states. Here sample selection was limited only up to 30 caregivers of Dementia patients in Ahmedabad city; therefore the results cannot be generalized

to a large sample using varied psychological dimensions.

### Implications of the present research

The present research could be implemented to generate better understanding of caregivers for caregiving aspect of elderly dementia. It can be useful to clinical and health psychologists, especially gerontologists. It can be useful to Neurology and Neuropsychology professionals, Medical professionals and nursing staff who are dealing with these patients and their caregivers on a daily basis. Also it can be helpful for society and community. Further extending training caregivers to establish effective relationship with elderlies of Dementia, thereby improving their own mental and physical well being.

### Reference

- American Psychiatric Association Diagnostic and Statistical Manual, 4th, APA Press, Washington, DC 1994.
- American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), American Psychiatric Association, Arlington, VA 2013.
- Baumgarten M.,(1989). The health of persons giving care to the demented elderly: A critical review of the literature. *Journal of Clinical Epidemiology*, 42 : 1137-1148.
- Baker, K. L., Robertson, N. (2008). Coping with caring for someone with dementia: The literature about men. *Aging and Mental Health*, 12, 413–422.
- Braithwaite V. (1992). Caregiving burden: Making the concept scientifically useful and policy relevant. *Research on Aging* (1992). Journals.sagepub.com
- Broota, K. D., *Experimental Design in Behavioural Research*. New Age

- International (P) Limited, Publishers. First Edition (1989). Reprint 2015.
- Chumbler, N. R., Grimm, J. W., Cody, M., Beck, C. (2003). Gender kinship and caregiver burden: the case of community dwelling memory impaired seniors. *International Journal of Geriatric Psychiatry*, 18, 722–732.
- Kothari C R: *Research Methodology, Methods and Techniques*. New Age International (P) Limited, (Second Revised Edition)
- McFarland, P., Sanders, S. (1999). Male caregivers: Preparing for nurturing role. *American Journal of Alzheimer's Disease and other Dementias*, 14, 278–282.
- Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, K., Sourtzi, P. (2007). Caring for a relative with dementia: family caregiver burden. *Journal of Advanced Nursing*, 58, 446–457.
- Parker, G., Tupling, H., & Brown, L. B. (1979). A Parental Bonding Instrument. *British Journal of Medical Psychology*, 52, 1–10.
- Parsons, K. (1997). The male experience of caregiving for a family member with Alzheimer's disease. *Qualitative Health Research*, 7, 391–407.
- Rosalia J. M. et al (2016) - Feelings of competence in the caretaking process. *The American Journal of Geriatric Psychiatry* 25 (8), 852-859, 2017
- Samuelsson, A. M., Annerstedt, L., Elemstahl, S., Samuelsson, S. M., & Graftström, M. (2001). Burden of responsibility experienced by family caregivers of elderly dementia sufferers: Analyses of strain, feeling and coping strategies. *Scandinavian Journal of the Caring Sciences*, 15, 25–33.
- Sanders, S., Power, P. (2009). Roles, responsibilities and relationships among older husbands caring for wives with progressive dementia and other conditions. *Health and Social Work*, 34, 41–51.
- Schoenmakers Birgitte, Buntinx Frank, Delepeleire (2010): *Dementia caregivers suffer most care burden*
- Yee, J. L., Schultz, R. S. (2000). Gender differences on psychiatric morbidity among family caregivers: a review and analysis. *The Gerontologist*, 40, 147–164.
- World Health Organization. *Dementia: a public health priority*. Geneva: World Health Organization; 2012.

#### Internet Sources:

- <https://www.crisisprevention.com/Blog/July-2013/Major-Neurocognitive-Disorder-Dementia>
- <https://en.wikipedia.org/wiki/Psychopathology>

#### Scales and Manuals:

- Zarit Burden Interview Scale (ZBI) by Zarit (1980) and its manual for scoring and interpretation
- Sense of Competence Questionnaire, (SCQ) and manual by Vernooij-Dassen, Persoon, & Felling (1996)

