



## RESEARCH ARTICLE

### BURDEN & COPING IN CAREGIVER OF PERSONS WITH DEMENTIA

\*<sup>1</sup>Dr. Priyajyoti Chakma and <sup>2</sup>Dr. H. K. Goswami

<sup>1</sup>Department of Psychiatry, Agartala Govt. Medical College, Agartala, Tripura West, India - 799006

<sup>2</sup>Department of Psychiatry, Assam Medical College, Dibrugarh, India -786002

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#### ABSTRACT

**Background:** Dementia is a serious loss of global cognitive ability in a previously unimpaired person, beyond what might be expected from normal aging. Dementia is often associated with physical, mental and financial burden. Care giving was associated with more psychological complaints & coping is most often conceptualized as a response to the demands of specific stressful situations.

**Aim:** To assess the Burden in caregiver of persons with dementia and also assess the coping strategies used by the caregivers.

**Settings and design:** The study was conducted in the Department of Psychiatry, Assam Medical College & Hospital, Dibrugarh. The samples for the study were recruited from the outpatient & indoor facilities of the department of Psychiatry, Assam Medical College & Hospital, Dibrugarh, after application of the inclusion and exclusion criteria (n=40) cases of Dementia and their caregivers (n=40) were included in the study.

**Materials and Methods:** Diagnosis of dementia were done by fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR). The tools used were burden assessment schedule (Thara *et al.*, 1998), Asamese version of ways of coping Questionnaire (Susan Folkman and Richard S. Lazarus). Statistical analysis was done by using SPSS- 20.

**Results:** The result revealed that level of burden reported by caregivers of dementia patients was high. The most common coping strategies used by caregivers of Dementia patients were confronting coping (72%), distancing (45%), seeking social support (45%) and self-controlling (45%).

**Conclusion:** The various findings in our study evidence that dementia can have serious consequences on families particularly the primary caregivers. Result highlight the importance of improving the mixed coping skills in burdened caregivers.

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## INTRODUCTION

Dementia (derived from Latin word, dementatus, meaning out of one's mind) is a serious loss of global cognitive ability in a previously unimpaired person, beyond what might be expected from normal aging. Although dementia is far more common in the geriatric population (about 5% of those over 65 are said to be involved). (Richards *et al.*, 2009) It can occur before the age of 65, in which case it is termed "early onset dementia" (Fadil *et al.*, 2009). Dementia is not a single disease, but a non-specific syndrome affecting many cognitive areas - memory, attention, language, and problem solving. Normally, symptoms must be present for at least six months to support a diagnosis (Dementia, 2007). Dementia is the development of multiple

cognitive deficits manifested by both memory impairment & impairment of at least one other cognitive domain including language, praxis, gnosis, & executive functioning (Richards *et al.*, 2009) The single strongest risk factor for dementia is increasing age. (Seeley William *et al.*, 2011) Prevalence doubles about every 5 years from about 5-8 percent at age 65 to 70 to 15 to 20 percent at the age 75 to 80 and up to 40 to 50 percent over age 85. In 2005, it was estimated that 24.3 million people worldwide were affected with dementia. (Murray *et al.*, 2001) In 2013, worldwide dementia is estimated to account for 4.1% of all DALYs & 11.3% of years lived with disability & 0.9% of years of life lost. (Ferri *et al.*, 2005) In India 1.8 million people have dementia. (Murray *et al.*, 2001) Across India, more than 42000 older people studied in eight centers suggest that Ballabgarh & Vellore have the lowest prevalence rates while Trivandrum & Thiropour have the highest rates. Among all North Eastern states, Assam has the highest number

\*Corresponding author: Dr. Priyajyoti Chakma,

Department of Psychiatry, Agartala Govt. Medical College, Agartala, Tripura West, India - 799006

of cases with dementia. (Prince and Jackson, 2009; Prince *et al.*, 2007; Prince *et al.*, 2000; World Health Organization, 2002; 10/66 Dementia Research Group, 2004; Dewey and Saz, 2001) Dementia is often associated with physical, mental and financial burden and evidence suggests that elderly people with dementia in developing countries do not often utilized health care services, and when they do, the health care system is often ill prepared to provide quality services for dementia. (Shaji *et al.*, 2002) The stress and burden experienced by many caregivers to the elderly has recently been the focus of considerable research. (Branch *et al.*, 1982) Caring for persons affected with dementia is associated with substantial psychological strain as evidenced by high level of stress in caregivers. Care giving was associated with more psychological complaints & coping is most often conceptualized as a response to the demands of specific stressful situations. From the above discussion it is clear that caregiver burden is quite common in patients with dementia. No such type of studies from the Northeastern part of India till now. There is dearth of study on this subject of burden & coping in caregivers of patients with dementia from North-Eastern part of the country as yet. Hence, the present study is a sincere effort in this direction

## MATERIALS AND METHODS

The study was done in Assam medical college hospital which is tertiary care center situated in Dibrugarh.

**The design of the study:** The study subjects were 40 consecutively selected diagnosed cases of Dementia and their caregivers (n=40) from the outpatient & indoor facilities of the department of psychiatry, the period of the study was one year (June 2012-May 2013). Sociodemographic information was gathered as per prepared standard questionnaire. Ethical approval & written informed consent of the patients & caregivers were obtained in the initial portion of the study. Caregiver burden evaluated by burden assessment schedule (Thara *et al.*, 1998), & Coping strategies evaluated by Assamese version of ways of coping questionnaire (Susan Folkman and Richard S. Lazarus).

**The aim of the study:** To assess the Burden in caregiver of persons with dementia & its socio demographic variation and also assess the coping strategies used by the caregivers.

**Inclusion Criteria:** a) Those caregivers giving consent to participate in the study. b) Duration of illness of at least 1 year. c) Caregivers who were 21 or above 21 years of age, living with & looking after the patient for at least one year prior to the interview (sole caregivers). d) Patients of both sexes. e) Caregivers of both sexes. f) Patients fulfilling the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV-TR) criteria for dementia. g) All the subtypes of dementia.

**Exclusion Criteria:** a) Patients with previous history of functional psychiatric disorder before the onset of dementia. b) Mental Retardation. c) Mental and behavioral disorders due to substance use. d) Caregiver with chronic debilitating physical illness & a history of past/current psychiatric consultation. e) Patients with comorbid chronic medical illness.

Tools which were used in the study are: a) written informed consent form, b) proforma for socio demographic data, c) burden assessment schedule (Thara *et al.*, 1998), d) Ways of coping questionnaire (Susan Folkman and Richard S. Lazarus).

### Burden assessment schedule (BAS, Thara *et al.*, 1998)

BAS, 1998 developed by Thara *et al.*, at the schizophrenia research foundation (SCARF) is based on the principle of ethnographic exploration at Chennai, with support from the W.H.O. South East Asian Regional Office. The BAS reflects the caregivers' perceptions & provides valuable & culturally relevant insights to Burden. This is a semi quantitative 40 item scale measuring 9 different areas of objective & subjective caregiver burden. Each item rated on a 3 point scale ("not at all", "to some extent" or "very much" with a total score ranging from 40 to 120 with higher score indicating greater burden. In BAS the minimum score is 40 & max score 120. Therefore for the requirement of the present study, the cut off has been taken as 80 & those caregivers who scored less than 80 were considered as experiencing lower burden & those who scored more than 80 were considered as having higher burden to maintain homogeneity within the group. (Thara *et al.*, 1998)

### Ways of coping questionnaire (WOCQ)

WOCQ (ways of coping questionnaire) was translated to local language (Assamese) WOCQ scales reliability Alpha values for 8 subscales of WOCQ came 0.87, 0.74, 0.92, 0.88, 0.97, 0.89, 0.87, and 0.96 respectively which suggests the statistical reliability of the scale. Ways of coping questionnaire is primarily a research instrument in studies for assessment of coping process. It was developed by Susan Folkman and Richard S. Lazarus in 1980. The questionnaire is designed to identify the thoughts and action of an individual has used to cope with a specific stressful encounter. The questionnaire measures total of 8 type of coping strategies namely Confronting coping, distancing, self-controlling, seeking social support, Accepting responsibility, escape avoidance, playful problem solving and positive reappraisal. There are total 66 questions in the full questionnaire. There are two methods of scoring the ways of coping questionnaire, raw and relative. The decision as to which set of score to use depends on the information desired. Raw score describe coping effort for each of the eight types of coping, whereas relative score describe the proportion of effort represented by each type of coping. In both methods of coping, individuals respond to each item on a 4-point Likert used "1-indicates "used somewhat", 2- indicates "used quite a bit and 3- indicates "used a great deal". In the raw scoring the raw scores are the sum of the subjects responses to the items that comprises a given type of coping was used in a particular encounter. (Lazarus and Folkman, 1984; Lazarus, 1993)

## RESULTS AND OBSERVATIONS

As per Table 1, 35% belonged to the age group 60-69 years, 25% were from 70-79 years age group, 15% were from 40-49 years age group, 15% were from 50-69 age groups, 7.5% were  $\geq$  80 years of age & only 2.5% were from 30-39 years age group.

Table 1. Sociodemographic profile of the dementia cases

Demographic details	No. of dementia cases	Percentage
<b>Age(in years)</b>		
30-39	1	2.5
40-49	6	15
50-59	6	15
60-69	14	35
70-79	10	25
≥80	3	7.5
<b>Gender</b>		
Male	25	62.5
Female	15	37.5
<b>Marital status</b>		
Married	20	50
Unmarried	1	2.5
Widow	5	12.5
Widower	14	35
<b>Educational status</b>		
Illiterate	13	32.5
Primary school	11	27.5
Middle school	3	7.5
High school	9	22.5
Intermediate	1	2.5
Graduate or Postgraduate	3	7.5
<b>Duration of illness</b>		
1-4 years	27	67.5
5-8 years	13	32.5
<b>Religion</b>		
Hindu	38	95
Muslim	2	5
<b>Locality</b>		
Rural	36	90
Urban	3	7.5
Semi-urban	1	2.5

Maximum no of the patients were male (62.5%) & only 37.5% were female. Most of the patients were married (50%), followed by widower (35%), widow (12.5%) and only 2.5% of the cases were unmarried. As per findings most of the patients were illiterate (32.5%), 27.5% were educated up to primary school, 22.5% up to high school, 7.5% up to middle school & graduate level and only 2.5% studied up to intermediate level. Majority of the participants' duration of illness was between 1 to 4 years (67.5%), rest had duration of illness between 5-8 years (32.5%). Most of the cases belonged to Hindu family (95%) and only 5% belonged to Muslim family. It is observed that in this study 90% of the patients were from rural background, 7.5% from urban background & only 2.5% from semi-urban background.

As per Table 2, majority of the caregivers belonged to the age group 31-40 years. The mean age of the caregivers was 43.825 years. Hindu caregivers (95%) comprised the bulk of the study group. Majority of the caregivers (90%) were from rural background, followed by (7.5%) from urban and (2.5%) from semi-urban region. Majority of caregivers (67.5%) had duration of care of 1-4 years while 32.5% caregivers' duration of care was of 5-8 years. 42.5% of the caregivers were illiterate. 95% of the caregivers were married while only 5% were single. Majority (40%) of the caregivers were related as sons to the patients. Most of the caregivers (65%) were male while 35% of the caregivers were female. Most of the caregivers were from joint family 62.5% followed by 25% from nuclear family & only 12.5% from extended family.

Table 2. Socio demographic profile of the caregiver

Age of the Care givers (Years)	Number of care giver	Percentage
21-30	9	22.5
31-40	12	30
41-50	7	15
51-60	6	17.5
61-70	5	12.5
71-80	1	2.5
<b>Gender</b>		
Male	26	65
Female	14	35
<b>Marital status</b>		
Single	2	5
Married	38	95
<b>Educational status</b>		
Illiterate	17	42.5
Primary school	12	30
Middle school	4	10
High school	4	10
Intermediate	1	2.5
Graduate or Postgraduate	2	5
<b>Duration of Care</b>		
1-4 years	27	67.5
5-8 years	13	32.5
<b>Religion</b>		
Hindu	38	95
Muslim	2	5
<b>Locality</b>		
Rural	36	90
Urban	3	7.5
Semi-urban	1	2.5
<b>Urban</b>	3	7.5
<b>Semi-urban</b>	1	2.5
<b>Relation to Patient</b>		
Wife	12	30
Son	16	40
Daughter	2	5
Husband	9	2.5
Father	1	2.5
	<b>Type of family</b>	
Nuclear	10	25
Joint	25	62.5
Extended	5	12.5

Table 3. Distribution of caregivers by age with burden

Age (in years)	Mean burden	Standard Deviation	F Value	P Value	Remarks
21-30	81.55	±12.86	3.381	.014	Significant*
31-40	80.25	±11.67			
41-50	92.85	±14.69			
51-60	94.33	±5.00			
61-70	99.4	±4.15			
71-80	90	0			

Degree of freedom (df) = 5, \*significant at <0.05, SD-Standard deviation

ANOVA test was applied & it was found that, there was a significant difference in burden among the various caregivers by age with highest burden found in the age group of 61-70 years (mean 99.4).

Table 4. Distribution of caregivers by religion with burden

Religion	Mean burden	Standard deviation	t test	P value	Remarks
Hindu	87.13	±13.062	0.7857	.436	NS
Muslim	94.50	±6.364			

NS= Not significant, Degree of freedom (df) =38, SD-Standard deviation

Unpaired 't' test was applied & it was found that, there was a no significant difference in burden among the various caregivers by religion. Although it may be commented that burden is more in Muslim caregivers.

**Table 5. Distribution of caregivers by duration of care giving with burden**

Duration of care giving (in years)	Mean burden	Standard deviation	t test	p value	Remarks
1-4	82.44	±12.17	3.929	.000	Significant*
5-8	96.61	±6.36			

SD-Standard deviation, \*Significant at < 0.01, Degree of freedom (df)= 38

Unpaired 't' test was applied & it was found that, there was a significant difference in burden among the various caregivers by duration of care giving with highest burden found in 5-8 years of duration of care (mean 96.61).

**Table 6. Distribution of caregivers by educational level with burden**

Educational level	Mean burden	SD	F value	P value	Remarks
Illiterate	95.53	± 8.125	13.327	.000	Significant*
Primary school	90.58	± 8.586			
Middle school	78.25	± 7.136			
High school	70.25	± 7.229			
Intermediate	68.00	0			
Graduate or post graduate	63.50	± 2.121			

SD-Standard deviation, Degree of freedom (df) = 5, \*significant at <0.01

ANOVA test was applied and it was found that there was a significant difference in burden among the caregiver by various educational level with highest burden found in illiterate (mean=95.53) and lowest among graduate caregivers (mean=63.50)

**Table 7. Distribution of caregivers by locality with burden**

Locality	Mean burden	SD	F value	P value	Remarks
Rural	87.19	±11.705	4.335	.020	Significant*
Urban	73.3	±14.742			
Semi urban	65	0			

SD-Standard deviation, Degree of freedom (df) =2, \*significant at < 0.05

ANOVA test was applied and it was found that there was a significant difference in burden among the various caregivers by locality with highest burden found in rural group (mean 87.19)

**Table 8. Distribution of caregivers by family type with burden**

Family type	Mean burden	SD	F value	P value	Remarks
Nuclear	90.90	±11.799	3.52	0.040	Significant*
Joint	73.92	±11.302			
Extended	87.60	±16.622			

SD-Standard deviation, Degree of freedom (df) =2, \*significant at <0.05

ANOVA test was applied and it was found that there was a significant difference in burden among the various caregivers

by type of family with highest burden found in nuclear family (Mean 90.92).

**Table 9. Distribution of caregivers by marital status with burden**

Marital status	Mean burden	SD	t test	P value	Remarks
Single	72	±14.142	1.796	0.0803	NS
Married	86.31	±12.466			

SD- Standard deviation, Degree of freedom (d f) =38, NS= not significant

Unpaired 't' test was applied & it was found that, there was no significant difference in burden among the various caregivers by marital status. Though it may be commented that burden is more among married caregivers (mean 86.31).

**Table 10. Distribution of caregiver by sex with burden**

Sex	Mean burden	SD	t test	P value	Remarks
Male	88.69	±13.448	0.793	0.432	NS
Female	85.29	±11.861			

SD- Standard deviation, Degree of freedom (df) = 38, NS = not significant

Unpaired 't' test was applied & it was found that, there was no significant difference in burden among the various caregivers by sex. Although it may be commented that burden is more in male caregivers as compared to female.

**Table 11. Distribution of caregivers by relation to patient with burden**

Relation to patient	Mean burden	SD	F value	P value	Remarks
Wife	82.91	± 12.777	1.187	0.334	NS
Son	84.75	±14.754			
Daughter	87.0	±5.657			
Husband	89.88	±8.604			
Father	99				

SD- Standard deviation, Degree of freedom (df) =4, NS= not significant

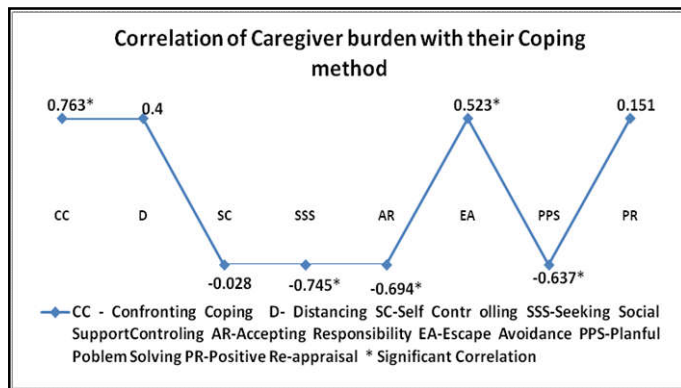
ANOVA test was applied and it was found that there was no significant difference in burden among the various caregivers by relation to patient. Although it may commented that burden is seen more among in father followed by husband (mean 99).

**Table 12. Distribution of care givers with respect to predominant coping behavior**

Coping behavior	No of caregivers	Percentage
Confronting coping	29	72.5
Distancing	24	60
Self-controlling	18	45
Seeking social support	18	45
Accepting responsibility	19	42.5
Escape avoidance	12	30
Planful problem solving	11	27.5
Positive reappraisal	14	35

All the caregivers in the study group used more than one style of coping behaviour. Most commonly used coping behaviors were "confronting coping" (72.5%) followed by "distancing" (60%) "Seeking social support" (45%), "self-controlling" (45 %)," accepting responsibility" (42.5%), "positive reappraisal" (35%), "escape avoidance" (30%) and "Planful

problem solving” (27.5%) was the least commonly used coping behavior.



Significant positive correlation (\*p value <0.01) was observed between caregiver burden & coping behaviors like “Confronting coping” & “Escape avoidance” which indicates that caregiver with higher burden adopted ‘confronting coping’, ‘escape avoidance’ as a coping style.

Statistical analysis reveals significant negative correlation (\*p value <0.01) observed between caregiver burden & coping behaviors like “seeking social support”, “accepting responsibility” and “planful problem solving” which indicates that caregiver with minimal burden or no burden adopted such type coping behavior.

## DISCUSSION

The mean age of the caregivers is 43.825 and mean burden of the caregivers is 87.50. By statistical analysis, it was seen in our study that caregivers of age between 61-70 years of age has more burden. Previous studies had similar findings (Khandelwal *et al.*, 2010) that older caregivers perceived more burden. Hindu caregivers comprised the bulk of the study group (95%) where as 5% were Muslim. This may be explained by the fact that Hindus are in majority in the catchment area of AMCH. Interestingly, it is seen that caregiver burden is more in caregivers from rural background, which could be due to lack of job opportunities to cover up their financial burden. In this study it was found that highest burden is in 5-8 years duration of care group. Previous studies have also found that the increased duration of illness & henceforth caregiving is associated with a higher burden in caregivers (Donaldson and burns, 1999; Gaugler *et al.*, 2005; Sink *et al.*, 2005). Interestingly, in this study it was found that highest burden was seen in caregivers from joint family. It may be explained from the fact that joint family system is quite prevalent in Indian society as in many other Asian societies and it may be expected that caregivers from these joint families would experience less burden, but sometimes he/she may not get enough assistance from the rest of the family (Shaji *et al.*, 2003), thereby leading to enhanced perception of burden. Significant burden was observed in those who were illiterate. Previous studies also had similar findings (Papastavrou *et al.*, 2007; Torti *et al.*, 2004). There was a significant difference in burden among various professions with high burden in unskilled workers (mean burden 98.5). This may be explained

by the predominance of rural patients. Previous studies also had similar findings that burden was related to caregiver income or employment status (Papastavrou *et al.*, 2007). Majority of our study group were from lower income group. There was a significant difference in burden among various income groups with high burden found in family income of Rs. ≤1600 which signifies that if income is low then burden is more. Previous study also had similar findings (Papastavrou *et al.*, 2007). In this study high burden was observed in married caregivers. Previous study also had similar findings (Abdollahpour *et al.*, 2012). In this study it may be commented that burden is seen more commonly among father followed by husband in relation with patient although it was not statistically significant. However, previous studies found that female caregivers to be more burdened as compared to male (Almberg *et al.*, 1998; Rinaldi *et al.*, 2005) (Donaldson and colleagues 1998). In this study it may be commented that burden is seen more commonly among male caregivers as compare to female. It may explained by the fact that in Indian families, the eldest male is often the head of family, makes important decisions pertaining to family welfare and is responsible for resolution of family conflicts. Previous studies found that female caregivers to be more burdened as compared to male (Almberg *et al.*, 1998; Rinaldi *et al.*, 2005) (Donaldson and colleagues 1998).

Statistically, this study found highest positive correlation between confronting coping and escape avoidance behavior with caregiver burden which signifies that caregivers who adopted such behaviors as a coping style had higher burden. These finding are well supported by previous studies Roolpalekha Jathanna *et al.*, (2010), Rukhsanakaasar and Graham E. Powel (1999), where they found that the above coping behaviors were associated with higher burden. Similarly, Sara Wilcox *et al.*, 2001, Young *et al.*, 2004; Valentina *et al.*, 2008 and Sun *et al.*, 2010, in their studies found that using avoidance coping strategies was associated with higher level of caregiver burden. In this study also reveals significant negative correlation of burden with “accepting responsibility” (Ian I. Kneebone *et al.*, 2003; Sun *et al.*, 2010), “seeking social support” (Brit Almberg UL *et al.*, 1997; Cooke *et al.*, 2001; Jathanna *et al.*, 2010) and “planful problem solving” (Rose and Colleagues, 1999; Endler and Parker, 1990; Carver, Scheier and Weintraub *et al.*, 1989) with caregiver burden. It signifies that burden is less in those who used the above coping behaviors to deal with burden.

## Conclusion

The various findings in our study have added to the growing evidence that Dementia can have serious consequences on families particularly the primary caregivers. This study demonstrates some of the important socio-demographic variables which have got influence on caregiver burden and therefore caregivers developed ways to alleviate burden, or more efficiently stated, cope. Results highlight the importance of improving the mixed coping skills in burdened caregivers. Therefore, the present study has given some insight in understanding the stress and burden among the caregivers of dementia patients.

## Limitations

The study sample was relatively small, The study being a hospital based may not reflect the true picture of the caregiver in the general Population, Some of the caregiver factors e.g. Personality of the caregiver, cultural background, and psychological profile were not assessed and may have influenced the caregiver responses. Severity of the Dementia was not assessed and may have influenced the caregiver responses.

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