



## COPING SKILLS OF CAREGIVERS OF PATIENTS WITH DEMENTIA

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### ABSTRACT

People living in the community with dementia are frequently supported by informal caregivers that are made up variously of spouses, other family members, friends or neighbours. Caregivers can experience negative mental and physical consequences as a result of the pressures of care giving. Resulting outcomes can include depression, strain, social isolation, financial burden and disruptions to sleep for the carer. Coping strategies play a fundamental role in modulating the psychological impact of the disease. The objective of this study was to identify coping skills among caregivers of patients with dementia. The sample comprised of 50 Caregivers of persons with dementia. The data collected from NIMHANS Geriatric Clinic. The patients who fulfilled the inclusion and exclusion criteria were identified based on information from the patient undergoing treatment at geriatric clinic in NIMHANS were selected using simple random sampling. The following tools were used for the current study: Socio-demographic data sheet was used to study the socio demographic details of the caregivers of persons with dementia and the Brief COPE developed by Carver, 1997 was used. It is seen that Substance use, Humor, Behavior Disengagement, Ventilation and Self-blame were found to have low mean. Self-Distraction, Active Coping, Denial Emotional, Support Instrumental Support, Positive Reinforcement, Planning and Acceptance were found to have moderate mean. Caregiving is one of the important aspects of the any persons who looked after the illness. The caregiving is not a simple task it involves various kinds of burden and distress. In many time caregivers are seriously affected their quality of life. In this connection this study was carried out to knowing the coping of the caregiver's of persons with dementia. Care services should facilitate easy access to counselling, relaxation, psychotherapy, and practical advice for those who needed it.

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### INTRODUCTION

Dementia has been defined as “An acquired syndrome of intellectual impairment produced by brain dysfunction. Which compromise at least three of the following shapes of mental ability, language, memory, visual spatial skills, emotion or personality and cognition (abstraction calculation, judgment and executive function” (Cummings, 1992.) Dementia may be distinguished from other forms of cognitive impairment by its persistent, progressive and often irreversible deterioration. Caregivers face many obstacles as they balance care giving with other demands, including child rearing, career, and relationships. They are at increased risk for burden, stress, depression, and a variety of other health complications (Cassie, 2008). The effects on caregivers are diverse and complex, and there are many other factors that may exacerbate or ameliorate how caregivers react and feel as a result of their role.

Numerous studies report that caring for a person with dementia is more stressful than caring for a person with a physical disability (Ory, 1999, Mohide, 1998, Schulz, 1990). Dementia leads to a burden of care which can manifest as strain in a number of ways that can be exacerbated (eg, by behavioral disturbance, physical or psychological ill-health in caregiver) or ameliorated (eg, by support, mature coping mechanisms). The findings of the study will help us to coping of care givers of person with dementia. It will give us an insight of need based programs addressing their concerns. Since the care giving personnel and persons with dementia are involved, it tends to be more practical and reality oriented.

### MATERIALS AND METHODS

The objective of this study was to identify coping skills among caregivers of patients with dementia. The sample comprised of 50 Caregivers of patients with dementia, who were coming to

NIMHANS Geriatric Clinic. The patients who fulfilled the inclusion and exclusion criteria were identified based on information from the patient undergoing treatment at geriatric clinic in NIMHANS were selected using simple random sampling. The interview schedule was administered for datacollection and data was gathered on every Saturday during the Geriatric Clinic. The researcher approached the clients who were diagnosed with dementia and took informed consent from the caregivers of persons with dementia. The following tools were used for the current study: Socio-demographic data sheet was used to study the socio demographic details of the caregivers of patients with dementia who were coming to geriatric clinic in NIMHANS and the Brief COPE developed by Carver, 1997was used.

## RESULTS

**Table-1** Socio demographic variables

Variables	Frequency	Percentage
<b>Caregiver age classification</b>		
25-35	21	42 %
36-45	10	20 %
46-55	9	18 %
56-65	6	12 %
66-75	4	8 %
<b>Family type</b>		
Joined	14	28 %
Nuclear	36	72 %
<b>Religion</b>		
Hindu	45	90 %
Muslim	3	6 %
Christian	2	4 %
<b>Domicile</b>		
Rural	22	44 %
Urban	28	56 %
<b>Educational Qualification</b>		
Illiteracy	4	8.0%
Primary	10	20.0%
High school	8	16.0%
PUC	15	30.0%
Graduate and above	13	26.0%
<b>Occupation</b>		
Business	5	10 %
Farmer	7	14 %
Government	7	14 %
Retired government servant	4	8 %
Private	9	18 %
Home maker	15	30 %
Unemployed	12	4 %
Daily wage labourer	1	2 %

The results show the different age categories of caregivers of dementia such as 42% of caregivers between the age group of 25-35 years, 20% between 36-45 years, 18% between 46-55 years, 12% between 55-65 years and similarly 8% of caregivers of dementia 66-75 years.

**Table 2** The various coping strategies utilized by the caregivers

Coping Strategies	N	Range	Min.	Max.	Mean	SD
Self Distraction	50	4.00	2.00	6.00	4.5400	.83812
Active Coping	50	6.00	2.00	8.00	5.7000	1.21638
Denial	50	6.00	2.00	8.00	4.7000	1.28174
Substance Use	50	5.00	2.00	7.00	2.5000	1.09265
Emotional Support	50	6.00	2.00	8.00	5.6400	1.20814
Instrumental Support	50	5.00	3.00	8.00	5.5600	1.19796
Behavioural disengagement	50	5.00	2.00	7.00	3.6200	1.44123
Ventilation	50	5.00	2.00	7.00	3.6000	1.08797
Positive Reinforcement	50	6.00	2.00	8.00	5.4000	1.57791
Planning	50	5.00	3.00	8.00	5.3200	1.33156
Humour	50	4.00	2.00	6.00	2.4200	.92780
Acceptance	50	5.00	2.00	7.00	5.2600	1.24228
Self Blame	50	6.00	2.00	8.00	2.6600	1.17125

In terms of family type, the study revealed that 72% of the caregivers belonged to nuclear family and 28% belonged to

Joint family. In terms of religion the study sample shows that 90% of the caregivers were belonging to Hindu religion, 6% were Muslim and remaining4% were belonging to Christian. The result suggests that the majority of caregivers 56% were from urban background and 44% of the caregivers from rural background. The result shows that majority of i.e 30% of the caregiver were homemaker, 18 % were private job holder, 14 % were farmers, 14% were Govt servants, 10% were business, 8% were Retd Govt servants, 6% were private job, 2% were daily wage labourer and 4% were unemployed. The result also shows that majority of the caregiver studied up to PUC 30%, graduation and above were 26%, 20% were primary , 16% were high school, and 8% were studied up to illiterate.

The above table depicts the various coping strategies utilized by the caregivers. It is seen that Substance use, Humour, Behaviour Disengagement, Ventilation and Self blame were found to have low mean. Self Distraction, Active Coping, Denial, Emotional Support, Instrumental Support, Positive Reinforcement, Planning and Acceptance were found to have moderate mean.

## DISCUSSION

The results show that majority the caregiver age groups between 25-35 years (42%), were studied up to PUC (30%) and mostly were home Maker (38%), maximum no of were belonging Hindu religion 45(90%), were staying in urban area is28 (56%) , nearly three fourth 36(72%) of the caregivers belonged to nuclear family type. This study results match with previous study done by Rosdinom (2001) and the author found that most of the caregivers were in the middle age group (mean age of 49.23 years), about two-thirds (66.2%) were female, more than half (55.4%) were Malays, majority were married (81.5%), mostly were patients' own daughters (40%), still employed (55.4%), and enjoyed shared caregiving with other family members (58.5%). Most of them had educational level up to secondary school level (43.1%) and reported no financial difficulties (81.5%).The present study results suggests that Substance use, Humour, Behaviour Disengagement, Ventilation and Self blame were found to have low mean. Self Distraction, Active Coping, Denial, Emotional, Support Instrumental Support, Positive Reinforcement, Planning and Acceptance were found to have moderate mean. It also shows most of the caregivers were using less negative coping and using positive coping strategies. Family caregivers present difficulties in handling coping with the diagnosis and the disease challenges as the disease progresses into later stages (AA, 2009; Boise).

An increment in the stressors and the burden experienced by family caregivers, result in adverse health outcomes (Cooper,

Donelan, *et al.*, 2002; Paun, Farran, Perraud, & Loukissa, 2004).

## CONCLUSION

Caregiving is one of the important aspects of the any persons who are look after the persons with any lines. The caregiving is not a simple task it involves various kinds of burden and distress. In many time caregivers are seriously affected their quality of life. In the meantime giving care for the persons with dementia is very difficult task because of their memory impairment and the decline in their various type of functioning. Even though they are bringing problems like visiting unknown persons 's house and giving trouble to them because of their memory impairment and absconding form the home is also causing lot of problems for the caregivers. In this connection this study was carried out to knowing the coping of the caregiver's of patients with dementia. Care services should facilitate easy access to counselling, relaxation, psychotherapy, and practical advice for those who needed it. These types of study and intervention should be part of statutory service provision. The present study would be useful to address these issues and outcome of the study can become a knowledge base for the hospital and government to frame welfare programmes and policies for treatment and rehabilitation of the caregivers and patients of dementia.

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