



# EVALUATING THE COPING STRATEGIES OF CAREGIVERS AMONG PATIENTS OF DEMENTIA

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## **ABSTRACT**

Being a caregiver for a person with dementia can be problematic and sometimes unnerving. Impatience is an emotional reaction to many of the problems of being a carer. Although some discomfort may be an integral component of caregivers' daily life, the feeling of intense frustration can severely affect him or the individual cared for. Frustration and stress can affect the physical health or make the carer aggressive towards the loved one physically or verbally. If care causes severe frustration or anger, the caregiver needs to discover innovative methods of coping.

**Objective:** This study was intended to evaluate the coping strategies of caregivers while caregiving among patients of Dementia.

**Method:** A total sample of 25 caregivers of elderly patients of dementia was selected by purposive sampling method from Ahmedabad, Gujarat. The sample consisted of 13 male and 12 female caregivers.

**Tool:** The Coping Strategies Inventory (CSI) by Tobin, Holroyd, & Reynolds (1995) was selected as tool. It has two subcategories – Problem focused and emotion focused strategies. Administration, scoring and interpretation were done as per the test manual. The collected data was then statistically analysed by using the Student's 't' test.

**Results and Conclusion:** The findings demonstrated the important difference between the gender of caregivers with regards to the two secondary subscales of the Inventory that is, Problem Focused Engagement (PFE) and Problem Focused Disengagement (PFD). The difference was indicative from the mean scores of the two subscales which was high among the males in comparison to the females. The other two secondary subscales Emotion Focused Engagement (EFE)

and Emotion Focused Disengagement (EFD) showed no significant difference. The overall mean scores of the coping strategies inventory showed no significant difference.

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*Index Terms: Caregivers, Coping Strategies, Dementia.*

## Introduction

Dementia is an umbrella term for several diseases affecting memory, other cognitive abilities and behaviours that significantly interfere with a person's ability to maintain his or her daily life activities. Although age is the strongest known risk factor for dementia, it is not a normal part of ageing. This influences memory, perception, orientation, comprehension, evaluation, capacity to learn, language and opinion. Consciousness is not affected. Impairment of cognitive function is frequently followed by impairment of moral regulation, social interaction, or motivation, and sometimes preceded by it.

Dementia affects each person in a particular way, depending on the severity of the disease and the temperament of the person before getting ill. The signs and symptoms associated with dementia can be identified in three stages.

**Early stage:** The early stage of dementia is usually neglected, because the progression is incremental. Common symptoms include:

- forgetfulness
- losing track of the time
- becoming lost in familiar and common places.

**Middle stage:** The signs and symptoms are becoming clearer and more restrictive as dementia progresses to the middle stage. These include:

- becoming forgetful of recent events and people's names
- becoming lost at home
- increasing difficulty with communication
- needing help with personal care
- experiencing behavioural changes, including wandering and repeated questioning.

**Late stage:** the late stage of dementia is one of near total dependence and inactivity. Memory disturbances are serious and the clinical signs and symptoms are more apparent. They include:

- becoming unaware of the time and place
- having difficulty recognizing relatives and friends
- having an increasing need for assisted self-care
- having difficulty walking
- experiencing behaviour changes that may escalate and include aggression.

There are nearly 10 million new cases every year. The estimated proportion of the general population aged 60 and over with dementia at a given time is between 5-8%.

Dementia is one of the main causes of impairment and dependence among elderly people worldwide. It can be devastating, not just for the people who have it, but also for their carers and families. There is indeed a lack of knowledge and awareness of dementia which results in stigmatization including diagnostic and care barriers. Dementia may have physical, psychological, social and economic effects on carers, the family and society at large.

Caring for someone who has Dementia can be difficult and stressful. It is crucial for the caregiver to take care of self. Some of the greatest obstacles while caring for a loved one with dementia are the changes in personality and behaviour that often occur. Caring for a dementia person is gruelling work, and it can be incredibly frustrating and stressful, if you don't know what to expect as the dementia progresses and deteriorates. Witnessing these new behaviours and complications in the loved one can be disturbing and confounding.

Using the following constructive approach for many caregiving tasks will allow loved ones with dementia to better understand what is happening and reduce anxiety, particularly in the middle to late stages of dementia.

- *Approach from the front:* This will help loved ones with dementia be aware that someone is coming. Approaching from the back can produce anxiety.
- *Walk slowly:* Allow time for loved ones with dementia to take in that someone is approaching.
- *Stand to the side:* This is a supportive stance, whereas standing right in front of persons with dementia may feel intimidated.
- *Call persons with dementia by name:* Use their names to get their attention. As dementia progresses, persons may respond best to their first names, as people often remember their given names the best.
- *Crouch low:* Crouching down if persons with dementia are seated or lying down helps them to feel less threatened.
- *Offer a hand:* Responses to this gesture will give caregivers an idea of whether persons with dementia would welcome further touch, such as hugs. While touch can be reassuring and pleasant, people differ as to whether or not they like to be touched.

**Coping Strategies** means investing one's own conscious effort, solving personal and interpersonal issues, trying to master, reduce or endure tension and conflict. The psychological coping mechanisms are commonly termed *coping strategies* or *coping skills*. The term coping generally refers to adaptive (constructive) coping strategies. That is strategies which reduce stress.

The coping effort's effectiveness depends on the type of stress, the person and the situations. Coping responses are controlled partly by personality (usual traits) but also in part by the social environment, especially the nature of the stressful environment.

Two different coping strategies-

*Problem-focused strategy -*

This technique relies on constructive ways to address the situation that caused the stress directly: you have to focus on the issue. Here are some examples:

- Analyze the situation - Pay attention, avoid taking on more responsibility than one can manage.
- Work harder and complete the task.
- Apply what you have already learned to your daily life.

*Emotion-focused strategy -*

Emotion-focused coping mechanisms are used to deal with feelings of distress, not the actual problem situation.

Focus is on emotions:

- Brood then accept new tasks instead of saying “no”, and keep complaining and saying it is unfair.
- Imaginary / Magic oriented thinking
- Avoid / Deny
- Blame game
- Social support

### **Objective of the present study:**

This study was intended to evaluate the effective engagement (problem focused and emotion focused engagement) or disengagement (problem focused and emotion focused disengagement) of coping strategies of caregivers while caregiving among elderly patients of Dementia.

## Hypotheses

The main hypotheses for the present research are as follows:

### Null Hypothesis:

- There will be no significant mean difference between scores of engagement coping strategies (problem or emotion focused engagement) and caregivers' gender (male and female) of elderly patients of Dementia.
- There will be no significant mean difference between scores of disengagement coping strategies (problem or emotion focused disengagement) and caregivers' gender (male and female) of elderly patients of Dementia.
- There will be no significant mean difference between scores of coping strategies and caregivers' gender (male and female) of elderly patients of Dementia.

## Methodology

**Sample:** The total sample consisted of 25 caregivers of elderly Dementia patients from the various hospitals and clinics in Ahmedabad, Gujarat were approached. They willingly became the part of this study as to give the necessary details. Since the study was of the elderly patients therefore the patients' age, whose caregivers were considered was above 65 years. To constitute the sample purposive sampling technique was used. Efforts have been made to select the sample as inclusive as possible with regards to the gender of caregivers. Proper rapport was established with the caregivers and was informed about the confidentiality of their details.

## Variables:

### Independent Variable:

- Gender: Male and Female

### Dependent Variable:

- The scores of Coping Strategies Inventory

## Research Measures:

### Inclusion Criteria:

- Only clinically diagnosed patients of Dementia by the Neurologists were considered.
- Gender of Caregivers of Dementia patients.



- Elderly patients of Dementia between 65 years to 75 years.

### Exclusion Criteria:

- Younger patients of Dementia who were below 65 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) For data on demographic features of participants, a personal information sheet has been used.

2) The Coping Strategies Inventory (CSI; Tobin, Holroyd, & Reynolds, 1995):

The Coping Strategies Inventory (CSI; Tobin, Holroyd, & Reynolds, 1995) is a 32-item self-report questionnaire that assesses methods of coping via thoughts and behaviors in response to a specific stressor. Responses are rated on a 5-point Likert scale (1 = none to 5 = very much). There are four secondary sub-scales includes eight primary scales of the CSI.

- *Problem Focused Engagement*: It includes Problem Solving and Cognitive Restructuring subscales which involves cognitive and behavioural strategies to change the situation or change the meaning of the situation for the individual. These coping efforts are focused on the stressful situation itself.
- *Problem Focused Disengagement*: It includes both Problem Avoidance and Wishful Thinking. The items reflect denial, avoidance, and an inability or reluctance to look at the situation differently. They reflect the cognitive and behavioural strategies to avoid the situation.
- *Emotion Focused Engagement*: It includes both Social Support and Express Emotions. The items reflect open communication of feelings to others and increased social involvement especially with family and friends. These coping efforts are focused on the individual's emotional reaction to the stressful situation.
- *Emotion Focused Disengagement*: It includes Social Withdrawal and Self Criticism. It involves shutting oneself and one's feelings off from others and criticizing or blaming oneself for what happened.

The reliability coefficient by Cronbach's alpha = 0.80. The validity of the scale was found by construct and criterion validity through several studies.

### Data Collection and Procedure:

The sample was drawn from 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 the caregiver was well informed about the purpose of the research. Before beginning the data collection a written consent was taken with the assurance that the data and name shall not be disclosed 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 and Interpretation:

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 Coping Strategies: Secondary Subscale 1 – Problem Focused Engagement for male and female caregivers of elderly patients of dementia:**

Group	N	Mean	SD	t value	Table Value	Level of Significance
Male	13	30.07	2.72	2.24	2.07	0.05
Female	12	27.75	2.45			

\*\* Significant at 0.01 level, \* significant at 0.05 level and NS Not significant

As it can be seen from above table the two groups under study differ significantly in relation to problem focused engagement coping strategy. According to scoring pattern, higher score indicated better coping strategy in terms of problem solving and cognitive restructuring. Thus from the result it could be said that male caregivers group show better behavioural and cognitive strategies in a stressful situation as compared to female caregivers of elderly patients of dementia.

**Table: 1(b)**

**Showing mean, SD and “t” value of Score of Coping Strategies: Secondary Subscale II – Problem Focused Disengagement for male and female caregivers of elderly patients of dementia:**

Group	N	Mean	SD	t value	Table Value	Level of Significance
Male	13	28.0	2.34	1.26	-	NS
Female	12	29.25	2.56			

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

As it can be seen from above table the two groups under study do not differ significantly in relation to problem focused disengagement coping strategy. According to scoring pattern, higher score indicated more application of problem avoidance and wishful thinking as coping strategies which is higher in female caregivers as compared to male caregivers. It clearly reflects denial, avoidance, and an inability or reluctance to look at the situation differently.

**Table: 1(c)**

**Showing mean, SD and “t” value of Score of Coping Strategies: Secondary Subscale III – Emotion Focused Engagement for male and female caregivers of elderly patients of dementia:**

Group	N	Mean	SD	t value	Table Value	Level of Significance
Male	13	18.15	3.44	2.81	2.81	0.01
Female	12	16.58	2.10			

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

As it can be seen from above table the two groups under study differ significantly in relation to emotion focused engagement coping strategy. According to scoring pattern, higher score indicated better coping strategy in terms of social support and expressing one's emotions. Thus from the result it could be said that male caregivers group show better emotional reactions in a stressful situation as compared to female caregivers of elderly patients of dementia.

**Table: 1(d)**

**Showing mean, SD and “t” value of Score of Coping Strategies: Secondary Subscale IV – Emotion Focused Disengagement for male and female caregivers of elderly patients of dementia:**

Group	N	Mean	SD	t value	Table Value	Level of Significance
Male	13	14.61	1.44	0.47	-	NS



Female	12	14.33	1.49			
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\*\* Significant at .01 level, \* significant at .05 level and NS Not significant

As it can be seen from above table the two groups under study do not differ significantly in relation to emotion focused disengagement coping strategy. According to scoring pattern, higher score indicated more social withdrawal and self criticism. It involves shutting oneself and one's feelings off from others and criticizing or blaming oneself for what happened.

**Table: 1(e)**

**Showing mean, SD and “t” value of Score of Coping Strategies for male and female caregivers of elderly patients of dementia:**

Group	N	Mean	SD	t value	Table Value	Level of Significance
Male	13	90.84	4.16	1.74	-	NS
Female	12	87.91	4.20			

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

As it can be seen from above table the two groups under study do not differ significantly in relation to coping strategy in stressful situations. According to scoring pattern, higher score indicated better coping strategies which were seen among male caregivers as compared to female caregivers.

## Discussion

In the Asian country like India, caregiving was a universal concept which was conventionally prevalent in the family. Elderly Dementia patients rely heavily on their carers and need lot of support and acceptance from them. The present study is viewed in the light of coping strategies implied while providing care to elderly dementia patients. The results showed that male caregivers group had higher mean scores as compared to female caregivers with regards to the coping strategies and its engagement (problem focused and emotion focused) and disengagement (problem focused and emotion focused) dimensions. *Women tend to provide more hours of care, more hands-on care, and are involved in more tasks than are men (Calasanti & Bowen, 2006).* Female caregivers are usually the homemakers and stay at home for longer hours and the responsibility of the entire family is on their shoulders. They are not well appreciated for the accountability of the added task of caregiving for patient of dementia. Any kind of

caregiving whether its family or work or for a patient of chronic illness is considered to be the part of their routine. In such cases of caregiving to the patient of chronic illnesses like Dementia keeps the caregiver on toes. The care continues for longer duration therefore the stress is likely to develop.

Managing the caregiving task for the elderlies having dementia along with effective coping strategies is very crucial. It cuts down the social life of the person and staying in the same environment for longer duration is very critical. Going out with family and friends and enjoying such moments are almost very less to none especially for female caregivers. This in turn increases their stress and makes the task of caregiving burdensome thus inversely decreasing the behavioural and cognitive strategies with regards to the problem solving and cognitive restructuring approach which is a most important factor of problem focused engagement coping strategy. Emotion focused engagement is about the social support and expressing emotions. Females are good in expressing and sharing emotions among their group whereas males utilize their social support effectively. Disengagement coping strategy (problem focused and emotion focused) results are non significant as it deals with problem avoidance and wishful thinking, and social withdrawal and self criticism respectively. It is due to the extremity of the task; here male and female caregivers show no significant difference. Overall coping strategies of male and female caregivers has shown no significant difference as deteriorating mental or physical health of the dementia patient raises sad feeling or concern among the caregivers as they have to see their loved one in such condition along with this their own stress constricts the effective implication of coping strategies in the situation that can change or worsen anytime.

A similar study was found where the task of caregiving shows burden symptoms among family caregivers with regards to ineffective coping strategies.

**Chen, H. M., Huang, M. F., Yeh, Y. C., Huang, W. H., & Chen, C. S. (2015): Effectiveness of coping strategies intervention on caregiver burden among caregivers of elderly patients with dementia. Psychogeriatrics-**

The purpose of this research was to review the results of Coping Strategies are a potential way to improve interventions designed to manage the caregiver burden of dementia. The purpose of this study was to develop an intervention targeted towards improving coping strategies and to examine its effectiveness on reducing caregiver burden. A controlled study design was used. Fifty-seven caregivers of dementia patients were enrolled. Coping strategies were assessed with the Revised Ways of Coping Checklist (WCCL-R) and caregiver burden was assessed with the Chinese version of the Caregiver Burden Inventory. The participants were randomly divided into two groups. The intervention group was offered a series of five interventions in which problem-solving skills, knowledge of dementia, social resources, and emotional support were taught every 2 weeks, and the control group was telephoned every 2 weeks for the usual clinical management. Two weeks after the end of the intervention, we again administered the WCCL-R and the Caregiver Burden Inventory. Two-way repeated-measure ANOVA was used to evaluate the changes in coping strategies and caregiver burden. Forty-six participants completed the study. **No statistically significant differences were noted in the demographic data between the two groups.** On the

problem-focused coping subscale on the WCCL-R, the intervention group's mean score increased by 3.8 points, and the control group's decreased by 5.1 points ( $F = 7.988$ ,  $P = 0.007$ ). On the seeking social support coping subscale on the WCCL-R, the intervention group's mean score increased by 3.8 points, and the control group's decreased by 3.1 points ( $F = 4.462$ ,  $P = 0.04$ ). On the Caregiver Burden Inventory, the intervention group's mean score decreased by 7.2 points, and the control group's increased by 2.2 points ( $F = 6.155$ ,  $P = 0.017$ ). Psychosocial intervention can help caregivers to adopt more problem-focused and social support coping strategies, which are beneficial in terms of reducing the caregiver burden.

On the whole a family is an essential element in one's life having dedicated, unconditional desire to provide a loving and caring home. Thus caregiving happens as a natural phenomenon. Hence,

making caregiving an incredibly critical job and getting a deeper understanding of the issues faced by caregivers.

### **Conclusions:**

Social acceptance and awareness of the elderly patients with dementia is required. They are going through a lot of emotional upheaval and stress. This makes caring very critical, because caregivers do have many issues that adversely affect their mental and physical health. Especially female caregivers are restricted to the household and have more responsibilities to the shoulder, making their task and responsibilities very exhaustive. Their emotional issues are more prominent diminishing their coping strategies. Being natural nurturer; hence the emotions of others are more important for them than their own. In countries like India, females tend to keep their family ahead of their own issues and concerns always. Therefore it is essential for all family members to contribute and express empathy for caregivers as well as the elderly patients with dementia.

### **Limitations and Suggestions**

The present study, just like other studies too has its own limitations. Owing to time constraint, the data has been collected from Ahmedabad city, Gujarat only. Further studies can be done and conducted in the other cities and states. The sample too was restricted up to 25 caregivers of Dementia patients; therefore the results cannot be generalized on a wider population using various psychological dimensions. Certain factors may also be considered about the effects of inadequate coping mechanisms on some kind of physical or mental disorders or vice – vice versa.

### **Implications of the present research**

The present work should be implemented to gain a broader understanding of carers for the 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, extend the training of health caregivers to build efficient relation elderly people with Dementia along with the preservation of their own mental and physical well-being.

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