

# Resilience of the Caregivers Attending to Alzheimer's Patients

## ABSTRACT:

The study used to measure resilience of the caregivers attending to Alzheimer's patients. Twin cities of Hyderabad and Secunderabad were selected and total 60 caregivers were selected purposively for conducting the present study. Multidimensional scale of perceived social support scale which was developed by Zimet, Dahlem & Farley (1988) was used to measure perceived social support of caregiver and resilience was measured by using Connor-Davidson Resilience Scale (CD-RISC) which was developed by Kathryn M. Connor and Jonathan R.T. Davidson (2003). Results showed that there was no significant impact of caregiver's demographic profile except relationship with the patient. And patient demographic profile had no significant impact on resilience of the caregiver. Multidimensional perceived social support had no significant impact on resilience of the caregiver. Hence it can be concluded that resilience is an individual characteristic.

**Key words:** Resilience; Social support; Alzheimer's; Caregivers

## INTRODUCTION:

"Dementia" is an impairment in a person's ability to "mentate" (thus, de-mentia). "Mentation" can involve memory, planning, and placing actions in the right sequence. So when a person has dementia symptoms, it means that they are unable to do this, in one way or another. (Hello Care - Journalist Team 2017). Dementia is a broad category of brain diseases that cause a long-term and often gradual decrease in the ability to think and remember that is great enough to affect a person's daily functioning. The most common type of dementia is Alzheimer's disease, which makes up 50% to 70% of cases. Other common types include vascular dementia (25%), Lewy body dementia (15%), and frontotemporal dementia.

The terms "Alzheimer's" and "dementia" are often used interchangeably, but the conditions are not the same. "Dementia" is a term that means a person is no longer able to function on their own because of a lasting impairment of multiple mental abilities affecting memory, attention, and reasoning.

AD is an irreversible, progressive brain disorder that slowly destroys memory and thinking skills, and eventually the ability to carry out the simplest tasks. In most people with Alzheimer's, symptoms first appear in their mid-60s. Estimates vary, but experts suggest that more than 5 million Americans may have Alzheimer's. (National Institute on Aging-2017)

A caregiver or carer is an unpaid or paid member of a person's social network who helps them with activities of daily living. Caregiving is most commonly used to address impairments related to old age, disability, a disease, or a mental disorder. Typical duties of a caregiver might include taking care of someone who has a chronic illness or disease; managing medications or talking to doctors and nurses on someone's behalf; helping to bathe or dress someone who is frail or disabled; or taking care of household chores, meals, or bills for someone who cannot do these things alone. Caregivers are important in the daily lives of Alzheimer's patients because they provide consistent care in a comfortable and familiar environment, both of which are necessary in providing care for individuals diagnosed with Alzheimer's disease (Alzheimer's Association, 2007).

Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress — such as family and relationship problems, serious health problems or workplace and financial stressors. It means "bouncing back" from difficult experiences.

A diagnosis of AD can be a heart-wrenching experience for both the person diagnosed and the caregiver. Alzheimer's disease is called a family disease, because the chronic stress of watching a loved one slowly decline affects everyone.

Naslund *et al.*, (2009) the findings from this study shows that psychological resilience was significantly associated with the well-being of spouses of persons with Alzheimer disease. The results suggest that the contribution of psychological resilience differs in strength and composition across various indices of caregiver well-being.

Wilks (2008) found stress was negatively influenced and accounted for most variation in resilience where as social support positively influenced resilience, and caregivers with high family support had the highest probability of elevated resilience.

Dias (2016) research findings indicated that caregivers' resilience was inversely related to their own depressive symptoms and anxiety. Caregivers with higher scores on resilience also showed higher scores in caregiver quality of life. The linear regression indicated that resilience was significantly related to the depressive symptoms ( $p < 0.01$ ) and the quality of life ( $p < 0.01$ ) experienced by the caregivers. Resilience is considered to act as a protective factor by increasing the quality of life.

Rutter (2012) found that resilience was an inference based on evidence that some individuals have a better outcome than others who have experienced a comparable level of adversity; moreover, the negative experience may have either a sensitizing effect or a strengthening "steeling" effect in relation to the response to later stress or adversity

Maintaining a close network of family and friends will be helpful for getting social and emotional support. This support plays a major key role in caregivers Alzheimer's in terms of providing day-to-day care in those who care for a loved one with Alzheimer's disease. Social support is a crucial element in keeping caregivers healthy.

Casado *et al.*, (2018) investigated on social support and subjective burden in caregivers of adults and older adults. Results revealed that there was a moderate, negative association of perceived social support on subjective burden ( $r = -0.36$ ; CI 95% = -0.40, -0.32).

Shurgot and Knight (2005) studies have shown that perceived positive social support was inversely related to burden; however. Multiple hierarchical regression indicated that neuroticism and patients' behavioral problems were significantly and positively related to burden.

One in ten people of age 65 and older have Alzheimer's. 89% increase deaths due to Alzheimer's between 2000 and 2014. Deaths from Alzheimer have nearly doubled during this period while those from heart disease –the leading cause of death have declined. 1 in 3 seniors dies with AD (National Center for Health Statistics of the Centers for Disease Control and Prevention -2014).

As the disease prevalence is increasing tremendously day by day, burden on Caregivers are also increasing and they are facing many difficulties with the patients and only some of the Caregivers are bouncing back. As Alzheimer's caregivers frequently report experiencing high levels of stress. It can be overwhelming to take care of a loved one with Alzheimer's, but too much stress can be harmful to the caregiver. More than 40% of family caregivers report that the emotional stress of their role is high or very high (Alzheimer disease International).

Surprisingly not many researches were generated on Resilience in caregivers of Alzheimer patients in India. Hence it is proposed to study "**Resilience of Caregivers attending to Alzheimer patients**". The present study was proposed to study the extent of resilience in Alzheimer's disease caregivers and their ability to withstand adversity and this study seeks to identify whether social support had its impact on resilience of caregiver or not.

## THEORETICAL FRAME WORK:

### Family stress theory -The Resiliency Model

Family stress theory The Resiliency Model was influenced largely by family stress theory and its counterpart framework, family resilience theory. The stress model is often used in research on resilient families (McCubbin & McCubbin, 1988). It makes five assumptions about family life: (i) hardships and changes are a natural part of family life; (ii) in the face of changes, families develop basic skills, patterns of functioning and abilities to promote the growth and development of family members and protect them against major stressors; (iii) such competencies are likewise developed to foster the family's recovery following a major crisis or transition; (iv) families draw from and contribute towards the network of resources and relationships in their community, particularly during stressful periods; and (v) families faced with a crisis situation strive to restore harmony, balance and order even in the midst of change.

In applying family stress theory, two general propositions have guided the study of resilient families. Firstly, when a resilient family faces a normative stressor, it will use the instrumental and expressive resources within the family to protect itself from damage and to promote adequate adjustment. Similarly, the second proposition suggests that when a resilient family faces a non-normative stressor, it will also employ these resources to prevent damage and promote adjustment.

## **The Resilience Theory**

The Resilience Theory states that resiliency is determined by both risk and protective factors (Greff, Vansteenwegen& Ide, 2006; Zauszniewski, Bekhet&Suresky, 2009).

**The Risk Factors:** These are the factors that pose a threat to caregiver resilience and mental health, examples of these include elements such as stigma, isolation and occupational restrictions. In relation to cognition, an example of a risk factor could be if a caregiver choses to appraise their situation as life threatening, burdensome and stressful

**The Protective Factors:** These are factors that facilitate and foster resiliency. They tend to focus predominantly on positive cognitions. These factors improve a caregiver's response to stress and strain, producing a positive outcome .There are said to be 7 main determinants for conquering adversity in order to become resilient, stronger, more flexible and healthier. They are 1. Acceptance, 2. Hardiness, 3.Mastery, 4.Hope/Optimism,5.Self-efficacy,6.Sense of coherence, 7.Resourcefulness

A 'resilient survivor' is an individual with a combination of damages and strengths; however they predominantly hold positive insights, independence, positive interpersonal relationships, initiative and humor (Marsh et al., 1996).

## **MATERIALS AND METHODS:**

Ex-post facto research design was used for the present investigation to know the resilience in caregivers attending to Alzheimer's patients. The data from the respondents was collected by both standardized and self constructed interview schedule, which includes the measurement of variables under investigation. Twin cities of Hyderabad and Secunderabad were selected for conducting the study. Total 60 caregivers were selected purposively for conducting the present study. Relationship between independent variables and dependent variables were studied. Independent variables consists of both caregiver and patient particulars. Caregiver variables includes age, education level, occupation, socio-economic status, perceived social support of caregiver. Patient variables includes age, gender, illness duration, illness stage, illness severity, frequency of hospital visit, other associated problems .Dependent variable of the present study was resilience of the caregiver.

Self developed interview schedule was used to collect demographic profile. Perceived Social support was measured by using Multidimensional scale of perceived social support which was developed by Zimet, Dahlem & Farley (1988).This scale consists of 12 questions relating to the extent to which they feel they feel they have support of their family, friends and a special person. Each of these forms a separate subscale relating to perceived support from a significant other subscale, from friends and from family. This scale was a seven point rating scale: very strongly agree (1), Strongly disagree (2),Mildly disagree(3),Neutral(4),Mildly agree (5),Strongly agree (6),very strongly agree(7).Resilience of the caregiver was measured by The Connor-Davidson Resilience Scale (CD-RISC) which was developed by Kathryn M. Connor and Jonathan R.T. Davidson as a means of assessing resilience.(CD-RISC) comprises of 25 items, each rated on a 5-point scale: Not at all true (1), Rarely true (2),Sometimes true (3),Often true(4),very much true (5) with higher scores reflecting greater resilience.

## **RESULTS AND DISCUSSION:**

The data was gathered for statistical analysis by using questionnaires from caregivers of Alzheimer's patients.

It was observed from the above Fig-1 that 41% of caregivers reported that they were having high resilience, 48% were having moderate resilience and 10% of the caregivers were having low resilience.

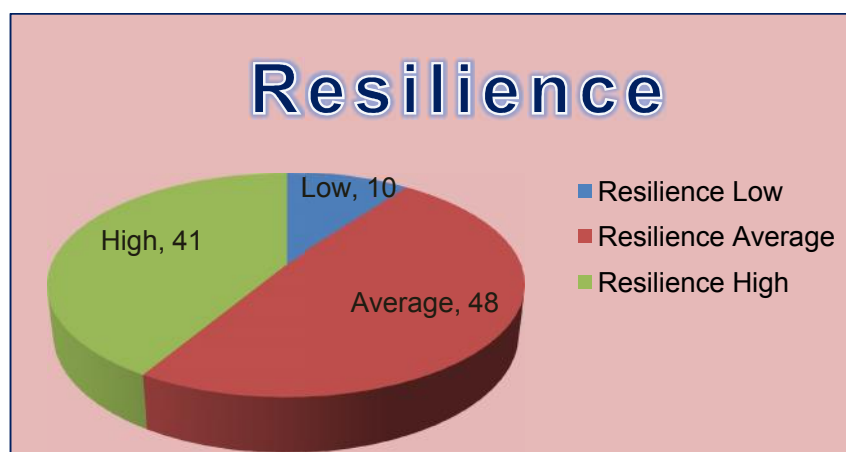


**Fig. 1. Resilience of the caregivers attending to Alzheimer's patients**

From the Fig 2 it was observed that with regard to caregivers getting social support from others 80% of caregivers were received high social support, 15% of caregivers received moderate support and 5% of caregivers received very low support. Regarding receiving social support from family members 78% of caregivers were received high support, 18% caregivers received moderate support and only 3% of caregivers low level of family support. Social support in terms of friends 58% of caregivers reported that they were received high support, 35% of caregivers were received moderate support and 7% caregivers received very low support.

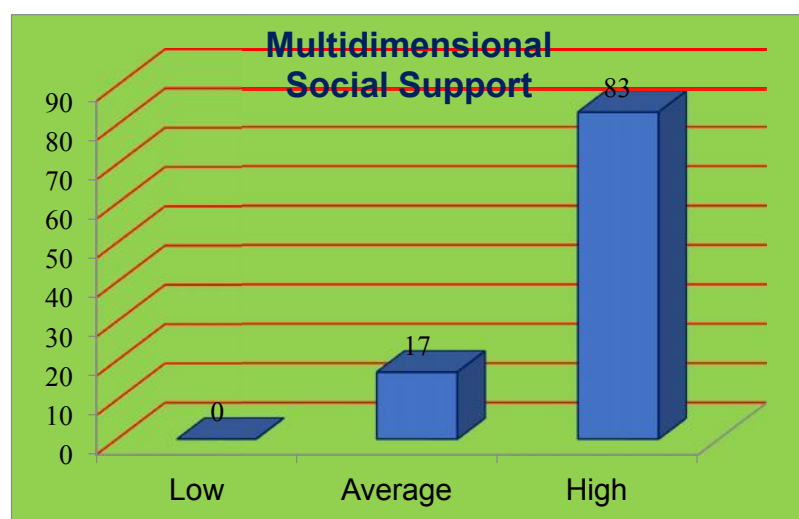


**Fig. 2. Perceived social support of the caregivers attending to Alzheimer's patients**

The regression analysis was used to test the influence of independent caregiver variables like age, gender, education, occupation, religion, marital status, number of marital years, number of dependents in the family, income of the family and relationship with the patient on dependent variable resilience and found none of the caregivers demographic profile was significant determinant of caregiver's resilience except relationship with the patient. The findings of present study was in line with the Dias *et al* (2016) did not find a relationship between resilience and caregiver's age, gender, educational level, duration of the disease, awareness of disease and concluded that there was no

significant relationship between caregivers' resilience and the socio-demographic and clinical characteristics of the person with dementia.

The regression analysis was used to test the influence of independent patient variables like age, gender, education, occupation, with the caregiver, illness progression, illness duration, visit to hospital and current health status on dependent variable resilience and found that there was no significant influence of demographic profile of patients on caregiver's resilience.

# **IMPACT OF INDEPENDENT VARIABLE (Multidimensional social support) on DEPENDENT VARIABLE (Resilience)**

## **Coefficients**

| S. No | Independent variables | Unstandardized Coefficients |            | Standardized Coefficients | T     | Sig. |
|-------|-----------------------|-----------------------------|------------|---------------------------|-------|------|
|       |                       | B                           | Std. Error | Beta                      |       |      |
| 3.    | Multidimensional      | .326                        | .267       | .150                      | 1.219 | .228 |

The above table provides the impact of independent variables i.e., multidimensional social support on resilience of caregiver.

The multidimensional social support the t value is 1.219 and the p value is .228  $p > 0.05$ , hence it can be inferred that the independent variable multidimensional social support has no significant impact on resilience of the caregiver. The theory of moderation proposed by Frazier *et al.*, indicated that perceived social support does not influence the resilience of caregiver burden. The present study findings are in confirmation with study of Plumb (2011) who noted from his study on resilience that higher levels of social support was not correlated with lower levels of stress. Higher scores on the SSI (Social Support Index) total scale correlated positively with higher scores on the PSI-SF (Parental Stress Index- Short Form total scale) ( $r_p = 0.38$ ,  $p < 0.01$ ,  $n = 50$ ).

The findings were in contradictory with the results of Joling (2016) low caregiver burden were positively related to caregiver resilience. The present study found that there was no significant relationship between perceived stress and resilience. This might be due to other factors that might be related to resilience, such as biological and physical characteristics or the presence of other major stressful life events.

## **CONCLUSION:**

The results of this study concludes that most of the caregivers were having high and moderate resilience. Social support was high in majority of the caregivers. There was no significant impact of general demographic profile of the caregiver on resilience except relationship with the patient. And also there was no significant impact of patient demographic profile on resilience of the caregiver. Perceived multidimensional social support of the caregiver had no significant impact on the resilience of the caregiver. Hence it can be concluded that resilience is related to individual characteristics and resilience is not a trait that people either have or do not have. It involves behaviors, thoughts and actions that can be learned and developed in anyone.

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