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Impact of perceived stress on resilience of the caregivers attending to Alzheimer's patients

Mandava Hemalatha and Dr. Nasreen Banu

Abstract

Diagnosis of Alzheimer's can be a heart-wrenching experience for both the person diagnosed and the caregiver. As the disease progresses, it will be harder for the caregiver and stress increases. The caregivers need to develop resilience to lead their life pleased. The present study was used to know the impact of perceived stress on resilience of caregivers attending to Alzheimer's patients. Connor-Davidson Resilience Scale (CD-RISC) which was developed by Kathryn M. Connor and Jonathan R.T. Davidson (2003) was used to measure resilience and checklist was used to measure perceived stress of caregivers. The study was conducted in the twin cities of Hyderabad and Secunderabad. Total 60 members were selected by purposive sampling method. Results revealed that there was no significant impact of perceived stress on resilience of the caregiver. It was found that there was no significant relationship between caregiver general demographic profile and caregiver resilience except religion. It was also found that there was no significant relationship between patient general demographic profile and resilience of the caregiver except occupation. Hence it can be concluded from the present study that resilience was an individual trait which was not affected by the external stimulus.

Keywords: Stress, Resilience, Alzheimer's, caregivers

Introduction

The terms "Alzheimer's" and "dementia" were often used interchangeably, but the conditions were not the same. "Dementia" was 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. Dementia was 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 was Alzheimer's disease, which makes up 50% to 70% of cases.

Alzheimer disease was named after Dr. Alois Alzheimer. Alzheimer was a type of dementia that causes problems with memory, thinking and behaviour. Alzheimer disease (AD) also referred to simply as Alzheimer. AD was an irreversible, progressive brain disorder that slowly destroys memory and thinking skills, and eventually the ability to carry out the simplest tasks. Estimates vary, but experts suggest that more than 5 million Americans may have Alzheimer. NIA (National Institute on Aging, 2017) [10]. In most people with Alzheimer's, symptoms first appear in their mid-60s.

The most common sign of Alzheimer was memory loss; especially forgetting recently learned information. Although it generally occurs in people over the age of 65, it does and has affected people even in their 40s and 50s. This situation was called early-onset Alzheimer. While some early signs of Alzheimer may appear similar to those that were age-related, there were ways to distinguish these symptoms from general signs of ageing.

East Asia was the region with the most people living with dementia 9.8 million, followed by Western Europe 7.4 million. These regions were closely followed by South Asia with 5.1 million and North America with 4.8 million (Indian Express, 2018) [11].

A caregiver was an unpaid or paid member of a person's social network who helps them with activities of daily living. Care giving was 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 were important in the daily lives of Alzheimer patients because they provide consistent care in a comfortable and familiar environment, both of which were necessary in

care for individuals diagnosed with Alzheimer disease (Alzheimer Association, 2007) [9].

Resilience was 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.

Caring for a person with AD can have high physical, emotional, and financial costs. The demands of day-to-day care, changes in family roles, and decisions about placement in a care facility can be difficult.

AD was called a family disease, because the chronic stress of watching a loved one slowly decline affects everyone. An effective treatment will address the needs of the entire family. Emotional and practical support, counseling, resource information, and educational programs about AD all help a caregiver provide the best possible care for a loved one.

A diagnosis of AD can be a heart-wrenching experience for both the person diagnosed and the caregiver. The person with AD may not remember or may not admit to having the disease or ever being told they had Alzheimer. Trying to convince them otherwise was fruitless and frustrating for the caregiver. The caregiver need to get appropriate emotional support. Depression was common in caregivers of people with AD.

Caregiver stress is described as a variety of circumstances, experiences, and resources that influence the caregiver’s health and behavior (Pearlin and others, 1990). Caregiver stress was a complex phenomenon. Burden was defined in terms of patients’ level of disability and the extent of care they required. The greater the disability, the more care was required and the greater the stress on the caregiver. Stress was associated with the type of care provided, which varies according to the care receiver’s illness and its progression.

Rutter (2012) [6] 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. Life course effects are reviewed in relation to evidence on turning point effects associated with experiences that increase opportunities and enhance coping.

Dwyer (2013) investigated in a pilot study on Suicidal ideation and resilience in family caregivers of people with dementia. Three themes were identified in the data – ‘experiences of suicidal ideation’, ‘risk factors’ and ‘resilience’. Four of the nine participants had experienced suicidal thoughts and two had made preparations for a

suicidal act. Risk factors included pre-existing mental health problems, physical health conditions, and conflict with other family or care staff. Factors positively associated with resilience included the use of positive coping strategies, faith, social support and personal characteristics.

Dias (2016) [2] 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 was considered to act as a protective factor by increasing the quality of life.

Wilks and Croom (2008) [7] found claimed that a moderately high level of resilience was found in caregivers and also they reported moderate levels on the primary factors which includes primary perceived stress, family support, friend support, and overall social support. It was also found that social support contributes to enhances resilience. Family support as having the greater impact on caregiver resilience than friend support.

As Alzheimer caregivers frequently report experiencing high levels of stress. It can be overwhelming to take care of a loved one with Alzheimer, but too much stress can be harmful to the caregiver. More than 40% of family caregivers reported that the emotional stress of their role was high or very high (Alzheimer’s disease International-2012). Hence it was proposed to study “Impact of perceived stress on Resilience of the caregivers attending to Alzheimer’s patients”.

Materials and Methods

Ex-post facto research design was used for the present investigation to know the Resilience and perceived stress of caregivers attending to Alzheimer patients. The data from the respondents was collected by both standardized and self constructed interview schedule. Twin cities of Hyderabad and Secunderabad were selected for the present study. Connor Davidson Resilience Scale (2013) was used to study resilience of caregivers and self constructed checklist was used to study perceived stress of caregivers. Total 60 members were selected by using purposive sampling method. Regression analysis was used to test the impact of perceived stress on resilience and correlation analysis was used to find out the relationship general demographic profile of both the caregiver and patient with resilience of the caregiver.

Results and Discussion

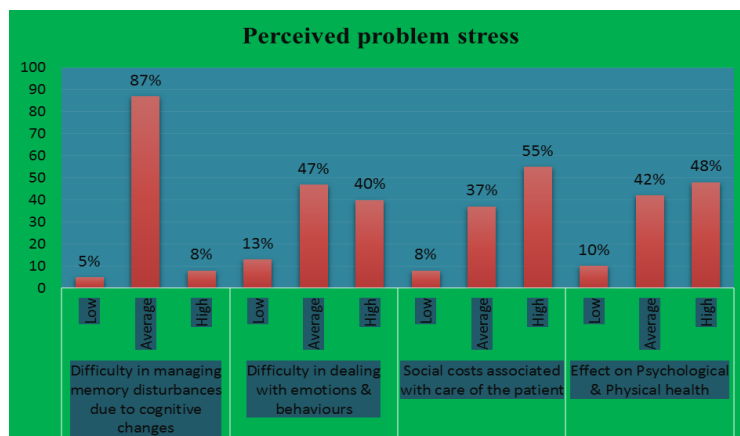


Fig 1: Graphical representation of Perceived stress of caregivers attending to Alzheimer’s patients

It was observed from the figure 1 that caregivers Perceived average level (88%) of stress in managing memory disturbances due to cognitive changes; Perceived average (47%) to high (40%) level of stress in dealing with emotions & behaviours; Perceived high (55%) to average level (37%) of regarding social costs associated with care of the patient;

and Perceived high (48%) to average level (42%) level of stress due to psychological & physical health. Over-all caregivers Perceived average (53%) to high (38%) level of stress in attending to Alzheimer’s patients. No gender variation was found in this regard.

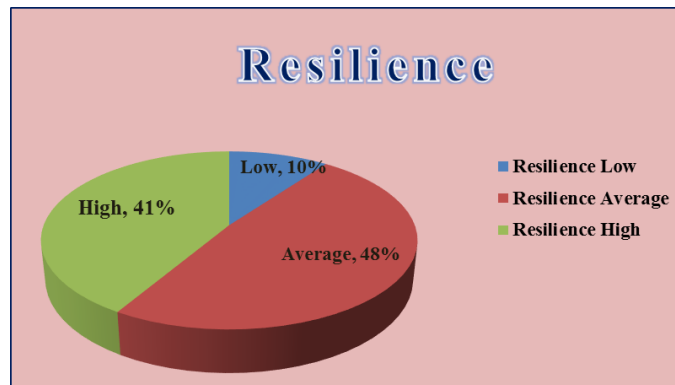


Fig 2: Graphical representation of caregivers attending to Alzheimer’s patients

It was found from the above figure 2 that 48% of caregivers reported that they were having moderate resilience, 41% of

caregivers were having high resilience, and 10% of the caregivers were having low resilience.

Table 1: Relationship between caregiver’s demographic variables and resilience of the- caregiver

| | | Resilience | Gender | Age | Education | Occupation | Religion | Marital status | Marital years | No. of dependents in the family | Family income | Relationship |
|------------|-------------------------|------------|--------|------|-----------|------------|----------|----------------|---------------|---------------------------------|---------------|--------------|
| Resilience | Pearson Correlation (r) | 1 | .173 | .055 | .094 | .061 | .353** | .100 | -.032 | .226 | .122 | .167 |
| | p Sig. (2-tailed) | | .186 | .678 | .477 | .642 | .006 | .447 | .810 | .083 | .354 | .201 |

* Correlation is significant at the 0.01 level (2-tailed).

The above table depicts the relationship between caregiver’s resilience and demographic variables. The present study found that among all the demographic variables of the caregivers, none of the variable had significant relationship on resilience, except religion. Religious expression seemed to facilitate care giving as it provided an emotional nourishment through prayer and reflection.

The results of the present were in line the findings of Wilks (2004) [8] indicated a strong association and positive, significant relationship between the extent of prayer usage as a method of coping, and resiliency. Another study examining burden and coping strategies utilized by AD caregivers (Pratt and others, 1985) documented that spiritual expression was a frequently utilized external coping strategy.

Table 2: Relationship between patient’s demographic variables and caregiver resilience

| | | Age | Gender | Education | Occupation | Relationship with caregiver | Illness progression | Illness duration | Visit to hospital | Current health |
|------------|-------------------------|------|--------|-----------|------------|-----------------------------|---------------------|------------------|-------------------|----------------|
| Resilience | Pearson Correlation (r) | .073 | -.092 | .076 | .317* | .229 | -.057 | -.141 | .012 | -.071 |
| | p Sig. (2-tailed) | .579 | .485 | .563 | .014 | .079 | .667 | .281 | .926 | .590 |

*Correlation is significant at the 0.05 level (2-tailed)

The above table depicts the relationship between caregiver resilience and patient related variables. No significant relationship was found between patient variables and resilience, except occupation. Occupation was assumed to be the most crucial factor today. It not only has social importance but also economic, psychological and human significance. If the patient was able to work even after getting Alzheimer, then caregivers too will

get time to focus on their career which results in high resilience among caregivers of these patients. According to Gisbert (2009), occupations have great therapeutic qualities for treating mental illness. It has been proved to be one of the best remedies to break the mental isolation of the patient by renewing the social contacts with his fellow- men.

Table 3: Impact of Perceived stress on resilience of the caregivers attending to Alzheimer’s patients

| S. No | Independent variables | Unstandardized Coefficients | | Standardized Coefficients | T | Sig. |
|-------|---------------------------|-----------------------------|------------|---------------------------|-------|------|
| | | B | Std. Error | Beta | | |
| 1. | Perceived problems stress | .239 | .194 | .152 | 1.231 | .224 |

The perceived problem stress the t value was 1.231 and the p value was 0.224 which was greater than 0.05, hence it can be inferred that the independent variable perceived problem

stress has no significant impact on resilience of the caregiver. The b coefficients shows how many units dependent variable resilience increases for a single unit increase in caregivers

independent variables. For a single unit of increase in independent variables perceived stress increases resilience of the caregiver by 0.239.

The findings from the present were similar with the findings of Lin Ong *et al.* (2018), on Resilience and burden in caregivers of older adults: moderating and mediating effects of perceived social support and found Perceived social support did not demonstrate moderating effect as there was no significant association between resilience and burden ($\beta = -0.014, p > 0.05$).

The findings were in contradictory with the results of Joling (2016) [3], 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

There was no significant impact of perceived stress on resilience of the caregiver. It was found that there was no significant relationship between caregiver general demographic profile and caregiver resilience except religion. It was also found that there was no significant relationship between patient general demographic profile and resilience of the caregiver except occupation of the patient. Hence it can be assumed that resilience might be related to individual characteristics rather than socio-demographic characteristics of the caregiver and patients. Resilience was not a trait that people either have or do not have. It involves behaviours, thoughts and actions that can be learned and developed in anyone. Future studies could compare male and female caregivers to determine whether gender socialization does, in fact, influence the caregivers resilience.

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