Resilience and Perceived Social Support of the Caregivers Attending to Alzheimer's Patients

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Authors' contributions

This work was carried out in collaboration between all authors. All authors read and approved the final
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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 a relationship
with the patient. And patient demographic profile had no significant impact on the 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.

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1. INTRODUCTION

A caregiver 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. 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 [1].

Informal Caregiver –any relative, partner, friend or neighbour who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care.

Formal Caregiver – a provider associated with a formal service system, whether a paid worker or a volunteer [2].

Alzheimer's disease is a progressive, neurodegenerative disease that occurs when nerve cells in the brain die. On a cellular level, Alzheimer's disease is characterized by the finding of unusual helical protein filaments in nerve cells of the brain. These twisted filaments are neurofibrillary tangles. In the brain, Alzheimer's disease involves degeneration of the cortical regions, especially the frontal and temporal lobes. 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 [3].

Alzheimer's disease is distinguished from other forms of dementia by characteristic changes in the brain that are visible only upon microscopic examination during autopsy. Brains affected by Alzheimer's disease often show presence of the following: 1. Fiber tangles within nerve cells (neurofibrillary tangles), 2. Clusters of degenerating nerve endings (neuritic plaques).

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 [4].

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 [5]. So studies on Alzheimer's caregivers should be extended.

Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress.

Wilks [6] found stress was negatively influenced and accounted for most variation in resilience whereas social support positively influenced resilience, and caregivers with high family support had the highest probability of elevated resilience.

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. [7] 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).

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 [8].

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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 [9]. Resilience means "bouncing back" from difficult experiences. According to research studies but this resilience is found to be observed in only few caregivers. Hence there is a need to study resilience of the caregivers attending to Alzheimer's patients.

The present study was proposed to study the extent of resilience and perceived social support 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.

1.1 Theoretical Frame Work

1.1.1 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 [10]. 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.

1.1.2 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. The sense of coherence, 7. Resourcefulness

Shaji et al [11] 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.

2. 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 and 60 patients were selected purposively for conducting the present study.

Criteria for sample selection: All those families experiencing stress, problems attending to Alzheimer's patients. The caregiver will be the respondent, if they are the part of the family. Caregivers may be male or female. Age group of caregivers varied between 20 to 55 years and above. The present study was carried out after getting ethical committee approval.

The relationship between independent variables and dependent variables are studied.

Independent variables consist of both caregiver and patient particulars. Dependent variable of the present study was resilience of the caregiver.

The self-developed interview schedule was used to collect demographic profile. Perceived Social support was measured by using a 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 disagree (1), Strongly disagree (2), Mildly disagree (3), Neutral (4), Mildly agree (5), Strongly agree (6), very strongly agree (7). Any mean total score ranging from 1 to 2.9 considered as low support; a score of 3 to 5 considered as moderate support; a score from 5.1 to 7 considered as high support.

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. The mean total score range below 42 considered as low resilience, mean total score range between 43 to 84 considered as moderate resilience, mean total score range between 85 to 125 considered as high resilience. Regression analysis was used to study the significant impact of the independent variable on dependent variable of the caregiver.

3. 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.

Naslund et al. [12] 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.

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.
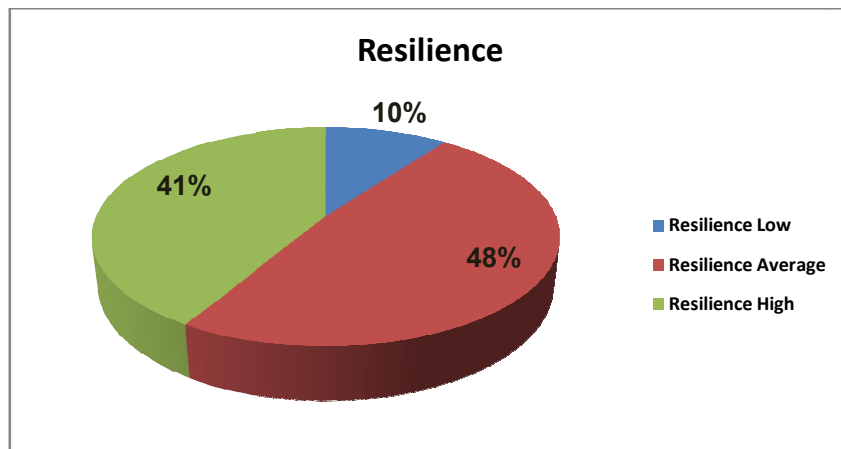

Fig. 1. Resilience of the caregivers attending to Alzheimer's patients

The regression analysis was used to test the influence of socio-demographic profile of caregiver on dependent variable resilience and found none of the caregivers socio-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. [13] 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.

Most of the caregivers were experiencing strain due to the lack of support from family and sometimes, criticism from other family members. Family conflict was commonly encountered. The majority of caregivers experienced significant deterioration in their mental health.

The regression analysis was used to test the influence of independent patient variables on dependent variable resilience and found that there was no significant influence of demographic profile of patients on caregiver's resilience.

Manzini [14], studied resilience of family caregivers of elderly with Alzheimer. Linear regression showed that some factors interfered with caregivers' resilience, being those: the level of kinship daughter-in-law/son-in-law or spouse, overload, the increment of days dedicated to care giving and practice of other activities besides care giving.

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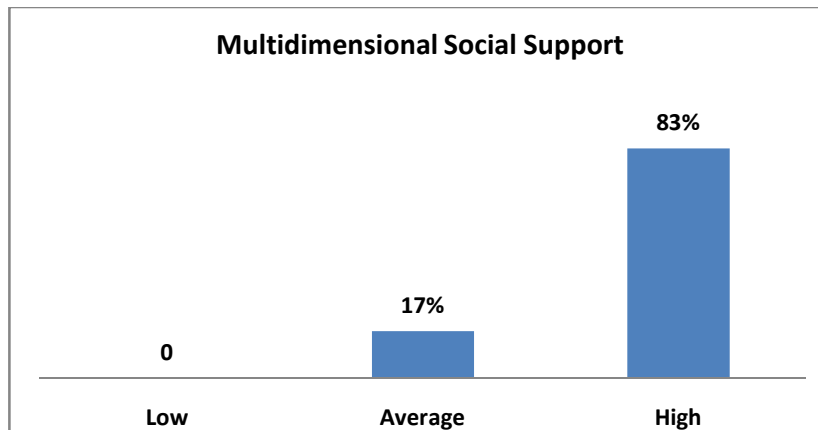

Fig. 2. Perceived social support of the caregivers attending to Alzheimer's patients

Table 1. Impact of independent variable (caregiver demographic profile) on dependent variable (resilience) of the caregiver coefficients

S. No	Care giver demographic variables	Unstandardized coefficients		Standardized coefficients	T	Sig.
		B	Std. error	Beta		
1.	Gender	3.959	9.658	.096	.410	.684
2.	Age	2.685	2.504	.310	1.072	.289
3.	Education	3.018	4.200	.232	.718	.476
4.	Occupation	2.275	2.212	.175	1.028	.309
5.	Religion	14.757	8.223	.431	1.795	.079
6.	Marital status	2.947	4.437	.170	.664	.510
7.	Number of Marital years	4.578	2.683	.329	1.706	.094
8.	No. of dependents in the family	1.362	2.359	.095	.577	.566
9.	Family income	1.261	2.810	.097	.449	.656
10.	Relationship with the patient	3.729	1.863	.472	2.002	.051*

Table 2. Impact of independent variable (patient demographic profile) on dependent variable (resilience) of the caregiver coefficients

S. No	Independent variable	Unstandardized coefficients		Standardized coefficients	T	Sig.
		B	Std. error	Beta		
1.	Age	1.171	4.279	.050	.274	.785
2.	Gender	7.806	8.909	.209	.876	.385
3.	Education	2.430	2.771	.205	.877	.385
4.	Occupation	5.411	2.872	.372	1.884	.065
5.	Relationship	1.793	1.974	.190	.908	.368
6.	Illness progression	5.545	6.051	.148	.916	.364
7.	Illness duration	4.775	4.436	.227	1.076	.287
8.	Visit hospital	2.634	4.683	.108	.562	.576
9.	Current health	.026	4.018	.001	.006	.995

Table 3. Impact of independent variable (multidimensional social support) on dependent variable (resilience) of the caregiver coefficients

S. No	Independent variables	Unstandardized coefficients		Standardized coefficients	T	Sig.
		B	Std. error	Beta		
3.	Multidimensional social support	.326	.267	.150	1.219	.228

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 present study findings are in confirmation with study of Plumb [15] 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) (rp = 0.38, p < 0.01, n = 50.

The findings were in contradictory with the results of Joling [16] 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. [17,18]

4. CONCLUSION

The results of this study conclude that most of the caregivers were having high and moderate resilience. Social support was high in the majority of the caregivers. There was no significant impact of the general demographic profile of the caregiver on resilience except a relationship with the patient. And also there was no significant impact of a 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 behaviours, thoughts and actions that can be learned and developed in anyone.

CONSENT

As per international standard or university standard written partcipants' consent has been collected and preserved by the authors.

ETHICAL APPROVAL

As per international standard or university standard, written approval of Ethics committee has been collected and preserved by the author(s).

COMPETING INTERESTS

Authors have declared that no competing interests exist.

REFERENCES

1. Alzheimer's Association.
Available:https://www.alz.org/oklahoma/in_my_community_16516.asp
(2007, October 13).
2. Family caregiver Alliance.
Available:https://www.caregiver.org/definitions-0
(2014, January 31).
3. National Institute on Aging.
Available:https://www.nia.nih.gov/health/alzheimers/basics
(2017, June 25).
4. National Center for Health Statistics.
Available:https://www.cdc.gov/nchs/data/misc/pr_act97.pdf
(2015, November 1).
5. Wilks SE, Croom B. Perceived stress and resilience in Alzheimer's disease caregivers: Testing moderation and mediation models of social support. National Center for Biotechnology Information. 2008;12(3):357-65.
6. Dias R, Neto JPS, Santos RL, Sousa MFB, Baptista AT, Lacerda IB, Santos NR. Caregivers' resilience is independent from the clinical symptoms of dementia. Arq Neuropsiquiatr. 2016;74(12):967-973.
7. Casado RP, Osuna AF, Moral PA, Morcillo AJR. Social support and subjective burden in caregivers of adults and older adults: A metaanalysis. National Center for Biotechnology Information. 2018;13(1): e0189874.
8. Alzheimer's Disease International.
Available:https://www.alz.co.uk/research/statistics
(2015,May 21).
9. Caroline Egan. Hello Care; 2018.
Available:https://hellocaremail.com.au/balancing-safety-personal-freedoms-people-living-dementia
10. McCubbin HI, McCubbin MA. Typologies of resilient families: Emerging roles of social class and ethnicity. Family Relations. 1988;37(3):247-254.
11. KS Shaji, Smitha K, Praveen Lal K, Prince Martin. Caregivers of people with Alzheimer's disease: A qualitative study from the Indian 10/66 Dementia Research Network. International Journal of Geriatric Psychiatry. 2003;18:1-6. 10.1002/gps.649.
12. Naslund J, Beattie BL, Kupferschmidt A. Psychological resilience and the wellbeing of spousal caregivers of persons with Alzheimer disease. Alzheimer's & Dementia the Journal of the Alzheimer's association. 2009;5(1):230-231.
13. Dias R, Neto JPS, Santos RL1, Sousa MFB, Baptista AT, Lacerda IB, Santos NR. Caregivers' resilience is independent from the clinical symptoms of dementia. Arq Neuropsiquiatr. 2016;74(12):967-973.
14. Manzini CSS, Brigola AG, Pavarini SCI, Vale FAC. Factors associated with the resilience of family caregivers of persons with dementia: A systematic review. Resilience in caregivers. 2016;19(4):703-714.
15. Plumb JC. The impact of social support and family resilience on parental stress in families with a child diagnosed with an autism spectrum disorder. Doctorate in Social Work (DSW) Dissertations; 2011.
16. Joling KJ, Windle G, Droes RM, Meiland F, Hout HPJ, Vroomen JN, Ven PM, Cook, Woods EMB. Factors of resilience in informal caregivers of people with dementia from integrative international data analysis. Dement Geriatr Cogn Disord 2016;42:198–214.
17. Cambells-Sills, Laura & Stein, Murray B. Psychometric Analysis and Refinement of the Connor-Davidson Resilience Scale (CD-RISK): Validation of a 10-Item Measure of Resilience. Journal of Traumatic Stress. 2007;20(6).
18. Zimet GD, Dahlem NW, Zimet SG, Farley GK. The Multidimensional Scale of Percieved Social Support. Journal of Personality Assessment 1988;52:30-41.