

A Study on Relationship between Perceived Problems and Resilience of Caregivers Attending to Alzheimer's Patients

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ABSTRACT

Family caregivers in particular play significant roles in the care of elders with advanced chronic disease and in the context of palliative and end-of-life care. Caring for a person with AD can have high physical, emotional, and financial costs. A diagnosis of Alzheimer's can be a heart-wrenching experience for both the person diagnosed and the caregiver. Twin cities of Hyderabad and Secunderabad were selected for conducting the study. Ex-post facto research design was used for the present investigation to know the Resilience in caregivers attending to Alzheimer's patients. The total sample comprised of 60 caregivers. Connor-Davidson Resilience Scale (CD-RISC) which was developed by Kathryn M. Connor and Jonathan R.T. Davidson was used as a means of assessing resilience which comprises of 25 items, each rated on a 5 - point scale. Self constructed questionnaire was used to measure perceived problems. Pearson correlation was used to find out the relationship between resilience and perceived problems. Results of the present study revealed that there was no significant relationship between resilience and perceived problems.

Key words: Alzheimer's, Caregivers, Resilience, Perceived problems.

INTRODUCTION

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. Other common types include vascular dementia (25%), Lewy body dementia (15%), and front temporal dementia.

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. Scientists were not absolutely sure what causes Alzheimer's but plaques and tangles are prime suspects in cell death and tissue loss in the Alzheimer's brain.

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Plaques were abnormal clusters of chemically “sticky” proteins called beta-amyloid that builds up between nerve cells. The most damaging form of beta-amyloid may be groups of a few pieces rather than the plaques themselves. The small clumps may block cell-to-cell signaling at synapses. They may also activate immune system cells that trigger inflammation and devour disabled cells.

Tangles form inside dying cells. Tangles were twisted fibers of a protein called tau. In healthy areas, tau helps keep the transport system on track. But in areas where tangles were forming, the twisted strands of tau essentially disintegrate the transport system so that nutrients and other essential supplies can no longer move through the cells, which eventually die.

Though most people develop some plaques and tangles as they age, those with Alzheimer’s tend to develop far more. The plaques and tangles tend to form in a predictable pattern, beginning in areas important in learning and memory and then spreading to other regions.

Alzheimer’s disease typically progresses slowly in three general stages — mild (early-stage), moderate (middle-stage), and severe (advanced-stage). Since Alzheimer’s affects people in different ways, each person will experience symptoms - or progress through Alzheimer’s stages - differently.

Mild Alzheimer’s disease (early-stage)

In the early stage of Alzheimer’s, a person may function independently. He or she may still drive, work and be part of social activities. Despite this, the person may feel as if he or she was having memory lapses, such as forgetting familiar words or the location of everyday objects. Friends, family or others close to the individual begin to notice difficulties. During a detailed medical interview, doctors may be able to detect problems in memory or concentration.

Moderate Alzheimer’s disease (middle-stage)

Moderate Alzheimer’s was typically the longest stage and can last for many years. As

the disease progresses, the person with Alzheimer’s will require a greater level of care. Others may notice the person with Alzheimer’s confusing words, getting frustrated or angry, or acting in unexpected ways, such as refusing to bathe. Damage to nerve cells in the brain can make it difficult to express thoughts and perform routine tasks.

Severe Alzheimer’s disease (advanced-stage)

In the final stage of this disease, individuals lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement. They may still say words or phrases, but communicating pain becomes difficult. As memory and cognitive skills continue to worsen, significant personality changes may take place and individuals need extensive help with daily activities.

“Family caregivers in particular play significant roles in the care of elders with advanced chronic disease and in the context of palliative and end-of-life care. These caregivers typically were involved in critical medical decisions, provide vital assistance with activities of daily living, and carry out most non-pharmacologic and pharmacologic treatment recommendations for community-based elders.”¹. 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.

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.

Medrano² found a significant association was found in the Pearson correlation coefficient between caregiver burden, anxiety and depression. It was reported that 84% of caregivers were female and 52% were older

than 50 years. A total of 36% were having caregiver burden, 19% exhibited anxiety symptoms and 43% were having depressive symptoms. There was no statistical significance between age, sex and number of hours of care.

Neena and Reid⁴ studied on Burden and well-being among caregivers: examining the distinction. Results shows that lesser the burden, higher the wellbeing of caregiver. Burden and informal hours of care were negatively associated with well-being, with lower burden scores and lower number of informal hours of care leading to higher well-being scores. Whereas perceived social support and self-esteem were positively related to well-being of caregiver.

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.

Wilks⁵ 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.

A diagnosis of Alzheimer's can be a heart-wrenching experience for both the person diagnosed and the caregiver. The caregiver need to get appropriate emotional support as depression was common in caregivers of people with Alzheimer's. Deaths from Alzheimer's have nearly doubled during this period while those from heart disease –the leading cause of death have declined. As

Alzheimer's caregivers frequently report experiencing high levels of problems. Hence there was a need for conducting research study on relationship between resilience and perceived problems of caregivers attending to Alzheimer's patients. The present study was proposed to study the extent of resilience in Alzheimer's disease caregivers and their ability to withstand adversity.

MATERIAL AND METHODS

Twin cities of Hyderabad and Secunderabad were selected for conducting the study. Ex-post facto research design was used for the present investigation to know the Resilience in caregivers attending to Alzheimer's patients. The total sample comprised of 60 caregivers. Connor-Davidson Resilience Scale (CD-RISC) which was developed by Kathryn, M., Connor and Jonathan, R. T., Davidson was used as a means of assessing resilience which 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. Internal consistency of the CD-RISC was found to 0.93 and test-retest reliability was found to be 0.70 ($p < 0.01$). Open-ended check list was used to find out perceived problems experienced by the caregiver. The items were arranged on a four point scale of Always (4) to Never (1). Higher the score, higher will be the problems experienced by the caregiver in that particular area. It traces caregiver problems in the 4 areas while attending to the Alzheimer's patient needs.

RESULTS AND DISCUSSION

Table 1: Perceived problems by the caregivers attending to Alzheimer's patients

N=60

	Area	Category	Males		Females		Total	
			F	%	F	%	F	%
1.	Difficulty in managing memory disturbances due to cognitive changes	Low	1	6	2	4	3	5
		Average	15	88	37	86	52	87
		High	1	6	4	9	5	8
2.	Difficulty in dealing with emotions & behaviours	Low	3	18	5	12	8	13
		Average	6	35	22	51	28	47

		High	8	47	16	37	24	40
3.	Social costs associated with care of the patient	Low	1	6	4	9	5	8
		Average	6	35	16	37	22	37
		High	10	59	23	53	33	55
4.	Effect on Psychological & Physical health	Low	1	6	5	12	6	10
		Average	8	47	17	39	25	42
		High	8	47	21	49	29	48
Total		Low	1	6	4	9	5	8
		Average	9	53	23	53	32	53
		High	7	41	16	37	23	38

It was observed from the table 1 that caregivers Perceived average level (88%) of problems in managing memory disturbances due to cognitive changes; Perceived average (47%) to high (40%) level of problems 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 problems due to psychological & physical health.

Over-all caregivers Perceived average (53%) to high (38%) level of problem in attending to Alzheimer's patients. No gender variation was found in this regard.

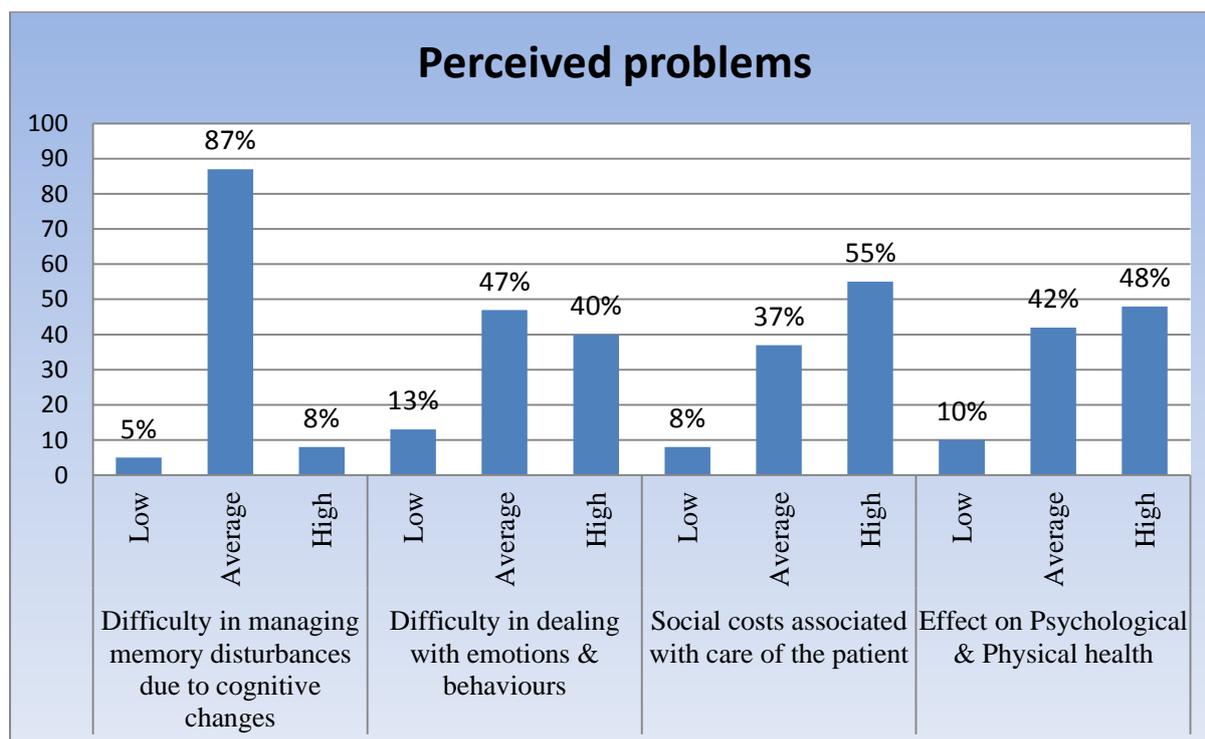


Fig. 1: Perceived problem by the caregivers attending to Alzheimer's patients

Table 2: Resilience of the caregivers attending to Alzheimer's patients

N=60

S. No	Area	Category	Males		Females		Total	
			F	%	F	%	F	%
1	Resilience	Low	3	17	3	7	6	10
		Average	7	41	22	51	29	48
		High	7	41	18	42	25	41

It was found from the above table 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.

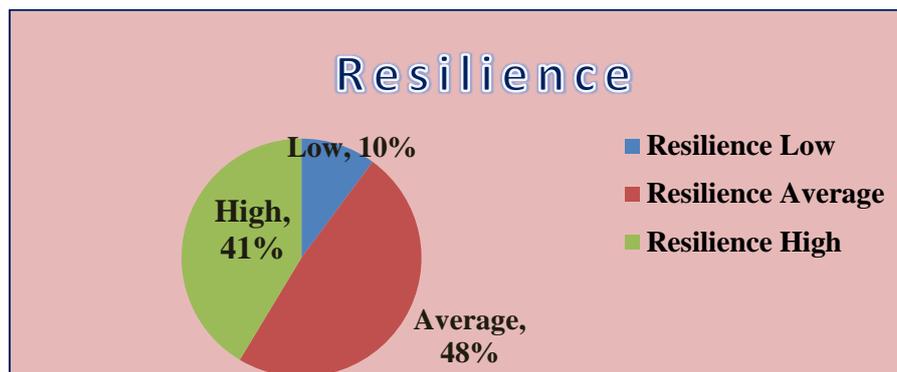


Fig. 2: Resilience of the caregivers attending to Alzheimer's patients

Table 3: Relationship between resilience and perceived problem scale dimensions

	PP -A	PP-B	PP-C	PP-D	PP-Total
Resilience	-.050	.134	.071	.124	.109

In the above table PPS means Problem perceived stress

- PP-A Difficulty in managing memory disturbances due to Cognitive changes
- PP-B Difficulty in dealing with emotions and behaviours
- PP-C Social costs associated with care of the patient
- PP-D Effect on Psychological and physical health

CONCLUSION

Statistical analysis revealed that there was no significant relationship between resilience and all the dimensions of perceived problems scale like Difficulty in managing memory disturbances due to Cognitive changes, Difficulty in dealing with emotions and behaviours, Social costs associated with care of the patient and Effect on Psychological and physical health. Hence from the present study it can be concluded that resilience was an individual trait which cannot be influenced by the external factors like perceived problems.

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