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# Caregiver Burden, Psychological Resilience and Well-being among Informal Caregivers of Persons with Dementia in South and West Regions in India

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# Introduction

- The World Alzheimer Report (Alzheimer's Disease International, 2015) – 4.1 million people in India with dementia in 2015; estimated to increase around 14 million by 2050.
- The varied intensity of responsibilities experienced by caregivers is essential to consider as the subjective perception of the burden can affect psychological well-being, low quality of life (Hoeing and Hamilton, 1966; Liu et al., 2020) wherein a resilient attitude can act as a protective factor and help informal caregivers adapt to the situation (Zauszniewski et al., 2010; Jonker & Greeff, 2009).
- Thus, the objectives of the present study is to find the relationship between caregiver burden, psychological resilience and well-being among informal caregivers of patients with dementia.
- The study also focuses on understanding whether caregiver burden mediates the relationship between psychological resilience and well-being.

# Method

## Participants

- Adult primary informal caregivers of any gender
- Have at least six months of experience in taking first-hand care of a patient with Dementia.

## Sampling

- Purposive and snowball sampling.

## Design

- Correlational design

## Tools used

- Zarit Burden Interview (1985)
- Connor-Davidson Resilience Scale (CD-RISC) (2003)
- Caregiver Well-being Scale by Susan Tebb (1995)

## Procedure

- The initial contact to recruit participants for the study was clinicians in the west and south regions and support groups.
- The informal caregivers were contacted through online medium.
- Confidentiality and other required ethics are followed.

## Analysis

- The present study employed correlation analysis and mediation.
- Jamovi 1.6.9 version was used for the analysis.

# Results

- The present study recruited 32 participants (females= 18 (56.25%), males= 14 (43.75%)) The average age of the caregivers is 52.125 years.
- The recruited informal caregivers shared different relationships with the patient with Dementia (Spouse= 2 (6.25%), Children= 21 (65.625%), Daughter/son-in law= 7 (21.875%), Relative= 2 (6.25%))
- As the data is normally distributed ( $p > 0.05$ ), Pearson's correlation analysis was run which indicated that there is a significant relationship between the variables.
- A positive relationship between psychological resilience and well-being was found ( $r = 0.46$ ,  $p < .01$ ). There is a negative relationship between caregiver burden and psychological resilience ( $r = -0.538$ ,  $p < .001$ ). Similarly, caregiver burden and well-being among informal caregivers was found to have negative correlation ( $r = -0.506$ ,  $p < .01$ ).

## Results (contd.)

- The caregiver burden demonstrated mediating effect of caregiver well-being (covariate) on resilience (dependent) through caregiver burden was statistically significant.
- There is a significant interaction between caregiver wellbeing and burden ( $\beta = -0.506, p < 0.01$ ) and between caregiver burden and resilience ( $\beta = -0.410, p < 0.01$ ). There is no significant direct interaction between caregiver well-being and resilience ( $\beta = 0.252, p = 0.131$ ) which indicates that an increase in levels of well-being will not incur any significant effect on resilience levels among informal caregivers of patients with Dementia.
- Thus, the mediation analysis indicated that caregiver burden serves as a mediating factor since only when informal caregivers perceive burden; will there be a change in a relationship between caregiver well-being and resilience levels.

# Discussion

- The present study found that there is a significant association between caregiver burden, psychological resilience and well-being.
- It suggests that the two major components of well-being(ADLs and basic needs) of informal caregiver can be understood in relation with how they contribute in higher resilience (Windle et al., 2008, Tebb, S, 1995)
- A perception of the burden makes caregivers vulnerable to risks, it becomes one of the crucial constructs to envision and ameliorate resilience levels among informal caregivers to act as a protective factor (Zauszniewski et al., 2010, Zarit et al., 1980)
- The study found out that the caregiver burden perceived by the informal caregivers mediated the relationship between resilience and caregiver well-being.

# Discussion

- As the informal caregiver perceives burden, it incapacitates them from fulfilling their basic needs and performing ADLs which affects the resilient attitude of the caregiver (Tebb, S, 1995; Zarit et al., 1980)
- While studying burden as a predictor of resilience as well as an outcome of caregiving, focusing on informal caregivers' financial situation becomes necessary as the economic status influences the perception of the burden by the informal caregiver (Shaji, K. S. & Reddy, M. S., 2012)
- Though resilience training, various techniques to enhance well-being can be employed (Kishita et al., 2018), the present findings also suggest that the perception burden affects the informal caregivers, thus, techniques to reduce burden should be employed (Zarit et al., 1980; Joling, K. J., 2016)



# Implications

- The findings indicate that informal caregiving costs require special attention in research as it can help the healthcare sector ascertain the economic provisions and benefits.
- Financial facilities and security can reduce the burden perceived by informal caregivers and, in turn, exacerbate levels of resilience and state of well-being.

# Limitations

- The research sample size is significantly small, and is heterogeneous since the participants were recruited from various ethnic and socioeconomic backgrounds. Thus, the generalizability of the results is restricted.
- Though the scales used for the present study are noteworthy and are widely accepted measures for the study variables, its lack of cultural appropriateness in the Indian context acted as a limitation.

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**Thank You!**