Research Paper

Impact of Social Support on Resilience in Care Providers of Older Adults with Dementia

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ABSTRACT

Dementia is one of the prevalent degenerative disorders in the world. Along with taking a toll on the person suffering from this disorder, the disease also adversely affects the caregivers of people with dementia (PWD). An important factor that determines the well-being of caregivers is their resilience. Resilience is defined as the capacity to take in any unforeseen circumstances or adversity and as caregivers, it is important to nurture this psychological capital. This study aims to trace the role of social support in the resilience of caregivers of PWD. Our study found a positive correlation between social support and resilience.

Keywords: *People with Dementia, Resilience, Social Support, Psychological Well-Being, Caregivers.*

Dementia is becoming 'the leading cause of disability and dependency' among the older adults across the world, impacting an estimated population of more than 50 million (Nguyen and Levkoff, 2020), People who are taking care of these patients form the backbone for the management of individuals suffering from dementia (Alzheimer's Research UK, 2015). In the process of caregiving, these care providers face both positive as well as negative consequences (Ruisoto et al., 2020). Positive outcomes include the feeling of being useful or fulfilling and the bolstering of relationships (Tarlow et al., 2004), whereas this process tends to take a huge toll on the lives of the care provider, as providing support to these patients can lead to stress, depression, social isolation, ignorance of self-health issues along with enhanced financial and emotional burden among the care providers (Seavey, 2005; Schulz and Sherwood, 2008; Han et al., 2019; Rusioto et al., 2020). Based on the fact that negative consequences may outweigh the positive outcomes, all these causes were labelled as a burden on caregivers and the caregivers were rightly called 'invisible patients' (Ruisoto et al., 2020). To improve the quality of life of the caregivers, there is an urgent need to balance their requirements so that the care providers experience minimal negative consequences (Jones et al., 2019). Apart from the above-mentioned negative issues, these processes also impact the psychological well-being and mental health of the care provider. To achieve better psychosocial health, the care providers have to be highly 'resilient' and need strong social support from their families and society as a whole (Rutter, 2012). By resilience, we mean a 'positive adaptation' that occurs due to stressful situations (Southwick

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et al., 2014). Thus, the prevalence of higher resilience is a desired characteristic in the caregiver. Moreover, it is assumed that the greater availability of social support should make it easier for the care provider. Therefore, it becomes extremely relevant to understand the factors of social support that can help in increasing resilience and decreasing the associated psychosocial burden. Our study intends to study the relationship of social support on resilience and its impact on psychosocial outcomes such as psychological well-being, mental health, and the extent of the burden. This study will be useful to validate the need and extent of social support in strengthening resilience and reducing the burden of the caregiver.

Theoretical background

Researchers have developed varying theoretical frameworks in order to understand the resilience resources available to the care providers (Sothwick et al., 2014; Bekhet and Avery, 2018; Han et al., 2019; Zhou et al., 2020). In a recent ecological model suggested by Han et al. (2019), the risk or resilience existed in factors such as societal, community, or individual. Within the societal factors, expenditures, organizational support, policy, insurance, religion, law, and culture were considered, whereas support from own family and friends, care facilities, communication with staff, homelike environment, and trust in providers formed the community factors and self-control, knowledge, self-care, coping strategies and health behaviour were individual factors. A model on resilience in the care of partners as described by Zhou et al. (2020) where personal traits and environmental resources form the part of the resilience process and cause outcomes related to adversity along with personal growth. In another model given by Nguyen and Levkoff (2020), four stages have been described to be witnessed by the care provider, which begins with the experience of illness and caregiving, followed by the acknowledgement of the challenges faced by the care provider, then experimenting with various strategies and finally acceptance of illness and the caregiving situation. These are affected by the caregiver's factors such as demographic and relationship components, personal beliefs and commitments, and any personal history of coping with the adversity of the care provider and structural factors such as social pressure, cultural values, and norms and social support, especially in the Asian countries. In the case of social support, it was broadly divided into three components: emotional, instrumental, and informational support (Östberg and Lennartsson, 2007). It seems to have a beneficial association with psychological well-being (Thomas, 2010) as well as the resilience of care providers (Wilks and Croom, 2008). However, social support is unable to be fully beneficial to the care providers as the care provider gets restricted within a small social circle (Brummett et al., 2006).

Current state of research

In the past few years, several studies have been conducted that described various theories of the association of resilience on the caregivers' burden (Jones et al., 2019; Han et al., 2019; Nguyen and Levkoff, 2020). It was observed previously that the support resources can facilitate resilience in care providers, but the relationship is highly complex and varies by relationship type (Donnellan et al., 2017). Ong et al. (2018) reported that social support mediated and did not moderate the association of resilience and caregiver burden in Singapore, thereby validating the protective nature of social support. This was also supported recently, where Ruisoto et al. (2020) also reported a partial mediation by the social factor. In a study by Nguyen and Levkoff (2020) on Vietnamese care providers, the psychological process of adjustment in the care provider's role was studied. However, it was realized thereafter that most of the studies were found to be qualitative in nature and conducted with a limited sample size covering only one location. In another study (Cao and

Yang, 2020), the role of social support in shaping the association of objective and subjective care providing burden on care providers from rural China was examined and it was realized that there is hardly any literature in this regard. Moreover, it was stated that the results from this study cannot be generalized even for urban parts of China or the rest of the world. In most of the prior studies, multiple aspects of the resilience framework had not been covered and the effectiveness or efficacy of the support extended has yet not been studied (Tyler et al., 2020). It should be realized that the burden on the care provider is merely a small part of the psychosocial outcome; the other aspects being mental health and psychological well-being. A gap in research was realized in this area as none of the studies included mental health and psychological well-being along with caregiver burden as a psychosocial outcome among care providers of adults with dementia in the evaluation of resilience and social support as protective factors.

Aim of the study
The present study aims to fill the present gap by evaluating the role of social support that shapes the relationship of the resilience of care providers of elders with dementia and their psychosocial outcomes in India.

Based on the theoretical background and current state of research that have been discussed above, the present study intends to study the following overarching research question:
How does social support work affect resilience in the care providers of older adults with dementia?

METHODOLOGY
Sample
The convenient sampling technique is the choice of method for data collection in this study, which will be collected by the researcher herself where participants are selected because of their convenient accessibility and proximity to the researcher. The study consists of 60 adults between the ages of 30-50 years, among which the data of 56 participants are considered. The adults considered for this study are residents of India and are caregivers for PWD (people with dementia). The minimal sample size of our study was estimated employing Cochran's (1977) formula at a 95% confidence level with ±5% precision. Only those participants will be included in the study who are willing to contribute to the study.

Tools
To evaluate social support and resilience 2 scales were used.
- *Adult Resilience Measure- Revised:* Adult Resilience Measure- Revised is a self-reporting tool used to measure social-ecological resilience. The scale uses a 5-point Likert scale and is suitable for users above 18+ years.
- *Multidimensional Scale of Perceived Social Support*: Multidimensional Scale of Perceived Social Support was developed by Zimet et al., 1988. It is a self-reporting scale with 12 elements having 8 options to choose from. It measures three sources of social support- family, friends, and partner.

RESEARCH METHODOLOGY
Sample and Sampling technique
For the study, stratified random sampling was undertaken. The sample selected for our study were caregivers of adults with dementia. The entire sample belonged to India and was between the age group of 30-50 years.

Inclusion or Exclusion
- The sample was restricted to people who took care of people with dementia
- The age group of the sample was restricted to 30-50 years
- The entire sample belonged to India
- Caregivers of people suffering from dementia along with any other psychological disorder were excluded from this study.

Statistical Tool
The correlation between social support and resilience was evaluated using IBM SPSS Statistics v23x64. The independent variable in the study was social support and the dependent variable was resilience.

RESULT

Our study consisted of adults among the age group of 30-50 years. 60 adults were asked to fill 2 questionnaires amongst which 56 adults' scores were considered. Our study shows a correlation of 0.874 between social support and resilience at a significance level of 0.01.

➔ Correlations

[DataSet1]

Correlations

		social support	resilience
social support	Pearson Correlation	1	.874**
	Sig. (2-tailed)		.000
	N	56	56
resilience	Pearson Correlation	.874**	1
	Sig. (2-tailed)	.000	
	N	56	56

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

Fig. 1: Correlation of social support and resilience.
The study shows that there is a positive relationship between 2 variables i.e. when social support increases, the resilience increases, and when social support decreases, resilience decreases.

DISCUSSION

Our result showed a positive correlation of 0.874 between social support and resilience of caretakers of older adults with dementia. To our knowledge, this study is one of the earliest studies in India to understand the impact of perceived social support on resilience. The results are in sync with the study finding the link between social support and resilience (Bonanno,2005). The study also stated that there is no one type of resilience and is a stable trait, not merely limited to exceptionally or pathologically healthy individuals.

Another study conducted by Ong et. al, (2018) showed that social support mediates the association between burden and resilience among caregivers of adults. Their study was conducted among the population of Singapore. Their study highlighted that perceived social

support acts as a third variable between resilience and burden, and our study tries to answer the relationship between resilience and social support.

Another study by Ruisoto et al., (2020) found that social support was an important factor in the role of burden and resilience. In their research, 283 primary and family caregivers residing in Spain were considered. Their study further highlighted the importance of resilience in the overall well-being of the caregivers. The results also highlighted that social support partially influenced the relationship between burden and resilience in caregivers.

There are certain limitations in this study to take into consideration. As the study contains self-reporting scales, there is a risk of social desirability effect. Although the scales have high reliability and validity and other psychometric properties, the social desirability effect can't be ignored. Secondly, the sample is exclusive to caregivers residing in India. Further investigation can be undertaken to understand the impact of social support on resilience. The study is important in understanding the impact of social support on caregivers of adults with dementia in India and can play an important role in deciding interventions and therapies that accentuate the well-being of caregivers, who play an important role in society.

CONCLUSION

Dementia takes a toll on not only the people suffering from it but also adversely affects the near and dear ones. The caregivers of people with dementia have to go through a lot and rigorously nurturing a person with dementia adversely affects their well-being. However, not every caregiver is alike and resilience is something that helps them sail through difficult times. Our study tries to establish the role of social support on the resilience of caregivers of people with dementia in India.

To conclude, this study showed a positive correlation between social support and resilience. Further studies can be undertaken to investigate how social support affects resilience and how the social support of caregivers can be improved.

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