



Assessment of Family Resilience, Mental Health, Burden and Quality of Life of Caregivers of Persons with Dementia

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Abstract : Caring for a person with Dementia can be both emotionally and physically challenging for family caregivers. The condition of the caregivers can be greatly impacted by the demands of providing care for a loved one with Dementia. The aim of the study is to assess family resilience, mental health, burden and quality of life of caregivers of persons with Dementia and to study the relationship between them. Researchers assessed the family resilience, mental health, burden and quality of life of 60 caregivers of persons with Dementia using appropriate tools. Based on the extensive findings of the present study it was found that caregivers of persons with Dementia experiences severe levels of depressive symptoms, anxiety symptoms with stress. A majority of them were found to have mid range quality of life and low family resilience. Depression, anxiety, and stress showed strong positive correlations with each other. Though caregivers of persons with chronic illnesses exhibit remarkable dedication and commitment towards taking care of their loved ones, they face significant emotional and psychological challenges which in turn have direct influence on their mental health and well being.

Index Terms - Caregivers, Family Resilience, Mental Health, Burden and Quality of Life

I. INTRODUCTION

Old age is basically the final stage of the life cycle of every organism. When a person gets older, they require utmost care. At this stage, a person suffers from multiple physical disabilities which may lead to disorientation, depression, confusion and psychosis (Kaye, 1991) which may result in severe cognitive distortions like Dementia (Administration of Ageing, 2001).

Here, the researcher has discussed about a particular type of disorder i.e., Dementia and the various related aspects. The International Classification of Mental and Behavioural Disorders ICD-10 (2009) defines Dementia as “a syndrome due to the disease of the brain, usually of chronic and progressive nature, in which there is disturbance of higher cortical functions including memory, orientation, comprehension, calculation, learning capacity, language, and judgement. These symptoms are commonly accompanied by impairments in cognitive function and deterioration in emotional control, social behavior or motivation.” There are impairments mainly in occupational or social functioning and a decline from previous higher level of functioning as defined by First, Frances & Pincus (2002). It is usually seen that a person with Dementia tend to become dependent and requires constant care with most of their activities of daily living, which in turn creates economic and social burden on the caregivers (National Institute of Health, 2011).

Caring for an elderly is usually long term in nature. Caregiving is a process which plays a crucial role at this stage when a caregiver fulfills their needs and requirements. In the Indian context, the people with Dementia continues to stay with their families as the family members care for the elderly. Among the family members one person is usually found to be more involved in the caregiving process and is considered as a primary caregiver (Alzheimer's and Related Disorders Society of India, 2010). Caregiving involves a significant amount of time, energy and money over a period of long time. It also includes the unpleasant and uncomfortable roles and responsibilities which can be stressful and physically exhausting (Schulz and Martire, 2004). The behavioural symptoms which require constant supervision tend to be more strongly associated with caregiver burden and experiences high level of distress (Brodaty, 1996). There is evidence of greater burden, strain and poor quality of life among the caregivers of persons with Dementia (George and Gwyther, 1986; Jennifer and Cay, 1998). This may contribute to the caregiver to experience psychiatric morbidity like experiencing a high level of depressive and anxiety disorder. It is usually seen, and most researches also suggest that gender of the caregivers play a crucial role in the dimension of caregiving process as it is found that most caregivers are women and experiences high levels of stress, depression or anxiety. It is also found that they have a low level of quality of life, the life satisfaction as compared to men (Schulz & Martire, 2004).

The family caregivers usually take the responsibility of caring for the person's need of dressing, other routine activities and also assistance with finances. The spouses tend to become the direct informal caregivers followed by the adult children of the person especially son and daughter-in-law and then followed by other relatives (Ory et.al., 1999). Caring for persons with Dementia throws many challenges. It affects the mental health of the caregivers, quality of life and can increase their level of burden. The current study thus aims to understand the family resilience, mental health, burden and quality of life of caregivers of persons with Dementia.

II. RESEARCH METHODOLOGY

The aim of the present study was to determine the family resilience, mental health status, burden and quality of life of caregivers of persons with Dementia and to study the relationship among these variables. The researcher adopted a cross sectional descriptive research design to conduct the present study. Purposive sampling was used for selection of sample. The sample consisted of 60 caregivers of persons with Dementia. The caregivers who fulfill the inclusion criteria were selected for the study (Jutten et.al., 2018). The following tools were administered: Socio-demographic datasheet, Family Resilience Assessment Scale (Sixby, 2005), Depression, Anxiety and Stress Scale (Lovibond, 1995), Zarit Burden Interview (Zarit, Reever & Bach- Peterson, 1980) and Adult Carer Quality of Life Questionnaire (Elwick et.al., 2010).

III. ANALYSIS AND DISCUSSION

The purpose of the study was to assess the family resilience, mental health status, burden and quality of life among caregivers of persons with Dementia. The study also explores the relationship among the family resilience, mental health status, burden and quality of life.

3.1 Frequency and Percentage distribution of the socio-demographic profile of the Persons with Dementia

The socio-demographic profile of the caregivers indicates that their mean age was 75.80 ± 8.69 years with an equal sex distribution. 76.7 % of the persons with dementia followed Hinduism and the rest 23.3% followed Islam religion. Most of them (30%) dropped out after primary school, followed by 20% who completed middle school, 16.7% of them are illiterate and 16.7% completed high school. A little more than 13% completed their intermediate and 3.3% of them completed Bachelors degree. 27% of the persons with dementia were unemployed, 6.7% were cultivators and the rest 3.3% had own business. 60% of the Persons with Dementia were married, 36.7% were widowed and the rest 3.3% were currently unmarried. A majority (93.3%) of the Persons with Dementia belonged to a joint family system and the rest 6.7% belonged to a nuclear family system. Dias et al. (2016) in their study found that the mean age of the Persons with Dementia was 78.2 years. It was also found that maximum (55.2%) of the persons with Dementia are married followed by 37.9% who were widowed.

Dementia is common among older adults. This could be attributed to the age of the persons with dementia who are identified for our current study. Ondee et al. (2013) in a study conducted on predicting depression among Caregivers of Persons with Dementia, found that the average age of persons with dementia was 75.73 years, with 39.4% being 80 years of age and older. Ong et al., (2018) in their study on resilience and burden in Caregivers of older adults found that a majority of the care-recipients were a parent of the participants (78.6%), while the rest of the caregivers were other relatives (14.4%), spouses (6.3%), or siblings (0.7%). Majority of the care recipients were either diagnosed as having physical illnesses such as hypertension, hyperlipidemia, diabetes mellitus, and/or mental illnesses including dementia. The clinical details of the caregivers signifies that all the patients who were taken in the study were diagnosed with Alzheimer's disease. The mean of the duration of illness was found to be 2.03 years with a standard deviation of .64. The mean of the duration of treatment was 1.35 years with a standard deviation of .54.

Table 1: Socio-Demographic Profile of Persons with Dementia

Variable	Category	Frequency (N=60)	Percentage (%)
Mean Age		75.80 ± 8.69	-
Gender	Male	30	50%
	Female	30	50%
Religion	Hinduism	46	76.7%
	Islam	14	23.3%
Education	Illiterate	10	16.7%
	Primary School	18	30%
	Middle School	12	20%
	High School	10	16.7%
	Intermediate	8	13.3%
	Bachelor's Degree	2	3.3%
Occupation	Unemployed	27	45%
	Cultivator	4	6.7%
	Own Business	2	3.3%
Marital Status	Married	36	60%
	Widowed	22	36.7%
	Unmarried	2	3.3%
Family Type	Joint Family	56	93.3%
	Nuclear Family	4	6.7%

3.2 Mean, Frequency and Percentage distribution of the Socio-demographic profile of the caregivers

The mean age of the caregivers was found to be 49.93 ± 16.37 years. There were more female caregivers (56.7%) than their male counterparts (43.3%). Most of the participants in the present study had completed middle school (33.3%), 26.7% of caregivers had high school education, 16.7% of participants had completed their intermediate level of schooling, 10% of participants had a bachelor's degree and another 10% of them had primary schooling and the rest (3.3%) were not literate. Majority (60%) of the Caregivers are employed and the rest 40% were unemployed. All the Caregivers are married. Half of the Caregivers were the daughters in law of the Persons with Dementia, 26.6% of the Caregivers were their sons or daughters, 16.7% were spouses and the rest 6.7% were the siblings. The mean duration of caregiving was $2.03 \pm .64$ years. Half (50%) of the Caregivers were providing care for 2 years, 20% were proving care for 3 years, 16.7% was providing care from a year, 6.7% for 1 years 6 months and 2 years 6 months each. The rest 3.3% were providing care to the Persons with Dementia for 4 years. The mean monthly income of the

family was Rs. 21,100 ± 15068.47. The minimum income of the caregivers family was found to be Rs. 5,000 and maximum income was Rs. 72,000 per month.

Ong et al. (2018) in their study found that mean age of the caregivers was 47 years, with the majority being older (40-65 years) (73.7%), female (64.6%), married (60.7%), with tertiary level education (33.5%), and employed (75.8%). Another study conducted by Ostojić et al. (2014) on prevalence of anxiety and depression in Caregivers included 30 participants of which 73.3% are females and 26.7% are males and the mean age is 57.6 years. 83.4 % of the Caregivers completed their middle of high level of education. The majority of the Caregivers were children living with parents suffering from Alzheimer's disease (63.3%). However, in the present study the caregiving responsibility was carried out by the daughters in law. This perhaps reflects the expected role of the daughters in law in the Indian society where the sons are expected to provide care for their aging parents.

The current findings also concurred with the findings of Verma et. al. (2011) in their study where they studied care givers of 30 consecutive in-patients receiving in-patient care in the neurology ward of a tertiary care hospital. The study included 18 male and 12 female caregivers. Majority (83%) was married and employed (66%). In a study by Anderson and Fields (1998) a total of 89 family Caregivers completed the survey. Caregivers were generally in their early 60's, female (68.5%), married (78.7%), adult children (61.8%) and spouses (25.8%) of the care recipients. The participants reported having been in the care giving role for an average of 18.1 years. Scott (2011) conducted a study in caregiver's burden, the ages of the Caregivers ranged between 25-89 years old, with a mean age of 63 years. The study consisted of both male and female caregivers. 80.2% of the Caregivers were female, while 19.8% were male. Dias et al. (2016) in their study found that most Caregivers were female (79.3%) and married (77.6%), with a mean age of 62.5 ± 13.4 years. Most of the caregivers were adult children of the person with Dementia (51.7%).

Ondee et al. (2013) found that 25.2% of the Caregivers were not employed outside the home, they most likely took more time to provide care to the person with dementia than the family members who were employed. The major reasons stated by the Caregivers for serving as a caregiver were: being a child of the person with dementia; being a close relative of the person with dementia; and, feeling a sense of gratitude toward the person with dementia. Another study by Ondee et al. (2013) on healthcare services for the family member with dementia it was found that the average duration of caregiving was 4.54 years, while the average time spent in caregiving was 11.8 hours per day. Similar findings were found by Ritteveerakul (2005). It was found that the mean period of caregiving was 3.8 to 4.3 years, with the average caregiving hours per day being 8.4 to 12.78. With regard to mean duration of care giving, the findings of the current study were different from that of those quoted here. It could be because, the study setting being primarily a mental health institute currently with little facility for indoor care of older adults with dementia, most of those diagnosed with dementia tend to seek further consultation nearer to their hometown after initial diagnosis.

Table 2: Socio-Demographic Profile of Caregivers

Variable	Category	Frequency (N=60)	Percentage (%)
Mean Age		49.93 ± 16.37	-
Gender	Male	26	43.3%
	Female	34	56.7%
Education	Illiterate	2	3.3%
	Primary School	6	10%
	Middle School	20	33.3%
	High School	16	26.7%
	Intermediate	10	16.7%
	Bachelor's Degree	6	10%
Employment Status	Employed	36	60%
	Unemployed	24	40%
Marital Status	Married	60	100%
Relationship with PwD	Daughter-in-law	30	50%
	Son/Daughter	16	26.6%
	Spouse	10	16.7%
	Sibling	4	6.7%
Duration of Caregiving	1 Year	10	16.7%
	1.5 Years	4	6.7%
	2 Years	30	50%
	2.5 Years	4	6.7%
	3 Years	12	20%
	4 Years	2	3.3%
Monthly Family Income (₹)	Mean ± SD	₹21,100 ± 15,068.47	-
	Minimum	₹5,000	-
	Maximum	₹72,000	-

3.3 Frequency and Percentage distribution of Resilience, Mental Health Status, Burden and Quality of Life

The findings of the frequency and percentage distribution of the variables: resilience, mental health status, burden and quality of life of the current study is different from that of a few other studies. Joling et al. (2016) they found that Caregivers were most often highly resilient when caring for a person with more severe dementia (43%), followed by caring for someone with limitations in self-care (42%) and providing care and support (41%). The prevalence of resilience was lowest when dealing with behavioural/ mood problems in the Persons with Dementia (35%). About 39% depicted high resilience when facing more than one high demands of caregiving.

The current study states that the Depressive symptoms among the caregivers were found to be in severe level (36.7%) and extremely severe level (36.7%) among many of the respondents. Some (13.3%) of the Caregivers showed mild level of depressive symptoms and 6.7% each of the Caregivers showed moderate and normal level of depressive symptoms. The findings of this study corroborates with that of several other studies.

Keicolt-Glaserm et al. (1991) in their study found that there is a greater incidence rate of depressive disorders among care givers. Similar kind of study was conducted by Malone, Zarit and Farbmán (1995) where they found that Caregivers were highly distressed because of the increasing demand of the caregiving process. Fisher et al. (2011) in their study found higher level of depressive symptoms among the caregiver is persons with dementia. A high level of depressive symptoms was also found among the Caregivers in a study conducted by Ostojić et al. (2014). Verma et al. (2011) also highlighted that 43% of the Caregivers were found to have depressive symptoms. Almost half of the Caregivers in a study conducted by Medrano et al. (2014) were found to have depressive symptoms.

In a study conducted by Ondee et al. (2013) the total caregiver depression scores ranged from 0 to 60, with a mean of 13.81. The component of caregiver depression, the mean scores were as follows: depressive effect = 2.88; positive effect = 6.26; somatic and retard activity = 4.32; and, interpersonal relationships = 0.35. These findings suggest, overall, the study's Caregivers had a low level of depression, unlike the findings in the current study.

In the current study 80% of the Caregivers were found to have extremely severe level of anxiety symptoms; 10% of the Caregivers have moderate level of anxiety symptoms and the rest were found to have 3.3% of severe, mild and normal level of anxiety symptoms each. Pinquart and Sorensen (2006) and Lu and Austrom (2005) also found a higher level of anxiety symptoms among the Caregivers of Persons with Dementia. The American Psychological Association (2009) found that 36% of the Caregivers reported to have anxiety symptoms. In a similar study by Ostojić et al. (2014), found that 46.7% of the Caregivers had anxiety in a pathological level. Mahoney et al. (2005) found 23.5% of the caregivers scored high level of anxiety.

The findings of the current study indicates that 43.3% of the Caregivers have moderate level of stress followed by 30% of them having severe level of stress and 10% of the Caregivers had extremely severe level of stress. Verma et al. (2011) found that the Caregivers of patients with dementia experienced a greater level of stress. Martire and Hall (2002) also found that care giving of a person with dementia produces a high level of stress.

The present study also shows that 50% of the caregivers were facing moderate to severe level of burden. 30% of the Caregivers have severe burden, 16.7% have mild to moderate burden and the rest 3.3% have little to no burden. Chakma and Goswami (2016) also found that the level of burden is high among the Caregivers of Persons with Dementia. Medrano et al. (2014) in their study found that 36% of the Caregivers exhibit caregiver burden. In a study conducted by Ondee et al. (2013) they found that the total scores of caregiver burden ranged from 0 to 88, with a mean of 23.82. The mean score for personal stress was 14.81, while the mean score for role strain was 9.01. Slightly over half of the Caregivers had little or no burden, followed by mild to moderate burden (30.5%), moderate to severe burden (15%), and severe burden (3.5%).

The current study also found that 86.7% of the Caregivers have mid range quality of life and the rest 13.3% have low quality of life. Truong (2015) found that the Caregivers of Person with Dementia have low quality of life. In another study conducted by Maithreyi et al. (2017) it was found that half of the Caregivers included in the study had poor quality of life. But Manninen et.al. (2003), contradicted these results by saying that the quality of life of the Caregivers of Persons with Dementia is relatively close or even little better than in the general population.

3.4 Correlation among Resilience, Mental Health Status, Burden and Quality of Life

Spearson's correlation test was administered to find the correlation among them. It is found that resilience has negative correlation with depression ($r = -.213$) and anxiety ($r = -.026$). However this correlation was not statistically significant. Resilience is found to be significantly negatively correlated with stress ($r = -.447$) at $p < .01$. Resilience is also found to have significantly negative correlation with burden ($r = -.371$) at $p < .05$ level of significance. On the other hand there is no significant correlation of resilience and quality of life ($r = .202$).

Depression was found to be significantly positively correlated with anxiety ($r = .831$) and stress ($r = .844$) at .01 level of significance. It was also significantly correlated with burden ($r = .638$) at .01 level of significance. Depression was found to have negative correlation with quality of life ($r = -.369$) at .05 level of significance.

Anxiety was also significantly positively correlated stress ($r = .709$) as well as with burden ($r = .588$) at .01 level of significance. It is found to be negatively correlated with quality of life ($r = -.179$). However, this correlation was not statistically significant.

Stress was also found to be significantly correlated with burden ($r = .756$) at .01 level of significance. On the other hand it was negatively significantly negatively correlated with quality of life ($r = -.485$) at .01 level of significance.

Burden was found to be negatively correlated with quality of life ($r = -.474$) also at the significance level of .01.

Lansac et al. (2012) found that caregivers achieved moderate scores for resilience, which was significantly associated with poor physical and emotional conditions among the caregiver, while higher scores were associated with less anxiety, less depressive symptoms, lower drug consumption and absence of psychological interventions. It was also found that higher resilience scores were also significantly correlated with levels of overburden, and self-esteem.

Ong et al. (2018), found a significant association between resilience and caregiver burden which was mediated by the level of perceived social support. According to Pinquart & Sorensen (2006), the effect of caregiver burden can reduce the informal Caregivers physical and psychological well-being, and shows significantly higher depression symptoms when comparing non-dementia Caregivers with dementia Caregivers.

Tay et al. (2016) in their study found that the total burden score had significant negative correlation with the total quality of life scores physical health and environmental domain scores indicating a similarity between caregivers' perception of their burden and quality of life. Li and Lewis (2013) in their study found that the caregiver depression was positively associated with Expressed Emotions (EE) and burden.

In short, the current study shows that care givers had low family resilience, poor mental health, moderate to severe level of burden and mid range quality of life. As the family resilience increased, stress and burden decreased. Depressive symptoms, level of anxiety and stress were positively correlated indicating that as one increased the other variables increased too. Mental health status and burden had a negative correlation with quality of life.

3.5 Conclusion

Caring for a person with Dementia often involves a team of people. Caring for someone with Alzheimer's disease can be challenging, but with proper knowledge, understanding, and support, it can be a fulfilling experience. Caregiving for someone with Alzheimer's disease is a journey that requires ongoing adaptation.

The present study underscores the profound and intense challenges that are faced by caregivers of persons with Dementia. It highlighted the need for tailor-made interventions that will focus on enhancing their resilience, reduce their mental health issues, and improve their overall quality of life.

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