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## The unrecognized burden of stress on family caregivers of dependent elderly

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#### Abstract

Family caregivers have played an important role in our society for granting care to the aged. They are playing crucial in our care system by providing a significant quantity of health and long-term care for the aged person, chronically ill, disabled. The act of care-giving is not an easy task and can become more tedious when one is caring for a family member who is solely depending on the primary caregiver for everything. This situation could be the reason for many challenges which can affect the quality of life of the primary caregivers. The present research has made an attempt to assess the burden of stress among the family caregivers who were primarily responsible for care of dependent elderly. The sample included 60 families of primary caregivers who were taking care of the dependent elderly in their family from the Ludhiana city. The Zarit Burden Interview developed by Zarit *et al.* (1980) was used to measure the burden of stress on caregivers.

**Keywords:** Burden, family caregivers, dependent elderly

#### Introduction

In Indian society, since earlier times family caregivers have played an important role of granting care to the aged. They have been playing pivotal role in the health care system by providing a remarkable quantity as well as quality of assistance and long-term care for the aged person who was incapable, disabled or terminally ill. In addition, most of the families preferred to care for their elderly person at all stages of their life. However, larger societal changes and changes into the patterns and structure of family system in the country have now placed a significant demand and importance on the family caregivers.

A family caregiver is the person from the family who takes primary responsibility for a dependent elderly in the family who cannot take complete care of himself or herself. Family caregiver has a significant personal relationship with the elderly 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.

Caregiver could be with no training in health care and other requirements of the elderly but taking care of his or her elderly family members. Thus, a family caregiver may be understood as a person who is responsible for taking care of the daily needs of the dependent elderly person. Family caregivers are accountable for the emotional, physical as well as financial support of the dependent elderly, suffering from illness, injury or any kind of disability.

During the caregiving of the dependent elderly, the overall target of interest is meeting the requirements of the elderly. Therefore, in this scenario, the needs and demands of the primary caregivers are often not taken care and are generally ignored. Consequently, the health status and wellbeing of the caregivers are often neglected and overlooked. The active role played by such primary caregivers is well entertained but often the underlying stress and burden which caregivers often experience during caregiving is poorly understood and goes unrecognized.

Stucki and Mulvey (2000) <sup>[10]</sup> defined caregiver burden as the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member. The burden and stress experienced by the caregivers, due to caregiving, is generally considered as multi-dimensional biophysical impact which results in unequal demands related to their physical and emotional state of mind as well as body of the primary caregiver. Their personal time, social roles, financial resources and the other roles they fulfill are over compromised and constricted.

Family caregivers often experience frustration, stress and distress as they dedicate their larger time in providing care to elderly who is suffering from a persistent disease. Caregiving in itself is a strenuous activity and the condition worsen when it is undertaken by only one individual

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which can double the exhaustion which occurs due to continuous working for the needs of the elderly. If this exhaustion is linked with unavailability of support from other members of the family then the condition will be more difficult to handle for the primary caregivers (Simonetti & Ferreira 2008) <sup>[9]</sup>.

Family caregivers are potentially at increased risk for adverse effects on their well-being in virtually every aspect of their lives, ranging from their health and quality of life to their relationships and economic security.

Another study shows that impairments in the health status of caregivers are led by the factors that make up the context of care. The dependence in daily activities, time spent in giving care and the severity of disorders of the elder members pose marked influences on the understanding of wellbeing and its bad impact on primary caregivers.

The process of caregiving is highly unpredictable and sometimes it is out of control. Due to such uncertainty, it generates physical as well as psychological exertion when performed for long periods of time and therefore, negative consequences of care giving responsibilities impact upon the quality of life of the caregivers.

Acton (2002) <sup>[1]</sup> stated that family caregivers pay little attention to their own health needs due to the lack of time. Most of their time is spent on managing memory and behavior problems of the patient which often leads to poor health and increases severe health issues. Specifically, caregivers for spouses with dementia experience greater risks of emotional stress, depression, and other health related problems or issues (Adams 2008; Mills *et al.* 2009; Von-Kanel *et al.* 2008) <sup>[2, 6, 11]</sup>.

Nguyen *et al.* (2015) <sup>[7]</sup> conducted a study on relationship of factors of burden and quality of life of primary caregivers and reported that primary caregivers had lower levels of mental well-being when the burden and related factors increased due to caregiving of the partially and completely dependent elderly. They demonstrated high prevalence of mood disorder like anxiety, depression among primary caregivers who were persistent in the caregiving task of the old age persons of the family.

Rosell-Murphy *et al.* (2014) <sup>[8]</sup> in their study conducted an intervention for family caregivers in order to reduce the caregiver burden. They found that by increasing the social and family support to family caregivers the quality of life significantly enhanced.

Cordoba *et al.* (2012) <sup>[3]</sup> quoted in their study that majority of

time family caregivers do not receive any training for daily care of the dependent elderly rather they are told about the medical condition of the disease which triggered negative thoughts and stress which ultimately affect their quality of life.

Thus keeping in mind the negative impact of burden of stress stress on the caregivers' life it is very important to understand. Understanding the burden of stress upon the caregivers provides ways to better manage the burden on the primary caregivers. Thus, keeping in view the above objectives for study were framed and they are as follows:

1. Distribution of the family caregivers as per their demographic profile.
2. Distribution of the family caregivers as per their stage of adulthood and level of burden of stress.

## Methodology

### Sample

A sample of 60 family caregivers was purposively selected with the help of doctors of neurology and neurosurgery department of different hospitals of Ludhiana district. Sample was also selected by using snowball sampling method.

### Tools

#### Zarit Burden Interview

Zarit burden interview by Zarit *et al.* (1980) <sup>[12]</sup> was used to assess the burden of stress. It contains 22 items which are to be assessed on a 5-point Likert scale, ranging from 0="never" to 4="nearly always". Item scores are added up to give a total score ranging from 0 to 88, with higher scores indicating greater perceived burden. The questions focus on major areas such as caregiver's health, psychological well-being, finances, social life and the relationship between the caregiver and the patient. High scores on the test indicate severe burden upon family caregivers whereas low scores on the test indicate mild or no burden.

## Results and Discussion

### 1. Distribution of Family Caregivers as Per Their Demographic Profile

The demographic profile of the family caregivers is presented in table 1. The socio-personal variables such as age, gender, education, occupation, marital status and stage of family life cycle of family caregivers, their relationship with the dependent elderly and monthly family income have been documented for the family caregivers.

**Table 1:** Distribution of the family caregivers as per their demographic characteristics (n=60)

S. No.	Variables	Category	Per cent (%)
1.	Gender	Female	91.67
		Male	8.34
2.	Stage of Adulthood	25-42 (Young adulthood)	40.00
		42-59 (Middle adulthood)	31.67
		59-76 (Late adulthood)	38.34
3.	Education	Illiterate	10.00
		Under matric	25.00
		Matric	18.34
		+2	20.00
		Graduation	20.00
		Post-Graduation	6.67
4.	Marital Status	Married	83.34
		Unmarried	6.67
		Divorced	1.67
		Widow	3.34
		Widower	0.00

5.	Relationship with dependent elderly	Son	3.34
		Daughter-in-law	60.00
		Daughter	6.67
		Spouse	25.00
		Brother	1.67
		Sister-in-law	1.67
		Grand daughter	1.67
		Grand son	0.00
6.	Caregiver's Stage of Family Life cycle	Still Single	6.67
		Beginning	0.00
		Expanding	28.34
		Contracting	31.67
		Married Children	3.34
		Grand Children	30.00
7.	Size of Family	Up to five	8.34
		Six-seven	61.67
		Above eight	30.00
8.	Monthly Family Income (Rs)	Up to 20,000	25.00
		20,000-50,000	58.34
		Above 50,000	16.67

Figures in parentheses indicate percentages

A probe into the gender revealed that 91.67 per cent of the family caregivers were females and only 8.34 per cent were males. When the trend of age range of the family caregivers was seen, it was apparent that 40.00 per cent of the respondents belonged to 25-42 years of age range, 31.67 per cent to 42-59 years and remaining 38.34 per cent to 59-76 years of age-range.

Data pertaining to the education of the family caregivers revealed that most of the family caregivers were literate. Further probe into educational qualifications depicted that 25.00 per cent were under matric, 18.34 per cent matric and only an equal per cent of family caregivers were educated up to plus 2 (20.00%) as well as graduate level (20.00%) 6.67 per cent were educated at post graduate level. However, only 10.00 per cent were illiterate.

Data relating to marital status of the family caregivers revealed that majority of the family caregivers (90.00%) were married, 6.67 per cent were unmarried and only 3.34 per cent were widow whereas merely 1.67 per cent of the family caregivers were divorced.

As far as relationship with care receivers was concerned the data clearly elucidated that 60.00 per cent of the family caregivers were daughter-in-law followed by, 25.00 per cent spouses, 6.67 per cent were daughters, 3.34 per cent were sons and an equal per cent of respondents were reported as

sister-in-law (1.67%), brother (1.67%) and grand daughter-in-law (1.67%).

Furthermore, the data pertaining to caregiver's stage of family life cycle revealed that among three stages of family life cycle caregivers from contracting stage of family life cycle were the highest (31.67%) and 28.34 per cent were in expanding stage of family life cycle. While 30.00 per cent family caregivers have grand children and only 3.34 per cent had married children. However, 6.67 per cent of the family caregivers were unmarried.

A major proportion of the family caregivers (61.67%) had six to seven members in their family, 30.00 per cent belonged to the families having eight and even more members in their family whereas few of them (8.34%) had up to only five family members in their family.

With respect to the monthly family income, 58.34 per cent of the family caregivers had families with monthly family income up to Rs 20,000. Nearly 25.00 per cent of the elderly have monthly family income of Rs. 10,000-20,000 whereas 16.67 per cent had monthly family income of above Rs 50,000.

**2. Distribution of The Family Caregivers As Per Their Stage Of Adulthood And Level Of Burden Of Stress.**

**Table 2:** Distribution of family caregivers with respect to their stage of adulthood and level of burden of stress

Level of burden of Stress upon family caregivers	Stage of Adulthood of family caregivers			
	Young Adulthood (n <sub>1</sub> =24) f(%)	Middle Adulthood (n <sub>2</sub> =19) f(%)	Late Adulthood (n <sub>3</sub> =17) f(%)	Total (n=60)
Severe	12 (50.00)	15 (78.95)	10 (58.82)	37 (61.67)
Moderate	5 (20.83)	2 (10.52)	5 (29.41)	12 (20.00)
Mild	7 (29.17)	2 (10.52)	2 (11.76)	11 (18.36)

Note: \* Significant at 10% level, NS: Non-significant, NA: Not applicable

The data in the table 2 illustrates the per cent distribution of family caregivers with respect to their stage of adulthood and level of burden stress being experienced by them. The overview of data elucidated that major proportion of the family caregivers across all stages of adulthood were concentrated in the severe level of burden of stress experienced by them (50.00%, 78.95% & 58.82%,

respectively). Thus, it could be inferred that the caregivers reporting to experience severe stress could possibly had minimal support from their family and acquaintances.

The above findings indicate that although family caregivers in young adulthood and were likely to be more dynamic, vibrant and energetic as compared to their counterparts in middle and late adulthood stage but the sudden role and responsibilities of

a caregiver creates re-adjustment situation in their lives whereas, on the other hand middle aged caregivers could better manage the caregiving task along with other household chores. Therefore, significantly a higher number of middle family caregivers (78.95%) reported who have severe stress as compared to their counterparts (50.00%).

Furthermore, family caregivers usually have lot of physical and emotional burden for which they look forward for emotional support from kith and kin. Taking short breaks from this burdensome task and sharing their emotions with someone from family could be good emotional catharsis. Continuous stress and strain takes toll on their lives both personal & professional and can exhaust them. Therefore, it is essential for family caregivers to take some time off in between the tiresome daily schedule.

This finding is supported with previous research work performed by Dominguez *et al.* (2009) <sup>[4]</sup> in which they demonstrated the importance of emotional needs of the caregivers. They suggested that caregivers must maintain relationships of trust to express and validate the motives of their emotional distress. They reported the need of recognition and appreciation as caregivers and also expected collaboration of family members in caregiving roles and responsibilities.

### Conclusion

Family caregivers can also be called as the 'hidden patients' who may possess some serious adverse physical and mental health consequences from their physically and emotionally demanding work as caregivers and reduced attention to their own health and health care. Kim *et al.* (2012) <sup>[5]</sup> reported that caregiver burden threatens various areas of health of caregivers such as physical, psychological, emotional and functional. The results of the study points out that there is more to be learned about the effect of caregiver stress on the family caregivers. Family physicians continue to play an important role in helping family caregivers become more confident and competent providers as they engage in the health care process.

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