

# CAREGIVING BURDEN AMONG FAMILY CAREGIVERS OF ELDERLY: SIGNIFICANCE OF SOCIAL SUPPORT

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**ABSTRACT:** *Elderly body gets affected due to degenerative changes. The life style diseases, socio-economic, psychological changes, environmental factors etc. accelerate the ageing process and they are susceptible to depend on family members for care and support. The new responsibility to care for both the older and younger generation for a longer period is causing significant stress among middle aged adults. Caregiver burden is the stress which is perceived by caregivers due to the home care situation. There are several symptoms that indicate caregiver burden and stress including: depression and anxiety, difficulty concentrating, irritability, exhaustion, easy annoyances, sleep disturbances, health problems, substance abuse, lack of interest in social or fun activities and withdrawal from responsibilities or obligations. In addition, higher levels of burden may correlate with increased morbidity and mortality in caregivers. Many studies have revealed that the incidence of depression among caregivers is high, ranging from 18 to 47 percent and caregivers who are depressed experience higher degrees of burden. Family support, specifically frequent arrangements for respite by other family members and the presence of a strong social support correspond with lower levels of caregiver burden. Hence, the present research on "Caregiving Burden among Family Caregivers of Elderly: Significance of Social Support" was carried out in five selected mandals of Nellore district to understand profile of caregiver of the elderly; to assess the health status and burden endured by caregivers and study the impact of social support intervention on caregivers burden levels. The assessment of caregiver burden and health status is done by adopting standardized tools. The study revealed that poor socio-economic status of the caregivers, poor health, low social support and lack of satisfaction entail to caregiving burden. There is significant impact of social support intervention on reducing the caregivers' burden*

**Key Words:** *Caregiver, Caregiving Burden, Elderly, Social Support*

In the twentieth century the proportion of population aged 60 or over has increased in all countries of the world. About 600 million people in the world were aged 60 or over at the turn of the new millennium and their number is expected to increase further due to improvement in public health and medical advancement in the prevention of many deadly epidemic diseases. This together with declining birth rate and fertility trends lead to increase in share of the aged in total population, especially in developing countries like India. The grey population is increasing alarmingly and expected to be more than 10 percent by the year 2021. It is very essential to initiate appropriate programmes and policy intervention to ensure life with dignity for the senior citizens of the country. The data from 2011 census revealed that there are 104 million elderly in the country constituting 8.6 per cent of the population.

The sandwich generation is growing more and more as older people live longer with the help of medical intervention. The sandwich generation are middle-aged adults who care for their aging and fragile parents and their still dependent children. A report from the American Association for Retired Persons (AARP) found that 44 percent of adults ranging from 45 to 55 years old were housing both an elderly parent and a dependent child under the age of 21 in their home. Unlike professional caregivers such as physicians and nurses, informal caregivers typically family members or friends provide care to individuals with a variety of conditions including advanced age, dementia and cancer. This experience is commonly perceived as a chronic stressor and caregivers often experience negative psychological, behavioral and physiological effects on their daily lives and health.

Caregiver burden is the stress perceived by caregivers due to the home care situation. Caregivers of family members are silent angels. They may not outwardly complain or whine about their responsibilities to care for so many individuals including themselves. There are several symptoms that can indicate caregiver burden and stress including: depression and anxiety, difficulty concentrating, irritability, exhaustion, easy annoyances, sleep disturbances, health problems, substance abuse, lack of interest in social or fun activities and withdrawal from responsibilities or obligations. Family issues often surface when discussing the specifics of respite care. Numerous and varied family stresses develop around providing care to the family

member. The primary caregiver can have difficulty accepting other family members' support while at the same time resenting a perceived lack of support.

In many instances, the sons' wives are delegated by their husbands to provide the more frequent hands-on care and these women just as is the case with daughters, are most often over age 50, may still have dependent children and may also be engaged in paid employment. The potential for stress increases with greater responsibilities and time demands and is invariably affected by the quality and history of the relationship with the older persons. According to Mehta (2005) article on "Stress among Family Caregivers of Older Persons in Singapore". In Singapore, close to 95 percent of older people co-reside with family members, highlighting the importance of community support for family caregivers. Using a study of 61 principal family caregivers in Singapore, this article highlights the nature and relationship between caregivers' stress and gender, patients' activities of daily living (ADL) and instrumental ADL dependency and caregivers' attitudes. Findings from the study suggest that female caregivers tended to be more stressed than male caregivers, samples of 61 family caregivers of homebound patients. The results revealed that 94 percent felt constantly under stress and 88 percent had restless, disturbed nights also showed a significant inverse relationship between the level of stress experienced by caregivers and the ADL and instrumental ADL dependency of patients.

Social Support groups are popular outlets for caregivers. One study revealed that educational support was most beneficial to caregivers when it was problem-focused such as on behavioral management. In another study, combination intervention that included individual and family counseling sessions as well as mandatory participation in support groups was found to delay the need for nursing home placement. Institutionalization of dementia patients was delayed by 329 days in the intervention group of caregivers compared with the group of caregivers who did not receive counseling and other forms of support.

Caregivers spend a significant amount of time interacting with their care recipients while providing care, support in a wide range of activities. On average, most of the caregivers dedicate 4.3 years to this work (Donelan, 2002). Most of the research on the health of caregivers has been focused on physical and psychological well-being. Depression is the most profoundly researched area in caregiver health. Grossfeld et al. (2010) study discovered that anxiety was present in 17.5 percent of caregivers and an augmented incidence of anxiety correlates with a higher amount of psychotropic drug use among caregivers. Kurasawa et al. (2012) research has revealed that viral illnesses last longer in caregivers than in control subjects due to low immunity levels among them. In a study by Perkins et al. (2012) on caregiver health shown that elderly spousal caregivers who experienced caregiver stress had a mortality risk that was sixty three percent higher than that in control subjects. The implications of this study make early identification of caregiver burden and appropriate intervention more essential.

Coping strategies can be divided into emotion-focused and problem-focused. Examples of emotion-focused strategies are worrying and self-accusation. Caregivers who use problem-focused strategies such as confronting issues and seeking information have less burnout. Respite care can be helpful in reducing depression, burden and anger. Interventions at the individual caregivers' level can be beneficial in reducing or stabilizing depression, burden, stress and role strain. Group support has a positive effect on caregivers' coping ability, knowledge, social support and reducing depression. Technology-based interventions can reduce caregiver burden, depression, anxiety and stress improve the caregiver's coping ability. Integrated support packages where the content of the package is tailored to the individual caregivers' physical, psychological and social needs should be preferred when supporting informal caregivers of frail elderly. It requires an intense collaboration and coordination between all parties involved. Researchers found that this negative forms of caring style occurs especially towards burdened caregivers. Hence, the present research on "**Caregiving Burden among Family Caregivers of Elderly: Significance of Social Support**" was carried out with some objectives

### **Objectives of the study:**

1. To understand the socio-demographic and economic profile of caregiver of the elderly;
2. To assess the health status of caregiver of the elderly;
3. To study the caregivers level of burden due to the task of caregiving to the elderly relative and impact of various socio-demographic variables on their level of burden
4. To study the impact of social support intervention impact on caregivers burden levels.

### **Hypothesis:**

- The health status of the elderly caregiver is influenced by their level of burden due to caregiving to elderly relative.

- The social support received by the caregiver has impact on their level of burden due to caregiving of the elderly relative.

**Methodology:** The universe of the present study belongs to family caregivers of the elderly residing in five selected mandals of Nellore district namely Ojili, Kommalapudi, Kantepalli, Mopuru and Sangammandals .250 family caregivers to elderly were selected from above areas by the method of simple random sample. The assessment of caregiver burden is done by using Burden Scale for Family Caregivers (BSFC Elmer et al, 2003) and the Perception of Social Support Inventory which was constructed and standardized by Ramamurthi and Jamuna (1991) were adopted for the study. The researcher obtained consent as ethical consideration from the elderly family caregivers by meeting them personally and explaining about the study and sought their cooperation. The interviews were arranged as per the convenience of the respondents and besides interview, observation method, FGDs was also used while collecting the data pertaining to family caregiver burden and stress. The data which was collected was analysed by using certain statistical techniques with the help of SPSS 16.0.

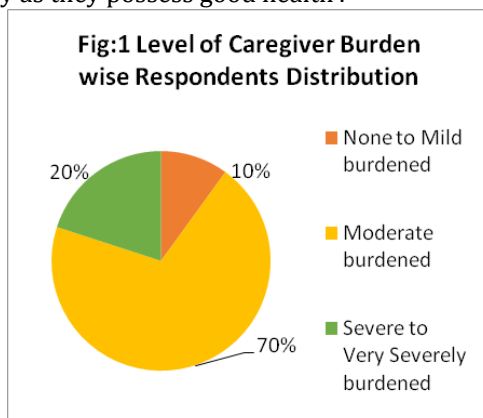
**Results and discussion:**

The socio-demographic characteristics of the present study sample revealed that 66 percent of the respondents i.e. caregivers are females, 54 percent are in the age group of 35- 55 years without any formal education. Regarding occupation of the respondents a significant number 32 percent of the caregivers are engaged as wage workers and 49 percent are having income of less than Rs 5,000 per month and 94.4 percent opined that their income is not sufficient to meet their needs. A majority of the respondents i.e. 82.4 percent belong to Hindu community and a significant number i.e. 51 percent belong to Backward caste. A majority of the caregivers of elderly i.e. 67 percent were married and living with their spouses and living in joint family. Living arrangements plays a significant role in a persons' life, when enquired about their satisfaction level 47.2 percent of the elderly were 'not at all satisfied' with the available living arrangements at home .

**Table No.1 : Respondents Distribution according to their present health status compared to last five years**

S. No	Health status	Frequency	Percent
1	Excellent	011	04.4
	Good	026	10.4
	Moderate	102	40.8
	Poor	101	40.4
	Very poor	010	04.0
2	<b>Health Problems</b>		
	Mild health problems	083	33.2
	Major health problems	064	25.6
	Psychological problems	043	17.2
	Not applicable	059	23.6

From the table No.1 It is found that a little above than two-fifths of the respondents each i.e. 40.8 percent have 'moderate' health status and 40.4 percent have 'poor' health' when compared to last five years and 33.2 percent have mild health problems and 25.6 percent have major health problems , 17.2 percent have psychological problems and 23.6 percent are under not applicable category as they possess good health .

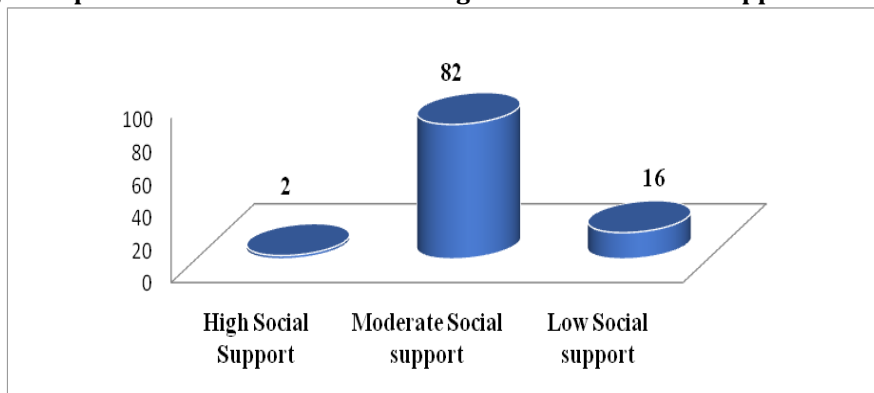


It is clear from the study that nearly three fourths i.e 70 percent of the respondents are moderately burdened due to caregiving to their elderly relative followed by 20 percent having severe to very severe by burdened and a less 10percent caregivers of elderly were in the category of none to mild burden ( Fig-1)

**Social support :**

Being a part and parcel of the family, the elderly get some sort of help (social support) especially from the members of their family. Generally one or two members in the family provide care to their elderly relative and the remaining family extends some sort of support to the caregivers. It is noticed from the results that more than four fifths i.e. 81.6 percent of the respondents received moderate social support from family members in their caregiving responsibilities followed by 16 percent received low social support and a less 2.4 percent received high social support from their family members in providing care for their elderly relative.

**Fig:2 Respondents distribution according their level of social support received**



**Table No.2: Levels of Caregiving Burden according to their Health status , Lifesatisfaction , social support etc**

S. No	V	N	Mean	Std. Deviation	F	P
<b>1</b>	<b>Health Status</b>					
	Excellent	11	1.5455	.68755	7.659	.000*
	Good	26	1.9615	.59872		
	Moderate	102	1.9902	.47710		
	Poor	101	2.2673	.52709		
Very poor	10	2.3000	.48305			
<b>2</b>	<b>Life Satisfaction</b>					
	Satisfied	7	1.2857	.48795	10.157	.000*
	Slightly satisfied	18	1.7778	.54832		
	Neutral	4	1.7500	.50000		
	Slightly dissatisfied	77	1.9610	.37842		
	Dissatisfied	115	2.2957	.51254		
Extremely dissatisfied	29	2.0690	.70361			
<b>3</b>	<b>Social Support</b>					
	Low social support	40	2.0750	.47434	9.482	.000*
	Moderate social support	204	2.1225	.54337		
	High social support	6	1.1667	.40825		
*Significant at 0.01% level, ** Significant at 0.05% level, @ not significant						

Health is a very important factor in the well-being of the individual. The health status affect the individual body functioning and also their performance. The caregiver burden mean scores distribution according to the respondents health status, life satisfaction and social support is presented in table no2, It is identified from the study that low mean score for caregiver burden is observed (1.5455) in the case of respondents with excellent health . The mean scores for caregiver burden differ significantly with regard to the caregiver

health status ( $t = 7.659, P < 0.01$ ). The caregiver life satisfaction is determined by their caregiver burden. The mean scores for caregiver burden differ significantly with regard to the caregiver life satisfaction level ( $t = 10.157, P < 0.01$ ). The results also observed that low mean score for caregiver burden observed (1.1667) in the case of respondents with high social support than respondents with low social support. The mean scores for caregiver burden differ significantly with regard to the caregiver's level of social support received ( $t = 9.482, P < 0.01$ ).

**Intervention:** Due to the high importance of the caregiver burden with regard to the caregiving process, it is necessary to develop interventions to reduce this burden and to examine their effectiveness. Successful interventions should be available to as many caregivers as possible. "The usefulness of an intervention is the multiplication of effectiveness and usage." (ElmarGräßel) It is therefore necessary both to develop interventions to improve and find ways to strengthen the awareness and use of these interventions. Based on the results few intervention strategies were planned to family caregivers who are in burden and stress through social work methods. Silva et.al (2013 ) stated that for unburdening interventions for caregivers should consider four central aspects: Information and training, Professional support, Effective communication and Public and financial support/awareness. There are different supporting services, e.g. caregiver counselling, professional training, self-help groups, ambulant nursing services or technical help like intelligent light to preserve the autonomy of the person in need of care. Another effective relief is the support given to caregivers by family members, friends and acquaintances. They provide emotional and instrumental support and are an important source to access supporting services. Further there is a lack of qualitative empirical studies on the impact of unburdening intervention, research should focus on that point.

The study revealed that poor socio-economic status of the care givers poor health, low social support and lack of satisfaction entail to caregiving burden. As the caregivers with poor economic status force them to attend their earning activities, if any emergencies aroused to elderly care receiver they have to attend the task by foregoing that dayslabour which is very inconvenient for them. Further the poor health status of caregiver itself led them to perceive the caregiving task as burdensome. Further non-availability of social support in any form hinder their checkups of respite care facilities and cause dissatisfaction in life. The post intervention assessment discovered that the low mean scores for caregiver burden is 1.8120 observed in case of post intervention level and there is a significant difference between pre and post intervention scores of caregiver burden ( $t = 7.890, P < 0.001$ ). Hence this could be concluded that the suitable interventions which are tailored according to the needs of caregivers will have an impact on minimizing the caregiver burden and stress in a significant manner.

**Table No :3 Correlation analysis between a set of Socio-demographic and Burden of caregivers , satisfaction in life and social support Variables**

variable	Age	Gender	Education	Income	Health	Living	Family	Satisfaction in life	Social support
Pre-BSFC	.324**	.146*	-.243**	.027@	.313**	.313**	.288**	-.088	.334**
Post BSFC	.123*	.117*	-.129*	.128*	0.88*	.168**	.115*	-.112*	.253**

\*\*p<0.01 level, \* p<0.05 level and @ not significant

Further the results revealed from table 3 that caregivers burden at pre intervention level positively correlated to age ( $r = .324$ ) gender ( $r = .146$ ). This shows that in individuals as age advances there was an increase in caregiver burden levels. Further, it is clear that the caregivers with good health ( $r = .313$ ), satisfaction regarding living arrangements ( $r = .313$ ) and those who lived in joint family ( $r = .288$ ) are more significant than income ( $r = 0.27$ ) and negatively correlated with respondents education level ( $r = -.233$ ). The correlation between other variables such as caregivers satisfaction in life impact towards caregiver burden at pre and post intervention levels were analysed. Similarly correlation between social support and caregivers burden at pre and post intervention levels were analysed and the same was reported in Table no:3 . It is clear that the satisfaction in life is significant but negatively correlated to life satisfaction in life at pre intervention caregiver burden ( $r = -.088$ ) and post intervention caregiver burden ( $r = -.112$ ) and positively correlated to social support at pre intervention caregiver burden ( $r = .334$ ) and post intervention caregiver burden ( $r = .253$ ). The results on correlation analysis indicated that lower the satisfaction in life beliefs that the higher the caregivers burden. Similarly individuals who are with low social support exhibited higher level of burden at pre and post intervention levels. Thus the individuals with good social support are found to be better equipped to face caregiver burden and its consequences.



**Conclusion:**

In general, we find that a variety of caregiver support services are useful in alleviating caregiver strain and helping caregivers to provide care. The magnitude of their utility, however is impacted by a variety of factors: the outcome chosen for measurement; the caregiver's background characteristics, including their psycho-social strengths and vulnerabilities; and the care recipient's type and level of dependency etc. Interventions in one service area, though useful have not been found to be as effective as programs utilizing more than one intervention. The success of these multi-component caregiver interventions will depend on the services that are available to address a wide variety of caregiver concerns for elderly caregivers. The study conclude that the health status of the caregiver, level of satisfaction in life and social support received has significant influence on burden on elderly caregiver. Further there is a significant impact of intervention on reducing the caregivers burden.

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