Section: Community Medicine

Original Research Article

A STUDY ON SOCIAL FACTORS ASSOCIATED WITH CAREGIVER STRESS AND SOCIAL SUPPORT PERCEIVED BY INFORMAL CAREGIVERS OF ELDERLY PERSONS

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Received *: 05/06/2025*
Received in revised form *: 20/07/2025*
Accepted *: 08/08/2025*

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DOI: 10.70034/ijmedph.2025.3.597

Source of Support: Nil,
Conflict of Interest: None declared

Int J Med Pub Health
2025; 15 (3); 3257-3262

ABSTRACT

Background: A large proportion of India's old population is ailing and has a number of comorbid diseases. Many policymakers encourage informal caring in an effort to lessen the burden associated with geriatric care. The objective of the study is to find out the social factors associated with the caregiver stress and how the stress is influenced by social support.

Materials and Methods: A community based cross – sectional study was conducted among 180 informal caregivers of elderly care – recipients in Padianallur primary health centre. Multistage sampling method was done. Study tool is comprised of 3 parts – a pretested, validated, semi-structured questionnaire on the social and economic characteristics of caregivers, caregiver stress scale and multidimensional scale for perceived social support. Data analysis was done using SPSS version 16.

Results: The prevalence of high stress among the caregivers was 43.9%. Female gender (48%), spouse (59.3%) and low education (5.1%) were found to be significantly ($p < 0.001$) associated with high stress. Caregivers with low support from friends (58%), family (65%) and significant other (75%) and those who perceived low social support (75%) were significantly ($p < 0.001$) associated with high stress.

Conclusion: Most of female caregivers were not employed and had to be dependent on family members. In the absence of family support, they were more likely to be stressed. Spousal caregivers by themselves were in the position of looming care recipients. With the emergence of co-morbid conditions, caregiving task might enhance stress within spousal caregivers. Unless the informal caregivers were able to extract social support most of them would remain highly stressed.

Keywords: Informal care, caregiver stress, social support

INTRODUCTION

At present India is the most populous country. The proportion of elderly population is on steady increase and it is expected that by 2050, they will constitute the 20% of the total population. A large proportion of India's old population is ailing and has a number of comorbid diseases.[1] Many policymakers encourage informal caring in an effort to lessen the burden associated with geriatric care. Both informal care and formal (professional) care are complimentary and function optimally in an environment with a significant formal support network.[2] Mostly formal caregivers are professional in nature and duly paid for their service.[3] The primary benefit of professional caregiving is that caregivers are trained in every aspect of caring. Unfortunately, formal caregivers may not be able to provide emotional support.

In a case of informal or family caregivers, they will have a close personal relationship with the elderly care recipients.[4] On the other hand, whether an

acute or chronic sickness strikes the elderly care recipient, informal caregivers are helpless or may mismanage. Informal caretakers typically receive no payment for their work, and in Indian society, this is typically seen as their only obligation.[5] A variety of factors influence the amount and quality of informal caring. These include each member's certain requirements, the family structure, the quality of relationship among family members, and their socioeconomic status.[6]

Both formal and informal support act as moderators and mitigate the detrimental effects of informal caregiving by serving as buffers. The presence of formal assistance, such as professional home care, can lessen the stress or load on caregivers. This formal support will only be supplemental. Informal or family support has 2 inter – related components. The direct component involves other family members providing care recipients with direct face to face emotional support. Perceived social support is thought to be an indirect component.[7]

The availability of a person or group of individuals that an individual may rely on, and who may also care for, value, and love the concerned individual, is known as social support. Assessing the degree of support that friends, family, neighbours, or other important sources are available when needed is known as perceived support. It alludes to the extent to which the quantity and quality of such support are deemed adequate.[8] The primary goal of the study is to identify the areas and factors linked to caregiver stress. Family members and friends can provide support that addresses those contributing elements. Thus, the objective of our study is to find out the social factors associated with caregiver stress and how the stress is influenced by social support.

MATERIALS AND METHODS

Study Design: Community-based cross-sectional study

Study Area: Area under the jurisdiction of Padianallur Primary Health Centre

Study Population: The study population was chosen from among informal caregivers of elderly individuals (60 years of age and older). Eligible caregivers were interviewed following an explanation of the study's objectives and obtaining their informed consent.

Inclusion criteria: Anyone who has been spending at least eight hours a day with an elderly care recipient for at least three months, whether or not they are related to them, without receiving formal training or paid for their services.

Sampling Method

Sample size

Sample size of the study population was calculated based on the study titled “study of the burden of informal caregivers of elderly in Kokkola” by Vincent Gleviczky.[9] With 95% confidence interval, prevalence (P) of 38%, 20% of relative precision (i.e.7.6%) and non – response rate of 10%, using the formula ($N = Z_{(1-\alpha/2)}^2 pq/d^2$), sample size was calculated as 180.

Multistage sampling method

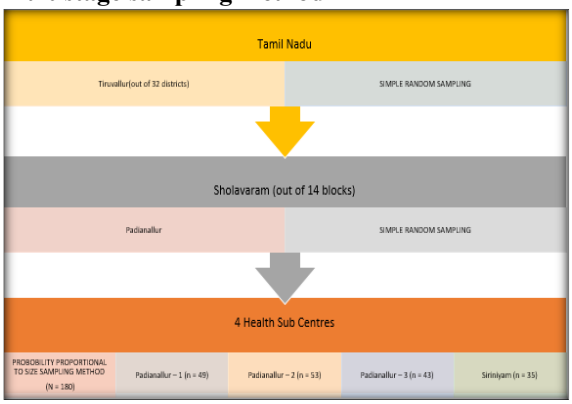

Figure 1: Flow chart of multistage sampling

The caregivers were informed about the study details in their native language, and after getting their consent the following study tool was used.

Study Tool

It comprised of 3 parts.

1. A pretested, validated, semi-structured questionnaire on the social and economic characteristics of caregivers.
2. **Caregiver Stress Scale (CSS):** It included 10 items and a dichotomous response (yes = 1 and no = 0). The highest possible score was 10. A respondent was deemed to be experiencing high stress if he or she had a score of five or higher. This scale was locally verified, and adapted from the Caregiver Strain Index by taking into account the sociocultural circumstances prevailing in developing South Asian countries such as Singapore, India, and others. CSS is found to be consistent as its Cronbach’s coefficient alpha is 0.82.[10&11]
3. **The MSPSS, or Multidimensional Scale for Perceived Social Support (Zimet, 1988):** The current version has 12 items and it is used to measure the social support perceived by the study participants. In terms of the sources of support—friends, family, and significant others—these 12 items, which sought to measure social support directly, were categorized. A seven-point Likert scale, ranging from very strongly disagree (1) to very strongly agree (7), was used. Overall, the internal consistency of the MSPSS, measured as Cronbach’s coefficient alpha is found to be 0.88.[12]

Data Management

After obtaining clearance from Madras Medical College's Institutional Ethics Committee in Chennai, the study was conducted.

Data Analysis

After entering the data into Microsoft Excel 2010, a master chart was created and exported to version 16 of the Statistical Package for Software Solutions

(SPSS) for analysis. Mean and standard deviation were used to describe continuous variables, whereas frequency distributions and percentages were used to describe categorical variables. Chi square test was used to find association between categorical variables. Spearman correlation was used to relate dependent and independent continuous variables.

Operational Definitions

Informal or family caregiver: Any family member, spouse, friend, or neighbour who has an intimate relationship to an older person or adult, whether or not they have a chronic or debilitating illness, and who offers a wide range of support.[13]

Caregiver stress: A state of exhaustion, rage, or guilt caused on by unrelieved caregiving for an elderly person or an adult with or without a chronic illness.[14&15]

Social support: The availability of a person or group of individuals that an individual may rely on, and who may also care for, value, and love the concerned person.

Perceived social support: Evaluation of the level of support that one can get from someone special, such as family, friends, and neighbours when needed. It relates to the degree to which the quantity and quality of such support are deemed adequate.[8]

RESULTS

About 142 (79%) of the 180 caregivers who participated in the study were female participants. In case of informal caregivers, their mean age with standard deviation was 42.3 ± 14.6 (in years).

Table 1: Distribution of Caregiver Stress

Mean +/- 2Standard deviation (SD)	**3.98 +/- 5.2**	
Median	4	
Level of stress among caregivers	Low stress 101 (56.1%)	High stress 79 (43.9%)

Nearly 44% of the caregivers were experiencing high stress (43.9%; 36.6% – 51.2%, 95% Confidence Interval) (table 1).

Table 2: Influence of Social Factors on Caregiver Stress

SOCIAL FACTORS RELATED TO CAREGIVERS	Low stress	High stress	total	Chi square value	p value
Gender					
Male	27(71%)	11(29%)	38	4.367	**0.037***
Female	74(52%)	68(48%)	142		
Gender influence					
Same gender	39(54.2%)	33(45.8%)	72	0.184	0.668
Opposite gender	62(57.4%)	46(42.6%)	108		
Marital status					
Married living with spouse	82(57.3%)	61(42.7%)	143	4.462	0.114
unmarried	9(75%)	3(25%)	12		
Widow(er) / separated	10(40%)	15(60%)	25		
Relationship with care recipient					
Spouse	22(40.7%)	32(59.3%)	54	10.187	**0.006***
Children	38(55.9%)	30(44.1%)	68		
Other relatives	41(70.7%)	17(29.3%)	58		
Educational status					
Up to middle schooling	46(46.9%)	52(53.1%)	98	7.349	**0.007***
High school & above	55(67.1%)	27(32.9%)	82		
Occupational status					
Employed	47(58%)	34(42%)	81	0.219	0.640
Not employed	54(54.5%)	45(45.5%)	99		

Statistically significant at p < 0.001

Factors like gender, education and relationship with the care recipient were significantly associated with the caregiver stress (table 2).

Table 3: Impact of Social Support Perceived by The Caregivers on Caregiver Stress

SOURCES OF SUPPORT	Low stress	High stress	total	Chi square value	p value
Friends					
Low	47(42%)	65(58%)	112	27.244	**P<0.001***
Moderate	21(68%)	10(32%)	31		
High	33(89%)	4(11%)	37		
Family					
Low	30(35%)	57(65%)	87	35.262	**P<0.001***

Moderate	27(66%)	14(34%)	41		
High	44(85%)	8(15%)	52		
Significant Other#					
Low	11(25%)	33(75%)	44	39.943	**P<0.001***
Moderate	15(69%)	24(31%)	39		
High	75(77%)	22(23%)	97		
PERCIEVED SOCIAL SUPPORT					
Low	14(23{%)	46(77%)	60	42.914	**P<0.001***
Moderate	49(65%)	26(35%)	75		
High	35(85%)	6(15%)	41		

Statistically significant at p < 0.001
#Any person who is intimately associated

Caregivers with low level of social support had significantly high level of stress (table 3).

Table 4: Correlation Between Various Variables and Caregiver Stress Score

Variable	Spearman's Correlation(r)	Strength of Linear relationship	p value
Family income	-0.223	Weak downhill (negative)	**0.003***
Friends support	-0.491	Moderate downhill (negative)	**<0.001***
Family support	-0.484	Moderate downhill (negative)	**<0.001***
Significant Other#	-0.457	Moderate downhill (negative)	**<0.001***
Caregiver's Perceived social support	**-0.603**	**Strong downhill (negative)**	**<0.001***

Statistically significant at p < 0.001
#Any person who is intimately associated

Caregiver's perceived social score has a strong negative association with the caregiver score (table 4).

DISCUSSION

The purpose of the study was to assess the degree of caregiver stress experienced by informal caregivers of the elderly. Among 180 of study participants, nearly 78% of them were found to be female. Daughters-in-law (27.8%) and wives (27.8%) comprised the majority of the study participants. It was found that 43.9% of caregivers were highly stressed (36.6% to 51.2%, 95% C.I.). Of the female caregivers, 48% were experiencing a lot of stress. Just 29% of male caregivers reported high stress, and the difference was statistically significant (p=0.037). Similar results were found in studies carried out in Egypt and Singapore. [16&10] However, there was no gender difference in the level of stress experienced, according to the Finnish study.[9] In contrast, male caregivers in the Nigerian study reported higher level of stress than their female counterparts.[17]

Women were expected to take on the role of homemaker in our sociocultural setting. Men were expected to earn for their families and thus they might not always be accessible to care for those in need. Women had to spend more time in care taking. They should also raise their kids and take care of other domestic chores. These could be the causes of the high level of stress among female caregivers.

Husbands reported lower levels of stress (mean – 1.95) than wives (mean – 3.14) among spousal caregivers in a Singapore study.[10] According to a Brazilian study, spouses experienced the highest levels of stress among family caregivers (mean: 34.77, p = 0.046).[18] Wives were found to be severely stressed (73%), followed by daughters (72%), in the Egyptian study (p < 0.05).[16] The current study revealed that 59.3% of spousal caregivers were under high stress, and the correlation was significant (p=0.006).

According to the study done in Nigeria, caregivers who have completed high schooling are less stressed (8.3%) than those completed middle (25.7%) and primary schooling (33.3%). This association was significant (p<0.022).[17] The Brazilian study indicated that although caregivers who completed middle schooling were highly stressed (stress score > 30) than those who completed higher schooling (stress score < 28), the difference was not statistically significant (0.825).[18]

The current study highlights that caregivers who completed middle schooling (53.1%) reported higher level of stress than those who completed high schooling, diploma or degree (32.9%) and the difference was deemed significant at p<0.01. All of the studies discussed here reveal similar findings. However, the study conducted in Finland found no correlation between the stress level and the caregiver's education.[9] There was a chance that someone with more education would be more equipped to comprehend and address old age-related issues than someone with less education.

According to the Malaysian study, caregivers who were employed had three times the odd of experiencing high level of stress compared to those unemployed (OR = 3.04, 95% CI: 1.05, 8.84). The results regarding the caregiver's employment status stood contrary to popular belief.[19] In the study conducted in Brazil, retired caregivers experienced higher levels of stress than others (stress score > 30). A statistically significant difference (p = 0.001) was found.[18] The caregivers' occupational status and stress levels did not significantly correlate in the current study.

Although a mild degree of stress was consistently observed in the high-income group in the Egyptian study, there was no statistically significant relationship between stress and monthly income (r = 0.187, p = 0.11).[16] The current study revealed a weak negative relationship (r = -0.223, p = 0.003) between caregiver stress and income. Numerous studies have demonstrated an inverse relationship between stress levels and high income.

According to the current study, 58% of caregivers who did not have the support of friends were under high stress. The social structure of India is restricted and inflexible and it demonstrates that even with friends, the level of intimacy would be uncertain. There are very few opportunities to discuss private matters with the friends. Without sharing personal information with friends, it was clear that the majority of caregivers would be lacking support by their friends and hence under a lot of stress.

The study revealed that caregivers who did not have family support were under a lot of stress (65.5%). Taking care of an old relative at home is regarded as an unavoidable sociocultural obligation of the spouse, children, or daughter-in-law. Unfortunately, other family members may have mistakenly believed that the task was the exclusive responsibility of those primary caregivers. Because of this unique situation, caregivers did not have the support of other family members.

The most significant assistance they require is psychological and emotional support from their family members, in addition to financial support and help with caregiving duties. Therefore, caregivers who don't have family support would be under a lot of stress. The study unequivocally shown that 75% of caregivers who experienced high level of stress did so because they received little support from their significant other person who will be closely related to them.

The study conducted in Finland revealed a significant negative relationship between stress and social support as perceived by the caregiver (r = -0.417, p <0.01).[9] Compared to caregivers without social support (stress level - 24.5%, p = 0.543), those who received social support reported lower levels of stress (20.4%). In the Egyptian study, the level of stress was significantly correlated with informal social support (Hierarchical regression, B = –0.083, p<0.01). Particularly, the degree of stress decreased as the size of group who helped the caregivers increased (r = 0.255, p <0.001).[16]

From our study, it was discovered that 77% of caregivers who lacked social support had severe stress. Caregivers who felt they had enough social support, on the other hand, reported feeling less stressed (26.9%), and the difference was statistically significant (p<0.001). A strong statistically significant negative correlation was found between Stress and perceived social support (r = -0.603, p<0.001). The stress level of caregivers would drop rapidly as they perceived more social support.

CONCLUSION

Most of the female caregivers were not employed and had to be dependent on earning family members. In the absence of family support, they were more likely to be stressed. Spousal caregivers by themselves were in the position of looming care recipients. In the event of getting older along with emergence of co-morbid conditions, caregiving task might enhance stress within spousal caregivers. Caregivers were definitely in the need of psychosocial support along with physical assistance from their family members, friends or neighbours. But the study findings revealed a reversed situation prevailing in the community. Almost half of the caregivers were lacking family support. Nearly two-third of the caregivers were lacking friends' support. Unless the informal caregivers were able to extract social support most of them would remain highly stressed.

Acknowledgment: Dr. R. Arunmozhi M.D., Ph.D., Professor (RETIRED), Institute of Community Medicine, Madras Medical College, Chennai-3

Conflict of Interest: Nil.

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