

PREVALENCE OF STRESS AMONG PRIMARY CAREGIVERS OF CHRONICALLY ILL PATIENTS AND THE IMPACT OF CARE GIVING ON PHYSICAL AND MENTAL HEALTH ON CAREGIVERS – A QUESTIONNAIRE BASED CROSS-SECTIONAL STUDY

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ABSTRACT

Introduction: Patients with Chronic diseases often depend completely or partially on primary caregivers. This continuous care giving responsibilities can lead to stress, burnout, and various physical and mental health challenges.

Methodology: A cross-sectional study was conducted among primary caregivers of patients with chronic illnesses. Stress levels were assessed using the pre-validated Modified Caregiver Strain Index (M-CSI).

Results: 136 eligible caregivers were included. The mean age of caregivers was 39.2 ± 10.8 years, and 63.2% were females. 26.5% were uneducated and 26.5% were graduate. About 39.7% were unemployed. The most common relationship to patients was spouse (39.7%), followed by children (30.1%). The mean duration of the patients' illness was 73.5 ± 56.3 days. The most prevalent chronic conditions were renal failure (21.3%) and cancer (19.9%). High stress scores were most commonly reported by caregivers of children (43.1%), followed by spouses (25%) and parents (18.1%), with statistically significant differences ($p < 0.001$).

Conclusion: A significant proportion of caregivers experience high stress levels, particularly those closely related to patients. Targeted interventions are needed to support their mental and physical well-being.

KEYWORDS: Caregiver/s, Stress, Chronic illness, Mental Health, Prevalence

INTRODUCTION

The burden of chronic illness has escalated due to factors such as increased life expectancy and a rise in non-communicable and terminal conditions, leading to prolonged caregiving requirements that frequently stretch over months or years.¹ Chronic illnesses present ongoing challenges not only to patients but also to their families, often requiring consistent support from primary caregivers—usually close relatives or household members. These caregivers provide a wide range of assistance, encompassing not just medical or physical help, but also emotional, financial, and social support, making their role complex and demanding.^{2,3} As a result, caregivers frequently experience negative consequences, including emotional distress, physical exhaustion, and a decline in overall quality of life.⁴

Numerous studies have highlighted the high burden of psychological stress among caregivers. For example, nearly all caregivers of cancer patients in one study exhibited significant levels of psychological distress, with around two-thirds reporting it as severe.^{5,6,7} variables are known to influence caregiver stress, including cultural background, socio-economic status, the nature and length of the patient's illness, the caregiver's relationship to the patient, coping mechanisms, and the level of available support.² In palliative care contexts in India, approximately one in three informal caregivers reported moderate to severe levels of burden, which was linked to lower scores in physical, psychological, and social quality of life domains.⁶ Similar findings have been reported globally, where factors such as gender, education, employment, and living conditions also correlate with stress intensity.^{2,4} In fact, caregiver strain has measurable effects on both mental and physical health-related quality of life (HRQoL), emphasizing the importance of distinguishing between caregiving-specific stress and general life pressures.⁷

Although caregiver stress is a widely recognized issue, few studies have systematically evaluated its prevalence across different chronic illnesses using standardized, cross-sectional approaches. Furthermore, assessing its impact on caregivers' mental and physical well-being is vital for designing effective support systems.

The present study aims to fill this gap by determining the prevalence of stress among primary caregivers of chronically ill patients and examining its influence on their overall health using a validated questionnaire tool.

AIMS & OBJECTIVES

Primary Objective: To determine the prevalence of stress among primary caregivers of patients with chronic illnesses.

Secondary Objectives: a) To study the relationship between caregiver stress and socio-demographic factors like age, gender, socioeconomic status. b) To assess the impact of caregiver stress on the mental and physical health of caregivers.

METHODOLOGY

This is a Cross-sectional study was done in Tertiary care hospital among the Caregivers of the chronic ill patients. The sample size was calculated using the formula $4pq/L^2$, where $p = 92.88\%$ [Taking prevalence of caregivers stress from the previous study done by Mengting LI and Xinqi Dong⁸], $q = 7.12\%$. 5% allowable error (L) and 95% confidence interval was taken. 20% non-response was considered. The final sample size calculated was 127. The pre-validated MCSI questionnaire was used to assess the stress in the care-givers.

Methodology:

After the Scientific and Institutional Ethics committee approvals were taken (Certificate No: MRIMS/DHR-IEC-FAC/2024/299), the list of all the chronic patients in the Outpatient and Inpatient ward was obtained daily from the main reception. The caregivers of patients who satisfied the inclusion and exclusion criteria were approached for the interview. Chronic Illness was defined as: A disease or condition that usually lasts for 1 month or longer and may get worse over time. Chronic diseases tend to occur in older adults and can usually be controlled but not cured. The most common types of chronic disease are cancer, heart disease, stroke, diabetes, and arthritis⁹.

The Family or Primary Caregiver were Defined as: One who cares for a spouse or parent, an extended family member, or even a friend or neighbor by providing any of the following¹⁰:

Transportation to medical appointment?

Purchasing or organizing medications?

Monitoring their medical condition?

Communicating with health care professionals?

Advocating on their behalf with providers or agencies?

Getting in and out of beds or chairs?

Getting dressed?

Bathing or showering?

Grocery or other shopping?

Housework?

Preparing meals?

Managing finances?

For the present study we considered the Inclusion criteria:

1. Primary caregiver who was taking care of the patient for ≥ 30 days.
2. Caregiver of either gender of 18 years and above.
3. One who cares for a spouse or parent, an extended family member.
4. One who helps in medical appointment and visit to hospital, Purchasing and organizing medications, Monitoring their medical condition, Communicating with health care professionals, Advocating on their behalf with providers or agencies, Getting in and out of beds or chairs, Getting dressed, Bathing or showering, other shopping for care eg; diapers, food supplements etc, Preparing meals and Managing finances.

Exclusion criteria:

1. Caregivers taking treatment for any mental health conditions
2. Caregivers who were not willing to participate.

Caregiver overall burden was assessed using the 13-item Modified Caregiver Strain Index (M-CSI)¹¹. The purpose of the index is to measure the level of strain on caregivers, which is a combination of stress and burden. It assesses five domains: financial, physical, psychological, social, and personal. The M-CSI was administered to caregivers by investigators to assess caregivers' reactions to impairment and objective (changing personal plans) and subjective (feeling completely overwhelmed) impacts of care giving.

M-CSI Score: Each item is scored 0-2; Total Score range = 0 to 26

0	No
1	Yes, sometimes
2	Yes, on a regular basis

Interpretation: Higher scores indicate greater caregiver strain, and a score of 7 or higher was considered as high level of stress.

Statistical analysis:

Data collected was entered in MS EXCEL sheet and statistical analysis done on SPSS (Version 20). The continuous data is represented as mean and standard deviation. The discrete data is presented as frequency and percentages. The correlation between the variables is done using the Pearson's chi-square.

RESULTS

136 caregivers were enrolled in the study and assessed using the Modified Caregiver Strain Index (M-CSI).

Caregivers: Mean age was 39.2 ± 10.8 years (95% CI: 37.3–41.0).

Table 1: Age distribution of Care givers (n=136)

Age (years)	Frequency (n)	Percentage (%)
16 – 35	57	41.9
36 – 50	61	44.9
51 – 65	18	13.2
Total	136	100.0

Gender distribution was 50 males (36.8%) and 86 females (63.2%).

Nearly half (44.9%, n = 61) belonged to the 36–50 years age group. Educational status varied: 26.5% uneducated, 8.1% primary education, 23.5% high school, 15.4% intermediate, and 26.5% graduates. Employment categories included 39.7% unemployed, 9.6% unskilled, 33.8% skilled, 2.9% clerical, and 14% professional. Caregivers were primarily spouses (39.7%), followed by children (30.1%), parents (16.9%), other relatives (9.6%), and siblings (3.7%).

Patients: Mean age was **48.4 ± 14.7 years** (95% CI: 45.9–50.9). Gender distribution was nearly balanced—64 males (47.1%) and 72 females (52.9%). The majority were illiterate (41.2%) and unemployed (47.1%). The average duration of illness of the study patients was **73.5 ± 56.2 days**, with the longest recorded at **420 days** in a case of falcotentorial meningioma.

The patient cohort exhibited a range of chronic illnesses such as renal failure (21.3%), cancers (19.9%), orthopedic issues (15.4%), gynecological conditions like AUB (5.1%), coronary artery disease (6.6%), neurological (4.4%), dermatological (2.9%), respiratory (2.2%), and surgical conditions (7.4%) and others (14.7%).

Table 2: Socio-demographic profile of the care givers and Patients (n=136)

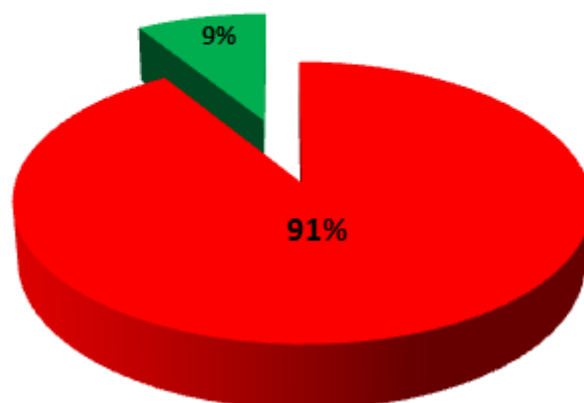
Socio-demographic Variables		Care givers (n,%)	Patients (n,%)
Gender	Male	50 (36.8)	64 (47.1)
	Female	86 (63.2)	72 (52.9)
Education	Uneducated	36 (26.5)	56 (41.2)
	Primary	11 (8.1)	13 (9.6)
	High School	32 (23.5)	35 (25.7)
	Intermediate	21 (15.4)	22 (16.2)
	Graduation	36 (26.5)	10 (7.4)
Occupation	Unemployed	54 (39.7)	64 (47.1)
	Unskilled	13 (9.6)	13 (9.6)
	Skilled	46 (33.8)	52 (38.2)
	Clerical	04 (2.9)	--
	Professional	19 (14.0)	07 (5.1)

Caregiver Comorbidities: Overall, 22.1% of caregivers had pre-existing health conditions: diabetes mellitus (6.6%), hypertension (3.6%), combined hypertension and diabetes (2.9%), thyroid disorders (3.7%), and other issues (5.1%). The majority (77.9%, n = 106) reported no health problems.

Caregiver Stress (M-CSI Score): High stress (M-CSI score >7) was found in **124 caregivers** (91.2%), while 12 (8.8%) had low stress (score ≤7) (Fig 1). The median score was 14, mode was 11, and scores ranged from 3 to 26.

Stress Score in Caregiver

■ High M-CSI Score (>7) ■ Low M-CSI Score (≤ 7)

**Fig 1:** Prevalence of Stress among Caregivers (M-CSI Score)

One sample t-test analysis showed that the M-CSI score was statistically significant as shown in the table below.

Table 3: One sample t-test analysis of M-CSI Score

One-Sample t-Test	
	Test Value = 7

	t	df	Sig. (2-tailed)	Mean Difference	95% Confidence Interval of the Difference	
					Lower	Upper
M-CSI SCORE	15.442	135	.000	6.897	6.01	7.78

Factors Associated with High Stress

Statistically significant associations were observed between high stress levels and patient gender and occupation; higher stress noted among caregivers of female patients ($p=0.008$) and caregivers of unemployed patients reported higher stress ($p=0.013$) respectively.

No significant associations were found between caregiver stress and caregiver sex ($p = 0.105$), caregiver occupation ($p = 0.580$), caregiver education ($p=1.000$), presence of caregiver or patient co-morbidities ($p >0.05$), or whether caregivers received assistance ($p=0.372$).

Table 4: Correlation of M-CSI Score with the different variables of patients and Caregiver

Variables	M-CSI Score		Total	p- value
	High	Low		
Sex of patient				
Female	70.0 (56.5%)	2.0 (16.7%)	72.0 (52.9%)	0.008
Male	54.0 (43.5%)	10.0 (83.3%)	64.0 (47.1%)	
Occupation of Patient				
Professional	4.0 (3.2%)	3.0 (25.0%)	7.0 (5.1%)	0.013
Skilled	48.0 (38.7%)	4.0 (33.3%)	52.0 (38.2%)	
Un Employed	60.0 (48.4%)	4.0 (33.3%)	64.0 (47.1%)	
Un Skilled	12.0 (9.7%)	1.0 (8.3%)	13.0 (9.6%)	
Sex of Care Giver				
Female	81.0 (65.3%)	5.0 (41.7%)	86.0 (63.2%)	0.105
Male	43.0 (34.7%)	7.0 (58.3%)	50.0 (36.8%)	
Occupation of Caregiver				
Professional	17.0 (13.7%)	2.0 (16.7%)	19.0 (14.0%)	0.580
Clerical	4.0 (3.2%)	0.0 (0.0%)	4.0 (2.9%)	
Skilled	40.0 (32.3%)	6.0 (50.0%)	46.0 (33.8%)	
Un Skilled	13.0 (10.5%)	0.0 (0.0%)	13.0 (9.6%)	
Un Employed	50.0 (40.3%)	4.0 (33.3%)	54.0 (39.7%)	
Patient health problems for which care is given@				
Carcinoma	26.0 (21.0%)	1.0 (8.3%)	27 (19.9%)	0.692
Renal failure	25.0 (20.2%)	4.0 (33.3%)	29 (21.4%)	
Orthopedic problems	19.0 (15.3%)	2.0 (16.7%)	21 (15.4%)	
Cardiac problem	9.0 (7.3%)	0.0 (0.0%)	9 (6.6%)	
Surgical conditions	9.0 (7.3%)	1.0 (8.3%)	10 (7.4%)	
Gynecological problem	7.0 (5.6%)	0.0 (0.0%)	7 (5.1%)	
Neurological problems	6.0 (4.8%)	0.0 (0.0%)	6 (4.4%)	
Dermatological problems	3.0 (2.4%)	1.0 (8.3%)	4 (2.9%)	
Respiratory problems	3.0 (2.4%)	0.0 (0.0%)	3 (2.2%)	
Others	17.0 (13.7%)	3.0 (25.0%)	20 (14.7%)	
Co morbidities in Caregivers				
None	96.0 (77.4%)	10.0 (83.3%)	106.0 (77.9%)	0.587
Diabetes	8.0 (6.5%)	0.0 (0.0%)	8.0 (5.9%)	
HTN	2.0 (1.6%)	1.0 (8.3%)	3.0 (2.2%)	
DM and HTN	2.0 (1.6%)	0.0 (0.0%)	2.0 (1.5%)	
Thyroid Problem	5.0 (4.0%)	0.0 (0.0%)	5.0 (3.7%)	
Others	11.0 (8.9%)	1.0 (8.3%)	12.0 (8.8%)	
Does Caregiver get help from others?				
No	23.0 (18.5%)	4.0 (33.3%)	27.0 (19.9%)	0.372
From Family members	37.0 (29.8%)	4.0 (33.3%)	41.0 (30.1%)	
From friends	64.0 (51.6%)	4.0 (33.3%)	68.0 (50.0%)	
Caregiver Treatment				
No	92.0 (74.2%)	11.0 (91.7%)	103.0 (75.7%)	0.178
Yes	32.0 (25.8%)	1.0 (8.3%)	33.0 (24.3%)	
Other Co-morbidities in Patient				
None	54.0 (43.5%)	8.0 (66.7%)	62.0 (45.6%)	

Hypertension	22.0 (17.7%)	1.0 (8.3%)	23.0 (16.9%)	0.341
Hypertension and Diabetes	14.0 (11.3%)	3.0 (25.0%)	17.0 (12.5%)	
Diabetes Mellitus	10.0 (8.1%)	0.0 (0.0%)	10.0 (7.4%)	
Thyroid	4.0 (3.2%)	0.0 (0.0%)	4.0 (2.9%)	
Diabetes, Hypothyroid	1.0 (0.8%)	0.0 (0.0%)	1.0 (0.7%)	
Miscellaneous	19.0 (15.3%)	0.0 (0.0%)	19.0 (14.0%)	

DISCUSSION

This study found a high prevalence of caregiver stress, with over 90% scoring above the M-CSI cutoff, indicating significant stress. Care giving for female and unemployed patients was significantly associated with higher stress, while caregiver age, sex, education, occupation, co-morbidities, and external help were not.

The findings are comparable to similar study done in Tamil Nadu among caregivers where the females predominated (76%). The mean age caregiver was 47.3±15.8 years, ranging from 15 to 80 years of age. The most common relationship of caregivers to their patients was parental (41.2%), followed by spousal (30.1%), child (9.5%), non-blood relations (9.5%), distant family (6.3%), and siblings (3.2%). Almost two-thirds (61.9%) were the sole caregiver in the household. Most caregivers were not employed (71.4%)¹².

Similar studies across chronic illnesses also report substantial caregiver burden. For instance, caregivers of psychiatric patients in Brazil experienced high stress influenced by socioeconomic and support factors¹³. Caregivers of Parkinson's disease patients also showed elevated burden, especially when patient functional impairment was greater¹⁴. High stress among caregivers of cancer patients undergoing therapy has likewise been documented¹⁵. Another study in Korea also found a positive correlation between care giving stress and depression. It also showed that older female spousal caregivers, spent more time and money on care giving, experienced the highest rates of depression¹⁶. Thus, our findings are consistent with global evidence showing that caregiver stress is common and multifactorial.

Some differences were noted. While other studies often find female caregivers¹² and those with lower education at higher risk^{13,17}, these associations were not significant in our sample. This may reflect cultural expectations, relatively higher education levels in caregivers, or sample composition. Interestingly, patient gender was a significant predictor, with caregivers of female patients reporting higher stress, which may be linked to social and economic dependence patterns in the local setting.

The lack of association between caregiver support and stress contrasts with prior findings where limited support predicted higher burden^{13,17}. This could be due to differences in how support was measured or the adequacy of available help.

The study has limitations of taking the convenience sampling in hospital due to ready accessibility to the caregivers in the hospital allowing efficient recruitment of the participants.

CONCLUSION

The study concludes that high stress levels are seen in female and unemployed caregivers. Overall, the results highlight the need for systematic caregiver screening and interventions such as counseling, financial support, and respite services. Addressing caregiver well-being is essential for sustaining patient care and preventing long-term health consequences in caregivers. We therefore recommend that training of the caregiver may help to address this problem. Well trained caregiver can not only improve the condition of the patient but also ease the burden on the health care providers in providing the care especially at home.

DECLARATIONS

Scientific and Institutional Ethics committee approvals were taken: Certificate No: MRIMS/DHR-IEC-FAC/2024/299

No conflicts of interest declared.

The data set is available with the authors and can be accessed on request.

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