ORIGINAL ARTICLE

Stressors from Caregiving for Cardiovascular Diseases: Insights from a Community-based Cross-sectional Study in New Delhi

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CITATION
Kaur P, Goel MK, Prasuna JG. Stressors from Caregiving for Cardiovascular Diseases: Insights from a Community-based Cross-sectional Study in New Delhi. Indian J Comm Health. 2024;36(5):721-728.
https://doi.org/10.47203/IJCH.2024.v36i05.015

ARTICLE CYCLE
Received: 16/05/2024; Accepted: 02/10/2024; Published: 31/10/2024

ABSTRACT

Background: Providing care for chronic conditions at home imposes various responsibilities on caregivers, affecting financial, physical, emotional, and social domains. Over time, these responsibilities can accumulate and become significant stressors. **Aims & Objectives:** The study aims to assess the magnitude, factors and reasons of stressors faced by caregivers of cardiovascular diseases (CVD). **Material and Methods:** Community-based cross-sectional study was conducted in Delhi. A sample of 384 households was obtained through systematic random sampling. The sampling unit was the household, and the study units were the primary caregivers of individuals with cardiovascular diseases. **Results:** Among 384 caregivers, 223 (58%) were female, and 50.3% were spouses of the patients. The magnitude of stressors ranged from 79.4% to 90.4%. The main stressors identified were economic burden (70.8%), knowledge about the medical condition (67.7%), and changed patient behavior (65.6%). Significant associations were found between stressors and certain socio-demographic factors (such as occupation and relationship to the patient) as well as disease-related factors (such as duration of caregiving, regularity of treatment, patient condition, ADL impairment, and multimorbidity of CVD). **Conclusion:** These results highlight the dyadic relationship between patients and caregivers, emphasizing that caregivers are a high-risk group that also requires attention and support.

KEYWORDS

Caregiving Stressors; Cardiovascular Diseases; Caregiver Health; Primary Caregivers

INTRODUCTION

In recent years, the field of family caregiving has garnered considerable attention, largely due to demographic changes and technological advancements in healthcare. These progressions have resulted in longer life expectancies and enhanced treatment options for chronic illnesses, which are frequently managed at home rather than in institutional settings. Consequently, the responsibility of caregiving increasingly falls on family members. (1)

Providing care for these chronic conditions at home imposes a variety of responsibilities on

caregivers, spanning financial, physical, emotional, and social domains. Over time, these responsibilities can accumulate and transform into significant stressors. Stressors are defined as circumstances or activities that present challenges to individuals, making them feel threatened, thwarted, fatigued, or defeated. Stressors encountered by caregivers can be divided into two main categories: primary and secondary. Primary stressors are directly linked to the needs of the patient and the level of care these needs necessitate. Secondary stressors, on the other hand, arise from the caregiver's prolonged and intense involvement in the patient's long-term care, introducing additional complexities and burdens. (1)

Due to transition over last 25 years from Communicable to Non-Communicable diseases, the non-communicable diseases (NCD) have become the leading cause of mortality and morbidity all over the globe, with cardiovascular diseases contributing the most in NCDs.(2) Due to the chronicity and marked burden of these diseases on global health, it becomes even more important to assess the stressors of caregiving among their caregivers.

Aims & Objectives:

- Assess the magnitude of stressors experienced by caregivers of individuals with cardiovascular diseases.
- Identify the factors and reasons of stressors faced by caregivers.

Material & Methods

Study Type & study design: This community based cross-sectional study was conducted in Palam area of South-West Delhi.

Study Setting: Palam area is a major suburb and residential colony, consisting of 5 wards with an estimated population of 2,00,000 in total.

Study Duration:12 months

Study Population: The study was carried out among primary caregivers of patients suffering from cardiovascular diseases residing in the Palam area.

Inclusion Criteria: The inclusion criteria for the study subjects:

1) Aged more than 18 years
2) A family member
3) Has been in caregiving role for at least 3 months

Exclusion Criteria: More than one cardio-vascular patients in the family to be given care to.

Sample size Calculation: The sample size of 384 has been calculated taking the prevalence of stressors in caregivers as 40%4 at 95% confidence level and 5% margin of error.

Strategy for data collection: One ward (Palam ward) was randomly selected, and a house-to-house survey was conducted. Systematic random sampling was used to select 384 households. To reach the required sample size, 914 households were visited, covering a population of 4835. Data on stressors were collected using a pretested semi-structured questionnaire. Households with cardiovascular disease patients were included, and information was obtained from primary caregivers after obtaining written informed consent.

Working Definition:

- Stressors: Conditions, experiences, and activities that are problematic, causing individuals to feel threatened, thwarted, fatigued, or defeated.(1)
- Primary stressors: Directly related to the patient's needs.(1)
- Secondary stressors: Arising from the caregiver's long-term involvement in the patient's care.(1)

Ethical Approval: Approval was obtained from the Institutional Ethical Committee. (Letter: LHMC/ECHR/2018/13 dated 26-10-2028)

Informed Consent: Written consent was obtained from caregivers in English or Hindi. Confidentiality was maintained.

Data Analysis: Data were entered and analyzed using SPSS version 25. Quantitative data were summarized using mean, median, and standard deviation, while qualitative data were analyzed using proportions. The Chi-Square test was used to assess differences in proportions, with a p-value of less than 0.05 indicating statistical significance.

RESULTS

Assessment of Caregivers' characteristics (Table 1):

Out of the total 384 caregivers enrolled in the study, 223 (58%) were women and 161(42%) were men. Nearly 30% of caregivers (111) were less than 30 years of age. Around 2/3rd (67%) of caregivers were in age group 31-60 years and 4.2% were more than 60 years of age. The mean age for the caregivers was 39.2 ±11.66 years (ranging between 18-78 years) with median age being 36 years. Mean age for men and women were found to be 40.3 years (with range from 18 to 78 years) and 38.45 years (with range from 20 to 78 years) respectively. Median age for men and women were found to be 40 years and 36 years respectively. Nearly half of the caregivers (50.3%) were spouses of the cases of Cardiovascular disorder patients, out of which 61% were wives and rest (39%) were husbands. Approximately 1/5th (19.8%) of the caregivers were daughters-in-law, followed by 16.4% were married son/daughter out of which 93.6% were married sons and 6.4% were married daughters. Nearly 56% of the caregivers had educational qualification of high school or above. One tenth of caregivers (10.4%) were illiterate, in which the proportion of women was 77.5% and rest 22.5% were men.

More than half (52.3%) of the caregivers were unemployed. Around 1/3rd of them belonged to Upper Middle (29.2%) and Upper Lower (32.8%) each, while it was slightly higher in Lower Middle class which was 36.7%. The rest of them (1.3% belonged to Upper Class of socio-economic status as per modified Kuppuswamy scale CPI 2019.(17)

Table 1: Gender-wise distribution of Socio-Demographic Characteristics of Caregivers for cardio-vascular diseases. (N=384)

	Socio-Demographic Characteristics of Caregivers	Men (n= 161)	% (42%)	Women (n=223)	% (58%)	Total (N=384)	% (100%)
Age (in years)	**<30***	40	24.8	71	31.8	111	28.9
	30-60	112	69.6	145	65.1	257	66.9
	>60	9	5.6	7	3.1	16	4.2
Education	**Illiterate/primary**	14	8.7	59	26.5	73	19
	High/secondary	94	54.4	110	49.3	204	53.1
	Above Secondary	53	32.9	54	24.2	107	27.9
Occupation	**Unemployed**	27	16.8	174	78	201	52.3
	Employed	134	83.2	49	22	183	47.7
Socio-economic status	**Upper/Upper middle**	42	26.1	75	33.6	117	30.5
	Lower middle	61	37.9	80	35.9	141	36.7
	Upper lower/lower	58	36	68	30.5	125	32.8
Relationship to the patient	**Spouse**	75	46.6	118	52.9	193	50.3
	Son/Daughter	0	0	76	34.1	76	19.8
	Son/Daughter-in-law	86	53.4	29	13	115	29.9

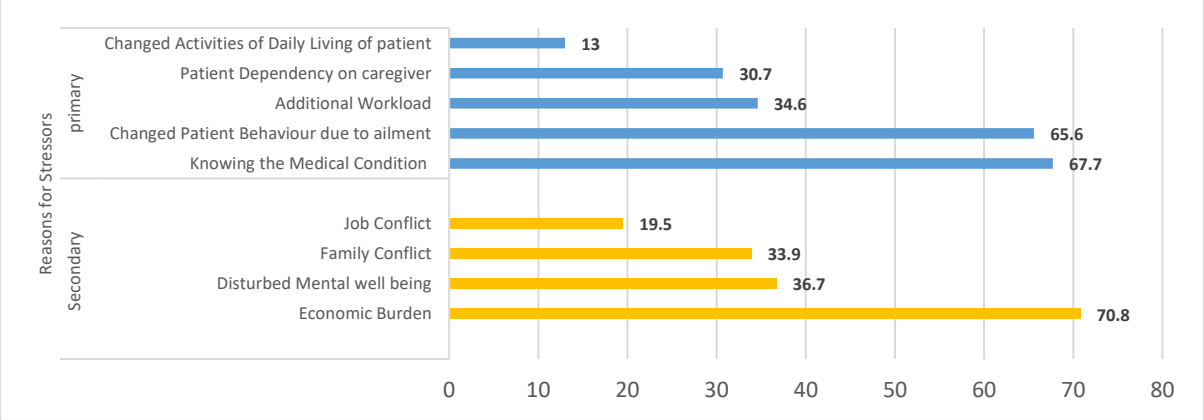
**18-30 years of age*

Assessment of Caregiver's Stressors:

Magnitude of the stressors: Magnitude of Stressors was found to be somewhere between 79.4% to 90.4% among the Caregivers. The primary stressor was seen in 82.6% of caregivers. The secondary stressor was seen in 79.4% of the caregivers. Magnitude of any stressor was found to be 90.4%.

Reasons for the stressors: When primary stressors were studied, which were 'directly related' to patient condition, the most common reason for primary stressor was Knowing the Medical Condition (67.7%) followed by Changed Patient Behaviour due to ailment (65.6%). When the secondary stressors were studied, which were due to immersion of caregiver in long-term care of the patient, it was found that the most common reason overall and among secondary stressors was the Economic Burden, present in 70.8% of the caregivers. Other reasons for primary and secondary stressors are given in Figure 1.

Figure 1 Reasons for Primary and Secondary Stressors among Caregivers (N=384)



Factors affecting stressors

Socio-demographic factors: The proportion of primary stressor was also found to have significant association with the relationship of the caregiver to the patient (p value= 0.047). The proportion of secondary stressor was found to have significant association with the employment status of the primary caregiver (p value=0.045). No significant associations were found between stressors and age, gender, education, or socioeconomic status in the study. (Table 2)

Table 2: Association between stressors and socio-demographic factors (N=384)

Socio-Demographic factors	Primary Stressor	Secondary stressor	Any stressor
Gender			
Men (161)	133(82.6)	124(77)	146 (90.7)
Women (223)	184(82.5)	181(81.2)	201 (90.1)
p value	0.980	0.321	0.857
Age (in years)			
<30*(111)	93 (83.8)	90 (81)	101
30-60 (257)	209 (81.3)	201 (78.2)	230
>60(16)	15 (93.8)	14	16
p value	0.411	0.590	0.372
Education			
Illiterate and primary school (77)	67 (87)	59 (76.6)	63 (81.8)
High and secondary school (204)	182 (89.2)	166 (81.3)	157 (77)
Above high school (107)	98 (91.6)	92 (86)	85 (79.4)
p value	0.718	0.543	0.238
Occupation			
Unemployed (201)	157 (78.1)	159 (79.1)	177 (88)
Employed (183)	148 (80.8)	159 (86.8)	170 (92.8)
p value	0.505	0.044	0.109
Socio-economic status			
Upper/Upper middle (117)	99 (84.6)	94 (80.3)	106 (90.5)
Lower middle (141)	119 (84.4)	116 (82.3)	130 (92.2)
Upper lower/lower (125)	99 (79.2)	95 (76)	111 (88.8)
p value	0.356	0.366	0.523
Relationship to the patient			
Spouse (193)	153(79.2)	149(77.2)	172 (89.1)
Son/Daughter-in-law (76)	68(89.4)	63(82.9)	69(90.8)
Son/Daughter (115)	101(87.8)	93 (80.8)	106 (92.2)
p value	0.047	0.525	0.673

**Percentages are given in brackets*

Disease related factors:

Relationship Between Duration of caregiving and Stressors: Caregivers with longer durations of caregiving (5-10 years and >10 years) experienced higher proportions of primary, secondary, and any stressors compared to those with shorter durations (<1 year and 1-5 years). There was a significant association between the duration of caregiving and the presence of stressors ($p < 0.01$ for primary stressor, $p < 0.00$ for secondary stressor, and $p < 0.00$ for any stressor).

Relationship Between Type of Cardiovascular Disease morbidity and Stressors: Among caregivers, different types of cardiovascular diseases (CVD) were associated with varying proportions of stressors. There were significant associations between the type of CVD morbidity and the presence of stressors ($p < 0.002$ for primary stressor, $p < 0.00$ for secondary stressor, and $p = 0.09$ for any stressor). When the proportion of primary and secondary Stressor among Caregivers was studied according to the type of Cardio-vascular disease present in the relative (single or multiple), it was found to be statistically significant.

Effect of Treatment Regularity and Patient Condition on Stressors: Caregivers experienced fewer stressors when the treatment for the patient was regular compared to when it was not. This difference was statistically significant (p-value = 0.015). The proportion of primary stressors among caregivers also showed a statistically significant difference based on the regularity of treatment (p-value = 0.023). Furthermore, caregivers faced fewer stressors when the patient's condition was under control compared to those whose condition was not under control. This difference was statistically significant for overall stressors (p-value = 0.007) as well as primary (p-value = 0.003) and secondary (p-value = 0.001) stressors.

Relationship Between activities of daily living (ADL) impairment and Stressors: Caregivers of patients with activities of daily living (ADL) impairment due to CVD reported higher proportions of primary, secondary, and any stressors compared to caregivers of patients without ADL impairment. ($p < 0.00$ for primary stressor, $p < 0.01$ for secondary stressor, and $p < 0.008$ for any stressor). (Table 3)

Table 3: Association between stressors and Disease related factors (N=384)

Disease related factors	Primary Stressor	Secondary stressor	Any stressor
Duration of Caregiving			
<1 year**(127)	94(74)	79(62.2)	98(77.1)
1 year to 5 years (144)	121(84)	123(85.4)	138(95.8)
5-10 years (57)	51(89.4)	51(89.4)	56(98.2)
>10 years (56)	51(91)	52(92.8)	55(98.2)
p value	0.01	0.00	0.00
Type of CVD morbidity Single			
Hypertension(n=304)	237(78)	225(74)	267(87.8)
Cerebrovascular disease(n=15)	15(100)	15(100)	15(100)
Coronary artery disease (CAD) (n=14)	14(100)	14(100)	14(100)
Rheumatic heart disease(n=11)	11(100)	11(100)	11(100)
Multimorbidity			
Hypertension and Stroke(n=27)	27(100)	27(100)	27(100)
Hypertension and CAD (n=13)	13(100)	13(100)	13(100)
p-value	0.002	0.00	0.09
Regularity of treatment			
Regular (n=319)	257(80.5)	248(77.7)	283(88.7)
Not regular (n=65)	60(92.3)	57(87.6)	64(98.4)
p value	0.023	0.07	0.015
Patient condition			
Under Control (n=303)	241(79.5)	232(76.6)	266(87.8)
Not under control (n=81)	76(93.8)	73(90.1)	81(100)
p value	0.003	0.001	0.007

Disease related factors	Primary Stressor	Secondary stressor	Any stressor
ADL impairment due to CVD			
Present (50)	50(100)	50(100)	50(100)
Not Present (334)	267(80)	255(74.8)	297(89)
p-value	0.00	0.01	0.008

**Percentages are given in brackets*

DISCUSSION

The high prevalence of stressors among caregivers across different caregiving roles underscores the need to recognize caregivers as a vulnerable population. The results in our study are noteworthy in terms of demonstrating that patient and caregiver form a dyad where caregivers become a high-risk group that also needs to be taken care of.

In our study, the majority of caregivers were women, frequently spouses of the patients, with primary or secondary education levels, often engaged in homemaking or retired. These findings mirror prior research on caregiver burden among individuals with mental illness and dependent older people, highlighting the disproportionate responsibility falling on women within the traditional family structure of Indian society.(5,6) Notably, men were primarily responsible for caring for their spouses, while women were equally distributed across different caregiving roles in the total sample. Recognizing the predominance of women caregivers in our study is crucial to understanding the disproportionate burden they face within the traditional family structure.

In our study, primary stressors predominantly revolved around understanding the patient's medical condition and managing changes in patient behavior due to illness. As for secondary stressors linked to extended caregiving, economic burden featured prominently, affecting 70.8% of caregivers. These trends align with previous research, including findings from Dirikkan F et al.(8), Dhandapani M et al. (18) and Brinda M et al.(6) Collectively, these studies emphasize the prevalence of stressors associated with comprehending the patient's medical condition and addressing behavioral changes, often stemming from the challenges of diagnosis and patient care. Economic burden was a common stressor, possibly due to the high out-of-pocket treatment expenses, especially when patients were the primary earners in their families. Notably, increased workload as a stressor was more prominent in studies involving caregivers of patients with conditions like stroke or intracranial tumors, where physical dependency on caregivers was higher compared to our study, which focused on cardiovascular diseases.

Primary stressors, directly related to the patient's condition, were found to have a significant association with the caregiver's relationship to the patient. Stressors were more prevalent among children or daughters-in-law compared to spouses, indicating a shift in family dynamics and the transfer of caregiving responsibilities from parent to child. These changes, while inevitable, add to the burden of caregiving and necessitate additional support for these caregivers as they adapt to their new roles. Secondary stressors, which arise from the challenges of caregiving itself, were found to be significantly associated with the employment status of the primary caregiver. This can be attributed to the fact that people at home can give greater time to look after the patient as compared to the caregivers who were employed outside the home faced additional stressors related to juggling work and caregiving responsibilities, potentially limiting their availability to provide care consistently.

Furthermore, our study revealed a significant association between the duration of caregiving and the proportion of stressors. Review of studies by Walke S et al(5) in their study on caregiver burden among caregivers of mentally ill, Dirikkan F et al (8) in their study on caregivers of cardiac failure patients, Cabral L et al (9) in their study in family caregivers of mentally ill, Kate N et al (7) in their study in

caregivers of Schizophrenia, Das S et al (4) in their study on stroke caregivers in Kolkata revealed a similar picture. This association can be attributed to the prolonged duration of caregiving and multiple hospitalizations, especially in cases of complications, which may lead caregivers to experience burnout and perceive a heightened burden of caregiving. In healthcare settings, establishing help desks or integrating regular communication with caregivers during patient follow-up can be advantageous in addressing their concerns and facilitating timely counselling or support. Additionally, creating disease-specific peer support groups can offer caregivers a supportive network and a platform to exchange experiences and coping strategies.

When the severity of the disease was studied in terms of type of morbidity and impairment in ADL activities, there was greater perceived stress among the caregivers. Similar pattern has been also found in study conducted by McCullagh E et al (15) on caregivers of stroke patients where caregiver burden was greater with increased severity. Our study revealed that caregivers experienced significantly fewer stressors when the treatment for the patients was regular and patient condition was under control as compared to when it was not. This highlights the importance of consistent and effective medical management in reducing the burden on caregivers and improving their overall well-being. Ensuring regular treatment and maintaining control over the patient's condition may play a crucial role in supporting caregivers in their caregiving responsibilities and enhancing their quality

Conclusion

In summary, our study fills a crucial gap in the literature by highlighting the stressors experienced by caregivers of individuals with CVDs in India. The findings indicate that caregiving certainly adds to stressors in the life of caregivers and most of them have to adjust to the new developments to help the patient. These results are noteworthy in terms of demonstrating that patients and caregivers form a dyad where caregivers become a high-risk group that also needs to be taken care of.

Recommendation

Patients and caregivers form a dyad where caregivers become a high-risk group that also requires attention. Caregivers should receive home care advice at discharge, followed by regular check-ins to monitor the medical condition and seek support and knowledge. Establishing a health-promoting information desk for all patients leaving the hospital could serve as a vital resource for stress-free caregiving. Interventions could focus on creating informal support groups for caregivers, where they can exchange knowledge and skills, enhancing both the quality of care and the well-being of caregivers. Involving patients in self-care, to the extent possible, can help reduce the burden on caregivers. Positive coping by seeking treatment at Government facilities or subsidies needs to be promoted. Additionally, social support networks, such as community groups, can offer a platform to share coping strategies and alleviate the challenges of caregiving.

Limitation of the Study

In this study we focussed on stressors among primary caregivers for Cardio-vascular diseases, hence it doesn't reflect the burden of caregiving among caregivers for any other illnesses/disability. Further, the characteristics of the primary caregivers can vary between different regions based on cultural and health care delivery differences.

Relevance of the Study

Currently, much evidence exists regarding mental health disorders and situations where patients are physically dependent on caregivers. However, NCDs, which are increasing, are often overlooked, despite their chronic nature and the additional stressors they impose on caregivers. By providing targeted support and resources, we can improve both caregiver well-being and patient outcomes, creating a more sustainable care model.

Authors Contribution

All authors have contributed equally.

Financial Support and Sponsorship

Nil

Conflict of Interest

Nil

Declaration of Generative AI and AI Assisted Technologies in the Writing Process

The authors haven't used any generative AI/AI assisted technologies in the writing process

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