


Strain and Burden among Caregivers of Stroke Survivors in Punjab:**A Cross-Sectional Study**Mohit Sharma¹, Shivesh Devgan², Sanjeev Mahajan³¹Associate Professor, Department of Community Medicine, Punjab Institute of Medical Sciences, Jalandhar, Punjab, India.²Assistant Professor, ³Professor and Head, Department of Community Medicine
Government Medical College, Amritsar, Punjab, India.**Correspondence** : Dr. Shivesh Devgan, Email : shiveshdevgan@gmail.com**Abstract:**

Introduction: Caregivers may feel stressed and burdened while caring for a stroke survivor. However, very few studies have assessed the burden among caregivers of Indian stroke patients. **Objectives:** The present study was done to assess the magnitude and predictors of strain and burden among caregivers of stroke survivors discharged from a tertiary care hospital in Punjab, India. **Method:** This cross-sectional study included consecutive newly diagnosed stroke patients from January 2021 till April 2022 at a tertiary care teaching hospital in Amritsar, India. The level of strain and burden among the caregivers was assessed using the Caregiver's strain index (CSI) and Zarit Caregiver Burden Scale (ZCBS) respectively. A minimum sample size of 110 stroke patients was calculated. Odds ratios were calculated for identifying predictors of strain and burden among caregivers using multivariate regression analysis. **Results:** Mean CSI for all caregivers was 6.67 ± 1.81 . Using a cut-off of ≥ 7 , authors found 40.2% of the caregivers to have great strain. Modified rankin scale (mRS) at the time of interview (AOR = 2.77, p value = 0.0063), presence of comorbidities in the patient (AOR = 3.07, p value = 0.023 and caregiver being female (AOR = 2.96, p value = 0.036) to be significantly associated with higher odds of having great strain. Using ZCBS, 18.1% had minimal burden, 53.5% had mild to moderate burden, 24.4% had moderate to severe burden and 3.9% had severe burden. mRS at the time of interview (AOR = 5.38, p value = 0.0048), presence of comorbidities in the patient (AOR = 7.63, p value = 0.0031), caregiver being female (AOR = 9.67, p value = 0.0072) and not being at all confident to care (AOR = 4.94, p value = 0.013) to be significantly associated with higher odds of having great burden, while rural residence (AOR = 0.55, p value = 0.0011) was associated with lower odds of high burden. **Conclusion:** High strain was observed among 40.1% of the caregivers of Indian stroke survivors and 24.4% had moderate to severe burden. Thus, the strain and burden among caregivers of Indian stroke patients is very high.

Key Words : Caregiver burden, Recovery, Rehabilitation, Strain, Stroke**Introduction:**

Caregiving can be defined as task-oriented assistance provided by individuals, usually family or friends,^[1] with this assistance not being part of formal community support services. Emphasis of stroke

rehabilitation has recently shifted from a stroke survivor focused to stroke survivor-caregiver dyad approaches, in recognition that caregivers play an essential role in preserving rehabilitation gains and the long-term well-being of stroke survivors.^[2] During

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the period leading to hospital discharge, family caregivers of stroke survivors may face immense uncertainties and new challenges.^[3] The caregivers must learn to cope with their concurrent grief and an uncertain future. Thus, the sudden need to care for a stroke survivor can be emotionally difficult and physically challenging. Caregivers are often unaware of their new role, unfamiliar with the disease, its progression, and the kinds of community support options available.^[4]

This can result in strain and burden among caregivers. Caregiver burden refers to alterations in caregivers' emotional and physical health which can occur when care demands outweigh available resources,^[5] the extent to which caregivers feel their emotional, physical, social life, and financial status has suffered as a result of caregiving.^[6] Caregiver burden is associated with negative outcomes for both caregivers and patients, including the reduction of their general health and quality of life.

There is a dearth of Indian studies aimed at understanding the complex and multi-layered phenomenon of care giving after stroke. The present study was done to assess the magnitude and predictors of strain and burden among caregivers of stroke survivors discharged from a tertiary care hospital in Punjab, India.

Method:

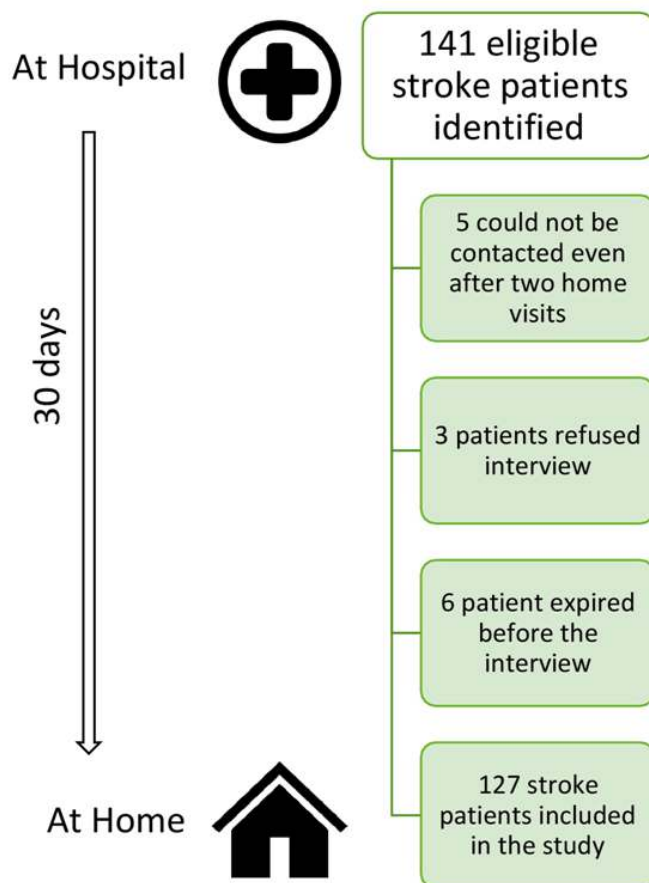
A cross-sectional study among stroke survivors and their caregivers was done by including consecutive newly diagnosed stroke (ischemic and haemorrhagic) patients identified in the emergency or medicine indoor ward of a tertiary care teaching hospital in Amritsar, India. Patients admitted during January 2021 till April 2022 were included in the study. The diagnosis of stroke was supported in every case by expert clinical opinion and Computed Tomography scan or Magnetic Resonance Imaging. Patients who recovered completely at the time of hospital discharge, expired during hospital stay, were unable to communicate, were unwilling to consent

for participation in the study, or resided outside of the Amritsar district were excluded. Matolia and colleagues used CSI and reported high strain among 84% of the stroke caregivers.^[7] Using the prevalence of caregiver strain as 0.84, α error of 5%, allowable error of 10% of 0.8, and sample size formula of $(Z\alpha/2)^2 \times (PQ)/E^2$, authors calculated the same size of a minimum of 81 patients. Adding 10% non-response rate, minimum sample size calculated was 90 patients. Eligible patients and their families were approached during the hospital stay, were explained the purpose of the study and a written consent was obtained. Once they agreed to participate in the study, a convenient time of a day one month after discharge from the hospital was chosen for an interview at their residences. Caregiver was defined as a person who usually provided the most important long-term support during recovery and rehabilitation of the stroke patient. In case of more than one caregiver, the stroke patient was asked to identify the caregiver spending majority of the time caring for them. Approval of the Institutional Ethics Committee was sought for the whole research before the commencement of the study.

Data Collection:

The patients were interviewed using a pretested, semi-structured questionnaire. While still admitted in the hospital, clinical information was noted. Remaining parts of the questionnaire were filled at patient's residence. The severity of disability of the stroke patients was assessed using the modified rankin scale (mRS).^[8] A score of 0 is no disability, 5 is disability requiring constant care for all needs and 6 is death. The level of strain among the caregivers was assessed using the Caregiver's strain index (CSI). It has a set of 13 questions about social stress (6 items), economy stress (3 items), and psychological stress (4 items) with dichotomous yes/no answers. Score ranges from 0 to 13, with a score of seven or more indicating great stress.^[9] The burden among the caregivers was assessed using the Zarit Caregiver Burden Scale (ZCBS), which is a 29-item scale specifically designed to measure feelings of burden

Figure 1 : Flow chart depicting selection of patients in the study



experienced by the caregivers. Score of 0 to 20 denotes minimal or no burden, 21 to 40 denotes mild-to-moderate burden, 41 to 60 denotes moderate-to-severe burden, and 61 to 88 denotes severe burden.^[10] All scales were translated to Punjabi (regional language) and reverse translated to check for consistency and validity of translation.

Statistical analysis:

The data were numerically coded and analysed in IBM SPSS Version 25.0. (Armonk, NY: IBM Corp). Frequency distribution tables were created for qualitative variables, while quantitative data were described as means and standard deviation. Sociodemographic variables of the patients and their caregivers associated with great strain (based on CSI) and moderate and severe burden (based on ZCBS) were analysed using logistic regression analysis after adjusting for the possible confounders. Predictor confounder variables reaching p value = 0.25 in the

univariate analysis were entered into the multivariate regression model to calculate adjusted odds ratios (AOR). Odds ratios were calculated with 95% confidence intervals (CI) and p value less than 0.05 was considered as statistically significant. Receiver Operating Characteristics (ROC) curves were made for both CSI and ZCBS.

Results:

During the study period, authors contacted 141 eligible stroke patients, of which 127 stroke patients were interviewed and included in the final analysis. (Figure 1) The mean age of the patients was 65.40 ± 7.88 years and 28% were females. At the time of admission, 43% and 28% of the patients had mRS score of >3 at the time of admission and at the time of interview respectively. Pre-existing comorbidities were present in 30% of the patients. Mean age of the caregivers was 38.39 ± 4.55 years, 65% being aged

Table 1: Baseline characteristics of the caregivers of stroke patients (N=127)

Variables	n (%)
Age group (years)	
20 to 40	83 (65%)
41 to 60	39 (31%)
More than 60	5 (4%)
Gender	
Female	50 (39%)
Male	77 (61%)
Marital status	
Married	112 (88%)
Single	15 (12%)
Type of residence	
Urban	90 (71%)
Rural	37 (29%)
Relation to stroke patient	
Son	65 (51%)
Daughter	32 (25%)
Wife	12 (9%)
Other	18 (15%)
Education level	
Illiterate	14 (11%)
Primary	25 (19%)
Middle	30 (24%)
High	42 (33%)
Intermediate	10 (8%)
Graduate/Professional	6 (5%)
Employed	
Yes	78 (61%)
No	49 (39%)
Previously seen a stroke patient	
Yes	25 (20%)
No	102 (80%)
How confident in providing care?	
Very confident	12 (10%)
Somewhat confident	98 (77%)
Not confident at all	17 (13%)

Problems encountered	
Do not have money	69 (54%)
Does not know how to care	65 (51%)
Patient's condition makes me sad	52 (41%)
Alone to care	44 (35%)
Difficult to find time for caring	34 (27%)
Treatment is not working	30 (24%)
Others	8 (6%)
Fears	
Weakness of the patient would not get better	72 (57%)
Not knowing the best form of care	56 (44%)
Patient's pain would not get better	46 (36%)
Patient would not survive	38 (30%)
Being the only one to care	38 (30%)
Not enough money to continue treatment	37 (29%)
Future of patient's dependents	20 (16%)
Others	3 (2%)

Table 2 : Caregiver burden according to Caregiver Strain Index (CSI) and Zarit's Caregiver Burden Scale (ZCBS) (N=127)

CSI components	Mean ± SD (range)
CSI social	2.94 ± 1.07 (1 to 3)
CSI economy	1.85 ± 0.76 (0 to 3)
CSI psychological	1.87 ± 0.78 (1 to 4)
CSI total	6.67 ± 1.81 (3 to 11)
Great strain according to CSI (≥7)	
Yes	51 (40.2%)
No	76 (59.8%)
ZCBS severity	
Minimal (0 to 20)	23 (18.1%)
Mild to moderate (21 to 40)	68 (53.5%)
Moderate to severe (41 to 60)	31 (24.4%)
Severe (61 to 88)	5 (3.9%)

Table 3: Multivariate logistic regression analysis of patient and caregiver factors associated with great strain on the caregivers based on CSI (N=127)

Factors	Unadjusted Odd's ratio	95% CI for OR		p value*	Adjusted Odd's ratios	95% CI for		p value
		Lower	Upper			Lower	Upper	
Stroke patient related factors								
Age	1.017	0.97	1.06	0.47	NA			
Female gender	1.16	0.53	2.57	0.71	NA			
mRS at admission	2.42	1.46	4.02	0.011	1.01	0.47	2.15	0.97
mRS at interview	3.16	1.89	5.28	0.003	2.77	1.36	5.66	0.0063
Comorbidities	4.66	2.07	10.48	0.004	3.07	1.17	8.02	0.023
Caregiver related factors								
Age	0.98	0.94	1.01	0.3	NA			
Female gender	2.59	1.24	5.41	0.0023	2.96	1.08	8.15	0.036
Single	1.83	0.62	5.41	0.27	NA			
Illiterate	1.13	0.36	3.48	0.82	NA			
Unemployed	0.59	0.28	1.25	0.17	0.43	0.16	1.17	0.11
Rural residence	1.41	0.64	3.03	0.39	NA			
Never seen a stroke patient	0.67	0.27	1.61	0.37	NA			
Confidence in caring								
Not at all confident	2.85	0.612	13.33	0.18	5.2	0.72	17.48	0.22
Somewhat confident	1.21	0.34	4.31	0.76	NA			

*variables with a p value of less than 0.25 on univariate analysis were included in the multivariate regression model

less than 40 years. (Table 1) It was observed that among the caregivers, 39% were females, 88% were married, 29% were from rural residence, 11% were illiterate and 39% were unemployed. Only 20% of the caregivers reported previously seeing a stroke patient, and of the total 10% were very confident in caring for a stroke patient. Most common problems among caregivers were 'not having enough money' (54%) and 'not knowing how to care' (51%). The most common fears among the caregivers were 'weakness of the patient not improving' (57%) and 'not knowing the best form of care' (44%).

Mean CSI for all caregivers was 6.67 ± 1.81 , ranging from 3 to 11. Using a cut-off of ≥ 7 , we found 40.2% of the caregivers to have great strain. (Table 2) On multivariate regression analysis, we found higher mRS at the time of interview [AOR = 2.77 (95% CI

1.36 to 5.66), p value = 0.0063], presence of comorbidities in the patient [AOR = 3.07 (95% CI 1.17 to 8.02), p value = 0.023] and caregiver being female [AOR = 2.96 (95% CI 1.08 to 8.15), p value = 0.036] to be significantly associated with higher odds of having great strain. (Table 3) Based on the model of these three factors, Receiver-operating characteristic (ROC) curve was created, which had an Area Under Curve (AUC) of $0.79 \pm SE0.04$ (95% CI 0.71 to 0.88), p value = 0.00081. (Figure 2) This demonstrates high accuracy of these three factors in predicting high strain among stroke caregivers.

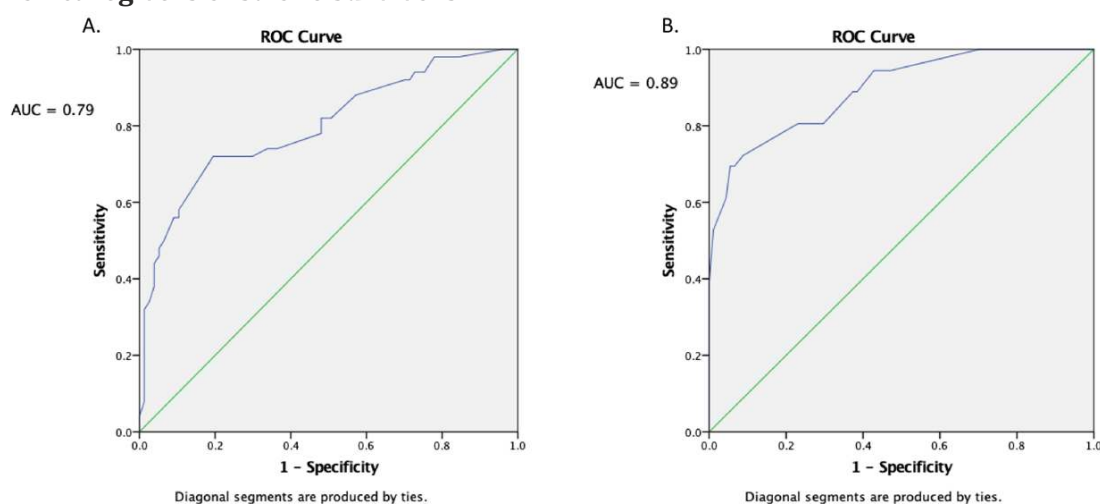
Using ZCBS, 18.1% had minimal burden, 53.5% had mild to moderate burden, 24.4% had moderate to severe burden and 3.9% had severe burden. (Table 2) On multivariate regression analysis, authors found higher mRS at the time of interview [AOR = 5.38 (95%

Table 4: Multivariate logistic regression analysis on factors associated with moderate and severe burden on the caregivers based in Zarit's Caregiver Burden Scale

Factors	Unadjusted Odd's ratio	95% CI for OR		p value*	Adjusted Odd's ratios	95% CI for		p value
		Lower	Upper			Lower	Upper	
Stroke patient related factors								
Age	1.01	0.96	1.06	0.51	NA			
Female gender	1.47	0.63	3.42	0.36	NA			
mRS at admission	2.99	1.66	5.38	0.0052	1.01	0.36	2.76	0.99
mRS at interview	4.77	2.51	9.05	0.0032	5.38	2.02	14.29	0.0048
Comorbidities	8.96	3.72	21.54	0.0047	7.63	2.25	25.89	0.0031
Caregiver related factors								
Age	0.99	0.95	1.03	0.86	NA			
Female gender	7.25	3.05	17.24	0.0063	9.67	2.69	14.79	0.0072
Single	1.3	0.41	4.12	0.64	NA			
Illiterate	1.47	0.45	4.72	0.51	NA			
Unemployed	0.73	0.32	1.63	0.44	NA			
Rural residence	0.38	0.14	1.02	0.057	0.55	0.13	0.94	0.0011
Never seen a stroke patient	0.64	0.25	1.61	0.34	NA			
Confidence in caring								
Not at all confident	1.57	0.35	6.99	0.25	4.94	1.22	6.62	0.013
Somewhat confident	0.4	0.11	1.41	0.15	1.16	0.21	6.6	0.86

*variables with a p value of less than 0.25 on univariate analysis were included in the multivariate regression model

Figure 2: ROC curves for predictors associated with great strain and moderate and severe burden on caregivers of stroke survivors



- A. ROC for factors associated with high strain on CSI (mRS at interview, patients with comorbidities, female caregiver, rural residence and caregiver not at all confident)
- B. ROC for factors associated with moderate and severe burden based on ZCBS (mRS at interview, patients with comorbidities and female caregiver)

CI 2.02 to 14.29), p value = 0.0048], presence of comorbidities in the patient [AOR = 7.63 (95% CI 2.25 to 25.89), p value = 0.0031], caregiver being female [AOR = 9.67 (95% CI 2.69 to 14.79), p value = 0.0072] and not being at all confident to care [AOR = 4.94 (95% CI 1.22 to 6.62), p value = 0.013] to be significantly associated with higher odds of having great burden, while rural residence [AOR = 0.55 (95% CI 0.13 to 0.94), p value = 0.0011] was significantly associated with lower odds. (Table 4) Based on the model of these five factors, ROC curve was created, which had an Area Under Curve (AUC) of $0.89 \pm SE 0.03$ (95% CI 0.83 to 0.95), p value = 0.0034. (Figure 2) This demonstrates high accuracy of these five factors in predicting severe burden among stroke caregivers.

Discussion:

In current study sample, approximately 40% of the caregivers had great strain while caring for stroke survivors. Higher disability severity (based on mRS), presence of comorbidities in stroke patients and caregiver being female were found to be significantly associated with higher odds of great strain. The tool used in the present study for assessing strain was CSI which incorporates social, economic and psychological stress. Using CSI, Kaur et al found that majority of the caregivers of stroke patients (73.5%) had severe strain of care and around one fourth (26.5%) were found to be having moderate level of strain.^[11] Bhattacharjee et al identified younger age associated with higher caregiver burden.^[12] Mandowara et al also found a weak correlation between increasing caregiver age and caregiver burden.^[13] Mean age of caregivers in the study was 38 years, which was much lower than that in these two studies and could be the reason why we did not observe an effect of caregiver age on strain and burden.

The initial few weeks after discharge can put enormous burden on the caregiver. It is not only frustrating but can have a negative impact on patients' outcomes.^[14] In addition, studies show that burden in caregivers of stroke patients will increase over time if the proper intervention is not

provided.^[15] A recent experimental pilot study from Iran showed that supportive home care program is effective in reducing caregiver burden and its domains.^[16] Ideally, such supportive programs should be instituted in all discharge cases. However, due to scarcity of healthcare professionals in India, caregivers who have a high likelihood of severe burden should be identified, who should then be supported by a home care program. In this study, higher disability severity (based on mRS), presence of comorbidities in stroke patients, caregiver being female, rural residence and not being confident to care were found to be significantly associated with higher odds of moderate and severe caregiver burden. Future research is required to assess the impact of supportive home care program in reducing caregiver burden in Indian setting.

Gender disparity in caregiver strain and burden is evident in current study as female caregivers experienced higher strain and burden. Menon et al observed that female caregivers of stroke patients were subjected to more sleep disturbance, physical and psychological stress, faced more difficulty regarding the patient's bladder, bowel, personal hygiene needs, and physiotherapy. Female caregivers felt less motivated in caregiving than male counterparts and time spent and burden perceived was more by female caregivers.^[17] In a patriarchal society like India, females are expected to make more physical and emotional adjustments while caring for a patient with chronic disease. In many cases, female caregivers would neglect their own health and give priority to the patient.^[18] In addition, having a male stroke patient would shift the financial burden on the female members. Thus, educating the family about the importance of family support in reducing caregiver stress and burden by sharing caregiving responsibilities is essential.

Limitations:

Generalization of study findings is limited to Indian caregivers of stroke patients who sought treatment from a public tertiary care hospital. Perceived caregiver strain might be different for caregivers who are attending private outpatient

clinics. Secondly, authors did not assess caregiver comorbidity level in great detail, which could also affect their perceived strain and burden. Also, repeated measurements of caregiver strain and burden after discharge over a longer follow up period would provide a better understanding of the dynamic nature of these characteristics.

Conclusion:

The study found that 40.1% of the caregivers of Indian stroke survivors experience high strain and 24.4% had moderate and severe burden. High disability level, comorbid patients and female caregiver to be common factors associated with great strain and burden. Understanding these factors is a key step and a valuable tool toward the design of early intervention strategies for caregivers who are at risk of distress.

Declaration:

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Conflict of Interest: Nil

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