

A Study to Measure Caregiver Stress in Stroke Patients using Caregiver Strain Index

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ABSTRACT

Introduction: Stroke survivors have moderate to severe disability that limits their employment status and social mobility. Family members are usually not prepared to deal with the consequences of a stroke. The care of stroke patients usually leads to stress and burden among the caregivers.

Aim: To assess the strain among the caregivers of stroke patients with the Caregiver Strain Index (CSI) and find the correlation between their age and duration of stroke with that of the caregiver strain.

Materials and Methods: A cross-sectional study was done at various hospitals in the South Gujarat region. After explaining the purpose and taking the informed consent, 50 participants were included in the study. The interviewer filled a pre-structured proforma for patients and their caregivers, as well as a CSI. Statistical analysis was done using SPSS 15.

Results: The mean age of participants and caregivers were 60.06 ± 15.43 years and 49 ± 15.07 years, respectively. Male stroke survivors were 60% among the sample of 50. Caregiver's strain was found to be high in 84% (n=42) and low in 16% (n=8) of the caregivers of stroke patients. A positive correlation was present between the patient's age and CSI score ($r=0.132$) and a negative correlation between the duration of stroke and CSI score ($r=-0.069$) with spearman correlation.

Conclusion: Among the caregivers of stroke patients, the strain was found to be high. Also, with the increasing age of stroke patients, the level of stress on caregivers increases. As the duration of stroke increases, the caregiver strain reduces.

Keywords: Caregiver stress, Mental health, Emotional stress, Stroke survivors, Caregiver Strain Index

INTRODUCTION

Stroke patients have a high rate of mortality and disability. Around 50 million stroke survivors worldwide suffer from physical, cognitive, and emotional issues, with around 25%-74% of them requiring assistance with daily activities (ADL) [1] Stroke occurs suddenly, unlike other non-communicable diseases, leaving the individual and his family unprepared and unequipped to deal with the repercussions. [2,3] Taking care of a physically challenged

family member is a difficult task and has an impact on the physical and psychological well-being of caregivers who provide emotional support or aid patients with their everyday routines. [4-7]

Caregivers are more likely to suffer unfavourable outcomes as a result of their caregiving. [8] Providing care to a family member with a chronic or life-threatening illness can be emotionally rewarding as well as upsetting. [9] The caregiver has minimal experience caring for someone with

physical or cognitive disabilities. [10] This causes caregivers to be unnecessarily stressed or burdened, impacting their physical and mental well-being. [2,3] According to studies, caregivers frequently exhibit symptoms and complaints connected to their caregiving responsibilities, such as increased anxiety, depression, and a restriction in attending social functions [11], and each caregiver is affected differently by the stress of caregiving tasks. [12]

Caregiver needs are overlooked, resulting in a decline in their health and quality of life. [13] As a result of the patient's physical and emotional requirements, family members may experience stress, misunderstanding, or a sense of neglect. [7] Anxiety, despair, dread, frustration, resentment, impatience, and guilt are common symptoms of this condition. As a result, determining the level of caregiver load and the factors that determine it is critical. [14] Using the caregiver strain index, this study intends to investigate the physical, mental, emotional, and financial stress of caregivers. Also, to see if there's a link between the patient's age and the duration of the stroke in terms of caregiver stress.

MATERIALS AND METHOD

A cross-sectional study was carried out at various hospitals in the South Gujarat region from Oct. 2018 to mid-2019. The study involved stroke patients aged 20 and 90, those patients with one-time stroke, who understand English and had completed 7th grade, and those who had informal caregivers. Stroke patients with paid caregivers were excluded from the study.

The Caregiver Strain Index was used. It is the most widely used scale to determine caregiver burden. It consists of thirteen yes or no questions. 'No' is assigned a value of '0', whereas 'Yes' is assigned a value of '1'. The final score is calculated by adding 0 and 1 for a total of 13 points. A positive response of 7 or more items on the index indicates a greater level of stress. The CSI was chosen for this study

because of its good validity and reliability, ease of access, and also the fact that it requires less time to administer. [15] Studies done on caregivers of patients with stroke have also recommended the CSI as the instrument of choice for assessing the burden of informal caregivers. [16,17]

After screening, a total of 50 participants were included in the study, and then patients with informal caregivers who satisfied the eligibility criteria and gave informed consent were interviewed after briefing about the purpose of the study. The interviewer filled out a pre-structured proforma addressing the demographic profile of the participant and caregiver, including age, gender, type and duration of stroke (participant), educational, employment, and financial status (participant), marital status, and premorbid condition (participant), type of caregiver, and duration of caregiving, and effect of patient's condition on caregiver's health. After the demographic form, CSI was filled by the interviewer with the caregivers.

Statistical Analysis

Descriptive statistics were used to assess the following variables: age, gender, duration of stroke, type and side of stroke, duration of caregiving, marital and financial status of the caregiver. The Spearman correlation of the age of the participant with the CSI score and the duration of the stroke with the CSI score were calculated using SPSS 15.

RESULT

The mean age of the stroke patients was 60.06 ± 15.43 years and the mean age of caregivers was 49 ± 15.07 years. In the sample space of 50 stroke patients, male participants were 60% and 40% were female. Among 50 caregivers, 40% were male and 60% were female. Caregiver's strain was found to be high in 90% (n=50) and low in 10% of the caregivers of stroke patients.

Table 1 Demographic variables of participants

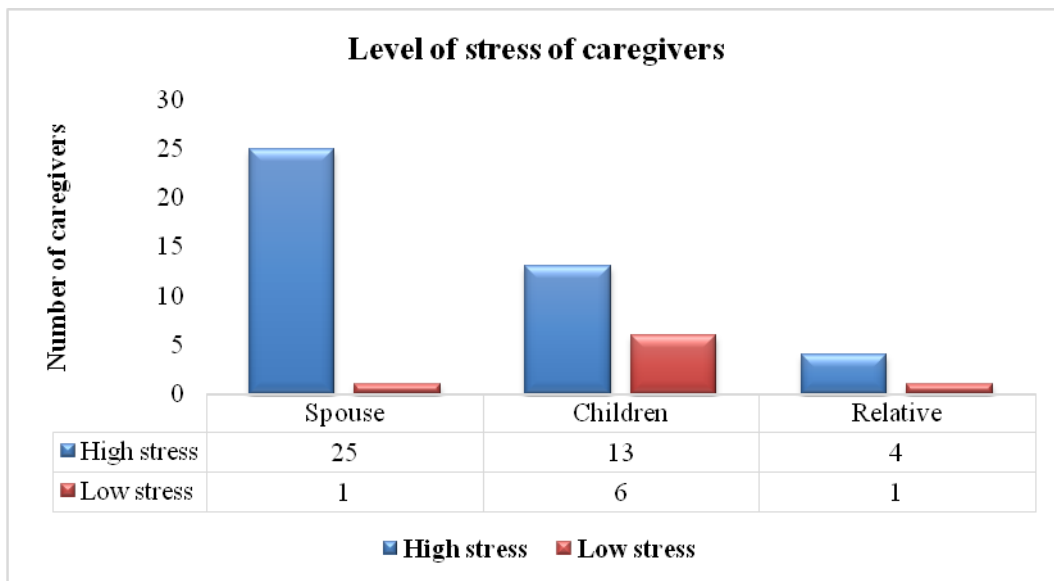
Variables	Frequency	Percentage (%)
Gender		
Male	30	60%
Female	20	40%
Duration of Stroke		
0-6 months	27	54%
6-12 months	10	20%
>1 year	13	26%
Type of Stroke		
Ischemic	24	48%
Haemorrhagic	26	52%
Side of Body Affected		
Right	29	58%
Left	21	42%
Continuous variable	Min/Max	Mean + SD
Age	21/88	60.06 ± 15.43

Among 50 caregivers, 42 had a high level of stress and 8 had a low level of stress. Thus, it contributes to 84% and 16% of our total caregiver population respectively. Out of 26 spouse caregivers, 25 had a high level of stress that contributes to 96% of total spouse caregivers of our sample. More number of children

caregivers(n=13) had a high level of stress which contributes to 31%.

Table 2 Demographic variables of Caregivers

Variables	Frequency	Percentage (%)
Gender		
Male	20	40%
Female	30	60%
Duration of Caregiving		
2-8 hrs	4	8%
9-15 hrs	10	20%
16-24 hrs	6	72%
Relationship to the patient		
Spouse	26	52%
Children	19	38%
Relative	5	10%
Marital status		
Married	43	86%
Single	7	14%
Financial status		
Changed	31	62%
Not changed	19	38%
Effect on health		
Deteriorated	21	42%
Same	29	58%
Continuous variable	Min/Max	Mean + SD
Age	21/80	49.00 ± 15.07



Graph 1 Distribution of level of stress in relation of the caregiver to patient

Out of 42 high-level stress caregivers, the majority were the spouse of the stroke survivors contributing 52% of the whole sample.

Table 3 Level of stress on CSI and its score

	Min/Max	Mean + SD
PAS score	5/12	9.00 + 1.97
	Frequency (n=50)	Percentage (%)
Level of stress		
High	42	84%
Low	8	16%

Table 4 Descriptive statistics of correlation between age of patient and CSI score

Spearman Correlation (ρ)		Age	CSI Score
Age	Correlation Coefficient	1	0.132
	Sig. (2-tailed)		0.360
	N	50	50
CSI Score	Correlation Coefficient	0.132	1
	Sig. (2-tailed)	0.360	
	N	50	50

As shown in the table, Spearman's correlation value of age with CSI Score is

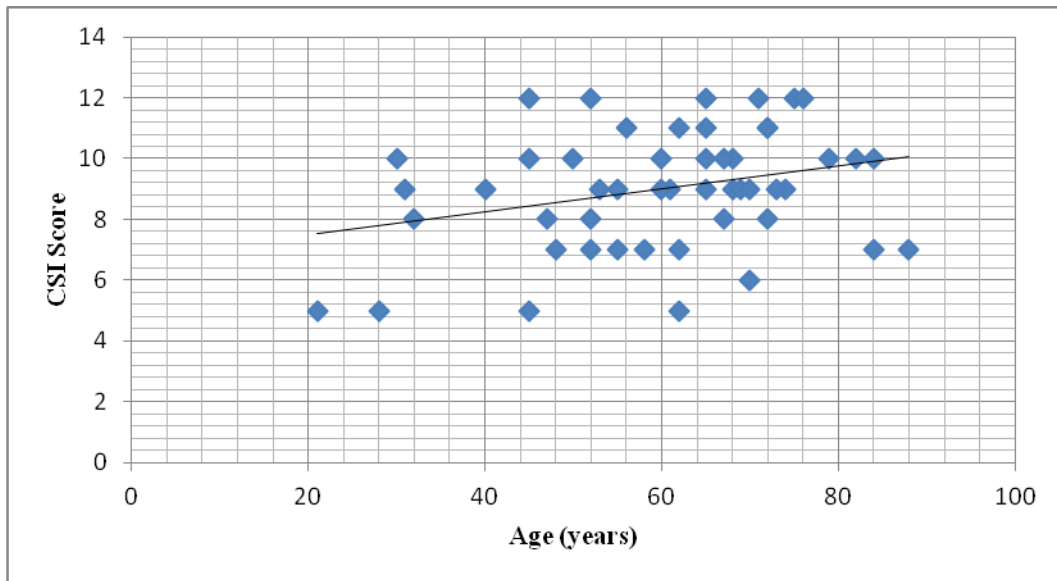
$\rho=0.132$. There is a positive correlation between the age of the patient and the CSI Score which means that with the increase in the age of the patient, the strain on the caregiver increases.

Spearman's correlation value of the duration of stroke with CSI Score is $\rho=-0.069$ as shown in table 5. Thus, there is a negative correlation between duration of stroke and CSI Score meaning as the

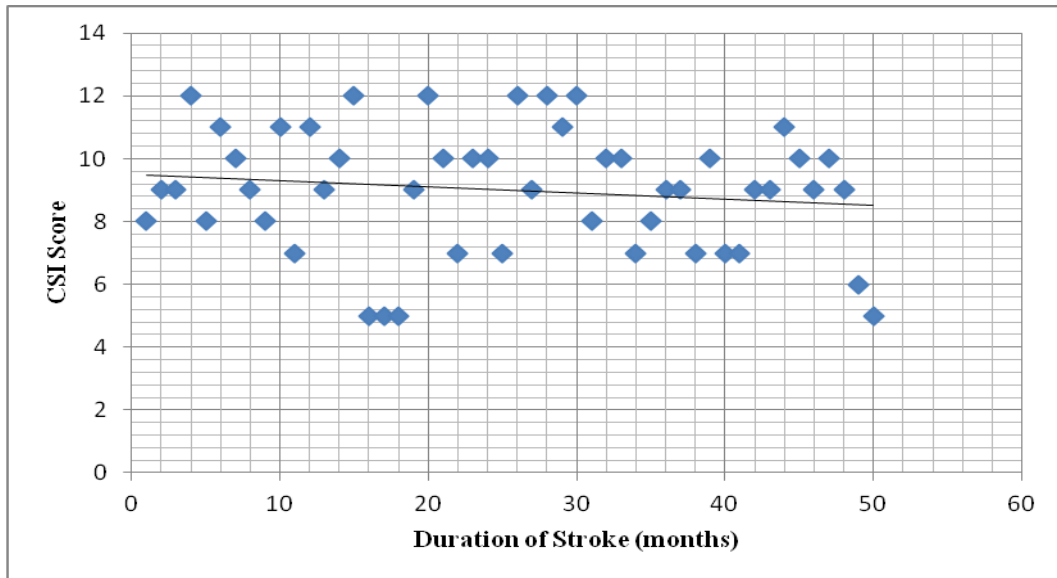
duration of stroke increases, the strain on caregivers decreases.

Table 5 Descriptive statistics of correlation between duration of stroke and CSI score

Spearman Correlation (ρ)		Age	CSI Score
CSI Score	Correlation Coefficient	1	-0.069
	Sig. (2-tailed)		0.636
	N	50	50
Duration of stroke	Correlation Coefficient	-	1
	Sig. (2-tailed)	0.636	
	N	50	50



Graph 2 Scatter diagram showing correlation between age of the stroke patient and CSI Score



Graph 3 Scattered diagram showing the correlation between duration of stroke and CSI Score

DISCUSSION

Stroke is a leading cause of long-term disability and death in developing countries, India is being no exception.

Because of its chronic nature and long-term recovery duration, caring for a stroke patient often out a great burden on informal caregivers. Caring for a stroke patient had a

great negative impact on all spheres of a caregiver's life.^[18]

In India caregiving is predominantly by females. Our study had more than 50% of female caregivers. This is attributed to the Indian culture and the social effects because of which females are assigned more responsibility to care for elderly persons.^[19] In a recent population-based study eighty percent of the CGs were women and a majority of the patients were cared for by immediate family members like spouses, children, siblings, etc.^[20] Gender differences in caregiving and their negative impact on well-being are well studied.^[21]

When compared to other relatives as carers, we discovered that caregivers who were spouses or children of stroke survivors had a higher level of stress. This is in line with the findings of a study, which found that caring for a spouse or children causes more stress than caring for other relatives such as siblings, parents, etc.^[22] These findings support previous findings on the more difficult nature of spousal caring, and they show that this is also true of parental caregiving.^[23,24]

In our study, 84 percent of caregivers had higher levels of stress as a result of caring for a stroke patient, whereas another study found 37 percent of caregivers with strain after 6 months of stroke duration, and also found that the amount of time a caregiver spent helping a stroke patient, the amount of time the caregiver spent with the patient, and the caregiver's health were all significantly associated with the level of strain experienced.^[25] Another study found that at 6 months after a stroke, 34% of people were under significant strain and 35% were under pressure, which contradicts our findings.^[26] A study of stroke caregivers indicated that more (60.8 percent) had moderate objective burdens, whereas 79.2 percent had mild subjective burdens, which is consistent with our findings of higher stress among caregivers.^[27]

The duration of caregiving, age, and functional state of the stroke survivor have all been identified as factors of caregivers'

quality of life in studies.^[28] We also discovered a positive link between the age of the stroke survivor and CSI scores, implying that as the stroke survivor's age increases, the burden on carers increases. Age-related declines in cognitive ability and impairment in doing daily activities worsen the disease's symptoms and effects and place a significant burden on caregivers.

In our study, we discovered that as the duration of stroke was increases, the caregiver's burden decreases. It could be because the study had a greater number of stroke survivors in the category of 12 months post-stroke period. This was backed up by the fact that as time passed, the disability decreased and the caregiver became more aware of their role and the patient's condition. Overall, the findings highlight the need for more study into the joint effects of age, duration, and style of caring across multiple dimensions utilizing various stress or strain measures. These findings, along with those outlined above, provide early evidence that supports future investigation into the character and significance of structural uncertainty for caregiving relationships that are not largely confined to those with a specific condition such as stroke.

The strength of our study was the inclusion of various caregiving relationships. However, there were some limitations as well. First, we studied the strain on caregivers at one-time point which limits the understanding and characteristics of it, there is a need for studies including regular follow-ups to better understand strain. In addition, we were unable to take into account some important relationship profiles such as children, children-in-law, and also the number of children. We also did not consider the number of caregivers present for a single stroke survivor.

CONCLUSION

The strain was found to be high in the caregivers of stroke patients, among these majority were spouse caregivers. A greater number of spouses as caregivers and

females among them had a high level of stress. With the increasing age of stroke survivors, the level of stress over the caregiver increases due to the addition of other comorbidities as the age advances. As the duration of stroke increases, the caregiver strain reduces because they have adapted to this new situation. There is a need for developing strategic home or community-based programs to reduce caregivers stress and improve their quality of life.

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