Burden Faced by Caregivers of Stroke Patients Who Attend Rural-based Medical Teaching Hospital in Western India

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Abstract

Background: Stroke results in significant caregiver burden and strain. Objective: The main objectives of this study is to assess the burden and its consequences in caregivers of stroke patients and to determine the associated factors to caregivers’ burden. Methods: A cross-sectional study was conducted over 1 year on 70 consecutive patients who attended the Shree Krishna Hospital, Karamsad stroke clinic. Demographic and clinical characteristics of all patients were recorded after obtaining the consent. The modified Rankine scale and Barthel index were administered to the patient, whereas Caregiver strain index, Caregiver burden scale, Patient Health Questionnaire-9, Generalized Anxiety Disorder-7, and Kuppuswami scale were administered to the patient’s caregiver. Descriptive statistics were used to portray demographic and clinical profiles. Correlation coefficients were used to assess the association between different scales, and t-test was applied to assess association of caregivers’ burden with different categorical variables. Results: The mean age was 60 years for patients and 47 years for caregivers. Nearly 72.8% of patients were male, whereas 57% of caregivers were female. The mean caregiver burden scale score was 28.26. Caregivers’ burden increased with increase in stroke duration (P = 0.01), increase in education level (P = 0.054), and upper socioeconomic status (P = 0.02). Caregivers’ burden increased with caring for male gender (P = 0.18), being a female caregiver (P = 0.31), longer caregiver hours (r = 0.51), and increased patient disability (P < 0.01). A strong correlation existed between caregivers’ burden and depression (0.72); anxiety and depression (0.84); caregivers’ burden and caregiver strain index (0.72). Conclusions: A structured and targeted caregiver intervention is urgently needed to relieve caregivers’ burden and related psychological comorbidities in an Indian setup.

Keywords: Anxiety, caregivers’ burden, stroke

INTRODUCTION

Stoke morbidity and mortality has assumed alarming proportions and is a major burden predominantly in low- and middle-income countries such as India which is not only a developing economy but also where aging population, changes in lifestyle, and rapid urbanization have contributed to a rise in noncommunicable diseases, including stroke.[1] A recent population-based study has confirmed the burden of stroke in the aging population.[2] In 2005, India accounted for >53% of all deaths and 44% of the disability-adjusted life years lost from chronic diseases (including stroke).[3,4]

As life expectancy increases, India will face an enormous socioeconomic burden to meet the costs of integrated rehabilitation of patients with stroke. The needs of a stroke survivor vary from ambulation (walking, transfer from bed to chair, and chair to toilet), communication (verbal and nonverbal with family members, friends), nursing (feeding, changing clothes, and personal toilet), and emotional and psychological changes to adapt to the consequences of the stroke. In oriental countries including India, the joint family system prevails, wherein in a small apartment (<800 sq. ft.), parents, spouse, children (son and daughter-in-law) stay together sharing infrastructural facilities. Currently, nearly one-third of stroke survivors stay at home and take domiciliary care. Due to its debilitating and chronic nature, caring for stroke patients often puts a considerable burden on their caregiver’s leading to caregiver strain, an unfortunately neglected domain in stroke patient care and rehabilitation even though there is evidence to suggest that caregiver stress may impact the recovery and successful rehabilitation of stroke patients.[5]

We aimed to identify factors related to increased caregivers’ burden in stroke survivors in India and assess the levels of anxiety and depression in caregivers and their association with caregivers’ burden.

METHODS

A cross-sectional study was conducted at the Shree Krishna Hospital, a rural medical teaching hospital in Karamsad, in Anand district of Gujarat state in western India, over the...
course of 1 year. Consecutive 70 patients who attended the stroke clinic and who had an modified rankin scale >1 and/or Barthel index <80 were included in the study. Stroke patients with modified rankin scale <1 or Barthel index >80, patients having other neurological conditions except stroke, transient ischemic attack, and a history of other comorbid debilitating systemic disease were excluded from the study. After obtaining the informed consent, general and clinical characteristics of all patients were recorded, including their occupation, education, and other particulars.

**Definition and details of scales administered are as below**

The caregiver is defined as “a person who lives with the patient and is most closely involved in taking care of him/her at home”. A caregiver can also be defined as “an unpaid person who helps with the physical care or coping with the disease”.

Caregivers’ burden: “the state resulting from necessary caring tasks or restrictions that cause discomfort for the caregiver:”

1. **MRS**: Modified rankin scale measures independence rather than performance of specific tasks. The scale consists of six grades from 0 to 5; 0 denotes no symptoms and 5 indicates severe disability. For clinical purpose, mild disability range is from 0 to 2; moderate disability ranges from 3 to 4, and 5 indicates severe disability.\(^\text{[6]}\)

2. **Barthel index**: It is a scoring technique that measures the patient’s performance in 10 activities of daily life, and it is considered a reliable disability scale for stroke patients. For clinical evaluation, 76–100 points denote “good function,” 51–75 points denote “moderate disability,” and score under 50 denotes “severe disability.” 0 score represents totally dependent bedridden state.\(^\text{[7]}\)

3. **Caregiver’s strain index**: It has a set of 13 questions. The CSI measures strain related to care provision. There is at least one item for each of the following major domains: employment, financial, physical, social, and time. Positive responses to seven or more items on the index indicate a greater level of strain.\(^\text{[9]}\)

4. **Caregiver’s burden scale**: The Zarit caregiver burden scale is a 29-item scale specifically designed to measure feelings of burden experienced by the caregivers of elderly persons with dementia. Score of 0–20 denotes minimal or no burden, 21–40 denotes mild-to-moderate burden, 41–60 denotes moderate-to-severe burden, and 61–88 denotes severe burden.\(^\text{[9]}\)

5. **PHQ-9** measures depression and total score for the nine items ranges from 0 to 27. This is calculated by assigning scores of 0, 1, 2, and 3, to the response categories of not at all, several days, more than half the days, and nearly every day, respectively. GAD 7 total score for the seven items ranges from 0 to 21. Scores of 5, 10, and 15 represent cut points for mild, moderate, and severe anxiety, respectively.\(^\text{[10]}\)

6. **Generalized Anxiety Disorder-7 (GAD-7) Anxiety Severity**

   This is calculated by assigning scores of 0, 1, 2, and 3, to the response categories of — not at all, several days, more than half the days, and nearly every day, respectively. GAD 7 total score

7. **Revised Kuppuswami Scale (2013)**: Kuppuswamy’s socioeconomic status scale is an important tool to measure socioeconomic status of families in urban areas. This scale takes into account education, occupation, and income of the family to categorize families into the upper, middle, and low-socioeconomic status.\(^\text{[13]}\)

Modified rankin scale and Barthel index were administered to the patient, whereas the Caregiver strain index, Caregiver burden scale, Patient Health Questionnaire-9, Generalized Anxiety Disorder-7, and Kuppuswami scale were administered to the caregivers by the investigator.

All scales were translated to Gujarati (regional language) and reverse translated to check for consistency and validity of translation. They were administered by investigator himself despite being self-administered questionnaire as study setup being rural setup participants may have difficulty in comprehending and answering the same.

**Statistical analysis**

Descriptive statistics (mean [standard deviation (SD)] and frequency [%]) were used to depict the profile of stroke patients and their caregivers. The associations between different scales were determined by the Karl Pearson’s correlation coefficient. The factors associated with caregivers’ burden were assessed using the independent sample \(t\)-tests.

**Results**

**Patients’ profile**

A total of 70 patients who attended the stroke clinic and their caregivers were invited to participate. The mean (SD) (median [interquartile range (IQR)]) age of the patients was 60.01 (14.81) (62.5 [55, 69]). All the patients and caregivers participated in the study (response rate 100%). Most of the patients were male (73%), suffering for >6 months (53%), and suffering from infract stroke (86%). The mean (SD) (median [IQR]) disability score on modified rankin scale was 2.99 (0.91) (3 [2, 4]). As per the classification criteria, disability among the patients was recorded as mild (35.7%), moderate (35.7%), and moderately severe (28.6%). The mean (SD) (median [IQR]) functionality score on Barthel index was 61.29 (22.44) (65 [55, 75]). As per the classification criteria, functionality among the patients was recorded as good functionality (21.4%), moderate disability (55.7%), and severe disability (22.9%) [Table 1]. The correlation coefficient between modified rankin scale and Barthel index was −0.89 indicating good construct validity.

**Caregivers’ profile**

The mean (SD) (Median [IQR]) age of the caregivers was 47.43 (12.32) (48 [38, 56]). Majority of the caregivers were female (57%), had higher secondary education (46%), and
residing beyond 10 Km from the hospital (59%). Spouse and children constitute the majority of the caregivers. More than one-fifth of the caregivers changed their current occupation. Majority of the caregivers belong to the middle and upper-middle social class as per Kuppuswami classification. The mean (SD) (Median [IQR]) of caregiver strain index, ZARIT caregiver burden score, PHQ9 depression score, and GAD7 anxiety score were 6.93 (2.94) (7 [5, 9]), 28.26 (14.07) (28 [18, 36]), 5.69 (4.90) (4 [2, 6]), and 4.67 (4.01) (4 [2, 8]), respectively. Majority of the caregivers reported high level of stress, mild-to-moderate burden, minimal-to-mild depression, and minimal-to-mild anxiety [Table 2].

Univariate analysis

According to the univariate analysis, caregivers’ burden significantly decreased with an increase in duration of months from the stroke event ($P = 0.01$), when the caregiver belonged to higher socioeconomic class ($P = 0.008$) and they had a higher level of education ($P = 0.05$). On the contrary, the caregivers’ burden increased with patients’ disability ($P < 0.001$) and caregiver’s occupation change (especially loss of job) ($P = 0.03$) [Table 3].

The correlation between caregivers’ burden and patient’s age was weak ($r = −0.02$) whereas it was moderate with disability (Rankin Scale) ($r = 0.51$), and number of caregivers’ hours ($r = 0.51$). The correlation between caregivers’ burden and anxiety was moderate ($r = 0.66$), whereas it was similar between anxiety and strain index ($r = 0.60$). The correlation between anxiety and depression was strong ($r = 0.84$). The correlation between depression and strain index was moderate ($r = 0.56$).

Stepwise regression analysis revealed that functional dependency as assessed by Barthel index ($P < 0.001$),

| Variable | Category | Frequency (%) |
|----------|----------|---------------|
| Gender   | Male     | 30 (42.86)    |
|          | Female   | 40 (57.14)    |
| Occupation change | No change (working) | 18 (25.71) |
|          | No change (not working) | 4 (5.71) |
|          | No change (housewife) | 3 (4.29) |
|          | Changed to part-time job | 5 (7.14) |
|          | Left job | 4 (5.71) |
|          | Housewife (changed/need assistance) | 6 (8.57) |
| Education | <10th standard | 21 (30) |
|          | 10th-12th standard | 32 (45.71) |
|          | Graduate | 15 (21.43) |
|          | Postgraduate | 2 (2.86) |
| Relationship with patient | Wife | 28 (40) |
|          | Husband | 5 (7.14) |
|          | Son | 20 (28.57) |
|          | Daughter | 3 (4.29) |
|          | Daughter in law | 7 (10) |
|          | Mother | 1 (1.43) |
|          | Father | 2 (2.86) |
|          | Mother in law | 2 (2.86) |
|          | Sister in law | 1 (1.43) |
|          | Brother | 1 (1.43) |
| Distance from nearby hospital (km) | <1 | 5 (7.14) |
|          | 1-10 | 24 (34.29) |
|          | >10 | 41 (58.57) |
| Kuppuswami scale | Upper (I) | 5 (7.14) |
|          | Upper middle (II) | 40 (57.14) |
|          | Middle/lower middle (III) | 20 (28.57) |
|          | Lower/upper lower (IV) | 4 (5.71) |
|          | Lower (V) | 1 (1.43) |
| Physiotherapy at home or not | Yes | 20 (28.57) |
|          | No | 50 (71.43) |
| Caregiver strain index | Low level of stress | 30 (41.10) |
|          | High level of stress | 43 (58.90) |
| Caregiver burden scale Zarit | Little or no burden | 20 (28.57) |
|          | Mild to moderate burden | 37 (52.86) |
|          | Moderate to severe burden | 11 (15.71) |
|          | Severe burden | 2 (2.86) |
| PHQ9 depression scale | Minimal depression | 39 (55.71) |
|          | Mild depression | 17 (24.29) |
|          | Moderate depression | 9 (12.86) |
|          | Moderately severe depression | 4 (5.71) |
| GAD7 anxiety scale | Severe depression | 1 (1.43) |
|          | Minimal anxiety | 40 (54.79) |
|          | Mild anxiety | 21 (28.77) |
|          | Moderate anxiety | 8 (10.96) |
|          | Severe anxiety | 4 (5.48) |

SD=Standard deviation, PHQ9=Patient Health Questionnaire-9, GAD7=Generalized anxiety disorder-7, IQR=Interquartile range

Table 1: Patient profile

| Variable                        | Category            | Frequency (%) |
|---------------------------------|---------------------|---------------|
| Gender                          | Male                | 51 (72.86)    |
|                                 | Female              | 19 (27.14)    |
| Duration from stroke (month)    | <1                  | 10 (14.29)    |
|                                 | 1-6                 | 23 (32.86)    |
|                                 | >6                  | 37 (52.86)    |
| Type of stroke                  | Infarct             | 60 (85.71)    |
|                                 | Bleed               | 10 (14.29)    |
| Modified rankin scale           | Slight disability   | 25 (35.71)    |
|                                 | Moderate disability | 25 (35.71)    |
|                                 | Moderately severe disability | 20 (28.57) |
| Barthel index                   | Good functionality  | 15 (21.43)    |
|                                 | Moderate disability | 39 (55.71)    |
|                                 | Severe disability   | 16 (22.86)    |

Table 2: Caregiver’s profile

| Variable                        | Category            | Frequency (%) |
|---------------------------------|---------------------|---------------|
| Patients’ age                   | 60.01 (14.81)       | 62.50 (55, 69) |
| Barthel index                   | 61.29 (22.44)       | 65 (55, 75)   |
| Modified rankin scale           | 2.99 (0.91)         | 3 (2, 4)      |

Contd...
The average age of the caregivers in this study was about 13 years younger than the patient, with immediate family members contributing as the primary caregivers in most cases. With more than half of the caregivers being female, and 55.7% of them being home makers, it comes as no surprise that a higher caregiver burden was seen among this demographic. As part of a typical Indian family setting, the men are generally the breadwinners, whereas the women tend to the homes. Having a male stroke patient in the house shifts the financial burden to the female members while also increasing their household duties of providing care to the patient. A study conducted by Bhattacharjee et al., identified similar factors of a younger age, female gender and longer caregiving hours as contributing to a higher caregiver burden. In contrast, a study that evaluated elderly patients and their care givers reported an increased burden with 40% of caregivers scoring moderate-to-high on the ZARIT burden scale with a mean ZARIT burden of 34.92 compared to 28.26 in this study. Their mean patient and caregiver ages were 73.9 years and 56 years, respectively, markedly higher than the study population. However, we did see a weak-positive correlation in this study between care giver’s burden and an increase in patient’s age, increased disability, and longer caregiving hours, especially among female caregivers and male patients.

In this study, we determined that the level of the caregiver’s education correlated with a reduced level of caregiver burden as it provided them a better understanding of the disease and its treatment course. It allowed them to better acclimatize themselves to the expectations of a caregiver’s role and played a significant role in decreasing their perceived burden (P < 0.05). More commonly in the Indian society, a lack of education often creates moments of disbelief and misunderstanding among caregivers and family members resulting in greater difficulty in understanding medical conditions and their course of management as well as higher levels of anxiety and strain, especially in chronic conditions such as stroke. In the case of stroke patients, it was observed that as the duration of time increased from the initial stroke event, the caregiver’s burden decreased supported by the fact that as time passed, not only did the disability decrease, but

The predictive value of the regression model was satisfactory (R² = 0.36)
76% employed men, many were affected financially and had to quit their jobs or take time off from work due to increasing hours of caregiving and coping with frequent follow-up appointments.[14] This is in contrast to a study conducted in Mumbai,[1] where education and employment status of the caregiver was not associated with higher stress, but the duration of care, financial stress, and anxiety were key factors leading to severe stress levels. Specific financially targeted interventions would greatly alleviate such scenarios where caregivers have to choose between financial stability and providing care to their family members.

Patients hailing from joint family systems in this study had a stronger support network with several family members helping with the caregiving, thus allowing primary caregivers to continue their occupational responsibilities. Those belonging to nuclear families had very limited resources and had to quit their jobs to meet the caregiving demands, thereby facing the greatest caregiver burden. Type of family and severity of the patient’s sequelae affected the caregiver’s burden due to shift in household responsibilities. The Indian cultural practice of living in an extended family system could prove to be beneficial compared to the nuclear family system commonly seen in the western world, as every member of the family plays a crucial role in providing physical care, managing finances, organizing medical care and appointments, assisting in household chores and maintaining an overall stable, healthy family environment.[15,16] Patients who suffered from severe disability required longer care hours leading to higher anxiety levels in the caregiver, even while they were away from the patient at work. A study from the Netherlands found spouses/partners of stroke patients to perceive maximum caregiver burden due to their involvement in care, but more specifically due to their feelings of heavy responsibility, uncertainty about patient’s care needs, constant worries, restraints of social life, and the patient’s feeling of dependence on them for care.[17] In contrast to western studies, social functioning was higher among Asian caregivers as they reported inconsequential suffering to their social lives. This may be explained by the vast difference in cultural norms and the subjective definition of “social life” between the two cultures.[17]

We also obtained a significant correlation between anxiety and depression among caregivers along with a strong correlation between the caregiver strain index and depression scale with caregiver burden (r = 0.72). Depression and anxiety were strongly correlated with 46% of our caregivers demonstrating mild anxiety and 45% of our caregivers demonstrating mild depression. In contrast, western studies reported depression and anxiety in over half of their caregivers. A study in Perth demonstrated anxiety in 58% and depression in 50% of the caregivers explained by their fear for leaving their patient unattended for all or part of the day.[18] The Atlanta’s data revealed increased the severity of depression and anxiety levels in caregivers with caregiver depression becoming the most important independent determinant of caregiver burden after 1 year.[19] The mild anxiety and depression, along with moderate correlation between anxiety and caregiver burden (0.66), anxiety and caregiver strain index (0.60), and depression and caregiver strain index (0.56) can be explained by the Indian societal setting and the joint family system which is the best source of social support to a family unit. The positive reinforcement along with strong religious beliefs improves the level of anxiety and depression as seen in this study population.

No association was seen between caregiver burden and location of the nearest hospital and availability of physical therapy. As we are a rural-based tertiary care hospital, these parameters were intentionally studied as our patients tend to travel from small villages where transport facilities are poor and physical therapy is not readily available. Thus, in spite of providing institutional care and physical therapy, no significant difference was observed in caregivers’ burden indicating that even though the two are mainstream modalities, caregiver burden has other contributing variables.

The findings from this study identify the need for targeted intervention for caregivers to optimize their caregiving abilities while providing them with resources to reduce their emotional, physical and financial strain and burden. These targeted interventions may be implemented right at the level of the stroke clinic where families and patients are educated together regarding the disease and various coping strategies as they continue through with the course of treatment. Hospitals and health-care centers should improve their ability in access and provision of rehabilitation care to all patients and their families regardless of socioeconomic status or residential location. Financial burden faced by low-income families should be referred to NGOs or government aid schemes to assist in medical care.

This study, however, is limited by its single time assessment of burden. Serial follow-ups at regular intervals would provide better insight and assessment of caregiver burden and strain. In addition, this study focused on outpatient department patients and their caregivers and may have missed many patients who are restricted to homecare only or patients with limited mobility who may not have attended the clinic. Finally, due to the numerous variables and scales used for both patients and their caregivers, a detailed evaluation of the individual questions among each scale was not done.

**Conclusions**

With the consequence of physical and emotional disabilities, financial constraints, need for chronic care, and the prevalence among an aging demographic, stroke significantly impacts a family’s day-to-day life. Further studies with strategies and interventions to reduce caregiver burden to develop structured and targeted caregiver interventions to alleviate their strain are the need of the hour.

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**Conflicts of interest**

There are no conflicts of interest.
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