Original Research Article

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Assessment of stress among caregivers of the stroke survivors: community based study

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ABSTRACT

Background: Stroke is the third most common cause of death. It disables individuals and places considerable burden not only on the individual and his family but also on the community as a whole. Caring for stroke patients often places considerable strain on caregivers, given that they have to take up multiple responsibilities. The study objective was to assess caregiver stress and to identify the factors such as emotional, financial and socio demographic factors.

Methods: The study adopted a cross sectional design. A total of 150 participants were chosen on the basis of being directly involved in patient care and consenting to participate in the study 1. Caregivers of all incident cases of stroke who survived beyond 28 days were included. The severity of strain was rated using the Caregiver Strain Index (CSI).

Results: The mean (SD) age of caregivers was 45.19 (4) years. Among the caregivers 130 (87%) of them were females and 20(13%) were males. The analysis of CSI showed that the mean (SD) score was 11.3 (0.93). All the CGs responded that financial difficulties, physical strain, family and emotional adjustments and sleep disturbance were found to have contributed to their stress.

Conclusions: In this study, it is found that there is an increase in strain on the caregivers of stroke survivors which impacted the personal life as well as the quality of care offered by them.

Keywords: Caregiver strain, Caregiver burden, Factors, Stroke survivors

INTRODUCTION

Stroke is a disabling chronic disease witnessing an increasing incidence. The Global Burden of Disease study (1997) reported 9.4 million deaths in India, of which 6,19,000 were from stroke. The Disability Adjusted Life Years (DALYs)lost to stroke were reported to be 28.5 million.¹

Unlike other non-communicable diseases, the onset of stroke is sudden, leaving the individual and his family unprepared and unequipped to deal with its consequences. Informal caregivers such as family members provide the majority of long-term care to stroke survivors in a domiciliary setting and these caregivers (CGs) play an important role in the post stroke rehabilitation of the stroke survivors which is often a neglected domain.

Stroke has shown to significantly affect the psychological and physical well-being of caregivers who provide emotional support or assist the patients' daily activities.² The burgeoning incidence of stroke and caregivers' adjustments have important implications on quality of life experienced by the patients. Thus, there exists a need to focus attention on the burden faced by the caregiver and to understand the factors affecting caregiver's strain which in due course leads to isolation and exhaustion.^{3,4}

Current literature focussing on caregiver stress has been far and few between . The objective of the present study was to assess stress and the factors responsible for caregivers strain.

METHODS

In this cross sectional study, the participants were recruited from the incident cases of stroke that were identified from the study titled "Establishment of Population based rural stroke registry in India" carried out in Chintamani Taluk of Chikkaballapura district in the state of Karnataka(ICMR supported project) by the Department of Community Medicine.

A minimum sample size of 140 was calculated with the absolute precision of 8% with desired confidence level of 95% with 10% non response rate. The study was carried out from March to November 2014.

The sample for the present study consisted of all the caregivers of the stroke survivors who survived beyond 28 days. A close rapport was established and the purpose of the study was explained to the caregivers at their residence and an informed consent was taken from all the CGs. In order to reduce the recall bias for the CG, the time gap from 28^{th} day of stroke to the interview of CGs was around 15 days.

Inclusion criteria

Incident stroke cases with single caregiver.

Exclusion criteria

Hired caregiver or with more than one CGs.

Data collection tool

The questionnaire consisted of 3 parts: A pre-tested semistructured questionnaire comprised of basic sociodemographic details (age, gender, relationship with the patient, educational qualifications, occupation of the CGs). The second part of the questionnaire comprised of information on training given by the treating doctor about the disease, its management, care aspect as well as basic physiotherapy exercises, and the activities performed by the CG. Another section was on Care giver strain Index (CSI). ⁵ The CSI tool showed a good internal consistency and reliability (Cronbachs alpha = 0.86) .CSI has a set of 13 questions which measures the strain related to provision of care. This tool includes at least one item for each of the following major domains such as employment, financial, physical, social, and time. For each question the scoring was either "Yes = 1" or "No = 0" and the scores were added based on the response given by the CGs. After that, total score was calculated and a score \geq 7 indicated a high level of stress.

Caregiver strain can be perceived differently depending on the stroke survivors' ability to perform their daily activities. This ability was evaluated using Barthel Index. They were categorised based on the score as totally dependent (0-20), severely dependent (25-55), moderately dependent (60-90) and independent (95-100). Caregiver strain was correlated depending on the severity of disease of the stroke survivor by Modified Rankin scale where it is scored from 0-6, ranging from perfect health without symptoms to death.

Operational definition

A caregiver (CG) is defined as a person who lives with the patient and is most closely involved in taking care of him/her at home.¹

Moderate disability (grading score 3 - 4) was defined as the patient not able to move without support.

Severe disability (grading score 5) was defined as any patient being bedridden, not being able to feed himself.

Statistical analysis

All the quantitative variables such as age, CSI score, were expressed as mean with SD. To test for differences in the mean CSI score between different factors such as type of family, gender, etc., student t test was employed.

Categorical variables were presented with percentages. The CSI score was analysed and evaluated according to various factors such as gender, marital status and the age of the caregivers.

The data was analysed using SPSS version 18 and P <0.05 was considered for statistical significance.

RESULTS

In the present study 150 caregivers were interviewed, among them 130 (86.3%) were females and 20 (13.3%) were males. The mean age (SD) of the caregivers was found to be 45.19 (3.6) of which the mean age of males and females was found to be 40.10 (7.02) and 45.98 (14.14). Most of the caregivers were found to be not literate (61%) and mostly belonged to Hindu religion (85%). The female caregivers were either wives (51%), daughters in law (21%) or daughters (10%) of the stroke survivors. The male caregivers were related to the stroke survivors as were sons (9%), sons in law or brothers (Table 1).

The CGs have to balance a dual responsibility of looking after a stroke survivor while making adjustments in his/her life. In this study, CGs performed various activities in their daily life (Table 2).

In this study it was noted that majority of the CGs (55%) were satisfied with the explanation given by the doctors

about the disease and its management. Most of the CGs (93%) did not receive any training on the care aspect and basic physiotherapy exercises. The analysis of the mean (SD) CSI score according to those who received and did not receive training was found to be 11.44 ± 0.92 and 11.19 ± 0.99 respectively. However, this difference was not found to be statistically significant (P=0.245).

Table 1: Characteristics of the caregivers of the stroke survivors.

Characteristics	N= 150 n (%)	
Gender		
Male	20 (13.3)	
Female	130 (86.6)	
Age in years - mean(SD); (%)	45.19 (3.6); (43.6)	
Type of family		
Nuclear family	71 (47.3)	
Non-nuclear family	79 (52.7)	
Caregiver – relation to the patient		
Wife	77 (51.3)	
Daughter	15 (10)	
Son	13 (9)	
Husband	2 (1.5)	
Daughter in law	31 (20.7)	
Son in law	2 (1.3)	
Brother	3 (2)	
Mother	5 (3.3)	
sister	2 (1.3)	
Literacy status of CG		
Graduate	3 (2)	
Diploma	6 (4)	
High school	26 (17)	
Middle school	13 (9)	
Primary school	10 (8)	
Not literate	92 (61)	

Among the CGs, 86.7% females and 13.3% males had CSI scores between 9 to 13 range. The overall mean CSI score was 11.3±0.93 (mean±SD). The mean CSI score of nuclear family was 11.38±1.48 as compared to 11.24± 0.93 in non nuclear family, and this difference in mean was not statistically significant (P=0.407). CGs perceptions of difficulty in providing care for stroke survivors are presented in Table 3. In addition to those, all the CGs had stress in areas such as disturbed sleep, family adjustments, physical strain and emotional adjustments. On analysis of caregivers stress with dependent stroke survivors by administration of Barthel Index, it was found that among the totally dependent stroke survivors the mean (SD) of CSI score was 11.59 (0.86) as compared to 11.09 (0.97) among the severely dependent survivors and 11.30 (1.01) among the moderately dependent survivors. However, this difference in the mean CSI score was not found to be statistically significant (P=0.063).

Table 2: Activities performed by the caregiver

Activities	N= 150
Care of the siblings of patient /	n (%)
Yes	104 (69.3)
No	46 (30.7)
Collecting medication	40 (30.7)
Yes	119 (79.3)
No	31 (20.7)
Household purchases	31 (20.7)
Yes	142 (94.7)
No	8 (5.3)
Monitoring of the patient	0 (3.3)
Yes	135 (90)
No	15 (10)
Domestic work related to patien	` '
Yes	127 (94.7)
No	23 (15.3)
Cooking special diet for the pat	
Yes	122 (81.3
No.	28 (18.7)
Accompanying patient to docto	
Yes	121 (80.7)
No	29 (19.3)
Administration of medicines	29 (19.3)
Yes	00 (65.2)
No	98 (65.3)
- ' *	52 (34.7)
For lab investigations(blood/ur Yes	
No	6 (4) 144 (96)
	144 (90)
Blood pressure check up Yes	6 (1)
No	6 (4) 144 (96)
Feeding	144 (90)
Yes	00 (65.2)
	98 (65.3)
No Personal hygiene	52 (34.7)
* 0	110 (70.2)
Yes	119 (79.3) 31 (20.7)
Yes No	31 (20.7)
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Yes No Changing clothes for the patient Yes No Changing of Ryles tube / Foley Yes No Bathing the patient Yes No Helping the patient with taking	31 (20.7) at 116 (77.3) 34 (22.7) as catheter 29 (19.5) 121 (80.7) 116 (77.3) 34 (22.7) athe patient to toilet 100 (66.7)
Yes No Changing clothes for the patient Yes No Changing of Ryles tube / Foley Yes No Bathing the patient Yes No Helping the patient with taking Yes No	31 (20.7) at 116 (77.3) 34 (22.7) as catheter 29 (19.5) 121 (80.7) 116 (77.3) 34 (22.7) at the patient to toilet 100 (66.7) 50 (33.3)
Yes No Changing clothes for the patient Yes No Changing of Ryles tube / Foley Yes No Bathing the patient Yes No Helping the patient with taking Yes No Wound cleaning /dressing for the	31 (20.7) at 116 (77.3) 34 (22.7) as catheter 29 (19.5) 121 (80.7) 116 (77.3) 34 (22.7) at the patient to toilet 100 (66.7) 50 (33.3) he patient
Yes No Changing clothes for the patient Yes No Changing of Ryles tube / Foley Yes No Bathing the patient Yes No Helping the patient with taking Yes No	31 (20.7) at 116 (77.3) 34 (22.7) as catheter 29 (19.5) 121 (80.7) 116 (77.3) 34 (22.7) at the patient to toilet 100 (66.7) 50 (33.3)

On employing the Modified Rankin Scale on the stroke survivors, it was found that the mean (SD) CSI score was 11.44 (1.05) among the severely disabled survivors when compared to 11.26 (0.88) among the moderately disabled survivors and 11.22 (1.02) among the mild disabled survivors. However, this difference was not also found to be statistically significant (P=0.267).

All the CGs in the present study was under stress and as such no further analysis could be attempted to identify the factors associated with stress.

Table 3: Caregivers perception of difficulty in providing care for stroke survivors.

Areas of difficulty	N=150 n (%)	
Are you feeling inconvenient?		
Yes	133 (88.7)	
No	17 (11)	
Are you feeling confined?		
Yes	76 (50.7)	
No	74 (49.3)	
Is there any change in personal plans?		
Yes	143 (95.3)	
No	7 (4.7)	
Are there other demands from the other family		
members?	•	
Yes	119 (79.3)	
No	31 (20.7)	
Are you facing any financial strains?		
Yes	135 (90)	
No	15 (10)	
Are you completely overwhelmed?		
Yes	96 (64)	
No	54 (36)	
Are you upset because of the patients' behaviour?		
Yes	133 (88.7)	
No	17 (11.3)	

DISCUSSION

In a developing country like India, changes in life style, rapid urbanization and an aging population has contributed significantly to the rise of non-communicable diseases especially stroke. It is found that most of the stroke survivors stay at home and take domiciliary care, which in reality is a burden on CGs. Stroke, may also compromise cognition, mood, functional abilities and quality-of-life of the survivor. It also results in caregiver burden and economic stress at individual, familial and national levels.⁸

There are limited employment opportunities for stroke survivors especially those who are aged or sole bread winners in the family. Financial difficulties arise due their long absenteeism, disability and the continued out of pocket expenditures on medicines and physiotherapy. In a study done on care giving: an emerging risk factor for emotional and physical pathology, it was found that the financial worries more common among slum dwellers and less educated CGs, probably due to their limited financial capability.⁹

In our study the caregivers predominantly (66%) belonged to poor socio-economics status. The B.G Prasad classification was used as the study done was centred on rural areas of Chintamani Taluk. More than half of the caregivers (61%) were not literate. There is paucity of data in India about the implication of socioeconomic factors on the caregivers. ¹⁰

A study done on caregiver stress in stroke survivor in a tertiary hospital in Pakistan found that stroke creates a situation where the whole family gets involved. This is due to joint family system in Pakistan, where parents, spouse and children and other in laws live together under one roof. This may lead to the neglect of the needs of the other family members. In the current study, the mean CSI score among the nuclear family was 11.38±1.48 when compared to 11.24±0.93 among the non nuclear family. However, this difference was not found to be statistically significant (P=0.407).

It was found in a study done on family caregivers of people with dementia that caregivers face many obstacles as they must balance care-giving with other demands, including child rearing, career and social relationships. They were at increased burden, stress, depression, and a variety of other health complications. The effects on caregivers are diverse and complex, with many factors exacerbating or ameliorating how caregivers react and feel as a result of their role. ¹²

In a study done on factors affecting burden on caregivers of stroke in a population based study done in Mumbai, found that majority of the caregivers were females and the determinants of stress among caregivers were most of the females being daughters-in-law, long care giving hours (P<0.001), disturbed sleep (P<0.001) and financial stress (P<0.001).

The needs of a stroke survivor ,which varies according to the level of disability, may be assistance in walking, moving from bed to toilet, communication (verbal and nonverbal cues to other family members), nursing (feeding, personal hygiene), emotional support (handling disruptive behaviour) along with an overwhelming financial demands. ¹

A study done on the burden of care giving in partners of long term Stroke Survivors in Netherlands found that the caregivers of the stroke survivors felt the burden in terms of heavy responsibility, uncertainty of the patients' care needs, restraints in social life and the feeling that patients entirely relies on their care. On multiple regression analysis it was revealed that the high level of burden was partly due to patients' disability ($R^2 = 14\%$) and emotional

distress $(R^2 = 16\%)$. In our study, the results of the above mentioned factors are expressed in Table 2.

The indirect victims of stroke are the caregivers who often take on the role under sudden and extreme circumstances, with minimal preparation, inadequate guidance and scant support from healthcare systems. ¹³

Given the heavy burden of stroke in our country, there is a dire need to bring about an organized predischarge training of the CGs. The domains of their training should include assisting stroke survivors in activities of daily living (moving, handling, transferring patient from bed to chair, chair to toilet), provision of nursing care(feeding) and communication (verbal and nonverbal). Such training will serve a twofold purpose by reducing the anxiety, stress in CGs while also improving the nature of care and the quality of life of stroke survivors. ¹

A qualitative study of caregivers of stroke survivors, found that caregiver stress begins soon after the initiation of care giving and lasts for more than a year after the stroke. In addition, they found caregivers to report psychological distress two and a half times more than non-caregivers ².

Recent research has linked mental and emotional strain in CGs to poor outcomes for stroke survivors. Caregivers who subjectively reported a high amount of strain also reported poorer physical functioning, fewer social contacts, and more emotional distress than other caregivers. ¹⁴

CONCLUSION

The finding of the study revealed an increased strain on the caregivers of stroke survivors. This influenced both the personal life of caregivers and quality of care experienced by the stroke survivors. One of the limitations was lack of follow up of the caregivers on account of time constraint. The present study revealed a pressing need for integrated stroke rehabilitation services inorder to address the issues of CGs suited to the local situations. Early initiation of rehabilitation services at home will help stroke survivors carry out their daily activities and perhaps even their previous occupation. This measure can potentially reduce the strain on the caregivers. This in turn will have a positive impact on the quality of care for persons with stroke. Simple training in nursing skills as well as counselling sessions for the CGs could reduce the burden faced by them.

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Institutional Ethics Committee

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