

## Strain among the Family Caregivers of Patients with Stroke

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### Abstract

Family caregivers are critical partners in the plan and provision of care for patients with various acute and chronic illnesses. Due to the sudden onset and unpredictable outcome of stroke, the caregivers are usually unprepared to deal with its associated problems. The present study aimed to assess the strain among the caregivers of stroke survivors. A total of 53 primary caregivers of the patients with stroke were conveniently selected. Only one member per family was interviewed and their strain of caring for the patients was evaluated by using Modified Caregiver Strain Index. Katz index was used to assess the functional status of the patients. The mean age of patients was  $54.94 \pm 16.94$  with the range of 13-80 years. Most of the patients were male (77.4%). 90.6% of the patients were fully dependent and only 9.5% were partially dependent. 43.4% of the caregivers were son of the patients and nearly half of them (49.1%) were between 21-40 years of age. Majority of the caregivers (73.5%) experienced severe strain of care. More the dependency level of the patients, higher was the level of strain amongst the caregivers.

**Keywords:** Primary caregivers; Strain; Stroke patients

### Introduction

Stroke being a devastating and physically debilitating disease may affect the routine activities, disrupt life, and decrease overall quality of life of survivors and their families as well. Majority of the stroke survivors have to live with various impairments of varying severity throughout their life making them partially or fully dependent on their caregivers. Family caregivers are critical partners in the plan and provision of care for the patients. 25-74% of stroke survivors require help with activities of daily living from informal care givers, often the family members [1,2]. Majority of the time the first degree relatives are directly involved in the care of patients [3]. Providing care to someone is an enormous task both physically and emotionally. The caregivers are usually inadequately trained, poorly informed, and dissatisfied with the extent of support available after discharge [4,5]. So, they are subject to be burdened of an existential nature which may result in weakened mental and physical functioning on their part. The strain has been reported in 46% and 43% of the caregivers at the 3<sup>rd</sup> and 6<sup>th</sup> month post stroke respectively. Various predictors of strain amongst the caregivers were patients with severe disability, poor cognition, depression, and recurrent stroke [6].

The current study was carried out to assess the strain among the primary caregivers of the patients admitted in acute care setting of a tertiary care hospital.

### Material and Methods

#### Study setting

This cross sectional study was carried out at the Emergency Medicine Department of a Post Graduate Institute of Medical Education and Research, Chandigarh, India. On an average 70-80 patients with various medical problems get admitted in emergency medical Out Patient Department, though there are number of patients who are just kept for observation, requiring no further management and then discharged from there only.

#### Participants and selection criteria

The study population comprised of only first degree relatives of patients with stroke who were admitted in emergency for at least last 24 h. Fifty three caregivers were conveniently selected depending on

their accessibility and proximity to recruit in the study. Around 10-12 caregivers of patients were interviewed daily.

#### Study instruments

Identification data sheet for patients and for their caregivers consisted of information like age, gender, habitat, and educational status etc. The information was also obtained regarding duration of hospital stay, dependency level, total number of earning persons, and per capita income etc.

#### Katz Index of activities of daily living [7]

It was used to assess the dependence level of the patient. It measures the performance of the patients in performing the activities such as eating, incontinence, bathing, dressing, toileting, and transferring. The maximum score is 6 for patients completely independent and minimum score is 0 for patients completely dependent. The tool is valid. Internal consistency has been reported to be 0.94 [8]

#### Modified Caregiver Strain Index [9]

The Modified Caregiver Strain Index (MCSI) is a tool that can be used to quickly screen the caregiver strain. It is a 13 item tool that measures strain related to care provision. Scoring is 2 points for each 'yes', 1 point for each 'sometimes', and 0 for each 'no' response. The higher the score, the higher the level of caregiver strain. The maximum attainable score is 26. The subjects were further categorized as having low, moderate and high strain as per their MCSI scores i.e.  $\leq 9$ , 10-18 and 19-26 respectively. The tool is valid. The reliability has been mentioned to be as  $\alpha=0.86$ .

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### Statistical analysis

The data was analyzed by using descriptive statistics.

### Results

The mean age (yrs) ± SD of the patients was 54.94 ± 16.94. 77.4% were male and 28.3% of the patients were illiterate. More than half (57%) of the patients had 1-5 number of family members in their homes. Around half each had one and two earning family members (Table 1).

Table 2 depicts the demographic details of the caregivers. 43.4% of the first degree relatives were son. Nearly half (49.1%) of the caregivers were in the age range of 21-40 years. 30.2% of them were educated upto high school. Most of the caregivers (73.6%) used to stay for 19-24 hrs with the patient.

Personal characteristics	f (%)
<b>Age (years)</b>	
<20	03(5.7)
21- 40	09(17.0)
41-60	20(37.7)
>60	21(39.6)
Mean ± SD= 54.94±16.94	
Range =18-80 yrs	
<b>Sex</b>	
Male	41(77.4)
Female	12(22.6)
<b>No. of family members</b>	
1-5	30(56.6)
6-10	22(41.5)
>11	01(1.9)
Mean ± SD = 6.06±2.31	
Range = 2-13	
<b>No. of earning members</b>	
1	26(49.1)
2	25(47.2)
>3	02(3.8)
Mean ± SD =1.55±0.574	
Range = 1-3	
<b>Educational status</b>	
Illiterate	15(28.3)
Primary	14(26.4)
Middle school	11(20.8)
High School	10(18.9)
Graduate and above	03(5.7)

Table 1: Information profile of the patients (N=53)

Variables	f (%)
<b>First degree caregiver</b>	
Mother	02(3.8)
Father	02(3.8)
Spouse	09(17.0)
Brother	07(13.2)
Sister	02(3.8)
Son	23(43.4)
Daughter	08(15.1)
Mean ± SD= 38.34±12.79	
Range = 18-79	
<b>Age(years)</b>	
< 20	05(9.4)
21- 40	26(49.1)
>40	22(41.5)
<b>Educational status</b>	
Illiterate	03(5.7)
Primary	09(17.0)
Middle school	11(20.8)
High School	16(30.2)
Graduate and above	14(26.4)
<b>Monthly Income (per capita in Rs.)</b>	
<1600	01(1.9)
1600-5000	03(5.7)
5000-10,000	04(7.5)
10,000-15,000	10(18.9)
15,000-30,000	12(22.6)
>30,000	06(11.3)
Not earning	17(32.1)
<b>Duration of stay with pts (hrs)</b>	
13-18	39(26.4)
19-24	14(73.6)

Table 2: Socio demographic profile of the caregivers (N=53)

As per overall score of the Katz index, majority of the patients (90.6%) were fully dependent and only 9.5% of them were partially dependant. Domain wise, maximum dependence was in bathing followed by dressing and toileting (Table 3).

Table 4 illustrates that majority of the caregivers (92.5%) always had disturbed sleep. 88.7% and 49.1% said that they always felt inconvenience and physical strain respectively. Around one third (37.7%) always had to do family adjustment. 49.1% of the caregivers verbalized that they always had to make changes in their personal plans to provide care to their patients. Around half (58.5%) always had upsetting behaviour. 56.6% always felt upsetting because the person they care has been changed so much from his/her former self. 67.9% of the caregivers were always burdened due to work adjustment. 60.4% of the caregivers were always considering caring as financial strain.

As per the CSI score, the subjects were categorized as having mild, moderate and severe level of strain with the score as <9, 10-18 and 19-26 respectively. Majority of the caregivers (73.5%) had severe strain of care and around one fourth (26.5%) were found to be having moderate level of strain. None of the subjects was in mild category of strain level (Table 5).

### Functional level of patient vs. strain on caregivers of stroke patients

Figure 1 depicts the relationship of the care giver strain and the dependency level of the patients. Although there was no statistically significant relationship between them but severe strain was experienced

Activities	Independent f (%)	Dependent f (%)
Feeding	4(7.5)	49(92.5)
Continenence	4(7.5)	49(92.5)
Transferring	4(7.5)	49(92.5)
Bathing	0(0)	53(100)
Toileting	3(5.7)	50(94.3)
Dressing	2(3.8)	51(96.2)
<b>Overall Functional status</b>		
Fully dependent (0 score)	48 (90.6%)	
Partially dependent (1-5 score)	5 (09.5%)	
Independent (6 score)	0%	

Table 3: Functional level of the patients as per Katz Index (N=53).

Items	Always	Sometimes	Never
	(2)	(1)	(0)
My sleep is disturbed	49(92.5)	4(7.5)	-
Care giving is inconvenient	47(88.7)	6(11.3)	-
Care giving is a physical strain	26(49.1)	27(50.9)	-
Care giving is confining	23(43.4)	29(54.7)	01(1.9)
There have been family adjustments	20(37.7)	31(58.5)	02(3.8)
There have been changes in personal plans	26(49.1)	22(41.5)	05(9.4)
There have been other demands on my time	23(43.4)	23(43.4)	07(13.2)
There have been emotional adjustments	27(50.9)	20(37.7)	06(11.3)
Some behaviour is upsetting	31(58.5)	18(34.0)	04(7.5)
It is upsetting to find the person I care has been change so much from his/her former self	30(56.6)	15(28.3)	08(15.1)
There have been work adjustment	36(67.9)	16(30.2)	01(1.9)
Care giving is financial strain.	32(60.4)	17(32.1)	04(7.5)
I feel completely overwhelmed	41(77.4)	12(22.6)	-

Table 4: Strain amongst the caregivers as per Modified Caregiver Strain Index (N=53).

Strain	f (%)
Mild	0
Moderate	14(26.5)
Severe	39(73.5)

Table 5: Severity of stress among the caregivers (N=53).

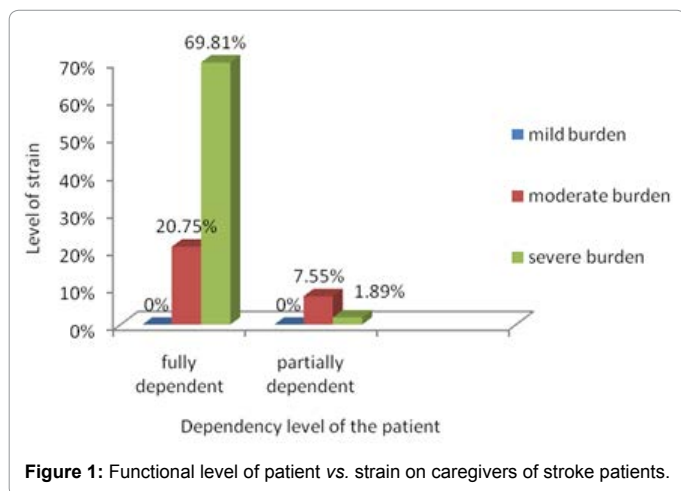


Figure 1: Functional level of patient vs. strain on caregivers of stroke patients.

by the patients while caring for the patients who were fully dependent on them.

## Discussion and Conclusion

Family caregivers play an important role in patient's health care team. They frequently perform many tasks associated with activities of daily living in the hospital as well as home care settings. These care giving activities may produce stress and strain on the caregivers. In the present study, the strain was assessed amongst the primary caregivers of the stroke patients admitted in emergency a tertiary care hospital. The patient's primary caregiver was defined as a close blood relative which includes the individual's parents or their children who are with the patients for most of the time and provide majority of the care to the patients in the hospital as well as home care settings. The burden falls most heavily on spouses, parents, adult children however secondary kins are less affected [10]. In one of the studies on home based caregivers of bedridden patients, 54% of the key caregivers were blood relations of the patients, out of them 29% were children of the patient [11]. The present study was specifically carried out on the first degree relatives of the patients wherein maximum number of first degree caregivers children (35.9%) followed by siblings (32.4%). In Indian settings, majority of the time it is the first degree relatives who primarily take care for the patients in case of crisis.

Many studies have recognized that family caregiving although has positive aspects for caregiver is often stressful as well [12,13]. They usually face many problems including physical, social, emotional, psychological and financial. In the current study, majority of the caregivers (73.5%) had severe strain of care and around one fourth (26.5%) were found to be having moderate level of strain. None of the subjects was in mild category of strain level. The findings are partially supported by Kumar et al. who also reported mild to moderate burden of care (63%) among caregivers of stroke survivors [14]. Stress and strain related to caregiving amongst the caregivers of the patients may vary depending upon the nature of illness, the experience of caregiving and setting of care. The current study was carried out in emergency settings of a tertiary hospital. It is obvious that the patient is more

sick in emergency and the caregivers are also less prepared to care for the patients. That could be the reason for more strain amongst the caregivers in the present study as compared to the study by Kumar et al. [14]

Several studies have investigated that caregivers of the patients felt a heightened level of role strain, decreased quality of life and imbalance in personal and professional life [15,16]. As per the findings of the present study, a relatively high level of strain was reported in terms of physical strain, financial strain, sleep disturbances, emotional adjustments, work adjustments, social strain etc. All these factors are basically the major contributors to caregiver stress. Similar findings were revealed in other study on factors affecting caregiver burden of patient with stroke which found that disturbed night sleep was amongst the primary stress factors along with long caregiving hours, anxiety, and physical strain [17]. Findings were also partially supported by Lang et al. who reported that 56% of caregivers experience a major change in lifestyle and 38% experience a major change with respect to their work [18].

The stress and strain amongst the caregivers definitely affect their lives directly or indirectly. Efforts are required in the acute care settings to reduce this potential complication in order to improve the quality of life of the patients and the caregivers as well.

## Ethics

The study protocol was approved by the Ethics Committee of National Institute of Nursing Education. Written informed consent was obtained from each participant. They were informed of the purpose of the study and were ensured regarding the confidentiality of information obtained.

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