Female Caregivers and Stroke Severity Determines Caregiver Stress in Stroke Patients

Bindu Menon, P. Salini¹, K. Habeeba, Jyoti Conjeevaram², K. Munisusmitha²

Departments of Neurology and ¹Physiotherapy, Apollo Speciality Hospitals, ²Department of Community Medicine, Narayana Medical College, Nellore, Andhra Pradesh, India

Abstract

Background: Stroke is among the major causes of short- and long-term disability. This study aimed to understand the caregivers (CGs) stress in stroke survivors. **Materials and Methods:** A 22-item questionnaire was administered to 201 CGs of stroke survivors. The variables tested were physical and mental health, social support, financial, and personal problems. CGs were divided into Group A (Barthel index [BI] <75) and B (BI >75) according to patient's BI, according to gender (male and female CG) and relation; spouses (wife, husband), daughters, sons, daughter-in-law, grandchildren, and rest (father, mother, brother, sister, and in-laws). Data were analyzed using SPSS software version–21. Data were analyzed to determine which variables of the patient effects the CG stress. **Results:** Majority of the CGs (74.62%) were females. 65% of CGs graded their burden as moderate to severe. 81% of CGs had left their work for caregiving. More than half of the CGs felt sleep disturbance and physical strain. Psychological instability and financial burdens were reported in 3/4th of CGs. Group A CGs faced more sleep, financial, health, and social life disturbance. Patient's bladder and bowel problems, shoulder pain, patients noncooperative attitude for medication administration, and physiotherapy were more upsetting for Group A CGs. Female CGs 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 CGs felt less motivated in caregiving than male CGs. Wives and daughters-in-law experienced more burden. Time spent and burden perceived was more by female CGs ($\chi^2 = 15.199$, $\chi^2 = 0.002$) than males ($\chi^2 = 11.931$, $\chi^2 = 0.018$); wives and daughters than other relations ($\chi^2 = 32.184$, $\chi^2 = 0.000$), ($\chi^2 = 35.162$, $\chi^2 = 0.019$). **Conclusion:** Our study showed that caregiving burden was predominantly shouldered by females CGs. CGs faced physical, psychological, and socioeconomic burden.

Keywords: Burden, caregiver, stroke

INTRODUCTION

Stroke remains one of the major causes of short- and long-term disability. Recent population-based studies have shown the incidence rates to be 119–145/100,000 and the adjusted prevalence rates in rural and urban areas to be 84–262/100,000 and 334–424/100,000, respectively. The disabling nature of the illness makes the patient to become emotionally and physically dependent on the caregiver (CG). The lack of support system in various countries makes the burden of caregiving to fall on the family members, a single individual in most cases. The sudden nature of the disease leaves the family unprepared to deal with consequences which include psychological and financial burden. Stroke rehabilitation involves several aspects of care in the form of speech, language, swallowing, toilet, memory, personality, and motor power. This added responsibility culminates in excessive stress

Access this article online

Quick Response Code:

Website:
www.annalsofian.org

DOI:
10.4103/aian.AIAN_203_17

on CGs leading to negative symptoms such as depression,^[2,3] anxiety,^[4] muscular fatigue, social isolation, relationship issues,^[5] and poor quality of life.^[6]

Depression in the CG affects the stroke rehabilitation outcome. [7,8] A study analyzing the health-related quality of life of stroke survivors and their CGs found that CG quality of life was inversely related to the disability of the stroke survivor. [6] CGs burden is complex and multifaceted involving physical and psychological stress, social isolation, and functional constraints. [9] This study aims to outline the sociodemographic

Address for correspondence: Dr. Bindu Menon,
Department of Neurology, Apollo Speciality Hospitals, Nellore - 524 002,
Andhra Pradesh, India.
E-mail: bneuro 5@rediffmail.com

This is an open access article distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as the author is credited and the new creations are licensed under the identical terms.

For reprints contact: reprints@medknow.com

How to cite this article: Menon B, Salini P, Habeeba K, Conjeevaram J, Munisusmitha K. Female caregivers and stroke severity determines caregiver stress in stroke patients. Ann Indian Acad Neurol 2017;20:418-24.

characteristics of CGs of stroke. We sought to find out the CG burden in the spheres of physical and mental health, social support, financial and personal problems, and to analyze the variables of the patients affecting the CGs stress.

MATERIALS AND METHODS

Research design and study population

This was a longitudinal, cohort study conducted in the neurology outpatient department (after approval from the institutional ethics committee) for 3 months. Ischemic stroke patients of 1-year duration were enrolled. CG was defined as a person who was related to the patient and not a paid employee and most involved in the patient care. Written informed consent was obtained from the CGs.

Data collection

Patient

Patients with ischemic stroke were included in the study. Transient ischemic attacks; intracerebral bleeds; comorbid disabling diseases of kidney, lung, heart, and liver; degenerative dementia; chronic severe arthritis; prostatic hypertrophy; and recurrent stroke were excluded. Demographic data, occupation, type of stroke, and functional disability by Barthel index (BI) were noted in patients. BI is a scoring method that measures patient's performance in 10 activities of daily life and is considered a reliable disability scale for stroke patients. [10,11] 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. [12]

Careaiver

CGs and patients were interviewed separately to overcome the emotional overlay. Demographic data, occupation, relationship with patient, and time spent for caregiving were noted. CGs suffering from chronic disabling illness were excluded from the study.

We used a 22-item questionnaire to study the CGs quality of life and burden which included physical, mental, financial, and psychosocial aspects. CGs were divided according to the patient's BI into Group A (BI <75) and B (BI >75). CGs were further divided according to gender and relation; spouses (wife, husband), daughters, sons, daughter-in-law, grandchildren, rest (father, mother, brother, sister, and in-laws). CGs burden was divided as none (no discomfort), mild (mild discomfort but not restricting CGs ADL), moderate (able to work with moderate discomfort), severe (having health issues but not under treatment), and extreme (having health issues and under treatment).

Statistical analysis

Data were coded and entered into a database designed for this study. Descriptive analysis was done for sociodemographic profile. The participant characteristics are presented as frequencies and percentages. Data were entered in MS-Excel and analyzed using SPSS software version 22. Proportions and

Chi-square were calculated. Comparison was done between Group A and B, male and female CGs and between different relations. P < 0.05 was considered significant.

RESULTS

A total of 243 stroke patients were enrolled. Forty-two patients were excluded; 28 were not with their CGs, 3 were unwilling to participate to leave early, and 11 did not have their previous reports. Finally, 201 patients with CGs were enrolled.

The mean age of patients was 55.67 ± 12.07 (range 18-80) years with male-to-female (M:F) ratio 1.6:1. The mean \pm standard deviation age of CGs was 42.16 ± 13.09 (range 20-80) years with M:F ratio 1:3. Majority of the CGs were females, 112 were spouses (wife - 91; husband - 21), 30 were daughters, 25 were sons, 15 were daughter-in-law, 6 were grandchildren, and rest were father, mother, brother, sister, in-laws. 107 CGs were educated and the rest were uneducated.

CGs burden was graded as none (15%) (no discomfort), mild (20%), moderate (31%), severe (13%), extreme (21%). 81% of CGs had left their productive work completely or partially for caregiving. 54% of CGs felt sleep disturbances at night during assisting stroke patients with 65% reporting physical strain, that is, muscle pains and fatigue. 79% of CGs experienced increased workload. Almost half of the CGs (47.5%) reported that they had developed physical health problems after the additional caregiving responsibility. General physical complaints were limb pains, musculoskeletal tenderness, fatigue, nausea, indigestion, breathlessness, and fainting. Mood disturbances in the form of forgetfulness, sadness, confusion, anger, and irritability during work were noted in 90% CGs. Interestingly, 81% stated that they were able to find enough time for their personal work and only 9% commented that their social life was compromised because of caregiving.

In our study, 34% CGs found it difficult to administer medication and take care of patient's personal hygiene. 69% of CGs were not upset by the patient's urinary and fecal incontinence. Shoulder pain was the most discomforting symptom (59%) followed by speech disturbance (44.5%), bowel incontinence (22%), swallowing (18%), bladder (11.5%), and physiotherapy (10%).

Seventy percent got support from family members. 77% of CGs acquired a knowledge on stroke patients after the caretaking and 52% were confident in undertaking care for stroke survivors and dealing with emergencies. 80% of CGs financial condition had worsened after the patient's stroke, even though 96% had received financial assistance for the treatment from government health schemes. The burden was predominantly related to child's education (20%), refunding loans (25.5%), or both (33%).

Even though 87% of patients extended support for physiotherapy and other personal hygiene, 47% CGs lost motivation toward caregiving. With continuous caregiving skills, 77% of CGs

improved their knowledge of stroke and 52% felt they could take care of emergency stroke management.

Between Group A (n = 59) and Group B (n = 142); Group A faced more disturbance in sleep, finances, health and social life, medication administration, physiotherapy, and patients incontinence were more upset over patient's bladder and bowel problems, shoulder pain, and patient's noncooperative nature. However, Group A CGs motivation for caregiving remained intact and they were more aware of symptoms and emergency management for stroke [Table 1].

Comparison between male and female CGs showed significant difference with females being subjected to more sleep disturbance, physical stress, feeling more upset and difficulty regarding the patient's bladder, bowel, personal hygiene needs, and physiotherapy. Sleep disturbance was in the form of difficulty falling asleep, midnight arousals, early arousals, and unrefreshing sleep. Female CGs also faced more physical and psychological health issues and felt less motivated in caregiving than male CGs [Table 2].

A subgroup analysis between relatives showed that wives and daughter-in-law experienced more difficulty in doing various chores when compared to other relations [Table 3]. Figure 1a shows the time spent by males and females for caregiving. Female CGs left work voluntarily or spent part of their productive time more when compared to male CGs for caregiving.($\chi^2 = 15.199$, P = 0.002). Wives and daughters-in-law left work voluntarily or spent part of their productive time to look after the patient ($\chi^2 = 32.184$, P = 0.000) [Figure 1b]. Females CGs felt more burdened than male CGs ($\chi^2 = 11.931$, P = 0.018) [Figure 2a]. Daughters-in-laws followed by wives felt the burden as compared to other relations ($\chi^2 = 35.162$, P = 0.019) [Figure 2b].

DISCUSSION

Our study found that 65% of CGs faced moderate-to-severe burden. Three-fourths of CGs were females, especially spouses. In India, caregiving is predominantly by females.^[12] This is attributed to the traditional culture and the social pressure because of which females are assigned more responsibility to care for elderly and disabled persons in a family.^[13]

About half of the CGs was suffering from sleep disturbance. Several patient variables contribute to CGs sleep disturbance. CGs of severe stroke and female CGs complained of insomnia. Insomnia could be initiating, middle, or late night insomnia. Multiple responsibilities and incontinence in the patients with nocturnal awakening were a major burden for the female CGs. Long-standing precipitating factors as per the Spielman's 3P Model of insomnia is initially responsible for the CGs insomnia; later the perpetuating factors may lead transient insomnia to become chronic insomnia. [14] Poor sleep habits precede insomnia and multiple awakenings for patient care are a major contributing factor. Moreover, severe stroke requires long-term rehabilitation which is probably the reason

Table 1: Comparison between caregivers of Groups A and B

Question	ВІ	Yes, n (%)	No, n (%)	Р	
Disturbance in sleep	A (59)	39 (66.1)	20 (33.9)	0.029	
•	B (142)	70 (49.3)	72 (50.7)		
Physical stress while	A (59)	44 (74.6)	15 (25.4)	0.0713	
attending to patients	B (142)	87 (61.3)	55 (38.7)		
Being upset over	A (59)	25 (42.4)	34 (57.6)	0.0226	
urinary/fecal incontinence of the patient	B (142)	37 (26)	105 (74)		
Enough time to attend to	A (59)	42 (71.2)	17 (28.8)	0.0563	
your personal work?	B (142)	118 (83)	24 (17)		
Has caregiving affected	A (59)	12 (20.3)	47 (79.7)	0.0003	
your social life & social responsibilities?	B (142)	6 (4.2)	136 (95.8)		
Has your workload	A (59)	50 (84.7)	9 (15.3)	0.1713	
increased after the stroke?	B (142)	108 (76)	34 (24)		
Difficulty in	A (59)	39 (66.1)	20 (33.9)	0.029	
Administration of medication	B (142)	70 (49.3)	72 (50.7)		
Personal hygiene needs	A (59)	44 (74.6)	15 (25.4)	0.0713	
	B (142)	87 (61.3)	55 (38.7)		
Bladder care	A (59)	25 (42.4)	34 (57.6)	0.0226	
	B (142)	37 (26)	105 (73.9)		
Bowels care	A (59)	42 (71.2)	17 (28.8)	0.0563	
	B (142)	118 (83)	24 (17)		
Physiotherapy	A (59)	12 (20.3)	47 (79.7)	0.0003	
	B (142)	6 (4.2)	136 (95.8)		
Speech disturbance	A (59)	50 (84.7)	9 (15.3)	0.1713	
	B (142)	108 (76)	34 (24)		
Eating difficulty	A (59)	2 (3.4)	57 (96.6)	0.1311	
CI 11 :	B (142)	16 (11.3)	126 (88.7)	0.0161	
Shoulder pain	A (59)	21 (35.5)	38 (64.4)	0.0161	
TT 1/1 1.1	B (142)	77 (54.2)	65 (45.8)	0.0167	
Health problems because of heavy physical work	A (59) B (142)	35 (59.3) 58 (40.8)	24 (40.7) 84 (59.2)	0.0167	
Feeling anxious, sad,	A (59)	38 (64.4)	20 (33.9)	0.0284	
depressed, confused, angry, or irritated	B (142)	75 (52.8)	77 (54.22)		
Do you tend to forget	A (59)	25 (42.4)	34 (57.6)	0.9876	
things?	B (142)	60 (42.3)	82 (57.7)		
Are you able to meet	A (59)	39 (66.1)	20 (33.9)	0.0284	
financial expenses for the treatment?	B (142)	77 (54.2)	65 (45.77)		
Did you receive any	A (59)	58 (98.3)	1 (1.7)	0.4411	
sponsorship/financial assistance for treatment?	B (142)	135 (95)	7 (5)		
Has your family's financial situation worsened since the	A (59) B (142)	50 (84.7) 109 (76.8)	9 (15.3) 33 (23.2)	0.2048	
patient's illness?					
Do you have any	A (59)	42 (71.2)	17 (28.8)	0.1589	
responsibilities?	B (142)	114 (80.3)	28 (19.7)		
Do you feel motivated	A (59)	49 (83)	10 (17)	0.0001	
enough to continue caregiving	B (142)	57 (40.1)	85 (59.9)		

Contd...

Table 1: Contd						
Question	BI	Yes, n (%)	No, n (%)	P		
Is patient cooperative with you?	A (59)	36 (61)	23 (39)	0.0001		
	B (142)	124 (87.3)	18 (12.7)			
Do you have family support?	A (59)	36 (61)	23 (39)	0.0861		
	B (142)	104 (73.2)	38 (26.8)			
Are you confident of	A (59)	40 (67.8)	19 (32.2)	0.0004		
undertaking emergency management now?	B (142)	60 (42.3)	82 (57.7)			
Has your knowledge of stroke victims enhanced during caretaking?	A (59)	54 (91.5)	5 (8.5)	0.0010		
	B (142)	99 (69.7)	43 (30.3)			

A (BI <75) and B (BI >75); percentage in parenthesis

Table 2: Compari	son between	male and	female car	egivers	
Question	Gender	Yes, n (%)	No, n (%)	Р	
Disturbance in sleep	Male (51)	17 (33.3)	34 (66.7)	0.0004	
	Female (150)	93 (62)	57 (38)		
Physical stress	Male (51)	25 (49)	26 (51)	0.005	
while attending to patients	Female (150)	106 (70.6)	44 (29.3)		
Being upset over	Male (51)	12 (23.5)	39 (76.5)	0.005	
urinary/fecal incontinence of the patient	Female (150)	67 (44.7)	83 (55.3)		
Attending to	Male (51)	8 (15.7)	43 (84.3)	0.050	
personal hygiene needs of the patients	Female (150)	55 (36.6)	95 (63.3)		
Feeling difficult to	Male (51)	9 (17.6)	42 (82.4)	0.041	
assist the patient during urination	Female (150)	49 (32.6)	101 (67.4)		
Feeling difficult to	Male (51)	12 (23.5)	39 (76.4)	0.008	
assist the patient during defecation	Female (150)	43 (28.6)	107 (71.3)		
Feeling difficult to	Male (51)	8 (15.6)	43 (84.3)	0.025	
assist the patient with physiotherapy	Female (150)	48 (32)	102 (68)		
Difficulty with	Male (51)	14 (27.4)	37 (72.5)	0.005	
speech disturbance of the patient	Female (150)	75 (50)	75 (50)		
Facing health	Male (51)	9 (17.6)	42 (82.3)	0.000	
problems because of heavy physical work	Female (150)	81 (54)	69 (46)		
Feeling anxious,	Male (51)	39 (76.4)	12 (23.5)	0.001	
sad, depressed, confused, angry, or irritated	Female (150)	140 (93.3)	10 (6.7)		
Do you feel	Male (51)	36 (70.6)	15 (29.4)	0.004	
motivated enough to continue caregiving	Female (150)	71 (47.3)	79 (52.7)		

for chronic insomnia. The consequences of sleep disturbance in the CG in turn affects the social functioning, health, and poor overall quality of life. [15] Sleep deprivation eventually affects mood and leads to anxiety and depression. Our study

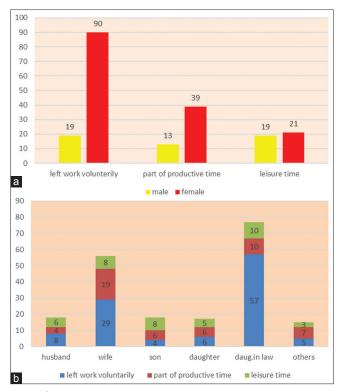


Figure 1: (a) Time spent by the male and female caregivers for stroke patients (n=201). $\chi^2=15.199$, P=0.002. (b) Comparison showing time spent by each relative in caregiving (n=201). $\chi^2=32.184$, P=0.000

also showed that Group A and female CGs had more mood disturbance and tended to be more anxious, sad, depressed, angry, and easily irritable. Sleep disturbance and poor social life could be one reason which has been studied in the earlier studies.^[16]

Our study reported that rehabilitation in the spheres of incontinence, administering medicines, physiotherapy, and shoulder pain was most challenging for the CG. Incontinence in the patient was a major burden experienced by female CGs. Managing incontinence is time-consuming, physically challenging as also induces shame and low self-esteem. A study on female CG experience in stroke survivors found that they undergo a process of chaos, hypervigilance, exhaustion in their life, and later, a gradual change of creating a new life.^[17]

Our study also showed that more than 50% of CGs faced fatigue and general physical complaints and less than half of them suffered from health complaints. Back pain has been reported as a health complaint in CGs in the earlier studies. [18,19] Sleep debt is a major risk factor for developing musculoskeletal tenderness. [20] Psychological and physical stress and forgetfulness were equally seen among wives and daughter-in-laws. Wives, daughter-in-laws, and Group A CGs felt more difficulty in administering medications which could be due to the poor cooperation of the patient. Shoulder pain in the patient was one feature which was felt as a hindrance for Group A patients. However, we did not note any gender

	Husband,	Wife, S	Son,	Daughter,	Daughter-in-law,	Others,	P
	n (%)	n (%)					
Disturbance in sleep							
Yes (110)	6 (5.5)	29 (26.4)	3 (2.6)	7 (6.4)	61 (55.5)	4 (3.6)	< 0.00001
No (91)	12 (13.2)	27 (29.7)	15 (16.5)	10 (11)	16 (17.5)	11 (12)	
Feeling physical stress/strain while attending to patients							
Yes (131)	9 (6.87)	40 (30.5)	5 (3.8)	8 (6.1)	61 (46.5)	8 (6.1)	0.000
No (70)	9 (12.9)	16 (22.8)	13 (18.6)	9 (12.9)	16 (22.8)	7 (10)	
Upset over urinary/fecal incontinence of the patient							
Yes (63)	3 (4.76)	16 (25.4)	1 (1.6)	2 (3.2)	40 (63.5)	1 (1.6)	0.000
No (138)	15 (10.9)	40 (29)	17 (12.3)	15 (10.9)	37 (26.8)	14 (10.1)	
Work load increased after patient's stroke							
Yes (155)	13 (8.4)	43 (27.7)	8 (5.2)	12 (7.7)	68 (43.9)	11 (7)	0.004
No (46)	5 (10.9)	13 (28.2)	10 (21.7)	5 (10.9)	9 (19.6)	4 (8.7)	
Difficulty in administering medicine							
Yes (65)	3 (4.6)	16 (24.6)	3 (4.6)	3 (4.6)	36 (55.4)	4 (6.1)	0.018
No (136)	15 (11)	40 (29.4)	15 (11)	14 (10.3)	41 (30.1)	11 (8)	
Difficulty in attending to personal hygiene needs of the patients							
Yes (70)	1 (1.4)	6 (8.6)	4 (5.7)	2 (2.8)	56 (80)	1 (1.4)	0.000
No (131)	17 (13)	50 (3.8)	14 (10.7)	15 (11.5)	21 (16)	14 (10.7)	
Feeling difficult to assist the patient during urination							
Yes (58)	0	2 (3.4)	2 (3.4)	2 (3.4)	52 (89.6)	0	0.000
No (143)	18 (12.6)	54 (37.7)	16 (11.2)	15 (10.5)	25 (17.5)	15 (10.5)	
Feeling difficult to assist the patient during defecation							
Yes (79)	1 (1.3)	8 (10.1)	3 (3.8)	4 (5)	62 (78.5)	1 (1.3)	0.000
No (122)	17 (13.9)	48 (39.3)	15 (12.3)	13 (10.7)	15 (12.3)	14 (11.5)	
Feeling difficult to assist the patient with physiotherapy							
Yes (56)	1 (1.8)	5 (8.9)	0	2 (3.6)	47 (84)	1 (1.8)	0.000
No (145)	17 (11.7)	51 (35.1)	18 (12.4)	15 (10.3)	30 (20.6)	14 (9.6)	
Difficulty with speech disturbance of the patient							
Yes (89)	3 (3.4)	30 (34)	6 (6.7)	10 (11.2)	37 (41.5)	3 (3.4)	0.016
No (112)	15 (13.4)	26 (23.2)	12 (10.7)	7 (6.2)	40 (360	12 (11)	
Difficulty in feeding the patient							
Yes (54)	2 (3.7)	12 (22.2)	3 (5.55)	1 (1.85)	36 (66.66)	0	0.000
No (147)	16 (10.9)	44 (29.9)	15 (10.2)	16 (10.9)	41 (27.9)	15 (10.2)	
Facing health problems because of heavy physical work							
Yes (90)	6 (6.66)	31 (34.4)	1 (1.1)	6 (6.7)	41 (45.5)	5 (5.5)	0.003
No (111)	12 (10.8)	25 (22.5)	17 (15.3)	11 (9.9)	36 (32.4)	10 (9)	
Feeling anxious, sad, depressed, confused, angry, or irritated							
Yes (179)	17 (9.5)	55 (30.7)	11 (6.1)	17 (9.5)	68 (38)	11 (6.1)	0.000
No (22)	1 (4.5)	1 (4.5)	7 (31.8)	0	9 (41)	4 (18.1)	
Do you tend to forget things							
Yes (86)	8 (9.3)	22 (25.6)	2 (2.3)	7 (8.1)	41 (47.6)	6 (7)	0.048
No (115)	10 (8.7)	34 (29.5)	16 (14)	10 (8.7)	36 (31.3)	9 (7.8)	
Is the patient cooperating with you	, ,	. /	` ′	` ′			
Yes (174)	18 (10.3)	45 (25.8)	17 (9.8)	17 (9.8)	62 (35.6)	15 (8.6)	0.023
No (27)	0	11 (40.7)	1 (3.7)	0	15 (55.5)	0	

difference for this variable. Studies have shown that the frequency of poststroke shoulder pain is almost 30%. [21] Shoulder pain and spasticity are among the hidden problems of poststroke rehabilitation which slows down the recovery and also increases the CG stress.

Poor communication from the patient further makes caregiving difficult which was noted with female CGs in our study. A meta-analysis studying the correlates of physical health of informal CGs concluded that patient's psychological status has the strongest associations with CG health, burden, and

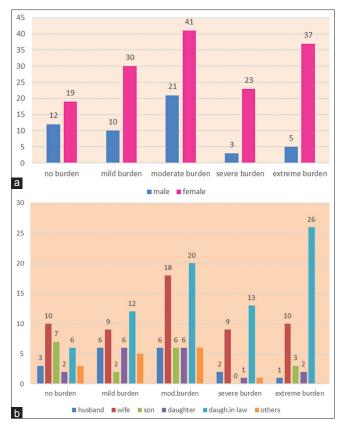


Figure 2: (a) Comparison between male and female caregiver's burden. $\chi^2 = 11.931$, P = 0.018. (b) Comparison between relatives burden. $\chi^2 = 35.162$, P = 0.019

depression.^[21] Indeed, our study showed that Group B CGs has lesser burden probably due to better patient cooperation. Wives and daughter-in-laws particularly experienced less cooperation from their patients. The daughter-in-laws felt particularly difficulty in attending to personal hygiene needs of the patient which included bowel and bladder care which was seen in an earlier study.[22] However, spouses did not feel any hindrance in doing so. This probably reflects the nonbonding between the CG and the care recipient. Daughter-in-laws are expected to fulfill the role of CG for their spouse parents. The physical and psychological stress of CG could have a negative impact on the outcome of the patient. A meta-analysis revealed that the higher level of behavioral problems exhibited by the care-recipient correlated with poor health of the CG.[23] CGs neglecting their own health lead to depression. Psychological complaints in CGs with dementia were studied in CGs of dementia where depression and anxiety were noted between 16% and 85%. [24,25]

Group A CGs felt that their social life was compromised. The stroke severity of the patient was an important contributor with 20% of CGs attending to severe stroke being deprived of social life compared 4% with independent patients.

Financial condition is a major problem in our developing country like India because there are responsibilities in the family for children's education and loans refunding. In our study, 80% of the CGS reported that the financial condition declined after the incidence of stroke. However, there was no difference between stroke severity and gender. In our study, most patients had government financial assistance for the treatment. Even with financial support, out of pocket expenditure is inevitable and moreover either the earning member is bed bound or is in the additional responsibility as the CG. A study suggest that financial conditions have an impact on CGs burden.[12,26] Policies and financial assistance programs should be implemented by government to give continuous supportive hand to the patients thus helping indirectly their families. Interventions such as CGs perceived social support and physical health helped in CGs problem-solving. Stroke nurses working with family during discharge and immediate postdischarge are ideal for giving this support.[27] Target areas such as psychoeducational, skills-training, and therapeutic counseling interventions for stroke CGs will help in decreasing the CG burden and eventually favorable stroke outcome. [28]

Positive point in our study was good family support for the majority of CGs. Family support is pivotal in reducing CG burden by sharing financial and emotional support because of the bondage and moral values.^[29] This moreover helps in recovery and rehabilitation. Another positive finding was the developing confidence in the CGs in undertaking emergency management which has been noted in the previous studies.^[30]

CONCLUSION

Our study showed that CGs faced physical, psychological, and socioeconomic burden. Caregiving burden was predominantly shouldered by females CGs. The burden was more evident in female CGs and in patients with severe stroke. CG stress could be potential barrier in the good outcome of the patient's health. This study paves way for further structured intervention to help CGs cope with the stress of caregiving.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

REFERENCES

- Pandian JD, Sudhan P. Stroke epidemiology and stroke care services in India. J Stroke 2013;15:128-34.
- Carnwath TC, Johnson DA. Psychiatric morbidity among spouses of patients with stroke. Br Med J (Clin Res Ed) 1987;294:409-11.
- Han B, Haley WE. Family caregiving for patients with stroke. Review and analysis. Stroke 1999;30:1478-85.
- Schulz R, Beach SR. Caregiving as a risk factor for mortality: The caregiver health effects study. JAMA 1999;282:2215-9.
- Bugge C, Alexander H, Hagen S. Stroke patients' informal caregivers. Patient, caregiver, and service factors that affect caregiver strain. Stroke 1999;30:1517-23.
- McCullagh E, Brigstocke G, Donaldson N, Kalra L. Determinants of caregiving burden and quality of life in caregivers of stroke patients. Stroke 2005;36:2181-6.
- 7. Glass TA, Matchar DB, Belyea M, Feussner JR. Impact of social support

- on outcome in first stroke. Stroke 1993;24:64-70.
- Scholte op Reimer WJ, de Haan RJ, Pijnenborg JM, Limburg M, van den Bos GA. Assessment of burden in partners of stroke patients with the sense of competence questionnaire. Stroke 1998;29:373-9.
- Kim H, Chang M, Rose K, Kim S. Predictors of caregiver burden in caregivers of individuals with dementia. J Adv Nurs 2012;68:846-55.
- Collin C, Wade DT, Davies S, Horne V. The barthel ADL index: A reliability study. Int Disabil Stud 1988;10:61-3.
- 11. Supervía A, Aranda D, Márquez MA, Aguirre A, Skaf E, Gutiérrez J, *et al.* Predicting length of hospitalisation of elderly patients, using the Barthel index. Age Ageing 2008;37:339-42.
- Bhattacharjee M, Vairale J, Gawali K, Dalal PM. Factors affecting burden on caregivers of stroke survivors: Population-based study in Mumbai (India). Ann Indian Acad Neurol 2012;15:113-9.
- Gupta R, Rowe N, Pillai VK. Perceived caregiver burden in India: Implications for social services. Affilia 2009;24:69-79.
- Spielman AJ, Yang C, Glovinsky PB. Assessment techniques for insomnia. In: Kryger MH, Roth T, Dement WC, editors. Principles and Practice of Sleep Medicine. Philadelphia, PA: W.B. Saunders Company; 2000. p. 1239-50.
- Colten HR, Altevogt BM, editors. Sleep disorders and sleep deprivation: An unmet public health problem. Institute of Medicine (US), Committee on Sleep Medicine and Research. Washington (DC): National Academies Press (US); 2006.
- Spira AP, Friedman L, Flint A, Sheikh JI. Interaction of sleep disturbances and anxiety in later life: Perspectives and recommendations for future research. J Geriatr Psychiatry Neurol 2005;18:109-15.
- Tseng CN, Huang GS, Yu PJ, Lou MF. A qualitative study of family caregiver experiences of managing incontinence in stroke survivors. PLoS One 2015;10:e0129540.
- Yiengprugsawan V, Harley D, Seubsman SA, Sleigh AC. Physical and mental health among caregivers: Findings from a cross-sectional study of open university students in Thailand. BMC Public Health 2012;12:1111.

- Schulz R, Visintainer P, Williamson GM. Psychiatric and physical morbidity effects of caregiving. J Gerontol 1990;45:P181-91.
- Moldofsky H, Scarisbrick P. Induction of neurasthenic musculoskeletal pain syndrome by selective sleep stage deprivation. Psychosom Med 1976;38:35-44.
- Adey-Wakeling Z, Arima H, Crotty M, Leyden J, Kleinig T, Anderson CS, et al. Incidence and associations of hemiplegic shoulder pain poststroke: Prospective population-based study. Arch Phys Med Rehabil 2015;96:241-70.
- Pinquart M, Sörensen S. Correlates of physical health of informal caregivers: A meta-analysis. J Gerontol B Psychol Sci Soc Sci 2007;62:P126-37.
- Campbell P, Wright J, Oyebode J, Job D, Crome P, Bentham P, et al. Determinants of burden in those who care for someone with dementia. Int J Geriatr Psychiatry 2008;23:1078-85.
- Cooper C, Katona C, Orrell M, Livingston G. Coping strategies and anxiety in caregivers of people with Alzheimer's disease: The LASER-AD study. J Affect Disord 2006;90:15-20.
- Prince M, 10/66 Dementia Research Group. Care arrangements for people with dementia in developing countries. Int J Geriatr Psychiatry 2004;19:170-7.
- Lai DW. Effect of financial costs on caregiving burden of family caregivers of older adults. SAGE Open 2012;2:2158244012470467.
- Lui MH, Lee DT, Greenwood N, Ross FM. Informal stroke caregivers' self-appraised problem-solving abilities as a predictor of well-being and perceived social support. J Clin Nurs 2012;21:232-42.
- Collins LG, Swartz K. Caregiver care. Am Fam Physician 2011;83:1309-17.
- Das S, Hazra A, Ray BK, Ghosal M, Banerjee TK, Roy T, et al. Burden among stroke caregivers: Results of a community-based study from Kolkata, India. Stroke 2010;41:2965-8.
- Hilgeman MM, Allen RS, DeCoster J, Burgio LD. Positive aspects of caregiving as a moderator of treatment outcome over 12 months. Psychol Aging 2007;22:361-71.