Female Caregivers and Stroke Severity Determines Caregiver Stress in Stroke Patients

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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 ($\chi^2 = 15.199, P = 0.002$) than males ($\chi^2 = 11.931, P = 0.018$); wives and daughters than other relations ($\chi^2 = 32.184, P = 0.000$), ($\chi^2 = 35.162, P = 0.019$). Conclusion: Our study showed that caregiving burden was predominantly shouldered by females CGs. CGs faced physical, psychological, and socioeconomic burden. The burden was more evident in female CGs and in patients with severe stroke.

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 on CGs leading to negative symptoms such as depression, anxiety, muscular fatigue, social isolation, relationship issues, and poor quality of life.

Depression in the CG affects the stroke rehabilitation outcome. 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. CG burden is complex and multifaceted involving physical and psychological stress, social isolation, and functional constraints. This study aims to outline the sociodemographic constraints.
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]

**Caregiver**

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 $55.67 \pm 12.07$ (range 18–80) years with male-to-female (M:F) ratio 1.6:1. The mean ± standard deviation age of CGs was $42.16 \pm 13.09$ (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 relatives [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 relatives (\(\chi^2 = 35.162, P = 0.019\)) [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

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**Table 1: Comparison between caregivers of Groups A and B**

| Question                                                                 | BI (n) | Yes, (n, %) | No, (n, %) | P       |
|--------------------------------------------------------------------------|--------|-------------|------------|---------|
| Disturbance in sleep                                                     |        |             |            |         |
| Group A                                                                  | 59     | 39 (66.1)   | 20 (33.9)  | 0.029   |
| Group B                                                                  | 142    | 70 (49.3)   | 72 (50.7)  |         |
| Physical stress while attending to patients                               |        |             |            |         |
| Group A                                                                  | 59     | 44 (74.6)   | 15 (25.4)  | 0.0713  |
| Group B                                                                  | 142    | 87 (61.3)   | 55 (38.7)  |         |
| Being upset over urinary/local incontinence of the patient               |        |             |            |         |
| Group A                                                                  | 59     | 25 (42.4)   | 34 (57.6)  | 0.0226  |
| Group B                                                                  | 142    | 37 (26)     | 105 (74)   |         |
| Enough time to attend to your personal work?                             |        |             |            |         |
| Group A                                                                  | 59     | 42 (71.2)   | 17 (28.8)  | 0.0563  |
| Group B                                                                  | 142    | 118 (83)    | 24 (17)    |         |
| Has caregiving affected your social life & social responsibilities?       |        |             |            |         |
| Group A                                                                  | 59     | 12 (20.3)   | 47 (79.7)  | 0.0003  |
| Group B                                                                  | 142    | 6 (4.2)     | 136 (95.8) |         |
| Has your workload increased after the stroke?                            |        |             |            |         |
| Group A                                                                  | 59     | 50 (84.7)   | 9 (15.3)   | 0.1713  |
| Group B                                                                  | 142    | 108 (76)    | 34 (24)    |         |
| Difficulty in Administration of medication                              |        |             |            |         |
| Group A                                                                  | 59     | 39 (66.1)   | 20 (33.9)  | 0.029   |
| Group B                                                                  | 142    | 70 (49.3)   | 72 (50.7)  |         |
| Personal hygiene needs                                                   |        |             |            |         |
| Group A                                                                  | 59     | 44 (74.6)   | 15 (25.4)  | 0.0713  |
| Group B                                                                  | 142    | 87 (61.3)   | 55 (38.7)  |         |
| Bladder care                                                             |        |             |            |         |
| Group A                                                                  | 59     | 25 (42.4)   | 34 (57.6)  | 0.0226  |
| Group B                                                                  | 142    | 37 (26)     | 105 (74)   |         |
| Bowels care                                                              |        |             |            |         |
| Group A                                                                  | 59     | 42 (71.2)   | 17 (28.8)  | 0.0563  |
| Group B                                                                  | 142    | 118 (83)    | 24 (17)    |         |
| Physiotherapy                                                            |        |             |            |         |
| Group A                                                                  | 59     | 12 (20.3)   | 47 (79.7)  | 0.0003  |
| Group B                                                                  | 142    | 6 (4.2)     | 136 (95.8) |         |
| Speech disturbance                                                       |        |             |            |         |
| Group A                                                                  | 59     | 50 (84.7)   | 9 (15.3)   | 0.1713  |
| Group B                                                                  | 142    | 108 (76)    | 34 (24)    |         |
| Eating difficulty                                                        |        |             |            |         |
| Group A                                                                  | 59     | 2 (3.4)     | 57 (96.6)  | 0.1311  |
| Group B                                                                  | 142    | 16 (11.3)   | 126 (88.7) |         |
| Shoulder pain                                                            |        |             |            |         |
| Group A                                                                  | 59     | 21 (35.5)   | 38 (64.4)  | 0.0161  |
| Group B                                                                  | 142    | 77 (54.2)   | 65 (45.8)  |         |
| Health problems because of heavy physical work                           |        |             |            |         |
| Group A                                                                  | 59     | 35 (59.3)   | 24 (40.7)  | 0.0167  |
| Group B                                                                  | 142    | 58 (40.8)   | 84 (59.2)  |         |
| Feeling anxious, sad, depressed, confused, angry, or irritated           |        |             |            |         |
| Group A                                                                  | 59     | 38 (64.4)   | 20 (33.9)  | 0.0284  |
| Group B                                                                  | 142    | 75 (52.8)   | 77 (47.2)  |         |
| Do you tend to forget things?                                            |        |             |            |         |
| Group A                                                                  | 59     | 25 (42.4)   | 34 (57.6)  | 0.9876  |
| Group B                                                                  | 142    | 60 (42.3)   | 82 (57.7)  |         |
| Are you able to meet financial expenses for the treatment?              |        |             |            |         |
| Group A                                                                  | 59     | 39 (66.1)   | 20 (33.9)  | 0.0284  |
| Group B                                                                  | 142    | 77 (54.2)   | 65 (45.7)  |         |
| Did you receive any sponsorship/financial assistance for treatment?     |        |             |            |         |
| Group A                                                                  | 59     | 58 (98.3)   | 1 (1.7)    | 0.4411  |
| Group B                                                                  | 142    | 135 (95)    | 7 (5)      |         |
| Has your family’s financial situation worsened since the patient’s illness? |        |             |            |         |
| Group A                                                                  | 59     | 50 (84.7)   | 9 (15.3)   | 0.2048  |
| Group B                                                                  | 142    | 109 (76.8)  | 33 (23.2)  |         |
| Do you have any responsibilities?                                        |        |             |            |         |
| Group A                                                                  | 59     | 42 (71.2)   | 17 (28.8)  | 0.1589  |
| Group B                                                                  | 142    | 114 (80.3)  | 28 (19.7)  |         |
| Do you feel motivated enough to continue caregiving                      |        |             |            |         |
| Group A                                                                  | 59     | 49 (83)     | 10 (17)    | 0.0001  |
| Group B                                                                  | 142    | 57 (40.1)   | 85 (59.9)  |         |

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

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.

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. Sleep debt is a major risk factor for developing musculoskeletal tenderness. 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

| 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 undertaking emergency management now? | A (59) | 40 (67.8) | 19 (32.2) | 0.0004 |
| | 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: Comparison between male and female caregivers

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

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

### Table 3: Comparison between relatives attending on stroke patients ($n=201$)

|                                | Husband, $n$ (%) | Wife, $n$ (%) | Son, $n$ (%) | Daughter, $n$ (%) | Daughter-in-law, $n$ (%) | Others, $n$ (%) | $P$  |
|--------------------------------|-----------------|--------------|-------------|------------------|-------------------------|----------------|------|
| **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 (10.5)        | 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 (5.5)     | 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%.\textsuperscript{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
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. 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. CGs neglecting their own health lead to depression. 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. 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. 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%. 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. 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. 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. 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. 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.

**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.

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**Conflicts of interest**

There are no conflicts of interest.

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