

Stress in Caregivers of Acute Stroke Patients in Two Diverse Environments (Hospital Setup and Home Care)-An Experience

K Pavithra¹, Radhika C M²

¹ Postgraduate Student, Faculty of Physiotherapy, Sri Ramachandra Institute of Higher Education and Research, Porur, Chennai, Tamil Nadu, India.

² Assistant professor, Faculty of Physiotherapy, Sri Ramachandra Institute of Higher Education and Research, Porur, Chennai, Tamil Nadu, India.

Corresponding Author: **Mrs. Radhika C.M**

Abstract:

Background: Stroke is a sudden and often devastating injury to the central nervous system caused by blood flow disruption to the brain, leading to long-term consequences such as neurological impairments. It is a major cause of disability and mortality among adults. Various studies have highlighted caregiver (CG) stress, but none have compared stress levels in hospital and home environments. Our study aims to explore factors influencing caregiver stress in both settings. **Aim and objective:** To identify the most common source of stress among those who care for acute stroke survivors as well as the overall experiences that caregiver has in hospital and home settings. **Methodology:** An observational study was conducted at Sri Ramachandra Hospital on caregivers of first-time stroke survivors. Demographic data and stress levels were assessed using MCSI on discharge day and 10 days post-discharge. Reasons for stress were identified through open-ended questions. **Results:** Quantitative data included mean and standard deviation for 60 participants, consisting of 44 males and 16 females with an average age of 57.35 ± 10.78 . Among the caregivers of acute stroke patients, 60 individuals were surveyed, including 19 males and 41 females with an average age of 46.23 ± 11.79 . The Modified Caregiver Strain Index (MCSI) with thirteen questions rated stress levels at home and in the hospital. Results showed higher stress levels at home for components such as sleep disturbance (90%) and caregiving inconvenience (86.6%), while hospital stressors included family adjustments (61.6%) and financial strain (95%). Overall, caregivers experienced different stress factors depending on the location. **Conclusion:** Study shows caregiver stress increases based on patient's impairment, needs, and caregiver's understanding of the condition. Stress levels vary between male and female caregivers, with modifiable and non-modifiable stress factors identified. Strategic programs are needed to enhance rehabilitation effectiveness, reduce caregiver stress, and enhance quality of life for both patient and caregiver.

Keywords: CGs, Rehabilitation, Stress, Stroke patients.

Introduction

Stroke is a sudden and often devastating injury to the central nervous system resulting from a disruption of blood flow to the brain. This interruption in blood supply can lead to neurological impairments and long-term consequences. The leading cause of disability and mortality among adults is due to increasing rate of stroke victims. Approximately 15 million people every year suffer from stroke (¹). Notably, there is a 43% risk of experiencing another stroke within 10 years after the initial event (²), which places a substantial burden on community-based health care.

Over 50 million individuals who had a stroke suffer from emotional, physical, and cognitive difficulties and need assistance for everyday tasks (³). Post-stroke patients often grapple with long-term physical or functional impairments, demanding continuous monitoring, medical care, rehabilitation, emotional support and methods of self-management for recovery and Quality of Life (QOL) (⁴).

In India, it is estimated that around 1.8% of the population has experienced a stroke. Approximately 40% of stroke survivors in the country use physical therapy services daily. Factors that affect their decision to continue rehabilitation include their financial status, gender, age, place of residence, and the need for assistance in daily activities (⁵).

Caregivers (CG) often play a significant role in providing long-term assistance to stroke survivors due to their resulting disabilities. These CG, primarily family members, offer sustained support during the patient's recovery and rehabilitation, delivering physical care and actively engaging in the patient's home-based care (⁶). Nonetheless, the demanding nature of caregiving places CG at risk of experiencing stress and strain over prolonged periods of care.

Taking care of stroke patients frequently cause the CG enormous amount of stress. Unfortunately, these factors have been neglected and adequate importance has not been given in stroke patient care (⁷). The high-stress levels experienced by the patient's family not only diminish their quality of life but also directly impact the patient's emotions. This, in turn, affects the patient's willingness to comply with rehabilitation and treatment, and may even lead to or worsen the patient's mental health.

There have been many studies discussing CG stress, but whether CG stress differs between a hospital setting and home care has not been fully explored. We hypothesize that there must be a difference, as in the hospital environment patients may have more support when compared to home care.

Numerous studies highlighted regarding CG stress in varied manners, but to our knowledge, no studies considered CG stress in two different environments. We intended to study even the modifiable and non-modifiable factors that may influence stress and

focus on the overall experience of CG in the hospital and as well as the home environment.

Materials and methods

The study is a cross sectional study which included CGs of First-time stroke survivors from Sri Ramachandra Hospital, Chennai was recruited. A verbal explanation of the research project was made followed by obtaining a written informed consent. The Institutional Ethics Committee for Student's projects approved the study with ref. no: (REF: CSP-III/24/APR/04/126). This study has been registered in Clinical Trial Registry – India (CTRI/2024/06/068325).

Sample size: 60 Caregivers of Acute Stroke patients

Inclusion criteria for the patients included First-time stroke survivors, Gender: Both male and female, requiring ADL assistance from their CGs, In MRS (Modified R) score of 3-5. Inclusion criteria for the caregivers included caregiver being a family member and >18 years of age, caregiver spending a minimum of six hours per day caring for a stroke sufferer. The participants were excluded if unwillingness to participate and if the patient had a recurrent stroke.

Study procedure:

Informed consent was provided for subjects who meet the inclusion criteria and they took part in the study.

Outcome measures:

1) The modified caregiver strain index (MCSI):The MCSI is an assessment method for immediately identifying stress in long-time CGs in the family. It comprises a 13-question questionnaire designed to evaluate the stress related to health care services.

Domains include Financial, Physical, Psychological, Social, and personal.

The scoring method works as follows: 2 points for every 'yes', 1 point for every sometimes response, and a zero for every no response. A higher score indicates greater CG stress (Travis et al., 2003; Thornton & Travis, 2003).

2) Modified Rankin scale (MRS):

The MRS measures the impairment of individuals with stroke. It evaluates independence rather than task performance. The scale contains six levels, With a score of 0 (no complaints) to 5 (extreme disability). For clinical purposes, moderate inability ranges from 0 to 2, major disability from 3 to 4, and serious impairment from 5 to 6.

MRS:

0=indicates not having symptoms at all.

1 = No significant impairment, although symptoms; capable of performing all routine occupations and activities.

2 = Mild impairment; incapable of performing all prior activities but capable of caring for themselves independently.

3 = Substantial impairment, needs assistance but attempts to accomplish things on their own.

4 = Substantial to serious impairment; unable to walk without help.

5 = Indicates severe disability, including bed rest, incontinence, and ongoing nursing care.

Procedure

An observational study was conducted at Sri Ramachandra Hospital among CG of Acute Stroke patients of both genders. Quantitative and qualitative stress level of CG was measured during their hospital stay and home care environment. Demographic details of patient and CG -Age, sex, disease duration, and occupation and any other details were collected. Disability Assessment-Standardized rating scale MRS to assess the level of disability among stroke patients The MRS includes levels 3,4 and 5. Validated questionnaire The MCSI to assess the various components of stress. This questionnaire will be done during the day of discharge and after 10 days of discharge through a telephonic interview. OPEN-ENDED questions were asked to CG to elaborate on their reasons for stress and their overall experience in diverse environments.

- OPEN-ENDED questions asked to CGs as mentioned below
- a) What are the factors or reasons that caused an increase in their stress levels?
- b) What were the challenges and difficulties the CG encountered?
- c) To elaborate on their overall experience in diverse environments.

Results

Quantitative variables were expressed as mean and standard deviation. Sixty patients comprised of 44 males and 16 females with a mean age of 57.35 ± 10.78 (Table 1). Sixty CGs of acute stroke patients comprised 19 males and 41 females with a mean age of 46.23 ± 11.79 (Range = >18 years). (Table 2)

Bar graph was used to assess numerical data to compare the CG stress at home and hospital (Figure 1). Questions were asked to CG to give responses as YES/NO on the various activities that cause stress, where "YES" denotes the CG stress on the

corresponding activity and “NO” denotes the caregiver does not experience stress on the corresponding activity.

These questions were asked during the hospital stay and, in their home, environment. CG experienced high levels of stress due to financial strain (n=57) in the hospital and (n=53) in-home care. Transportation of the patient (n=47) in the hospital, and (n=55) at home, Physical strain (n=35) at hospital and (n=55) at home care, Managing household chores (n=49) in the hospital and (n=37) at home care, Self-grooming activities of the patient such as dressing, and bathing which needs assistance from the CG (n=30) in the hospital and (n=48) at home care, Family members with a low education degree were more likely to experience high levels of stress due to the poor understanding of the condition and rehabilitation techniques. The Presence of comorbidities among CGs subsequently caused an extra burden and increase in physical and mental stress.

Modified caregiver Strain index (MCSI) consisting of thirteen questions with scores of 0-2, was given to the CGs to rate each question on stress at the hospital and home. Sixty participants responded and the overall participant's percentage of responses for each question is given in table 3. On comparing both responses, the components such as sleep disturbance(n=90%), caregiving is an inconvenience(n=86.6%), Physical strain of CG(n=90%), Confinement (n=66%), and behavioral issues of the patient (78.3%) were found to have more percentage on the score of 2 at home indicating higher level of stress compared to hospital. At the hospital, the components such as family adjustments(n=61.6%), time adjustments(n=86.6%), emotional adjustments(n=76.6%) and work adjustments (81.6%), change in personal plans (83.3%), financial strain(n=95%), burden due to the patient's condition (n=48.3%) was found to have more percentage indicating increased stress of CG at the hospital compared to stress at home. (Refer table 3)

Discussion

We evaluated the stress levels of CG for acute stroke patients in two different settings. In the hospital, the patient receives support from staff and therapists, but at home, a single CG is responsible for both the patient's needs and household chores, significantly raising their stress levels. The results of the study supported various merits and demerits of CGS stress in both hospital and home.

Caregiving in hospital setup

Merits

In the hospital, there are various merits such as support from the staff, nurses, and therapists. The CG need not face the hurdles alone. Medications are administered to the

patients by the nurses hence there might not be any confusion. There are physical therapists assisting to rehabilitate and mobilize the patients. The availability of advanced facilities, equipment, expert guidance, and 24/7 monitoring supports the patient as well as CG.

Demerits

The demerits include disturbed sleep patterns of the CG (n=90%) due to frequent checking of patients and assisting them with toileting activities, limited access to other family members, hospital-associated infections, financial strain (n=91.6%) due to medical expenditures, food and miscellaneous, individual decisions that cannot be taken by the CG as he/she needs to abide by hospital policies, looking for help and support constantly, poor social relationships, work adjustments (n=81.6%) if the patient or CG runs a business on his/her own, need to temporarily shut off or seek for help to look after, when the hospital is far from home transportation becomes difficult, change in personal plans (n=83.3%) as there will be a change in the work schedule or quitting job to look after the patient.

However, the CG in the hospital might overlook some social factors (n=86.6%) as other people in the family need their time and CG encountering family (n=61.6%) and emotional adjustments (n=76.6%) but these can be addressed at home, such as emotional support from the family and a well-trained and supportive environment, which could positively impact the patient's recovery.

Caregiving in-home care setup:

Merits

The presence of family members and a familiar environment enables the patient to faster recovery and improve functional mobility, less exposure to infections, the presence of other family members and social relationships, more independence, and less transportation.

Demerits

In the case of a single CG, he/she feels overwhelmed (n=95%) as only he/she needs to manage the household and attend to other members of the family as well as the patient. If the patient is obese difficulty in the transportation of the patient and if the patient has behavioral (n=78.3%) and cognitive issues difficult to manage, and needs to rely upon other family members, when a patient has bowel and bladder issues it causes infections as well as an extra workload to the CG, in case of hiring a paid CG it might add expense, frequent visit to hospitals for checkups, cooking a separate meal for family and patient,

difficulty in administering medications, the patients feeling of uncomfortable when the CG assisting him /her in toileting, eating and other self-grooming activities. Patients in remote areas find it difficult to access to hospital in case of emergency or for checkups. Physical strain among CGs (n=90%) as transferring techniques are not known by the CG which causes shoulder pain and. CG feels confined (n=66.6%) as caregiving restricts CGs leisure time or visit places. Of all these Literacy among CG plays a vital role as understanding the disease, patient condition, and basic rehabilitation makes caregiving easy to a certain extent ⁽⁸⁾.

We also investigated if there is stress between male patients attended by female CGs and female patients attended by male CGs. In a traditional Indian household, males are the primary earners, while females care for the home ⁽⁹⁾

Male patient cared by a female caregiver

Maintaining a male stroke patient in the family increases the economic demand and housekeeping tasks for female CG ⁽¹⁰⁾. Females are the primary CGs in India. Our study included more than half of female CG. This is ascribed to Indian culture and the societal influences that result in females being handed more responsibility ⁽¹¹⁾⁽¹²⁾. Female CGs are prone to a higher amount of stress due higher amount of dependency on other people for help and a lack of family social relationships.

Previously, the female CG wouldn't have taken an active role in decision-making or financial record keeping, making it difficult to manage records, and the CG herself has health difficulties, which would raise their expenses and leave them feeling fatigued all the time.

When a patient demands complete assistance in performing their ADL, extended hours of caregiving are required, which adds to the burden⁽¹³⁾ ; if the patient has bowel and bladder disturbances⁽¹⁴⁾ , it is inconvenient(n=86.6%) for both the patient and the CGs; and when the patient is on a Ryle tube, frequent changes and care are required.

Female patient cared by a male caregiver:

While men are the CG the finances are managed but there might be changes in their work schedule

and some might even lose their jobs⁽¹⁵⁾. Females typically engaged in household chores ⁽¹⁶⁾)earlier might now be done by the male or would have hired a person for help which increases the expenses⁽¹⁷⁾) ⁽¹⁸⁾). Many women would not have attended menopause and during their menstrual time, the male CG would find it very difficult to manage the patient and if the female patient had bowel and bladder disturbances, male attendants have to rely on female CG or relatives for help. Relying on a person itself increases stress.

Modifiable and non-modifiable stress factors:

The primary factor in analyzing stress is to classify them into modifiable and non-modifiable stress factors. In the case of non-modifiable factors, they can be recognized, and a support system, counseling, or advice can be provided.

"When unexpected events occur, CG should be prepared to face them. It is also important to educate them about what actions to take or not to take, and to identify tasks that they can handle on their own versus those for which they need to seek help from others. Therefore, this study focuses on the overall experience of CG in hospital and home care settings, their stress levels, and how their stress levels have changed from hospital care to home care. "When unexpected events occur, CG should be prepared to face them. It is also important to educate them about what actions to take or not to take, and to identify tasks they can handle on their own versus those they need to seek help from others.

Conclusion

This study concludes that CGs' stress levels increase according to the impairment that occurred to the patient, their needs, and the CG's understanding of the condition. Though the same CG is present in both environments their stress level and factors have been changing according to the needs of the patient and their family. Female CGs are comparatively prone to a high stress level, but this study also highlights the stress male CGs face in descriptive. Modifiable and non-modifiable stress factors among CGs were identified which gives us an insight into recognizing these factors and preparing the CG to face these challenges. The study also highlights the need for Education to CG about the DOs and DONTs, basic transferring strategies, relaxation techniques, sharing responsibilities, positive reinforcement, and making them face the challenges when unexpected events occur. Strategic home- or community-based programs are needed to optimize the efficacy of rehabilitation, lower stress levels in CG, and improve the patient and CG's quality of life.

Limitations

This study does not measure the CG stress for ischemic and hemorrhagic stroke individually.

The number of samples included was comparatively a smaller group and a shorter follow-up period. The study assessed various stress factors but did not include any exclusive supportive program or intervention for the CG.

Clinical implication

Stroke incidence is high and CGs play a vital role in a patient's recovery, assessing the CG's stress should be an essential component of Stroke care. Hence, to lessen CG stress and promote patient recovery, stroke therapy should also address CG issues in addition to patient issues.

Assessing CG stress and framing strategies and intervention programs not only improves QOL in CG but also in CG and further enhancement of patient's compliance with rehabilitation and positive outcomes in recovery.

References

1. Chu YM, Choi KS. Effectiveness of patient education in acute stroke: a comparison between a customised computer system and a pictorial information booklet. *BMJ health & care informatics*. 2020;27(3).
2. Hardie K, Hankey GJ, Jamrozik K, Broadhurst RJ, Anderson C. Ten-year risk of first recurrent stroke and disability after first-ever stroke in the Perth Community Stroke Study. *Stroke*. 2004 Mar;35(3):731-5. D9. Epub 2004 Feb 5. PMID: 14764929.
3. van Dongen, L., Hafsteinsdóttir, T. B., Parker, E., Bjartmarz, I., Hjaltadóttir, I., & Jónsdóttir, H. (2021). Stroke survivors' experiences with rebuilding life in the community and exercising at home: A qualitative study. *Nursing open*, 8(5), 2567–2577.
4. Norrving, B., Barrick, J., Davalos, A., Dichgans, M., Cordonnier, C., Guekht, A., Kutluk, K., Mikulik, R., Wardlaw, J., Richard, E., Nabavi, D., Molina, C., Bath, P. M., StibrantSunnerhagen, K., Rudd, A., Drummond, A., Planas, A., & Caso, V. (2018). Action Plan for Stroke in Europe 2018-2030. *European stroke journal*, 3(4), 309–336.
5. Bharati, Bhavna & Sundar Sahu, Kirti & Pati, Sanghamitra. (2021). Rehabilitation of Stroke Patients in India: An Exploratory Study from a National-Level Survey Data. *Indian Journal of Physiotherapy & Occupational Therapy*. 15. 8-18. 10.37506/ijpot.v15i3.16457.
6. She, R., Yan, Z., Hao, Y., Zhang, Z., Du, Y., Liang, Y., Vetrano, D. L., Dekker, J., Bai, B., Lau, J. T., & Qiu, C. (2022). Comorbidity in patients with first-ever ischemic stroke: Disease patterns and their associations with cognitive and physical function. *Frontiers in Aging Neuroscience*, 14, 887032.
7. Rigby, H., Gubitz, G., & Phillips, S. (2009). A systematic review of caregiver burden following stroke. *International journal of stroke : official journal of the International Stroke Society*, 4(4), 285–292.

8. Wu, X., Liang, Y., Zheng, B., Wang, H., Ning, M., Zheng, H., & Shi, B. (2020). Care stress in caregivers of disabled stroke patients: a cross-sectional survey. *Annals Of Palliative Medicine*, 9(4), 2211-2220.
9. Sohkhlet, G., Thakur, K., David, S. I., Verma, P., Jadav, V., S, J., Palal, D., Borah, N., Banerjee, A., &Nallapu, S. (2023). Stress in Caregivers of Stroke Patients During Rehabilitation: An Observational Study. *Cureus*, 15(4), e37410.
10. Mandowara, B., Patel, A. N., Amin, A. A., Phatak, A., & Desai, S. (2020). Burden Faced by Caregivers of Stroke Patients Who Attend Rural-based Medical Teaching Hospital in Western India. *Annals of Indian Academy of Neurology*, 23(1), 38-43.
11. Menon, B., Salini, P., Habeeba, K., Conjeevaram, J., &Munismusmitha, K. (2017). Female Caregivers and Stroke Severity Determines Caregiver Stress in Stroke Patients. *Annals of Indian Academy of Neurology*, 20(4), 418-424.
12. Matolia, Riddhi&Anandwala, Khadija &Verma, Neha. (2022). A Study to Measure Caregiver Stress in Stroke Patients using Caregiver Strain Index. *International Journal of Health Sciences and Research*. 12. 276. 10.52403/ijhsr.20220432.
13. Kumar, A., Yadav, A. K., Singh, V. K., Pathak, A., Chaurasia, R. N., Mishra, V. N., & Joshi, D. (2022). Caregiver Burden in Caregivers of Stroke Survivors: A Hospital-Based Study. *Annals of Indian Academy of Neurology*, 25(6), 1092-1098.
14. Putri, I., Saleh, A., &Citrawati, M. (2020). The relation between informal caregiver's stress towards quality of life stroke patients. *Konselor*, 9(3), 125-131.
15. Sharma, Mohit&Devgan, Shivesh&Mahajan, Sanjeev. (2023). Strain and Burden among Caregivers of Stroke Survivors in Punjab: A Cross-Sectional Study. *Healthline*. 14. 201-09.
16. Tsiakiri A, Vlotinou P, Paschalidou A, Konstantinidis C, Christidi F, Tsiptsios D, Detsaridou G, Petridou A, Gkantziou A, Karatzetzou S, et al. A Scoping Review on Coping Strategies and Quality of Life of Stroke Caregivers: Often Underestimated Variables in Stroke Recovery Process? *BioMed*. 2023; 3(3):349-368.
17. Bekele, G., Yitayal, M. M., Belete, Y., Girma, Y., Kassa, T., Assefa, Y. A., Nigatu, S. G., &Eriku, G. A. (2023). Caregiver burden and its associated factors among primary caregivers of stroke survivors at Amhara regional state tertiary hospitals: A multicenter study. *Frontiers in Stroke*, 2, 1226140.
18. Rajan, B., G., S., S., P., & K., R. (2016). Assessment of stress among caregivers of the stroke survivors: community-based study. *International Journal Of Community Medicine And Public Health*, 4(1), 211-215

Demographics	Mean ± SD
Age	57.35 ± 10.78
Gender	Male- 44, Female - 16

Table 1 – Patient Demographic data

Caregivers demographics	Mean ± SD
Age	46.23 ± 11.79
Gender	Male- 19, Female- 41

Table 2- Caregiver demographic data

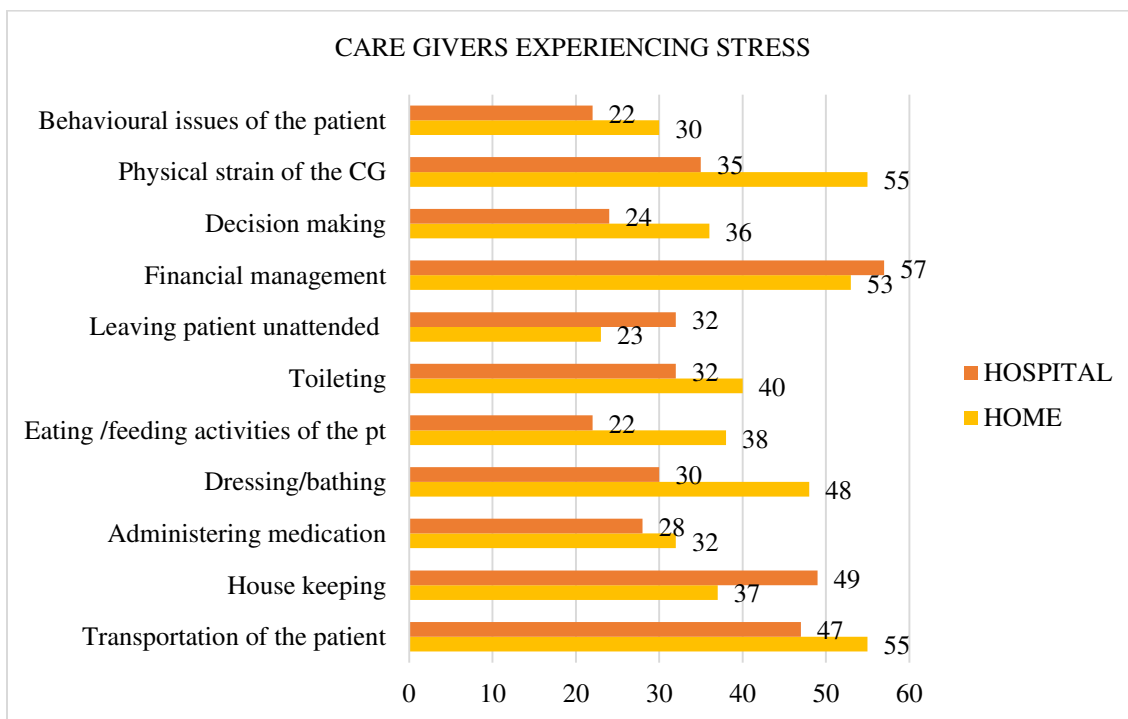


Figure 1-Caregivers stress for different activities of acute stroke patients

S no	Questions (score 0-2)	At Hospital N=60 n =%	At Home N=60 n =%
1	(CG) sleep disturbance		
	2	54(90%)	50(83.3%)
	1	8(13.3%)	5(8.3%)
	0	2(3.3%)	1(1.6%)
2	CG's inconvenience		
	2	48(80%)	52(86.6%)
	1	10(16.6%)	6(10%)
	0	2(3.3%)	2(3.3%)
3	CG experiencing Physical strain?		
	2	38(63.3%)	54(90%)
	1	10(16.6%)	6(10%)
	0	12(20%)	0
4	CGs confinement		
	2	30(50%)	40(66.6%)
	1	15(25%)	10(16.6%)
	0	15(25%)	10(16.6%)
5	Family adjustments due to caregiving		
	2	37(61.6%)	35(58.3%)
	1	17(28.3%)	15(25%)
	0	6(10%)	10(16.6%)
6	Changes in Personal plans of CG		
	2	50(83.3%)	40(66.6%)
	1	9(15%)	15(25%)
	0	1(1.6%)	5(8.3%)
7	Time demands faced by CG		
	2	52(86.6%)	30(50%)
	1	8(13.3%)	20(33.3%)
	0	0	10(16.6%)
8	Emotional adjustments of CG		
	2	46(76.6%)	38(3.3%)
	1	12(20%)	17(28.3%)
	0	2(3.3%)	5(8.3%)

9	Behavioral changes of patient		
	2	35(58.3%)	47(78.3%)
	1	18(30%)	13(21.6%)
	0	7(11.6%)	0
10	CGs feeling of upset on patients' condition		
	2	29(48.3%)	20(33.3%)
	1	10(16%)	10(16.6%)
	0	21(35%)	30(50%)
11	There have been work adjustments		
	2	49(81.6%)	45(75%)
	1	10(16.6%)	10(16.6%)
	0	1(1.6%)	5(8.3%)
12	Economic burden on CG		
	2	57(95%)	55(91.6%)
	1	3(5%)	5(8.3%)
	0	0	0
13	CGs feeling of overwhelmness		
	2	45(95%)	40(66.6%)
	1	10(16%)	10(16.6%)
	0	5(8.3%)	10(16.6%)

Table 3: MCSI percentage at hospital and home

List of abbreviations:

1. CG: Caregiver
2. QOL: Quality of Life
3. MRS: Modified Rankin Scale
4. MCSI: Modified Caregiver Strain Index

Acknowledgment: I want to thank the management of Sri Ramachandra Hospital for their invaluable support and cooperation throughout this study. Their commitment to providing a conducive environment and their unwavering assistance have been instrumental in completing this research. I am also deeply grateful to all the participants who took part in this study.

Conflict of interest: The authors do not have any conflicts of interest to declare.

Funding sources: This research did not receive any external funding.

Ethics:

Institutional Ethics Committee: The study received approval from the Institutional Ethics Committee for student projects (**REF: CSP-III/24/APR/04/126**).

Clinical Trial Registry India(CTRI):The study has also been registered in the Clinical Trial Registration India (CTRI)CTRI/2024/06/068325).