# KNOWLEDGE AND PRACTICE OF POST STROKE REHABILITION, STRESS AND BURDEN AMONG CARE GIVERS OF STROKE PATIENTS

# Sridevi B 1\*, Vignesh V 2, Kavitha M 3 and Deepika D 4

Assistant Professor, Department of Medical Surgical Nursing, Saveetha College of Nursing, Saveetha Institute of Medical and Technical Sciences, Thandalam.
 \*Corresponding Author Email: sri86peter@gmail.com, ORCID ID: 0009-0005-4883-0657
 B.Sc. (N) IV Year, Saveetha College of Nursing, Saveetha Institute of Medical and Technical Sciences, Thandalam. Email: 171901093.scon@gmail.com
 Tutor, Department of Community Health Nursing, Saveetha College of Nursing, Saveetha Institute of Medical and Technical Sciences, Thandalam.

 Email: kavithakarthik98@gmail.com

 Tutor, Department of Medical Surgical Nursing, Saveetha College of Nursing, Saveetha Institute of Medical and Technical Sciences, Thandalam.

 Email: dpkasri94@gmail.com

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#### Abstract

Background: Stroke is a critical healthcare issue because it is one of the top causes of mortality, disability, and dependence on daily living activities globally. The recovery of stroke patients is greatly aided by home care. Relatives and carers from the patient's family can be crucial in the patient's care. Nevertheless, they lack knowledge and experience regarding how to continue providing the patient with proper care at home after discharge. According to this viewpoint, the researcher believes that teaching others about stroke and the care of stroke patients at home may be very beneficial for both patients and their careers. Materials and Methods: The quantitative approach, descriptive correlational research design was conducted in the patient admitted in Saveetha Medical College and Hospital A total of 60 study participants were recruited by using convenience sampling technique, based on the inclusion criteria, the demographic and clinical data was collected by using a self-structured questionnaire, Psychological distress scale and Zarit scale (caregiver burden scale) was estimated during care taking. Results: The outcome results identified that 31 (51.7%) had inadequate, 26 (43.3%) had moderate adequate and 3 (5%) had adequate the level knowledge and practice of post stroke rehabilitation among care givers. The living condition of care giver and relationship with patient had shown statistically significant association with level of knowledge and practice on post stroke rehabilitation among care givers of patient with stroke p=0. 049. Karl Pearson's Correlation value of r = 0.913 between stress and burden shows a positive correlation which was found to be statistically significant at p<0.001 level. Conclusion: This study demonstrates and concluded that there is strong relationship between level of knowledge and practice on post stroke rehabilitation, stress, and burden among care givers of patient with stroke. This clearly infers that when stress among caregivers of stroke patients increases then ultimately the burden among caregivers of stroke patients increases.

Keywords: Caregiver, Knowledge, Patient, Practice, Rehabilitation, Post Stoke.

#### INTRODUCTION

Health is state of total health in all respects and not merely the lack of illness or disability. If something blocks blood flow to a portion of the brain or when a blood artery in the brain bursts, a stroke, also known as a brain attack, happens [1]. One of the major causes of death and disability in India is stroke. Stroke prevalence rates are expected to range from 84–262/100,000 in rural areas to 334–424/100,000 in metropolitan areas. According to recent population-based studies, the incidence rate ranges from 119 to 145/100,000. Due to a staffing shortage, stroke rehabilitation is not well established in India [2].

The second most common cause of death worldwide, behind coronary artery disease, is stroke. It is also the most typical reason for prolonged adult impairment. After the age of 55, one in five women and one in six men will experience a stroke in their lifetime. In underdeveloped nations, strokes account for more than 45% of all cases [3,4,]. The common risk factors, such as smoking, diabetes, hypertension, and dyslipidemia, are relatively common and insufficiently addressed, primarily due to low public awareness and inadequate infrastructure. Strokes can result in the loss of the ability to move an arm or a leg, as well as make it difficult for a person to perform daily tasks like cooking, cleaning, going shopping, or using public transportation. Strokes can also make it difficult for a person to walk independently, take a shower, or get dressed. Simple actions like shaving, cleaning one's face, and brushing one's teeth seem impossible to do [5,6].

The number of stroke and transient ischemic attack patients treated annually is roughly 62,000. This may be a challenging period of adjustment for the patients, family, and care [7]. The emphasis of these suggestions is on patient, family, and care support, education, and skill development; efficient discharge planning; interprofessional communication; adjustment in resuming daily living activities; and transition to long-term care for patients who are unable to return home or stay at home. For successful transitions and return to the community after a stroke, all members of the health care team who work with stroke patients, their families, and carrier must work together [8,9].

The term "carer" covers a broad range of circumstances and experiences. Caregiving can involve providing support to a loved one whether they live with the carer, the care recipient, or in a facility. It could entail taking care of a person's bodily and/or emotional wellbeing. It may entail providing long-term care to a person who has a physical impairment or a chronic illness, or it may be sporadic and intermittent, as in the case of caring for someone who has an acute sickness or an acute episode of a chronic condition [10].

Considering all the constraints and probable consequences of a stroke, carers need to be familiar with the fundamentals of caregiving. These involve executing or assisting the patients with fundamental everyday tasks like feeding, moving around, using the restroom, bathing, and dressing. They also call for higher-level abilities including managing the healthcare system (appointments, refilling prescriptions), handling medical equipment (e.g. dressing, regular turning), supervising and administering drugs, coordinating transportation, and acting as the patient's advocate [11,12].

Therapy for stroke rehabilitation is typically required. It requires assistance with making safety adjustments, dressing, cooking, and using the restroom [13]. A speech therapist could be helpful for those who have problems speaking or interacting with others after a stroke. The muscles, joints, and nerves, trouble going to the toilet, trouble swallowing, and trouble eating, depending on the severity of the stroke. These recommendations support the expanding and evolving body of research evidence that is currently available to direct continuous screening, assessment, and management of people who have had strokes so that they can move seamlessly from one phase and stage of care to the next [14,15].

Caring for a sick family member is the responsibility of all family members, and family support is critical for the patient's rehabilitation, both mentally and physically. However, family carers are frequently unable to meet the expectations of the patient due to a lack of professional training and understanding, as well as a lack of social resources

[16]. These carers are frequently stressed, and the stress of family members has a direct impact on their attitudes towards the patient and the quality of care. The family member must combine the dual responsibilities of caring for a disabled stroke survivor and implementing lifestyle changes [21]. Physical (walking, transfer from bed to chair, chair to toilet), communication (verbal and nonverbal with family members, friends), nursing (feeding, changing clothes, personal toilet), emotional and psychological changes to adapt to the consequences of stroke, and financial (loss of employment, medical bills) needs of a stroke survivor vary. When caring for disabled stroke victims, a significant proportion of family members experience severe levels of stress. The patient's family members' high stress levels not only diminish their quality of life, but also have a direct impact on the patient's emotions, which affects the patient's compliance with rehabilitation and therapy and even creates or worsens the patient's depression [21,22].

## **METHODS AND MATERIALS**

Study Design: The quantitative approach with non-experimental, descriptive correlational research design was adopted for the current study to assess the level knowledge and practice of post stroke rehabilitation among care givers of stroke patients. Study Setting: The study was conducted for the duration of 3 months from Jan 20<sup>th</sup> 2023 till 30<sup>th</sup> April 2023 from the caregivers of stroke patients admitted in Saveetha Medical College and Hospital. Ethical Approval: After obtaining an ethical clearance from the institutional ethical committee (IEC) of Saveetha Institute of Medical and Technical Sciences and a formal permission from the selected hospital, the study was conducted. **Study Participants:** A total of 60 care givers who are taking care of stroke patients in the selected hospital (n=60) and who met the inclusion criteria were recruited as study participants. The inclusion criteria for the study participants were the caregivers being older than 18 years of age, willing to participate. responsible for care to the post stroke patients, provide care to the client's at least 3 months, reside with the patient at home, provide care to the client's at least 4 hours per day, speak and write Tamil or English. Sampling Technique: A total of 60 caregivers of stroke patients were recruited based on the inclusion criteria using convenience sampling technique. Informed Consent: The purpose of the study was explained clearly in depth to each of the study participant and a written informed consent was obtained from them. Assessment: The demographic data and level of knowledge and practice about post stroke rehabilitation among care givers was collected using self- structured questionnaire, Psychological distress scale and Zarit scale (caregiver burden scale) and the collected data were tabulated and analyzed by using descriptive and inferential statistics.

#### **RESULT AND DISCUSSION**

## Section A: Demographic variables of the Caregivers of Stroke Patients

With regards to the demographic characteristics, among 60 study participants with regards to age 35(58.3%) were aged between 31-40 years, 41(68.3%) were male, 37(61.6%) belonged to nuclear family, 23(38.3%) were clerks, 14(23.3%) had intermediate education, 40(66.7%) had family monthly income of 10000/-150000/-15000/-15000/-15000/-15000/-15000/-15000/-15000/-15000/-150

With regards to the clinical characteristics (36) 36% were of previous history of diabetes mellitus, (38) 38% of them given care more than 4 hours a day.

# Section B: Assessment of Level of Knowledge and Practice on Post Stroke Rehabilitation, Stress and Burden Among Caregivers of Stroke Patients

# Assessment of Level of Knowledge on Post Stroke Rehabilitation Among Caregivers of Stroke Patients

The current study identified that, among our study participants, with regard to general information 28(46.67%) had moderately adequate knowledge, 26(43.33%) had inadequate knowledge and 6(10%) had adequate knowledge. Knowledge on diet revealed that, 32(53.33%) had inadequate and 28(46.67%) had moderately adequate. Knowledge on Range of motion shows that, 29(48.33%) had moderately adequate, 24(40%) inadequate e and 7(11.67%) had adequate. Knowledge on communication, 44(73.33%) had inadequate, 14(23.33%) had moderately adequate and 2(3.33%) had adequate.

Table 1: Frequency and Percentage Distribution Level Knowledge Post Stroke Rehabilitation Among Caregivers of Stroke Patients

Level of Knowledge Frequency (F) Percentage (%)

Adequate 10 16.7

Moderately Adequate 15 25

Inadequate 35 58.3

LEVEL OF KNOWLEDGE

16.7%

■ Adequate
■ Moderately Adequate
■ Inadequate

Figure: 1 Level of Knowledge among Caregivers of Stroke Patient

The present study findings is consistent with the findings of the 200 patients in general (OPD), who were consecutively selected after satisfying the inclusion criteria, participated in a hospital-based cross-sectional study done by **Jogindra Vati & Parveen Sandha (2022)**, demographic profiles, clinical profiles, and knowledge tests on risk factors, symptoms, and reactions to stroke similar percentage of patients (43%) had a strong understanding of stroke risk factors, and nearly half of the patients (43.5%) had very good knowledge. The participants acknowledged hypertension (77%) and binge drinking (73%) as the two most prevalent risk factors for stroke. Only 7% of patients had adequate knowledge of warning signs, whereas most patients (92,5%) had poor knowledge [16].

The present study findings is consistent with the findings of the **Vishnu Sharma (2020)** applied descriptive design and purposive sampling technique to collect data with 100 primary care givers. Data were collected using a self-structured questionnaire about CVA symptoms and treatment. According to the results of the study, more than half (52%) of the primary caregivers of CVA patients had an adequate level of knowledge, while the other half (48%) had a moderate level of knowledge [17].

The present study findings is consistent with the findings of the **Bhavya and Vidya's (2017)** aimed to assess the expertise of care givers for stroke patients about home care management. In J.S.S. Hospital, a descriptive design and non-probability convenience selection technique were used to choose 60 care givers. Results showed that 25 (41.65%) had average knowledge, 23 (38.3%) had strong knowledge and 12 (20%) had bad knowledge [18].

Hence the current study and the above supportive studies revealed that, more resources should be made available to raise awareness among stroke carers about prevention, home care management, and rehabilitation. Strategies to educate both the public and first-contact physicians to promote stroke literacy must be an intrinsic part of any program aimed at reducing the burden of stroke in any population.

# Assessment of Level of Practice on Post Stroke Rehabilitation Among Caregivers of Stroke Patients

The current study findings identified that, among our study participants with regards of practice on lifting and transferring, 32(53.33%) had inadequate, 26(43.33%) had moderately adequate and 2(3.33%) had inadequate. Practice on hygiene and positioning, 26(43.33%) had moderately adequate, 25(41.67%) had inadequate and 9(15%) had adequate. Practice on naso gastric tube feeding, 35(58.33%) had inadequate, 21(35%) had moderately adequate and 4(6.67%) had adequate.

Table 2: Frequency and Percentage Distribution Level of Practice Post Stroke Rehabilitation Among Caregivers of Stroke Patients

		N= 60
Level of Practice	Frequency (F)	Percentage (%)
Adequate	10	16.7
Moderately Adequate	20	33.3
Inadequate	30	50

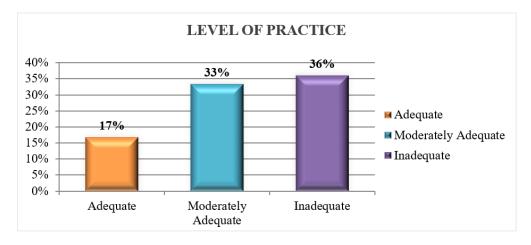


Figure 2: Level of Practice among Caregivers of Stroke Patient

The present study findings is consistent with the findings of the **Hanaa Moukhtar et al. (2021)** conducted a quasi-experimental design between caregivers and their patients in a neuropsychiatric and neurosurgical hospital. Convenience sampling technique is used to collect data from 125 stroke caregivers. According to the results of the study, the level of patient care in family caregivers was 100% inadequate in the preparatory program. These levels improved to appropriate practice at post-program and follow-up (72.0% and 75.2%, respectively) [19].

The present study findings is consistent with the findings of the results of a quasi-experimental study conducted by **Eman Ali et al. (2020)** among 50 caregivers of stroke patients showed that there was a low level of awareness and competency of home care practices prior to the intervention. After the intervention, both the control group and the experimental group's scores improved, but the experimental group's score increased [20].

As a result, the current study and the studies mentioned above show that care training boosted the self-efficacy of stroke patients. After patients are discharged, it is crucial to implement a planned health education program to improve the caregivers understanding of post-stroke patients' home care procedures and the patients' functional ability.

# **Assessment of Level of Stress Among Caregivers of Stroke Patients**

N = 60

Level of Stress	Frequency (F)	Percentage (%)
Mild Stress	10	16.7
Moderate Stress	35	58.3
Severe Stress	15	25

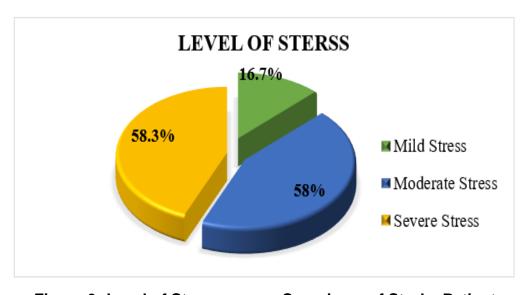


Figure 3: Level of Stress among Caregivers of Stroke Patient

The present study findings is consistent with the findings of the **Riddhi R et al. (2022)** conducted a cross-sectional study was done to examine the strain among 50 carers of stroke patients at hospitals in the South Gujarat region. The data suggest that carer strain was high in 90% and low in 10% of stroke carers, with 42 (84%) having a high degree of stress and 8 (16%) having a low level of stress among caregivers of stroke patients [23].

# **Assessment of Level of Burden Among Caregivers of Stroke Patients**

N = 60

Level of Burden	Frequency (F)	Percentage (%)
Mild Burden	10	16.6
Moderate Burden	30	50
Severe Burden	20	33.3

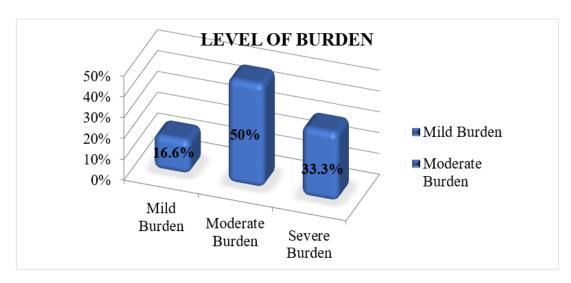


Figure 4: Level of Burden among Caregivers of Stroke Patient

The present study findings is supported by the observational study was carried out by **Sohkhlet G, Thakur K, David S I, et al. (2023)** to measure the perceived load on carers during stroke rehabilitation. The study included 76 carers, and the perceived carer burden score was low (mean-19.61), indicating that not all assistance is stressful. Each burden metric has a substantial connection with the Modified Rankin Scale for Disability (r=0.7, P0.0001). Further study found that carers experienced significantly higher levels of stress when the patient needed to exercise, walk, or use the restroom [24].

The present study findings is supported by **Azar Kazemi et al. (2021)** conducted a descriptive and cross-sectional study among 110 Iranian carers of elder stroke patients to assess the association between the severity of the burden of care and coping mechanisms. Most carers (n = 74, 67.3%) reported mild to moderate burden. Positive reappraisal and seeking social support were the most frequently stated coping mechanisms. Pearson correlations revealed a strong positive relationship between carer load and emotional-focused methods such as escape (r = 0.245, p = 0.010) and distance (r = 0.204, p = 0.032) [25].

Hence the current study and the above supportive studies revealed that, Informal carers with a greater burden of care used emotion-focused tactics, which do not always assist reduce carer stress. As a result, training programs teaching carers effective coping methods are required to promote their usage of effective and healthy coping strategies.

Section- C: Correlation between the of Level of Knowledge on Post Stroke Rehabilitation, Stress, and Burden Among Caregivers of Stroke Patients.

N = 60

Variables	Mean	S. D	Karl Pearson's Correlation 'r' value
Knowledge	13.83	4.28	r= -0.812
Stress	29.11	5.66	p=0.0001, S***
Knowledge	13.83	4.28	r= -0.829
Burden	55.35	17.14	p=0.0001, S***
Stress	29.11	5.66	r= 0.913
Burden	55.35	17.14	p=0.0001, S***

<sup>\*\*\*</sup>p<0.001, S – Significant

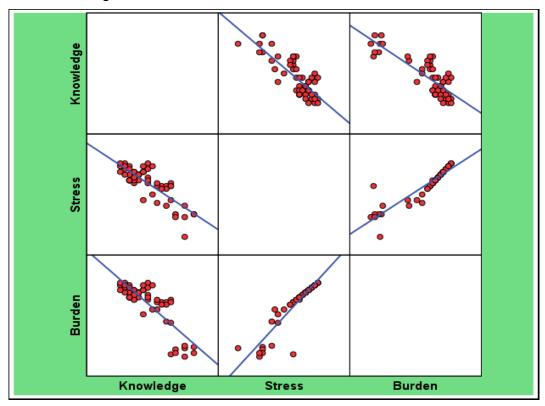


Fig 5: Correlation between the of Level of Knowledge on Post Stroke Rehabilitation, Stress, and Burden Among Caregivers of Stroke Patients

The mean score of knowledge was  $13.83\pm4.28$ , mean score was  $29.11\pm5.66$  and the mean score of burden was  $55.35\pm17.14$ . The Karl Pearson's Correlation value of r = -0.812 between knowledge and stress, r = -0.829 between knowledge and burden shows a negative correlation which was found to be statistically significant at p<0.001 level.

This clearly infers that when knowledge regarding post stroke rehabilitation decreases then stress and burden among caregivers of stroke patients increases. The Karl Pearson's Correlation value of r=0.913 between stress and burden shows a positive correlation which was found to be statistically significant at p<0.001 level. This clearly infers that when stress among caregivers of stroke patients increases then ultimately the burden among caregivers of stroke patients increases.

# Section- D: Association between the of Level of Knowledge and Practice on Post Stroke Rehabilitation Among Caregivers of Stroke Patients with selected demographic variables.

In our present study, the demographic characteristics including duration of stay and living condition of caregiver had statistically significant association with level of knowledge and practice on post stroke rehabilitation among caregivers of stroke patients at p<0.05 level and the other demographic variables had not shown statistically significant association with level of knowledge and practice on post stroke rehabilitation among caregivers of stroke patients.

The present study findings is supported by **Vishnu Sharma (2020)** applied descriptive design and purposive sampling technique to collect data with 100 primary care givers. Data were collected using a self-structured questionnaire about CVA symptoms and treatment. According to the results of the study there is significant association found between level of knowledge and practice regarding care of patient with CVA at p<0.05 level with education, duration of care and health issue of care giver [17].

The present study findings is supported by 200 patients in general (OPD), who were consecutively selected after satisfying the inclusion criteria, participated in a hospital-based cross-sectional study done by **Jogindra Vati & Parveen Sandha (2022),** demographic profiles, clinical profiles, and knowledge tests on risk factors, symptoms. The study there is significant association found between level of knowledge and practice regarding care of patient with stoke at p<0.05 level with duration of care [16]

#### **LIMITATIONS**

The researcher could not generalize the study findings as the sample size is relatively small and limited to 60 caregivers. Only caregivers admitted in selected hospital were included into the study. Another limitation is selected hospital area used for data collection. Only the cognitive and psychomotor skill of caregivers were considered. The current study has only few supportive studies in Indian Population due to paucity of literature.

#### CONCLUSION

The results of the current study showed that the majority of caregiver lacked enough information about post-stroke rehabilitation, indicating the necessity of providing caregiver with an adequate education program in order to effectively manage post-stroke rehabilitation of stroke patients. Understanding and meeting the needs of different caregiver subgroups is crucial as the to protect the health and wellbeing of caregiver. Significant numbers of caregiver expressed burden and unpreparedness. To enable informal caregiver to carry out their tasks, healthcare professionals should offer sufficient assistance. Strategies to educate both the public and first-contact physicians to promote stroke literacy must be an intrinsic part of any program aimed at reducing the burden of stroke in any population. Health education, empowerment/guidance, home-based rehabilitation, and information and emotional support are all strategies that can effectively decrease carer stress, boost patient family support, and improve the quality of life for both patients and carers. Lower the financial pressure of family carers, improve the family support for disabled stroke patients, reduce the patient's low mood, encourage the confidence of the patients on

upcoming rehabilitation, increase their rehabilitation compliance, and ultimately improve the rehabilitation efficacy.

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#### **Authors Contribution**

Sridevi.B developed the study concept and design, Vignesh collected the clinical data, Kavitha.M and Deepika.D statistical analysis and interpretation of data, Sridevi.B study supervision, critical revision of the manuscript for the intellectual content and drafting of the manuscript. All authors read and approved the final manuscript.

### **Conflict Of Interest And Finding Support**

The authors for the current project has no financial investment and are not the investor in any of the health sectors related to the project and not received any consultation payments. They did not have any patents linked to the project. The authors have no personal or professional contact with any of the health care organisations.

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