

# Hurdles Faced by Stroke Survivors and Their Caregivers in India: A Qualitative Study

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## ABSTRACT

**Background:** Stroke is a seriously disabling disease that can affect both the patients and their caregivers in different ways but in equal proportion. This study aimed to explore the experiences of stroke survivors and along with their caregivers after one year of stroke in India.

**Methods:** Twenty stroke survivors and their caregivers were selected for our qualitative, study. Participants who attended two rehabilitation centers were selected using a random sampling method. A previously standardized questionnaire was used to collect information during the interview process.

**Results:** Post-stroke occupational demands were less met and poor awareness of stroke led to various systems of medicines (Indigenous medicine) being tried even after the neuroplasticity had weaned out.

**Conclusions:** The study highlights the need for stroke education for setting up post-stroke recovery expectations from the patient as well as the caregivers. The physiotherapy sessions should commence at the earliest for better results and there should be an emphasis on return to occupation or occupational modification.

**Keywords:** Stroke, stroke survivors, caregivers, physiotherapy

## INTRODUCTION

Stroke is one of the leading causes of death and the third leading cause of disability worldwide. In 2013, it caused 6.5 million deaths and 113 million disability-adjusted

life years. With Asia accounting for 60% of the world's population, life expectancy is expected to increase as infectious disease control improves in South Asia. (1,2) This may lead to greater exposure to stroke-related risk factors and thus higher stroke rates, especially if the risk factors are modifiable, not controlled. The limited availability of health care in developing countries can lead to higher mortality rates and more survivors with disabilities. (3) In addition to the physical harm caused by a stroke, the emotional, social and economic impacts of a stroke can be enormous for stroke survivors and their families. (4) Post-stroke depression is thought to affect about one-third of people with chronic stroke, is difficult to diagnose and therefore remains undetected and untreated. (5) Post-stroke depression, as well as factors such as social isolation, age, and functional impairment, are associated with reduced participation. The majority of stroke survivors living at home 6 months after their stroke reported a lack of social, recreational, and meaningful activities. (6,7) Balancing the dual responsibility of caring for a stroke survivor, while maintaining necessary lifestyle adjustments, is a challenge for caregivers. It is therefore essential to consider the effects of stroke on caregivers, especially given the sudden onset of stroke and the unexpected lifestyle changes needed to adapt to the situation. Naturally, this can lead to chronic stress, affecting the

caregiver's physical health, subjective well-being, and self-confidence. Although the effects of stroke on survivors and caregivers are well documented, little is known about these outcomes compared with the Indian population due to the availability of rehabilitation services. limited function for stroke survivors. Therefore, the aim of this study was to explore the experiences of stroke survivors and their caregivers one year after a stroke in India.

## **METHODOLOGY**

A qualitative study explores the experiences of stroke survivors and their carers in India. Participants were informed about the study and informed written consent was obtained prior to the commencement of the interviews through oral and written communication in Bengali. Speakers: Stroke survivors and caregivers from two different rehabilitation units, one in rural and one in urban, were selected for this study. They were randomized using a randomized panel method where patients from both units were cumulatively entered into the table and then randomly selected. The inclusion criteria were patients with a residual disability after 1 year of stroke for whom they attended physical therapy sessions. A year was chosen to identify the long-term challenges that stroke survivors and their carers face in reintegration into the community, thereby identifying rehabilitation and social needs unmet potential back home. Patients are treated by a professional physiotherapist every day with different practice guidelines. To be included in the study, patients had to be diagnosed with a stroke by a licensed control physician, which was necessary due to the number of other medical professionals such as Siddha, homeopathy, acupuncture, etc. Indigenous medicine practice in India. This will ensure that an accurate diagnosis has been made by a qualified medical professional. One of the goals of the study was to collect information from caregivers, so caregivers must be present at the follow-up to provide this information. Patients were excluded if they had a recurrent stroke,

stroke surgery, or transient ischemic attack. Patients with severe communication impairment or cognitive impairment were excluded due to the subjective nature of the study.

## **Data collection**

The sample population was selected according to the random sampling method using a random number table. A small number of participants were suitable for our qualitative study, of which twenty participants were sufficient to reach the data saturation point. Data were collected from September 1, 2021, to January 31, 2022, from participants who attended a post-stroke rehabilitation follow-up session. A semi-structured questionnaire was developed to guide the researchers in their data collection during the interview process. All socioeconomic information was collected and questionnaires were completed during face-to-face interviews. All interviews were conducted in Tamil and recorded. The interviews lasted approximately thirty minutes and no repeat interviews were conducted. Data is stored in the form of transcripts and voice recordings; All patient-identifiable information is kept securely in a locked office.

## **Data analysis**

Three data encryption experts manually reviewed the recording and qualitative content analysis was performed to verify the data and decipher common themes. The information was later translated into English. Transcripts were not returned to participants for comment and participants provided no feedback on the results. The researchers did not provide the treatment or have any prior relationships with the participants.

## **RESULTS**

Of the 25 stroke survivors and caregivers approached, 20 agreed to participate in this study and complete their interviews. The majority of our stroke survivors are male (65%), employed (70%) and have some

level of education, with only 5% having no formal education. Every stroke survivor has a caregiver who supports them at home with various daily tasks. Carers are aged between 16 and 75 and most are women (70%). (See Table 1 for details on social demographics).

#### **Theme1: Prior knowledge of stroke**

Although the majority had some form of education, only one stroke survivor reported prior knowledge of the stroke and associated risk factors.

All stroke survivors do not know they have a stroke until the diagnosis is confirmed by a doctor.

#### **Theme 2: Hospitalization after stroke**

All stroke survivors are hospitalized after a stroke. The length of stay (LOS) in the hospital ranges from 1 to 30 days. Stroke survivors were asked about their experiences in the hospital. None of the stroke survivors received rehabilitation (physical therapy, occupational therapy, or speech therapy) on admission. 55% said there was no improvement in their physical, psychological or social health during their hospital stay, while 45% said there was some improvement.

Stroke survivors were asked about the healthcare system in India. 90% have poor awareness of government health services but cannot determine how to improve them. 10% have a good experience using the health system.

#### **Theme 3: Access to the rehabilitation after hospital discharge**

Stroke survivors have heard about CRP from a variety of sources, 45% were referred by relatives for CRP and 40% were referred by doctors. The remaining 15% are encouraged to attend by friends and neighbors who have received CRP treatment. All stroke survivors received physical therapy interventions at CRP, with 60% receiving occupational therapy in addition to physical therapy. 35% received speech therapy along with physical therapy and occupational therapy.

#### **Theme 4: One-year degree of independence after leaving CRP**

18 stroke survivors reported being able to switch from lying to sitting position on their own, and 14 reported being independent in some activities of daily living. Eight said they were able to move without assistance and four said their mood improved. One stroke survivor reported regaining movement only in the fingers and another reported no improvement in function.

#### **Theme 5: Challenges of returning home after rehabilitation at CRP.**

All stroke survivors need some support from their carers. 80% cannot access safe and effective rehabilitation. 70% of stroke survivors are unable to return to work or home due to the physical, emotional and social effects of a stroke.

#### **Theme 6: Difficulties faced by caregivers**

Caregivers were asked about the impact of their loved one's stroke on their lives. Common challenges include financial difficulties and lack of time for their social, educational and personal needs. When asked how their health was affected, only 10% of caregivers had no physical problems. 55% of caregivers experience back pain and more than 25% report neck pain while caring for a loved one. 10% of caregivers reported upper limb paresthesia.

Most caregivers do not know how the healthcare system can be improved. However, some feel that caregivers should have easier access to prevention and rehabilitation programs and that public hospitals should provide therapy.

## **DISCUSSION**

Our study showed that knowledge about stroke and its associated risk factors in participants was low before they had a stroke. With little knowledge of the risk factors associated with stroke, it is possible that very few people understand the importance of seeing a doctor to manage any modifiable risk factors. The mortality

rate from stroke is higher in Asia than in Western Europe, the Americas and Australia. Many of these strokes could be prevented if awareness improved and these risk factors were better managed. (8)

Research has shown that the use of mass media and public education campaigns are effective in raising awareness about stroke and its risk factors. In the past, various obstacles may have affected the ease of disseminating information through the media in India, including low literacy levels and difficulty in accessing the Internet in rural areas. As these barriers ease, it is essential that governments and healthcare professionals work closely together to educate the public to mitigate this growing epidemic. (3.9-10)

Although hospital stays vary, none of our stroke survivors received any form of rehabilitation during their acute care hospital stay. A Cochrane review found that acute stroke patients receiving multidisciplinary rehabilitation were more likely to survive, regain independence, and return home. Stroke guidelines have emphasized the importance of early multidisciplinary assessment and rehabilitation, which is associated with better functional outcomes at discharge and follow-up and shorter hospital stay. . Lack of in-hospital counseling and rehabilitation contributed to stroke survivors' dissatisfaction with the healthcare system in our study. (13-11)

Common challenges faced by stroke survivors in our study were financial problems, social isolation, and travel difficulties, which is consistent with previous research. Returning to work is another challenge identified in our study. Previous research has shown that it is affected by walking ability, cognitive function and occupation and is associated with better life satisfaction. Therefore, return to work programs should be included in rehabilitation. Although 40% said they were able to move independently and 70% said they were independent in some daily activities, only 30% of stroke survivors in

our study returned to work. job. This may be the result of a lack of ongoing community recovery in India. In addition, the lack of regulatory bodies for professions such as physical therapy causes stroke survivors to seek ineffective and dangerous treatment from unqualified and unqualified therapists. controlled. (14.15)

Challenges caregivers faced in this study included financial difficulties and lack of time for social, educational, and personal needs. For example, a young nurse assistant does not have time for her studies. While caregiving can improve caregivers' self-efficacy, allowing them to learn new skills and strengthen family relationships, it often leads to chronic stress, negative effects on the physical and psychosocial well-being of caregivers. In the absence of government nursing homes or support for informal carers, we find that the responsibility to support stroke survivors can force a shift in the relationship between caregivers and stroke survivors, carers refer to affected family members as "my patients". Significant changes in roles and responsibilities within the family were also identified by family caregivers in Sri Lanka and India, with their lifestyle significantly altered in adverse ways. These studies also recognize the need to provide better training and support for caregivers, which is consistent with our findings. (16.17)

## **CONCLUSION**

Knowledge about stroke and its risk factors is low. Governments and healthcare professionals need to improve education on this topic to raise awareness and reduce stroke rates. None of the participants received rehabilitation while in hospital and all experienced delays in accessing rehabilitation upon discharge. Implementing a stroke pathway that raises awareness and then referral to rehabilitation can improve access and reduce these delays. Thus, improving possible outcomes for stroke survivors and reducing the burden on caregivers. Stroke survivors and carers experience socioeconomic, psychological,

and physical stress. Therefore, ongoing support and training is needed to reduce these burdens. Most stroke survivors do not return to work. Future research should investigate this issue and the experiences of stroke survivors and caregivers without rehabilitation.

### **Declaration by Authors**

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