



A Scoping Review in Indian Post-Stroke Patients

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Abstract

Stroke is the second most common cause of death worldwide and the third most common cause of disability-adjusted life years (DALYs) worldwide. According to the available evidence, 85.5 % of total stroke fatalities are reported in low- and middle-income countries compared with high-income countries. In addition, the prevalence of DALYs in low-income countries is very high. The major challenge is the vastness of India and its humongous population size, which makes it nearly impossible to reach patients far away. The quality of life (QoL) of stroke survivors is an important factor in predicting the burden of the disease and determining the effectiveness of treatment. Many research studies provide an overview of the overall estimates of QoL and contribute to research on QoL after stroke in India. Owing to the bleak post-stroke rehabilitation facilities in India, stroke patients don't get the post-stroke care they ought to. The gap is not only in the patient care management system but also in the policies laid out by the government. The unmet gaps in post-stroke rehabilitation and patient care remain a major setback in patient care management, which impacts the clinical outcomes at large. These challenges are the reasons for the increasing disease burden on society and the hampering of the socio-economic status of the country at large. The government authorities should lay down the policy that will help the patient seek the correct in-time treatment for stroke and help the post-stroke patients to live a QoL.

Key words: Quality of life; Rehabilitation; Post-stroke rehabilitation; Patient care management; Patient education.

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Introduction

In India, the rate of stroke-related hospitalisations is 46 out of every 100,000 people (Figure 1 and 2). The average and median cost per stroke-related episode is approximately ₹40,360 (about 539.75 US\$) and ₹17,140 (about 229.22 US\$), respectively. There are a lot of out-of-pocket expenditures for post-stroke hospitalisations across different wealth quintiles. About 29 % of households looking for stroke treatment in public hospitals had to pay out of pocket, while 37 % of households had to use borrowed health financing from relatives and neighbours. On average, drugs make up 38 % and outpatient care 73 % of public sector hospitalisations. Patients who were

hospitalised in a private facility and stayed there for more than 7 days were more likely to have catastrophic expenses.¹

The unmet need for post-stroke rehabilitation services is due to the limited rehabilitation resources available in India, the development of an accessible, innovation-driven, patient-centric and culturally sensitive rehabilitation intervention has public health implications. Developing technology-based stroke rehabilitation strategies is essential for low and middle-income countries such as India to meet the increasing rehabilitation demands of stroke survivors. One

of the main reasons for this is a lack of knowledge about stroke and how to manage stroke-related disabilities. The financial burden of stroke treatment and support increases for stroke survivors and families.

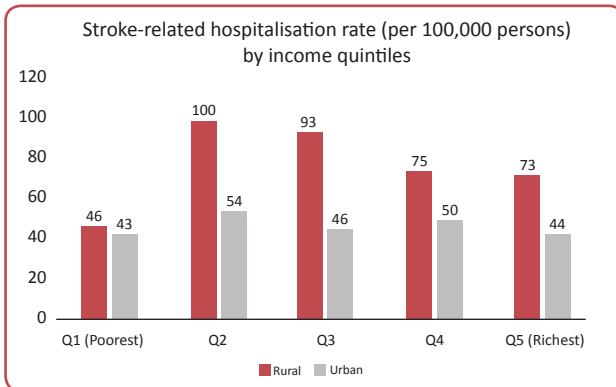


Figure 1: Stroke hospitalisation rates by income quintiles in India in 2017-2018¹

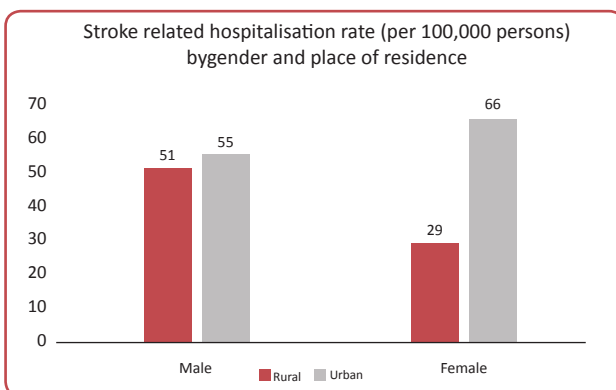


Figure 2: Stroke hospitalisation rates by gender and place of residence in India¹

Due to a lack of rehabilitation resources in India, the development of innovative, multi-disciplinary, patient-oriented and culturally sensitive rehabilitation interventions is of paramount public health importance. In India, there is a lack of information on the rehabilitation needs of people with disabilities, particularly after stroke, where people with disabilities generally face several obstacles in accessing rehabilitation services.²⁻⁵

Roadblocks in post-stroke management

While the number of acute stroke units in India is growing as resources become more accessible, they serve only a small fraction of India's population and most Indians do not receive rehabilitation services either in the hospital or after discharge. Developing effective, low-cost community rehabilitation interventions

for emerging chronic diseases like stroke in India has the potential to significantly impact public health. These interventions, if proven to be cost-effective and feasible, could be scaled up or generalised. The research challenge of how to develop sustainable and multifunctional rehabilitation systems for the rural population in low and middle-income countries, including providing services to the poor, was ranked as the second-most important research priority for disabled people (after equal access to healthcare) by a recently published Lancet expert panel.⁶

For stroke patients, mobility issues and the inability to do basic functional tasks like walking and feeding with the affected handled to sudden reliance on their spouse for basic care and day-to-day activities. As a result, spouses had to shoulder the burden of caregiving, while most participants had little or no access to rehabilitation or health services at a community level.⁷

The care management of stroke survivors is too poor for patients coming from humble backgrounds in India. The post-stroke care is not at all understood and well-practiced by hospitals and stroke care units. Once the patient gets discharged from the hospital the rehabilitation takes a backseat and the patient becomes dependable on his/her family for daily routines.

The most common post-stroke disability is motor impairment, which occurs either as a direct result of the loss of signal transmission from the cerebral cortex, as a gradual accumulation of cerebral injuries, or as a result of muscle atrophy caused by learned disuse. According to Divani et al,⁸ the risk of fall and fall-related injury was higher among stroke elders.

Risk factors associated with an increased fall risk in stroke survivors include: gender (women are more prone to falls), poor general health, time since the first stroke, psychiatric problems, urinary incontinence, pain, previous injury from fall, psychological problems, uterine incontinence, impairment of hearing, motor impairments, multiple strokes, motor function deficits and increased fall risks.

Fall-related injuries can severely impact the patient's mobility and daily life, which limits their ability to participate in social activities and other professional activities.⁸⁻¹⁰

Lack of patient education and stroke awareness

The level of patient education and stroke awareness among common Indians is bleak and very poor. Stroke patients are not getting help once they have a stroke regarding the disease and rehabilitation which leads to poor outcomes and impacts of disability-adjusted life years (DALYs).

Patients often have very limited knowledge about the impaired mobility after a stroke which can lead to the development of pressure sores (pressure ulcers), which in turn can lead to the formation of deep vein thromboses (DVTs) and pulmonary embolisms. Pressure ulcer occurs when there is an imbalance between the external forces acting on the skin and soft tissues and the internal sensitivity of the skin and its soft tissues to injury.

The lack of knowledge of patients with pressure ulcers is more likely to die after a stroke. Both men and women aged 60 years and older are more likely to develop pressure ulcers after a stroke. Stroke patients are also more likely to develop deep DVTs and pulmonary embolisms due to their immobility and increased prothrombotic activity. The primary risk factors for poststroke DVT are advanced age, male sex, congestive cardiac failure, malignancies and fluid and electrolyte abnormalities. These lacunas often impact the clinical outcomes and patients are forced to live with disability and this leads to an increase in mortality rates.¹¹⁻¹⁴

As the population ages, the local government has implemented several initiatives to improve access for the elderly to overcome the mobility issues that elderly stroke survivors face. These include the installation of a ramp and additional lifts at the local subway stations, the introduction of wheelchair-accessible public buses, a lift upgrading program to ensure lift access at every level of the public housing block and a heavily subsidised public housing home improvement program that includes ramp and steps at the entrance of the housing units.¹⁵

For elderly stroke survivors who don't have caregivers to accompany them to outpatient rehabilitation centres, authors recommend the implementation of an affordable home rehabilitation program or inexpensive telerehabilitation services. The ongoing local trial on telerehabilitation during the first 3 months post-stroke may provide more insight into

the potential benefits and cost-effectiveness of telerehabilitation in the Singapore post-stroke population. Home based robotic therapy (HBRT) could be considered for elderly stroke survivors who had difficulty accessing outpatient rehabilitation. In addition, HBRT has been shown to reduce costs and improve access to rehabilitation for stroke survivors. To correct the common misconception that rehabilitation is the same as home exercises without the support of a rehabilitation team, it is essential to provide education on rehabilitation during acute admission. Evidence-based educational guidance has helped stroke survivors (and their families) to understand the value of rehabilitation, manage their co-morbidities and CV risk factors and reduce their recurrence risk.^{16,17}

Role of patient education in post-stroke rehabilitation

It is important for patients and the community to be informed about the signs and symptoms of stroke. Teaching the patient to return to as much self-care as possible is very important. Assistive devices should be provided as indicated in guidelines from time to time. An occupational therapist should make a home assessment and recommendations to assist the patient in becoming more independent. Coordinated care provided by multiple healthcare providers; assisted the family in planning aspects of care; advised the family that the patient may be fatigued easily, irritable and agitated by minor events and less interested in daily activities. Therapist should recommend home speech therapy; recommend family involvement, provide practical instructions to assist the family between speech therapy appointments. If necessary, talk to the physician about possible antidepressant therapy for the patient. He/she should encourage the patient to participate in community-based stroke clubs to provide a sense of belonging and companionship to others; encourage the patient to pursue hobbies, recreational and leisure interests; keep in touch with friends to avoid social isolation; encourage the family to support the patient and provide positive reinforcement, as well as remind the family that they need to attend to their health and well-being.

While stroke education during hospitalisation is necessary, its impact on secondary prevention and early detection of new events is still poorly understood. One of the reasons for this is that providing high-quality patient education

is expensive in terms of human resources, especially when many hospitals are unwilling and unable to provide extra full-time nurses to support other aspects of care that go beyond physical needs. While hospitals typically provide written materials about stroke for patients and caregivers, it is not clear whether many utilise high-engaged stroke team (HES) members for the kind of comprehensive education authors used in a pilot study. While it was not evaluated how uneducated patients / primary caregivers would have performed on these test items, the results would likely have been similar, if not worse, compared to the pilot study cohorts. This raises the question of whether more than a written handout is necessary given such poor retention rates.^{18,19}

Requirements in post-stroke management in India

Acute ischaemic stroke is still a life-threatening condition that has a considerable impact on individuals, their loved ones and the healthcare system, despite the advances in diagnosis and treatment over the past decade.²⁰ As evaluations, medications and care for acute stroke have evolved over the past decade, the best practices of nursing and interdisciplinary care need to be adapted and updated to reflect the principles of best practice. Through continuous observation and assessment, nurses can identify patients at risk of clinical deterioration. Prompt and appropriate action is also taken when changes in a patient's health status are detected.²¹

Medical attendants should conduct extensive and precise actual assessments for all patients who have experienced a stroke, including checks of the primary 5 essential signs: internal temperature, pulse rate, respiration rate, chest extension, oxygen saturation and mental state/level of consciousness. Evidence-based nursing care and ongoing assessment are essential to reduce unfavourable outcomes for patients following stroke.²²⁻²⁴ Better flow of stroke recovery program is necessary for better clinical outcomes (Figure 3).^{26,29}

Recent rehabilitation of stroke patients in India

Analysing the physiotherapy management, it was divided into three levels:

Level 1: easy to do at most set-ups, including District hospitals. Necessary equipment is 3-4 pillows, 2 sandbags, a shoulder sling (one can be made at home), a simple mirror and a static ankle foot orthosis.

Level 2 requires some equipment and expertise, but it's still pretty easy to get. Necessary equipment is a postural mirror, a functional electrical stimulator, an electrical neuro-muscular stimulator, a static cycle, a tre-admill and an indirect pneumatic compression unit.

Level 3 is for more advanced rehabilitation centres and necessary equipment is a surface EMG biofeedback system, body weight support

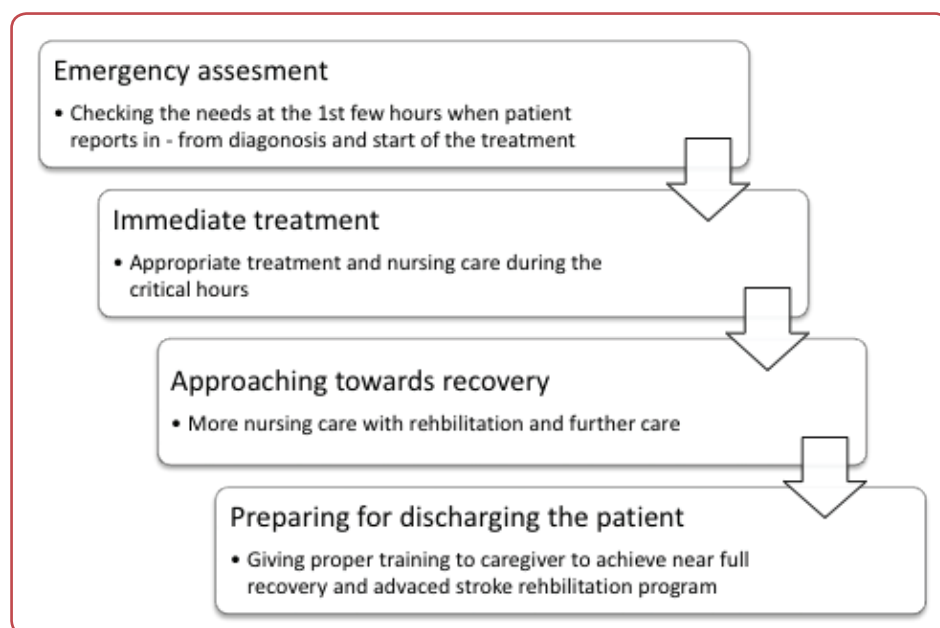


Figure 3: Flow of stroke recovery program for better clinical outcomes^{26, 29}

treadmill trainer, arm ergometry, robotics, mental imagination, visual scanning training, force platform, balance and gait analysis system.²⁵

Owing to the diversity in India a multidisciplinary approach is necessary to create awareness and support groups for post-stroke patient care management. The needs are numerous and diverse for post-stroke patients and caregivers to cater to the variety of requirements for improving the DALYs. Patient education is not widely available to help patients live a quality life post-stroke when they reach home for recovery. The usual approach of post-stroke patients has not been up to the mark as compared to developed nations wherein the patients get home-based post-stroke rehabilitation and they are more likely to live an independent life. In India stroke patients specifically from the lower income groups are not getting the due rehabilitation when they reach home. The caregivers are not being educated by the nursing staff or the clinicians about post-stroke care which can be pivotal in enhancing the quality of life (QoL) of the stroke patients post-discharge from the critical care unit.^{27,28}

Rehabilitation is essential to reduce the recurrence of stroke-related complications and patients who receive ongoing professional and systematic rehabilitation after the acute phase of the stroke tend to recover quickly.²⁹ Currently, drug and rehabilitation therapy is practiced as a rehabilitation treatment for stroke. The various interventions that can be employed in the recovery process include bilateral training, repetition of tasks, movement therapy based on constraint, electrical stimulation, robotics and exercise.^{30,31} Exercise is of paramount importance to assist patients in returning to activities of daily living by restoring the functioning of damaged muscles and enhancing physical function. Furthermore, exercise is necessary to prevent secondary complications, as demonstrated by a study that found that post-stroke exercise and physical activity reduce the risk of recurrent cardiovascular disease and mortality.^{32,33}

The government or health ministry should create a robust plan for creating awareness about the available resources that may help post-stroke patients to a large extent in living an independent life after they get back home with limited abilities.

Conclusion

There is little or no research on the role of nurses in post-stroke management and the role of physiotherapists which is home-based. The lack of research on this topic persists despite evidence that stroke patients are better treated when treated by a multidisciplinary team. It is hoped that this review will serve as a tipping point for recommendations for the streamlined role of clinicians, the nurse and the physiotherapist in post-stroke care and rehabilitation, as well as serve as a motivation for other researchers to conduct real-world studies using larger and more representative samples for the larger good of Indian society.

Stroke rehabilitation needs are on the rise in low and middle-income countries like India, so it's essential to create technology-based stroke rehabilitation plans to meet these growing demands.

Acknowledgement

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Conflict of interest

None.

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