

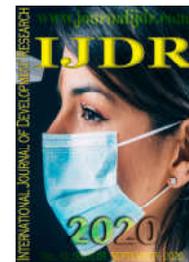


ISSN: 2230-9926

Available online at <http://www.journalijdr.com>

IJDR

International Journal of Development Research
Vol. 10, Issue, 09, pp. 40776-40780, September, 2020
<https://doi.org/10.37118/ijdr.20029.09.2020>



RESEARCH ARTICLE

OPEN ACCESS

BARRIERS AFFECTING EFFECTIVE STROKE REHABILITATION IN KERALA

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ARTICLE INFO

Article History:

Received 17th June 2020

Received in revised form

06th July 2020

Accepted 14th August 2020

Published online 30th September 2020

Key Words:

Stroke, Physiotherapy Rehabilitation, Barriers.

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ABSTRACT

Introduction Stroke is a major life changing health condition caused due to interruption of blood supply to the brain. The rehabilitation of stroke subjects is vast and time consuming and physiotherapy is the integral part of it. Although physiotherapy treatment plays a vital role in rehabilitation of stroke survivors, the number of people receiving regular physiotherapy service is much lesser than expected. **Objective** This study was conducted to identify the barriers for effective rehabilitation of stroke subjects in Kerala. **Method** 300 stroke survivors from different parts of Kerala were recruited and were asked to fill out a customized questionnaire to identify the barriers in physiotherapy rehabilitation. The different barriers included were Economic, Geographical, Socio-cultural and Facility barriers. **Result** Out of the four main barriers presented, it was found that the most common barrier was Facility barrier. Socio-cultural barrier was found to be the second most faced barrier followed by financial and geographical barriers. **Conclusion** The study concluded lack of easily available rehabilitation centers and lack of efficient communication between stroke survivors and rehabilitation professionals to be the major barriers in effective rehabilitation of the subjects.

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Citation: Binu James, Dr. Raj S Chandran, Mr. Unnikrishnan R, Mr. Jimshad TU, Dr. Anilkumar P and Dr. Rajmohan B P. 2020. "Barriers affecting effective stroke rehabilitation in Kerala", *International Journal of Development Research*, 10, (09), 40776-40780.

INTRODUCTION

Stroke is defined by WHO as 'the rapid development of clinical signs and symptoms of a focal neurological disturbance lasting more than 24 hours or leading to death with no apparent cause other than vascular origin' (Hatano 1976). Stroke is caused due to interruption of the blood flow to the brain, mainly due to ruptured or blocked blood vessel (Murray 1996). Stroke is a major global health concern. The Global Burden of Disease (GBD) study showed nearly 5.87 million stroke deaths globally in 2010 compared to 4.66 million in 1990 (Strong, Mathers 2007). With the rising extent of mortality, stroke still remains the second most found reason for death around the world. As per the appraisals from the GBD contemplate in 2001, more than 85 percent of the worldwide weight of stroke was borne by low-and middle income countries (LMICs) (Strong, Mathers, 2007).

Due to the lack of reliable sources and disease or mortality registration systems in LMICs, the epidemiological findings from the GBD study for most of the LMICs are likely to be incorrect (Murray CJL *et al.*, 2012). A systemic review that included all published articles from year 1960 to 2015 depicted that the total incidence of stroke in India ranged from 105 to 152 in every 100,000 persons per year, and the prevalence of stroke was around 44.29 to 559 in every 100,000 persons (Kamalakaran *et al.*, 2017). These numbers are much lower in developed countries. Stroke is therefore an important cause of untimely demise and disability in poor nations (Pandian *et al.*, 2013).

While remarkable advances have been made in the medical management of stroke, most post-stroke care will continue to rely on rehabilitation services without a widely applicable or appropriate medical treatment (Langhorne *et al.*, 2011). Physiotherapy plays a significant role in stroke

recovery among other health-care programs (Khan *et al.*, 2012). Poor adherence to physiotherapy can negatively affect outcomes and healthcare cost. Most stroke survivors in India continue to live with disabilities for whatever reason, and the costs of ongoing rehabilitation and long-term care are largely borne by family members, which impoverish their families (Pandian *et al.*, 2013). Information on the rehabilitation needs of people with disabilities, especially after stroke, is lacking in India, where people with disabilities typically face many barriers to accessing rehabilitation services (Kamalakaran *et al.*, 2016). While Kerala is a role model state for an efficient healthcare system in India, effective rehabilitation of strokes is still at an early stage (Khan *et al.*, 2012). Because stroke rehabilitation is a multidimensional approach and disability is viewed today in terms of the interaction between the individual, the environment and other coexisting factors, knowledge of such factors as facilitators or barriers is needed to decelerate the process of disability creation and accelerate patient rehabilitation. While there is a growing acknowledgement of the significant role that engagement plays in rehabilitation, there is limited knowledge of the factors that may help or hinder engagement in stroke rehabilitation. Thus, this study was conducted to identify the barriers in achieving effective rehabilitation of stroke survivors in Kerala.

METHODS

Pilot Study: Prior to the main study, a pilot study with 10 subjects from Government Medical College Trivandrum was conducted to check the effectiveness of the questionnaire. The short assessment of patient satisfaction (SAPS) questionnaire was used for the pilot study. The questionnaire was filled by the subject/ relative on the day of their discharge, and the subjects were instructed to meet the investigator on their first follow-up. The average time of their first follow-up was after 3 weeks of discharge. The data showed that SAPS questionnaire did not give all the relevant information which was needed to meet the demand of the study. So a customized questionnaire consisting of 30 questions was prepared and scrutinized by the higher authorities.

The content validity of the customized questionnaire was verified and later used as outcome measure in the main study.

Main Study Data Collection: A multi central cross sectional study was conducted from August 2016 to September 2017. The information about stroke subjects was collected from the Community Health Centers in rural areas and from Medical Records Division of Government hospitals in urban areas. 375 subjects were recruited by cluster sampling from three different regions of Kerala state, namely Extreme South, Mid Kerala and Extreme North.

Participants: Out of 750 subjects, total 300 subjects were selected for the study after giving due consideration to inclusion and exclusion criteria. The 300 subjects included in the study were selected from three different regions of Kerala, 100 from each. Inclusion criteria mainly included both male and female subjects aged between 40-60 years and post discharge duration for 1-2 months. Recurrent stroke survivors and subjects with other related co-morbidities were excluded from the study. Detailed discussion about the benefits and risks about the study was done after which permission was sought in this regard and informed consent form was signed by the subject/relative. The subjects were then asked to fill the questionnaire to have precise information regarding the barriers in the rehabilitation process of stroke survivors.

Questionnaire Variables: The customized questionnaire incorporated questions to assess four major domains:

Socio-cultural barriers: This included education level of the subject and the family, co-operation and physical support from family members, the psychological well being of the subject. It also incorporated the cultural aspects like religious faith and beliefs. Example: “Do you have enough people to accompany you for rehabilitation?”; “Do you think that any of your culture/ beliefs/ rituals prevents you from rehabilitation?”

Economical Barriers: This included the financial status of the family, monetary support from relatives and aids from NGO's or local bodies. Deficiency of basic utilities like bed, coat, commode, wheel chair etc was also included in this domain.

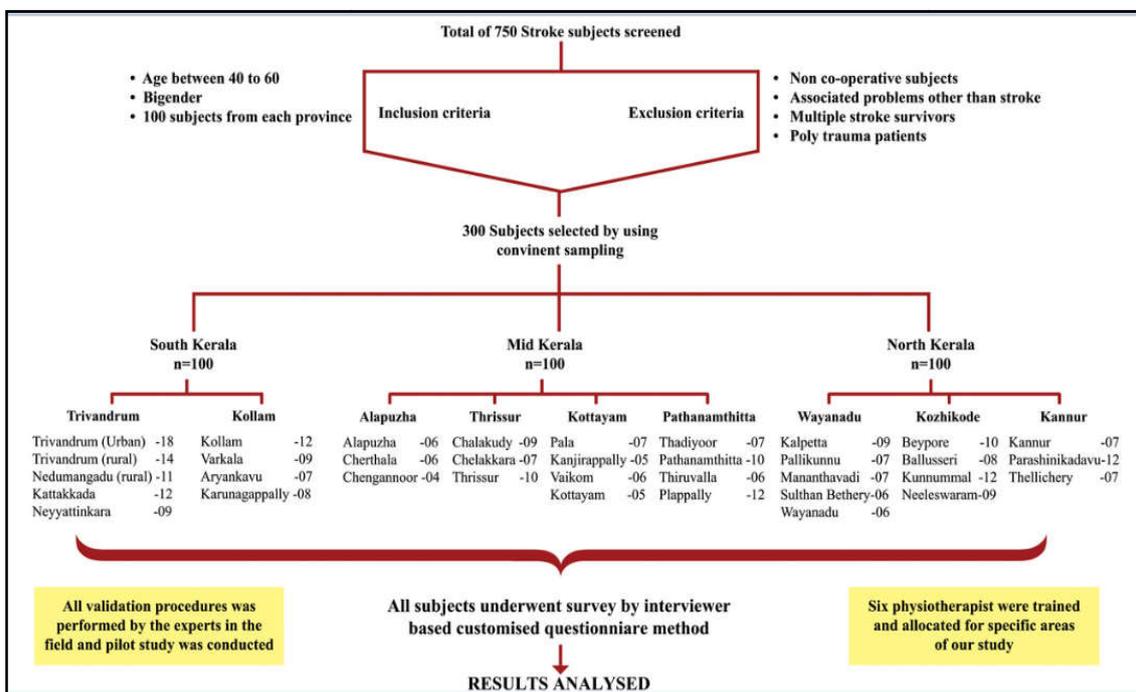


Figure 1. Methodology Flow Chart

Example: “Is the stroke survivor the only earning member of the family?”; “Are you getting essential medicines from the local hospital or health care provider for free of cost?”

Geographical barriers: The topography and terrains which affect rehabilitation process such as lack of accessibility, transportation difficulties, and extreme climatic conditions were incorporated in this domain. Example: “Do you get transportation whenever you are in need?”; “Whether any geographic factor affects your visit to rehabilitation center?”

Facility barriers: This domain is comprised of rehabilitation facilities, professional team, required treatment time, medications, home care visits, depth of explanation regarding protocols, the time spent waiting for rehabilitation and attitude of rehab expert towards subjects. Decision to seek alternative treatments was also considered under this domain to understand if lack of facility derived them for alternative methods. Example: “Do you get a good explanation from the rehabilitation experts regarding your treatment?” Is the physiotherapy unit is fully equipped with the modalities you need?”

Data Analysis: Descriptive analysis of the data collected was done to analyze and interpret the information.

RESULTS

Out of 300 subjects, there were 148 females and 152 males. Mean age of male subjects was 60.5 years and that of female subjects was 59.6 which was not significantly different with p-value >0.110.

Table 1. Demographic Variables

Variable	Male	Female	p-value
Age (years)	60.5	59.6	>0.110
Gender	152	148	>0.8

Out of the four main barriers presented in this study, it was found that the main barrier was Facility barrier. Within facility barrier, lack of rehabilitation centers across the state was the most common and major concern. Socio-cultural barrier was found to be the second most faced barrier. Surprisingly financial issue was not the primary concern for many, with economic barrier and geographical barriers standing more or less equally with lowest numbers comparatively.

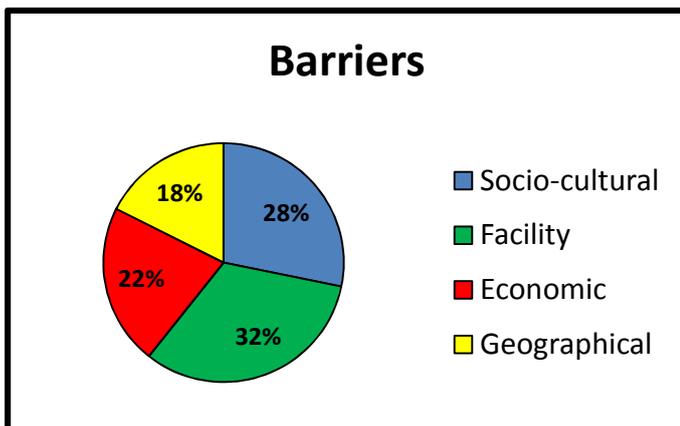


Figure 2. Barriers Affecting Stroke Rehabilitation

DISCUSSION

Stroke rehabilitation is a time consuming process and is increasingly becoming an essential part of healthcare in stroke subjects. It is extremely important to understand the interaction between subjects with stroke and their physical, financial and emotional environment. Therefore, this study was conducted to identify the barriers in effective stroke rehabilitation in Kerala and existing knowledge about it in affected population.

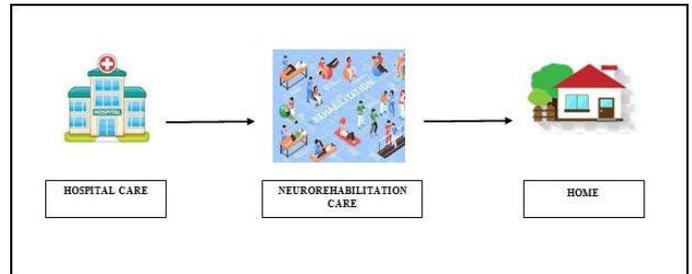


Figure 3. Proposed format of Neuro-rehabilitation Care Centers

This study found lack of facilities to be the most commonly faced barrier in stroke rehabilitation. Among many variables under facility barrier, common barrier brought forth by participants was lack of rehabilitation centers. Even though Kerala is one of the most progressive states in India when it comes to healthcare services, there is a lack of rehabilitation centers in every nook and corner of the state. In one of the previous studies conducted in stroke population in Chennai, India, it was concluded that there was a wide gap between the demand and supply of stroke rehabilitation services in Chennai. The findings from the study revealed that there was an acute insufficiency of rehabilitation services for people with disabilities in general, even in a major metropolitan city like Chennai. Rehabilitation programs to support disabled persons were hardly available to those most in need (Kamalakkannan *et al.*, 2016). One of the factors affecting the recovery of subjects was not just the shortage of rehabilitation facilities, but also the shortage of a means of transport. In Kerala, the unavailability of handicapped accessible means of transportation continues to be a problem. Since rehabilitation is not a one-day or two-day process, the subjects were unable to get ample time or motivation to travel to rehabilitation centers for longer hours. Lack of specialists in recovery has also been found to be a significant obstacle. Lack of communication between the physiotherapists and failure to make subjects understand about ongoing health conditions seemed to be one of the drawbacks from the side of healthcare professionals (Kamalakkannan *et al.*, 2016). In one of the studies by Rahman *et al.*, in 2012, it was concluded that beliefs and assumptions of physiotherapists related to stroke rehabilitation in Kerala had some key issues that were necessary to be addressed. Many of the highlighted disadvantages in the physiotherapy sector were the issues such as lack of coordination, disparity in treatment protocols between each physiotherapist and insufficient skills (Khan *et al.*, 2012).

Similar study was done in Ghana in 2017 which had concluded socio-cultural barrier to be the most hindering aspect of stroke rehabilitation in their setting with other major barriers being financial issues (Nketia-Kyere, *et al.*, 2017). Similar results were obtained in this study in socio-cultural strata where most people were of the belief that stroke has a spiritual cause and

hence would require other remedies other than physiotherapy. People were reluctant to accept that they were suffering from treatable disability and were found ready to accept the illness as one's fate. In previous literatures, social aspect has shown to correlate with physical activity in general populations (Sallis *et al.*, 1987) and older adults (Orsega-Smith *et al.*, 2003). Also, family support for physical activity was correlated with greater physical activity participation (Wilcox *et al.*, 2003) and similar correlation can be found even in stroke subjects and their exercise regime. Even though Kerala is one of the highly literate states, it is evident that people still consider illness as decision of Almighty and learn to live with it. Although economic barrier was one of the hindrances in the stroke rehabilitation, it was not the primary barrier in majority of population as compared to facility and socio-cultural barrier. In low economy class stroke survivors, the major concern was difficulty to bear expense of medicine rather than physiotherapy rehabilitation cost.

However, unavailability of government rehabilitation centers in nearby areas where they could get services in affordable price was the major issue in most of the low income population. Low income stroke survivors complaint of having to travel a longer distance everyday to reach government rehabilitation centers, which was not feasible in many ways. As a result, they were forced to visit nearby private clinics which left deep holes in their pockets. The problem was even more concerning when the stroke survivor was bread-earner of the family. Similar result was obtained in a study conducted by K. Suresh Kumar *et al.*, in 2016 (Kamalakaran *et al.*, 2016) where the researcher concluded that the main financial barrier in physiotherapy rehabilitation in stroke subjects was unavailability of physiotherapy rehabilitation centers at affordable price and in feasible areas. The least concerning aspect in rehabilitation services of stroke survivors seem to be the geographical distribution of state.

Participants didn't feel that the topographical makeup of their surrounding areas created hindrance in their treatment protocol. However, they raised concerns about the vehicles not being disabled friendly. People living in rural part of Kerala need to assess rehabilitation centers that use public vehicles, many of which have no provision to assist people with disabilities when driving. Even though majority of the public sector facilities are being constructed and even renovated in Kerala nowadays for the ease of access of the disabled but there still lacks abundant availability of such resources. This element appeared to make people demotivated to go to treatment centers. The knowledge obtained through this study is intended to be used to create a comprehensive set of quality metrics that can assist in a successful course of recovery and achieve positive goals for improving the condition of stroke population.

Limitations and Future Recommendations

This research was performed only in three separate provinces in the state of Kerala, therefore it is important to undertake future investigations on a larger scale to obtain a better understanding and detailed outcome. Different research can be carried out in the future to examine the impact of the age, gender, awareness level, or educational level of the stroke subject on their rehabilitation and to identify the connection between each variable. This research can also be considered as

a fundamental analysis for identifying obstacles in different Indian states and bringing about changes accordingly.

Conclusion

The study sought to assess the barriers to physiotherapy services for stroke subjects around Kerala. Barriers were assessed by means of feedback of subjects and relatives for a customized questionnaire. The study concluded that the lack of readily available public rehabilitation facilities and the lack of effective communication between stroke survivors and rehabilitation providers were the main barriers to successful recovery of the subjects. For successful recovery for stroke survivors, the role of NGO's, Palliative care team, Community services team, Asha workers and other social workers should be considered. Recovery awareness along with rehabilitation activities should also be of utmost importance.

Implementation

A proposal was made to start two or three Neuro-rehabilitation Care Centers / Homes in different parts of Kerala, so that subjects can be admitted to rehabilitation facilities in these nearby centers when discharged from hospital. In this regard a detailed proposal was submitted to the Kerala government, and they received a positive response. The proposal has been sent via the correct channel to the Health and Family Welfare Department, Government of Kerala (via the Superintendent of Super specialty, Government Medical College, Trivandrum).

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