

# Awareness and Perception about the Stroke and Post Stroke Physiotherapy among Stroke Survivors - A Qualitative Study from Western India

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## ABSTRACT

**Purpose:** Stroke is one of the major causes of disability and death globally. Treatment approach to stroke patients is multidisciplinary, and physiotherapy plays an important role in reducing the disabilities among stroke survivors. The present study aims to know the awareness and perception about stroke and the importance of physiotherapy in stroke rehabilitation among stroke survivors.

**Material and Methods:** A qualitative study was carried out using focus group discussion (FGD) among patients with stroke. A total of 12 patients, suffering from stroke were enrolled for the study after obtaining written informed consent. The study was conducted at two different

settings of a tertiary care hospital in western India. Patients diagnosed with stroke and willing to participate were included, while those with severe cognitive impairment or communication difficulties were excluded. Two FGD sessions with six patients in each were conducted with the help of a self-structured questionnaire covering the key areas of research question. The discussion was audio/video graphed and the verbatim was narrated for the analysis.

**Results:** The participants varied in age, gender, duration since stroke, and level of functional dependence. The results were analyzed by thematic analysis, which shows significant lack of awareness about the disease, its warning signs and risk factors/causes among stroke survivors. Very few (41.67%) patients were aware about the

term “stroke” and opted for physiotherapy, and almost all the patients had significant psychological insult post stroke.

**Conclusion:** The present study reflects significant lack of knowledge about the disease and disease process, including its causes, warning signs, etc., among stroke survivors. Though majority of patients were referred for physiotherapy treatment after stroke, many of them did not opt for the same due to various reasons. This reflects that the health care providers and/or various government agencies should work at various levels of health care delivery to bridge these lacunae and to provide effective multidisciplinary care to the stroke survivors.

**Keywords:** Focus group, Stroke, Rehabilitation, Physiotherapy, Awareness, Perception

## INTRODUCTION

A Stroke, also known as cerebrovascular accident, is defined as sudden death of brain cells due to lack of oxygen, caused by either blockage or rupture of an artery to the brain. Sudden loss of speech, weakness or paralysis of one side of the body can be the symptoms of stroke.<sup>1</sup> The most recent Global Burden of Disease (GBD) 2021 stroke burden estimates showed that among non-communicable disorders (NCDs), stroke remains the second leading cause of death (about 7 million) and the third leading cause of death and disability combined (as expressed by disability-adjusted life-years lost-DALYs; over 160 million DALYs) in the world.<sup>2</sup> Increasing prevalence of the major modifiable risk factors such as alcohol and tobacco use, diabetes, hypertension, dyslipidaemia, etc., and the demographic changes like lower socioeconomic status and education further double the burden of such non-communicable diseases in developing countries. The individuals from lower socioeconomic backgrounds are increasingly affected by stroke, because of enhanced exposures to risk factors and,

unfortunately due to not being able to afford the cost of stroke care. As commonly seen, the huge population of stroke survivors lives with disabilities throughout their life, and the costs of long-term post stroke care, including rehabilitation, are largely undertaken by family members, this leads to impoverishment of their families.<sup>3</sup>

However, despite the high burden of stroke and availability of rehabilitation services, there is limited evidence exploring the awareness, beliefs, and perceptions of stroke survivors themselves regarding the disease and post-stroke rehabilitation, particularly in low- and middle-income countries like India.

Studies have demonstrated that low awareness of symptoms and warning signs of stroke affects the early access of patients to emergency medical services and leads to poor prognosis. Reducing delays in seeking treatment in the presence of stroke symptoms has been an area of ongoing interest, as delaying emergency access from the onset of symptoms is known to play a significant role in the outcome of stroke survivors.<sup>4</sup>

Apart from opting for emergency care, prevention and effective rehabilitation strategies are paramount to reducing the burden of stroke in the community. After a stroke, rehabilitation starts as soon as the diagnosis is confirmed and any life-threatening conditions are under control, during the acute stage of hospitalization. Early use of rehabilitation techniques can increase neurological function recovery, lessen disability following a stroke, and boost long-term outcomes and stroke patients' quality of life. Physiotherapy, being a part of the post-stroke rehabilitation team, plays a vital role in facilitating the recovery process and enhancing independent living. Immediate and rigorous physiotherapy after stroke has been associated with a reduction in morbidity, mortality, and disability-adjusted life years (DALYs). In many stroke units, early mobility and functional training administered by physiotherapists in

intensive care units are regarded as the most crucial components of acute therapy. Therefore, timely access to physiotherapy is always appreciated.<sup>5</sup>

Most available studies have focused on quantitative assessment of knowledge levels, while qualitative insights into lived experiences, misconceptions, and perceived barriers to rehabilitation among stroke survivors remain underexplored. Understanding patients' perceptions and experiences is crucial for designing effective awareness programs, improving referral pathways, and strengthening physiotherapy utilization in stroke rehabilitation services.

It has been observed that many patients do not opt for or continue physiotherapy treatment after stroke due to one or another reason. One of these reasons can be lack of awareness about the importance of physiotherapy among stroke patients. Lack of knowledge about its possible treatment measures can significantly affect the quality of life of stroke survivors. In this context, exploring stroke survivors' perspectives becomes essential to identify gaps in knowledge and barriers to physiotherapy utilization. Therefore, the present study aims to identify the awareness and perception about stroke and the importance of physiotherapy in stroke rehabilitation among stroke survivors.

## **MATERIALS & METHODS**

A qualitative research study was carried out using Focus Group Discussion (FGD) after obtaining ethical clearance from the Institutional Ethics Committee, H. M. Patel Centre for Medical Care and Education (IEC/HMPCMCE/103/Faculty/4/).

The demographic data (including name, age, gender, address, contact number) of total 1755 patients admitted at Shree Krishna Hospital, Karamsad with diagnosis of hemiplegia/ ischemic stroke/ hemorrhagic stroke was collected from an in-house patient registration software of hospital named SOLACE. Patients were divided into clusters according to their residential areas

in Anand district like Karamsad, Vidhyanagar, Petlad, Bakrol, Valasan, Anand, Simarada, Bhatiel, Sihol, Agas, Pandoli, Virol, etc. Out of 1755, 301 patients responded to the phone calls. Out of 301 patients, 47 patients gave their consent to meet personally. All the patients were explained about the research purpose when met in person. Based on inclusion and exclusion criteria, out of 47, 16 patients were invited to take part in FGD.

Patients, both males and females, with the diagnosis of hemiplegia/Ischemic stroke/Hemorrhagic stroke were included in the study. However, patients who were bed bound; with any other neurological, musculoskeletal or cardiorespiratory problems along with stroke, which can affect their functional abilities; patients with difficulty in speech, having any psychiatric illness or problem with understanding and who decline to participate were excluded from the study.

Total of two FGD sessions were conducted based on geographical locations of patients. One FGD was conducted at Shree Krishna Hospital, Karamsad and the second one at Sudhrai Hospital, Petlad.

The written informed consent form was obtained from all the participants before initiating the FGD, including their approval for audio/video-recording. Basic demographic details, history, present complains and their functional status using Barthel Index were obtained. Out of 16 patients agreed to participate in FGD, only 12 made up to attend the sessions. Participants varied in age, gender, and duration since stroke.

Both the sessions of FGDs having six participants in each, were facilitated by a team, having two moderators, two persons for transcribing verbatim, one making sociogram and the one with the audio/video recordings. FGD was begun with the introduction of all the team members by the moderators followed by introduction of all the participants. The FGDs were moderated/facilitated by two physiotherapists trained in qualitative research, and both had prior

experience in conducting FGDs. No prior relationship existed between the moderators and participants. Participants were informed about the professional background and purpose of the moderators. Potential researcher bias was minimized through reflexive discussions among the research team.

An FGD guide was developed having 18 questions to cover the key issues related to research question. Discussion during both sessions was conducted in Gujarati language for better understanding and communication, and each discussion lasted for approximately 55-56 minutes. The interaction was represented by a sociogram for a better understanding and analysis. Participants were given an opportunity to clarify their responses during the discussion. The study was guided by a descriptive qualitative approach. Based on audio/video recordings, the transcript was prepared and was analyzed qualitatively by narrative analysis. The moderators were free to word and sequence the questions in the most

appropriate manner and to pursue area in greater depth. No further FGD was conducted due to unavailability of the participants.

Two researchers independently analyzed the transcripts. Codes were grouped into categories and themes. Themes were derived inductively from the data. Manual analysis was performed. Findings were discussed among the research team to ensure credibility.

## RESULT

Two focus group discussion with 12 patients of stroke (six in each) were held at two different settings of a tertiary care hospital of western India. The characteristics and basic demographic details of all the participants are presented in Table 1.

Various themes emerged out from the discussion held during the two FGD sessions. Interpretation of findings was performed with awareness of the researchers' clinical background.

**Table 1 Demographic details of participants**

Demographic data of Stroke patients	N=12	Percentage (%)
Age (Mean years)	64.25	--
<b>Gender</b>		
Males	11	91.67
Females	1	8.33
<b>Education</b>		
Illiterate	2	16.67
Primary Education (up to 7th Std.)	4	33.33
Higher Secondary Education (up to 12th Std.)	5	41.67
Graduate	1	8.33
Post Graduate	0	0
<b>Socio Economic Status (Revised Modified B G Prasad socioeconomic classification scale, 2023)</b>		
Upper class	2	16.67
Upper middle class	0	0
Middle class	4	33.33
Lower middle class	3	25
Lower class	3	25

### Knowledge and understanding of stroke:

This theme describes participants' limited understanding and terminology used to describe stroke. The most common word

cited by participants was "paralysis" for the condition from which they are suffering from. 5 out of 12 participants (41.67%) were able to term the disease as "Stroke" as

they were explained by their health care provider, however, 7 (58.33%) participants termed it as "Paralysis". One of the participants also referred it as a "sudden attack" and was unable to explain what happened to him.

*"Blood does not reach to the brain; it is called as stroke."*

*"Doctor told that it is due to the effect of stroke."*

### **Perceptions about the causes and risk factors:**

This theme reflects poor awareness and uncertainty regarding the causes and risk factors of stroke. All the patients instinctively declared that they did not know anything about the stroke and its risk factors and expressed an urge to spread the knowledge about the same in the community through various health programs.

*"Seminars or presentations should be organized for layman to spread the awareness about the disease."*

Stroke had an ambiguous impression on most of the participants and they all doubted about its origin, causes and symptoms even though they have observed few patients suffering from stroke before. Certainly, they were utterly unclear about the condition they had understood, including the difference between ischemic and hemorrhagic stroke.

On inquiring about their knowledge about the risk factors for stroke, almost all the participants were apprehensive about the unpredictability of the disease and the fact that there is no standard profile for a stroke survivor. For most participants, it can affect anyone. Only one participant, having hypertension reported it being one of the risk factors for stroke. He further elaborated that though he was on regular medication and follow-up, still he had an incidence of stroke- explaining the uncertainty of the disease.

*"It is a natural event/it is our fate, so there is no point in getting bugged."*

### **Symptoms and warning signs of stroke:**

This theme highlights participants' inability to recognize early symptoms and warning signs of stroke. In both focus groups, when asked about how to identify stroke, the majority of participants initially declared they were not familiar with any symptoms of stroke. Gradually, elaborating further, when recalling their own or their relatives' experiences of stroke, participants started explaining few symptoms, among which paralysis and difficulty in speech were the most cited ones.

*"We have seen few individuals in our neighbourhood with one sided paralysis, however never knew that it was stroke..!"*

### **Physical and functional problems:**

This theme outlines the physical limitations and functional dependence experienced after stroke. Most participants had associated negative outcomes of stroke, like physical disability and wheelchair use. Almost all the participants were having physical problems like weakness of one side of body, difficulty in speech, shoulder pain on affected side, and had difficulties in performing ADLs independently like bathing, dressing, grooming, transfer, toileting activities, commuting, etc.

8 (66.67%) patients left their jobs due to stroke and 2 (16.67%) modified their work according to their functional limitations.

*"There is no one to take care of our business in my absence which leads to financial loss."*

*"Even if our business is handed over to someone else, they will not run it that efficiently as we are running."*

### **Consequences and the impact of stroke:**

This theme captures the emotional, psychological, and social impact of stroke on participants' lives. While reporting the impact of stroke on their lives, all participants (100%) felt very depressed, frustrated, agitated and helpless. All were

worried about their recovery and the future of their family members especially their children.

*“We feel sad as we have to be dependent on others.”*

*“We are worried about the future as our children are still very young.”*

*“It feels bad when we have to hear constant poking from our own family members.”*

*“We should accept what has happened and change our attitude as every time we can not expect people to center their attention on us.”*

*“We have to accept the fact and should feel positive. Keep smiling... we should adapt to others if we want to work well.”*

*“Keep your mind calm and keep working.”*

*“We expect that the caregivers should show positive attitude towards us and we ourselves should have positive attitude.”*

Despite experiencing significant emotional distress, several participants demonstrated a positive and adaptive mindset, emphasizing acceptance of their condition, emotional resilience, and the importance of maintaining a hopeful attitude to cope with post-stroke challenges.

### **Health-seeking behavior and rehabilitation choices:**

This theme explores patterns of health-seeking behavior, rehabilitation uptake, and barriers to physiotherapy. Though not being aware about the stroke, having sudden weakness and difficulty in speech, all the patients were immediately taken to the nearby hospital where the primary treatment was initiated promptly. However, none of them was explained about the disease process.

Out of 12, only 2 patients had an idea about what physiotherapy is before they had stroke. This suggests significant unawareness about physiotherapy.

Though 11 out of 12 (91.67%) patients were advised/referred for physiotherapy treatment after acute post stroke care, none of them were explained the importance of physiotherapy by their primary health care providers. Out of those 11, who were

referred for physiotherapy treatment, 10 opted for the same and only 5 (41.67%) were on regular exercise program. One patient consulted a massage practitioner instead of a physiotherapist.

The patients, not consulting physiotherapists had various personal whys and wherefores, viz. financial problems, non-cooperative family members, difficulties in accessibility of vehicles due to their distant residential location, difficulty in transportation due to their physical disabilities, unavailability of services, etc. However, they showed readiness to continue physiotherapy if the physiotherapy services are available.

*“We would like to continue the treatment if good facilities are provided.”*

Apart from medical care and physiotherapy, 5 out of 12 patients (41.67%) were advised for diet modification, 3 (25%) for smoking cessation, and 1 (8.33%) for avoiding alcohol consumption. 2 (16.67%) patients did not get any advice from their health care provider apart from medications.

These findings reflect substantial gaps in awareness, perceptions, and utilization of physiotherapy services among stroke survivors.

### **DISCUSSION**

In the present study the mean age of stroke patients was 64 years, affecting 91.67% males and 8.33% females, which can be associated with the fact that males are more prone to the risk factors linked with stroke, especially, those with poor lifestyle such as smoking and alcohol consumption compared to females. Only 16.67% of the patients were illiterate and 25% respondents reported to belong to lower socio-economic class, rest reported to have had at-least primary education and were from lower middle, middle and upper class. Two FGD sessions were held for these stroke sufferers at two different health care facilities. Various themes emerged from the discussion held during these conversations which reflect the awareness and perception

about post stroke physiotherapy among the stroke survivors.

Quick identification of signs and symptoms of stroke and prompt management has been identified as vital factors in reducing both morbidity and mortality. The present study reports significant lack of knowledge about the disease, its risk factors, warning signs, and symptoms of stroke. Several misconceptions about the causes of stroke have also been identified in the literature which shows how significantly the people are unaware about the disease. In a study carried out by Dar NZ, et al. (2019), out of those surveyed (384), 43.8% of patients believed stroke to be a hereditary disease, whereas few thought it to be associated with an ancestor's sin or a contagious disease.<sup>6</sup>

A study to identify the knowledge of the risk factors and warning signs of stroke was carried out by Saengsuwan J et al. (2017), among 140 patients with recurrent stroke and TIA (Transient Ischemic Attack). Though it was a recurrent episode of TIA/stroke, 13.6% patients were unable to identify any of the warning signs and 25% patients could not name any of the risk factors. Majority of patients had information about the stroke being affected recurrently, with the main source of information for the disease knowledge being healthcare professionals (nurses (76.4%) and doctors (69.3%). Yet, for the risk factors and warning signs of stroke, majority of patients rated their dearth of knowledge being moderate to high.<sup>7</sup>

Majority of patients in present study were found having one and the other physical and functional problem post stroke which had led them to quit their jobs or made them to modify their work according their functional limitations. Apart from physical disabilities, the stroke survivors suffer from many psychological issues too, among which depression, anxiety, psychological distress and social isolation are the most prevalent. Nearly one third of stroke patients report depressive symptoms and anxiety during their early recovery phase after stroke and these psychosocial problems impact

significantly on their long-term functioning and quality of life, lessening the positive outcomes of rehabilitation and leading to increased mortality.<sup>8</sup> In the present study, these psychological issues are mainly found to be associated with functional dependency on caregivers or family members, loss of job, concern about coping up with the responsibilities of the family members especially children, negligence and poking from our own family members, etc.

Health seeking behavior of stroke survivors and their caregivers is another issue affects the outcome of the disease. The factors found to be affecting this include lack of knowledge, fear of hospitals, denial, reticence, living alone, and preexisting health concerns.<sup>9,10</sup> In the present study, though not being aware about the disease, all the patients were immediately taken to the nearby hospitals where the primary treatment was provided and out of all, 91.67% of patients were referred for physiotherapy treatment too during their acute care by their treating medical practitioners. However, only 41.67% were found to be on regular exercise program. Post stroke physiotherapy requires good compliance and follow-up for the long-term exercise regimen. Poor compliance to physiotherapy may negatively affect the outcomes and increases the overall health care cost.<sup>11</sup>

Majority (80-90%) of patients report inability to access the health care facility due to muscles/limb weakness which hinders their ability to move independently. Disturbed coordination, balance, fatigue and depression are the other intrinsic factors which affects their mobility leading to inability to contact health care providers. Wheelchair usage, unavailability of physiotherapy facility in close vicinity are the external factors found as barrier to the compliance for physiotherapy treatment. Slow recovery from the stroke makes patients and their caregivers/family members tiered and less adherent with the treatment. Also, more than half of the stroke survivors remain dependent on others for

their daily needs including transport to the health care centers which again in turn reduces the compliance to the therapy.<sup>12</sup> Also, only 16.6% patients were aware about what physiotherapy is before they had stroke, which suggest overall unawareness about the specialty. General population is usually less aware about the role of physiotherapy until they suffer and have experienced the therapy sessions; many often consider physiotherapy as being same to that of massage therapy and they too insist to consult the later instead of a qualified physiotherapist.<sup>12</sup> One of the patients in present study reported to have consultation and few visits to a massage practitioner for stroke without even inquiring about the qualification.

Thus, multiple approaches are required to reinforce the knowledge through verbal, written and visual sources among the patients and their caregivers to increase the knowledge and awareness about the disease and its possible management strategies. Improved knowledge and changes attitude can help to improve the practice for stroke management, thereby reducing the burden of stroke in community. Further studies involving caregivers and healthcare providers could provide a more comprehensive understanding of barriers to post-stroke rehabilitation.

## CONCLUSION

The qualitative design using focus group discussions enabled in-depth exploration of stroke survivors' lived experiences and perceptions regarding rehabilitation. The present study shows significant negligence about the disease, its warning signs and risk factors. It reflects poor knowledge and compliance with physiotherapy services too. This needs an immediate attention to educate the community at large about the disease and scope of physiotherapy management in stroke. Apart from this, health care providers should also provide detailed information about the condition and treatment going to be provided to the stroke patients during their acute phase or routine

consultation to improve on acquiring health care services, self-management strategies, and quality of life after stroke. Also, incorporating structured counseling and early physiotherapy education into routine stroke care may improve adherence to rehabilitation and long-term outcomes.

## Declaration by Authors

**Ethical Approval:** The study has been approved by the Institutional Ethics Committee (IEC).

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