

# Assessment of Stroke Case-fatality, Disability, Perceived Needs and Barriers for Care among First-ever Stroke Patients Attending a Tertiary Care Neuro-specialty Center in India: A Cross-sectional Study

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## Abstract

**Background:** Stroke is a major public health and clinical challenge that results in significant mortality and disability. Stroke survivors require care and support, particularly during the crucial 3 months post-stroke when 95% of functional neurological recovery occurs. To estimate case-fatality and extent of disability, assess perceived needs, barriers, and unmet needs for care, and ascertain pathways to care post-discharge (at 3 months) among first-ever stroke patients attending a tertiary care neuro-specialty center in India. **Material and Methods:** A cross-sectional descriptive study was conducted among patients receiving care within [NIMHANS]. Patients with confirmed computed tomography (CT) scans experiencing their first-ever stroke between September 1 and October 31, 2022, were contacted between November 1, 2022, and March 31, 2023. A pre-tested semi-structured questionnaire was used to collect information. Descriptive statistics were performed using STATA version 16. **Results:** Stroke fatality among study subjects was 13.8%. Almost half (49.09%) had some form of disability, with 40% having moderate to severe disability. The majority perceived the need for follow-up visits (87%) and compliance with stroke medication (84%). Distance and transportation (60%) were cited as the main barriers to care. After discharge, the majority preferred healthcare facilities close to their homes (60%). **Conclusions:** This study emphasizes the need for stroke survivors to have follow-up and compliance with medication, along with various unmet needs such as de-addiction services, vocational training, and emotional support. A network-based multi-disciplinary approach, along with a comprehensive hub and spoke model of stroke management services, could help address these challenges and improve patient outcomes.

**Keywords:** Barriers, case-fatality, disability, perceived needs, stroke

## INTRODUCTION

Globally, stroke is the second-leading cause of death. As expressed in terms of disability-adjusted life-years (DALYs) lost, it is the third-leading cause of death and disability combined.<sup>[1]</sup> From 1990 to 2019, stroke incidence and prevalence increased by 70% and 102%, respectively, deaths due to stroke by 43%, and 143% increase in DALY in the world.<sup>[2]</sup> Over 143 million years of healthy life are lost each year due to stroke-related deaths and disability.<sup>[3]</sup> Developing countries contribute to 75% of all stroke deaths and 82% of DALYs lost.<sup>[4]</sup> Similar to other low- and middle-income countries, India is experiencing a stroke epidemic. It is the fourth leading cause of death and the fifth leading cause of disability.<sup>[5]</sup>

One of the critical challenges in stroke management is the treatment gap, particularly in the crucial 3-month period following an acute stroke event. Factors such as limited accessibility and lack of availability of services, financial constraints, and patient's perception of disease and treatment contribute to the treatment gap. There is a need to understand the sequelae of stroke after discharge in terms of survival,

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**How to cite this article:** Devyani A, Banandur PS, Kulkarni GB, Sukumar GM, Mythirayee S, Himani R. Assessment of stroke case-fatality, disability, perceived needs and barriers for care among first-ever stroke patients attending a tertiary care neuro-specialty center in India: A cross-sectional study. Indian J Community Med 2025;50:25-33.

**Received:** 17-10-23, **Accepted:** 25-06-24, **Published:** 23-01-25

### Access this article online

#### Quick Response Code:



**Website:**  
www.ijcm.org.in

**DOI:**  
10.4103/ijcm.ijcm\_713\_23

disability, care, and other factors. Meeting unmet needs reduces substantial health expenditure. Understanding the needs of the affected is required to further reorganize care delivery and prevention strategies. Needs assessment, which considers the economist, epidemiologist, and patient's perspective of such healthcare needs, is essential for planning health services.

Considering these, we aim to estimate case-fatality and disability among first-ever stroke patients attending a tertiary care neuro-specialty center in India, assess perceived needs and barriers for care, evaluate the proportion of unmet needs for care, and ascertain pathways of care post-discharge.

## MATERIALS AND METHODS

A cross-sectional study was conducted over 5 months (November 1, 2022 to March 31, 2023) among patients who received care for first-ever stroke within [NIMHANS]. To identify eligible participants, the case records with ICD codes I63 and I63.9 of the international classification of diseases-10 (ICD-10) admitted/treated between September 1, 2022, and October 31, 2022, were retrieved from medical records. All cases recorded as first-ever strokes in [NIMHANS] between September 1, 2022, and October 31, 2022 were included. Ethical approval for the study was obtained on 21-11-2022 from the Institutional ethics committee of NIMHANS vide letter no. NIMH/DO/IEC (BS & NS DIV)/2022.

First-ever stroke as defined by the World Health Organization (WHO) (also called "first in a lifetime") refers to people who have never had a stroke before. Patients attending [NIMHANS] with CT-confirmed diagnosis of ischemic/hemorrhagic stroke. The CT scan of all patients was confirmed for stroke by a resident and a consultant neurologist. Those with a confirmed diagnosis of first-ever stroke as per clinical records whose CT scan was not available were also included. Subjects who were not willing to participate were excluded.

As per medical records, 204 cases of stroke were treated within the study hospital during the study period. Out of these, 123 cases were available for the study. Among them, 13.8% died. Considering the survival rate of 86.2% and an absolute precision of 5%, this sample of 123 patients would yield a power of at least 99.9%. This calculation was conducted using the Openepi sample size calculator. All cases satisfying inclusion criteria with physical records available at the Medical Records Department (MRD) and digital records available as e-hospital data within [NIMHANS] were included in the study. A pre-tested semi-structured questionnaire was used to collect information on survival, disability, perceived needs, and barriers and pathways to care among study subjects. The modified Rankin scale (mRs) was used to assess the disability among study subjects. This is a widely used scale as a measure of functional outcomes in patients with stroke.<sup>[6]</sup> This scale has a 6-point disability scale with possible scores ranging from 0 to 5. A separate category of 6 is usually added for patients who died. For the assessment of perceived needs and

barriers to care among stroke patients, a questionnaire was included, which was developed based on the Perceived Need for Care Questionnaire (PNCQ) by Meadows *et al.*<sup>[7]</sup> It is the first validated instrument that measures people's perceptions of service needs for mental health problems and barriers to receiving care. The approach and concept used in PNCQ were followed to develop this questionnaire to assess the perceived needs and barriers to care among stroke patients.

All eligible patients were contacted over the phone, 3 days in advance of the patient completing 90 days since stroke onset, utilizing the phone number provided at registration. The investigator interviewed all eligible and consenting study subjects on day 90 either personally or by telephone. The data were collected using the questionnaire mounted on a low-literacy, user-friendly digital platform using EPIINFO.

The data analysis was performed using STATA version 16. The analysis included descriptive statistics to summarize the socio-demographic, health, and substance use-related characteristics of study subjects. For categorical variables, frequency and percentages were calculated. The mean and standard deviation (SD) (median and interquartile range) were calculated for continuous variables. In addition, the functional disability of stroke patients was assessed using the mRs. The scores were grouped into three categories: 0–1 (no disability), 2 (mild disability), and 3–5 (severe disability).

## RESULTS

Overall, there were 204 patients with ICD-10 codes I63 and I63.9 during the study period. However, 81 were excluded for various reasons and 123 were eligible. The 28<sup>th</sup> day stroke fatality was 13.8% (17/123). The average age of first-ever stroke patients was 49.8 years (SD-17.6 years). The majority of them were men (71.5%), from outside Bengaluru (61.0%), high school educated (52.8%), Hindu (87%), currently married (79.7%), and had a median monthly income of INR 15,000/- (interquartile range [IQR] of 10,000/month). Ischemic stroke (~78%) was the most common type observed. Among survivors, nearly half had the lowest disability score (50.9%) and almost 40% had high disability score (37.5%). Monthly income was associated with severity of disability ( $P = 0.025$ ) [Table 1].

Approximately, one-third of stroke patients had a history of alcohol use (31.1%), tobacco smoking (28.7%), and 10% had used smokeless tobacco products. A considerable proportion of stroke patients who died had hypertension (43.8%) and diabetes (37.5%). Stroke survivors also had hypertension (34.9%) and diabetes (23.6%), with 6.6% of patients diagnosed with these conditions post-stroke. Moderate to severe disability was observed among a few patients who were newly diagnosed with hypertension (12.8%), diabetes (10.2%), and cardiac problems (2.6%) post-stroke [Table 2].

After 3 months of stroke occurrence, the majority of first-ever stroke patients recognized the need for follow-up visits (87%)

**Table 1: Socio-demographic characteristics, survival and disability among first-ever stroke patients in a tertiary care neuro-specialty centre, India**

FACTORS		SURVIVAL		DISABILITY (mRs Score)					
	Fatality <i>n</i> =17 (13.8%) <i>n</i> (%)	Survivor <i>n</i> =106 (86.2%) <i>n</i> (%)	Total ( <i>n</i> =123) <i>n</i> (%)	Crude odds ratio (95% CI)	No disability (0–1) <i>n</i> =53 (50.9%) <i>n</i> (%)	Mild (2) <i>n</i> =12 (11.5%) <i>n</i> (%)	Severe (3–5) <i>n</i> =39 (37.5%) <i>n</i> (%)	Total ( <i>n</i> =104) <sup>e</sup> <i>n</i> (%)	<i>P</i> <sup>a</sup>
Age (in completed years)									
≤40	3 (17.6)	36 (34.0)	39 (31.7)	Ref	16 (30.2)	5 (41.7)	14 (35.9)	35 (33.6)	0.493
41–60	6 (35.3)	40 (37.7)	46 (37.4)	0.556 (0.129–2.386)	19 (35.8)	6 (50.0)	15 (38.5)	40 (38.5)	
>=61	8 (47.1)	30 (28.3)	38 (30.9)	0.313 (0.076–1.283)	18 (34.0)	1 (8.3)	10 (25.6)	29 (27.9)	
Mean±SD	58.1±15.8	48.4±17.6	49.8±17.6		48.4±20.4	43.2±10.3	49.9±14.8	48.4±17.5	0.50 <sup>c</sup>
Gender									
Female	5 (29.4)	30 (28.3)	35 (28.5)	Ref	19 (35.8)	1 (8.3)	10 (25.6)	30 (28.8)	0.141
Male	12 (70.6)	76 (71.7)	88 (71.5)	1.056 (0.342–3.253)	34 (64.2)	11 (91.7)	29 (74.4)	74 (71.2)	
Place of residence									
Bengaluru	9 (52.9)	39 (36.8)	48 (39.0)	Ref	33 (62.3)	9 (75.0)	23 (59.0)	65 (62.5)	0.604
Outside Bengaluru	8 (47.1)	67 (63.2)	75 (61.0)	1.933 (0.689–5.419)	20 (37.7)	3 (25.0)	16 (41.0)	39 (37.5)	
Highest standard studied									
Illiterate	8 (47.1)	26 (24.5)	34 (27.6)	Ref	14 (26.4)	0 (0.0)	11 (28.2)	25 (24.0)	0.179 <sup>b</sup>
High School	7 (41.2)	58 (54.7)	65 (52.8)	2.549 (0.836–7.774)	26 (49.1)	10 (83.3)	21 (53.8)	57 (54.8)	
Pre-university or higher	2 (11.8)	22 (20.8)	24 (19.5)	3.385 (0.650–17.628)	13 (24.5)	2 (16.7)	7 (17.9)	22 (21.2)	
Marital status									
Never Married	0 (0.0)	20 (18.9)	20 (16.3)	–	13 (24.5)	2 (16.7)	5 (12.8)	20 (19.2)	0.450 <sup>b</sup>
Currently Married	17 (100)	81 (76.4)	98 (79.7)		36 (67.9)	10 (83.3)	33 (84.6)	79 (76.0)	
Widowed	0 (0.0)	5 (4.7)	5 (4.1)		4 (7.5)	0 (0.0)	1 (2.6)	5 (4.8)	
Religion									
Muslim	2 (11.8)	12 (11.3)	14 (11.4)	Ref	3 (5.7)	1 (8.3)	8 (20.5)	12 (11.5)	0.131 <sup>b</sup>
Hindu	14 (82.4)	93 (87.7)	107 (87.0)	1.107 (0.224–5.478)	49 (92.4)	11 (91.7)	31 (79.5)	91 (87.5)	
Christian	1 (5.9)	1 (0.9)	2 (1.6)	0.167 (0.007–3.890)	1 (1.9)	0 (0.0)	0 (0.0)	1 (1.0)	
Monthly income (INR)									
≤9,999	3 (17.6)	21 (19.8)	24 (19.5)	Ref	6 (11.3)	6 (50.0)	8 (20.5)	20 (19.2)	0.029 <sup>b</sup>
10,000–39,999	12 (70.6)	70 (66.0)	82 (66.7)	0.833 (0.215–3.233)	36 (67.9)	6 (50.0)	27 (69.2)	69 (66.3)	
>39,999	2 (11.8)	15 (14.2)	17 (13.8)	1.071 (0.159–7.220)	11 (20.8)	0 (0.0)	4 (10.3)	15 (14.4)	
Median (IQR)	15000 (10000)	15000 (10000)	15000 (10000)		15000 (15000)	10000 (11000)	13000 (10000)	15000 (10000)	0.025 <sup>d</sup>
Type of stroke									
Hemorrhagic	5 (29.4)	13 (12.3)	18 (14.6)	Ref	7 (13.2)	2 (16.7)	4 (10.3)	13 (12.5)	0.381 <sup>b</sup>
Ischemic	11 (64.7)	85 (80.2)	96 (78.1)	2.972 (0.888–0.942)	44 (83.0)	8 (66.7)	31 (79.5)	83 (79.8)	
Others	1 (5.9)	8 (7.5)	9 (7.3)	3.077 (0.302–31.330)	2 (3.8)	2 (16.7)	4 (10.2)	8 (7.7)	

All percentages shown are column percentages <sup>a</sup>*P* value for Chi-square test for independence; <sup>b</sup>Fisher's exact test; <sup>c</sup>one-way ANOVA; <sup>d</sup>Kruskal–Wallis test; <sup>e</sup>Data of two patients are missing as they did not completed the interview mRs–modified Rankin scale; INR–Indian Rupee; IQR–interquartile range; SD–standard deviation, others include brachialpalsy (1), optic neuritis (2), CVT (5), both (1)

**Table 2: Stroke outcome (fatality) by determinants among first-ever stroke patients**

Factors	SURVIVAL					Disability (mRs score)			
	Fatality <i>n</i> =16 <sup>a</sup> (13.1%)	Survivor <i>n</i> =106 (86.9%)	Total <i>n</i> =122	No disability (0-1) <i>n</i> =53 (50.9%)	Mild (2) <i>n</i> =12 (11.5%)	Severe (3-5) <i>n</i> =39 (37.5%)	Total <i>n</i> =104		
Ever-used substance use									
Alcohol	5 (31.3)	33 (31.1)	38 (31.1)	17 (32.1)	4 (33.3)	12 (30.8)	33 (31.7)		
Smoked tobacco	4 (25.0)	31 (29.2)	35 (28.7)	14 (26.4)	3 (25.0)	14 (35.9)	31 (29.8)		
Smokeless tobacco	1 (6.3)	12 (11.3)	13 (10.6)	6 (11.3)	2 (16.7)	4 (10.3)	12 (11.5)		
Body side affected									
Left	6 (37.5)	42 (39.6)	48 (39.3)	24 (45.3)	3 (25.0)	15 (38.5)	42 (40.4)		
Right	7 (43.8)	54 (50.9)	61 (50.0)	26 (49.1)	7 (58.3)	20 (51.3)	53 (51.0)		
Both	3 (18.7)	10 (9.4)	13 (10.7)	3 (5.7)	2 (16.7)	4 (10.3)	9 (8.6)		
Family history of stroke									
Parents	0 (0.0)	6 (5.7)	6 (4.9)	3 (5.7)	1 (8.3)	2 (5.1)	6 (5.8)		
Grandparents	0 (0.0)	5 (4.7)	5 (4.1)	3 (5.7)	2 (16.7)	0 (0.0)	5 (4.8)		
Sibling	1 (6.2)	3 (2.8)	4 (3.3)	1 (1.9)	1 (8.3)	1 (2.6)	3 (2.9)		
Others <sup>c</sup>	0 (0.0)	3 (2.8)	3 (2.5)	1 (1.9)	1 (8.3)	1 (2.6)	3 (2.9)		
Health-related factors	<i>n</i> (%)	Before <i>n</i> (%)	After-diagnosed <i>n</i> (%)	Before <i>n</i> (%)	After-diagnosed <i>n</i> (%)	Before <i>n</i> (%)	After diagnosed <i>n</i> (%)	Before <i>n</i> (%)	After diagnosed <i>n</i> (%)
Hypertensive	7 (43.8)	37 (34.9)	7 (6.6)	51 (41.8)	25 (47.2)	1 (1.9)	3 (25.0)	9 (23.1)	5 (12.8)
Diabetes	6 (37.5)	25 (23.6)	7 (6.6)	38 (31.1)	14 (26.2)	2 (3.8)	2 (16.7)	9 (23.1)	4 (10.2)
Cardiac problems	3 (18.8)	9 (8.5)	1 (0.9)	13 (10.6)	7 (13.2)	0 (0.0)	0 (0.0)	2 (5.1)	1 (2.6)
Obesity	0 (0.0)	2 (1.9)	2 (1.9)	4 (3.3)	1 (1.9)	1 (1.9)	1 (8.3)	0 (0.0)	0 (0.0)
Others <sup>b</sup>	1 (6.3)	5 (4.7)	0 (0)	6 (4.9)	0 (0.0)	0 (0.0)	3 (25.0)	2 (5.1)	0 (0.0)
All percentages shown are column percentages <sup>a</sup> information related to one patient who died is missing; <sup>b</sup> Others-cholelithiasis (1), chest pain (1), epilepsy (1), gall stone-induced pancreatitis (1), HIV (1) <sup>c</sup> others- maternal aunt (1), wife (2)									

and compliance with stroke medications (84%). Around 70–80% of these needs were met. Over 50% of patients expressed their need for various care services, including BP monitoring, physiotherapy, mobility training, speech therapy, health education, and dietary care. Nearly 70% of these needs were either fully or partially met. However, >50% reported unmet needs for tobacco and alcohol de-addiction, social security, vocational training, emotional support, counseling, cognitive training, and speech therapy. Other care needs, such as treatment of general ailments, and managing swallowing difficulties, were perceived as necessary by only a few patients. Some critical care needs such as cognitive training, emotional support, fall prevention treatment, blood pressure monitoring, mobility training, speech therapy, and physiotherapy were not recognized as a perceived need by a sizable number of stroke survivors [Table 3].

Among stroke survivors, distance (60.2%), transportation (58.3%), and economic barriers (57.2%) were the most commonly cited barriers to care. About one-third of survivors preferred self-management (33.9%), and were ignorant about where to get help or how to access care (33.0%) and the presence of facilities for such care (30.1%). Stigma (0%) and pessimism (3.9%) were not among the perceived barriers [Table 4].

Over two-thirds of patients visited at least one other healthcare center (68.6%) before reaching the tertiary care center. Mostly, they visited a government facility (60.8%), or hospital (80.2%) before reaching the tertiary care center. Post-discharge, almost

three-fourths of patients went to a hospital (75%) and half of them preferred a healthcare facility closer to their home. Interestingly, 22% lacked confidence in the care received at the tertiary care center [Table 5].

## DISCUSSION

The present study investigated 28-day stroke fatality, disability, and perceived need for healthcare services and barriers to meet the perceived needs among first-ever stroke patients at a tertiary care neuro-specialty center in India. The study used an established scale to measure disability and functional status among stroke survivors. Stroke fatality at 28 days was 13.8%. Almost half had some form of disability, with about 40% having moderate to severe disability. A large majority of first-ever stroke patients perceived the need for follow-up visits and compliance with stroke medications after 3 months of stroke. Distance and transportation were the main barriers to accessing healthcare services with the majority preferring healthcare facilities closer to their homes after discharge.

Stroke fatality of 13.8% found in our study is in line with the global estimates that range from 4%–29%.<sup>[8]</sup> Across countries, the case-fatality rates seem to be varied between 10.9% in Taiwan and 33.28% in Nigeria.<sup>[9,10]</sup> Compared to a few Indian studies, stroke fatality in this setting was low.<sup>[11]</sup> In addition to care, the mode of interview and selection of study subjects could have influenced the lower stroke fatality observed. We mostly employed telephonic interviews for data collection. Twenty-six subjects were not available for contact.

**Table 3: Perceived and unmet needs among first-ever stroke patients at a tertiary care neuro-specialty center in India**

Perceived need for care	Perceived as a care need (n=103)	Fully met*	Partially met*	Unmet*
BP Monitoring	57 (55.3)	34 (59.7)	12 (21.0)	11 (19.3)
Physiotherapy	60 (58.8)	33 (55.0)	9 (15.0)	18 (30.0)
Mobility training	59 (57.8)	32 (54.2)	9 (15.3)	18 (30.5)
Mobility aids	59 (57.8)	32 (54.2)	9 (15.3)	18 (30.5)
Fall prevention treatment	51 (50.0)	27 (52.9)	8 (15.7)	16 (31.4)
Bowel/Bladder treatment	44 (43.1)	23 (52.3)	5 (11.4)	16 (36.4)
Pain Management	69 (68.3)	34 (49.3)	17 (24.6)	18 (26.1)
Manage swallowing difficulties	19 (18.5)	10 (52.6)	3 (15.8)	6 (31.6)
Emotional problem	44 (43.1)	7 (15.9)	6 (13.6)	31 (70.5)
Speech therapy	45 (58.0)	9 (20.0)	11 (24.4)	25 (55.6)
Cognitive training	40 (39.6)	6 (15.0)	9 (22.5)	25 (62.5)
Treatment for visual problem	27 (26.2)	9 (33.3)	4 (14.8)	14 (51.9)
Activities of daily activities	59 (57.8)	25 (42.4)	13 (22.0)	21 (35.6)
Counseling/emotional	42 (41.2)	6 (14.3)	9 (21.4)	27 (64.3)
Follow up visit	90 (87.4)	63 (70.0)	16 (17.8)	11 (12.2)
Compliances to stroke medicine	87 (84.5)	74 (85.0)	9 (10.3)	4 (4.6)
Treatment of general ailments	13 (12.6)	8 (61.5)	3 (23.0)	2 (15.4)
Dietary care	56 (54.4)	41 (73.2)	8 (14.3)	7 (12.5)
Tobacco de-addiction (n=14)	10 (71.4)	2 (20.0)	0 (0.0)	8 (80.0)
Alcohol de-addiction (n=7)	5 (71.4)	1 (20.0)	0 (0.0)	4 (80.0)
Vocational training	7 (6.8)	1 (14.3)	1 (14.3)	5 (71.4)
Health education	72 (70.6)	40 (55.6)	13 (18.0)	19 (26.4)
Social security	22 (21.4)	1 (4.6)	3 (13.6)	18 (81.8)

\*Enquired only among those with perceived need

**Table 4: Barriers faced to receiving care among first-ever stroke patients at a tertiary care neuro-specialty center in India (n=104)**

Barriers faced to receiving care	Yes, definitely	Yes, to some extent	No	Definitely no
Patients preferred to manage themselves (self-reliance)	9 (8.7)	26 (25.2)	68 (66.1)	0 (0.0)
Patients did not think anything more could help (pessimism)	1 (1.0)	3 (2.9)	99 (96.1)	0 (0.0)
Patients did not know how or where to get help (ignorance)	8 (7.8)	26 (25.2)	69 (67.0)	0 (0.0)
Patients was afraid to ask for help (stigma)	0 (0.0)	0 (0.0)	101 (98.1)	2 (1.9)
Patients could not afford the money (economic)	31 (30.1)	28 (27.2)	44 (42.7)	0 (0.0)
Distance was a problem to access care	40 (38.8)	22 (21.4)	38 (36.9)	2 (1.9)
Transportation was a problem to access care	35 (33.1)	26 (25.2)	40 (38.8)	2 (1.9)
Doctor, health professional related barrier	3 (2.9)	11 (10.8)	80 (78.4)	8 (7.8)
Facilities not available in the hospital	3 (3.0)	8 (7.8)	84 (81.6)	8 (7.8)

**Table 5: Pathways of care for stroke patients**

Variables	Survivors n=105 (86.8%) n=105 (%)	Fatal cases n=16 (13.2%) n=16	n=121 Total n=121
Number of HCFs visited before reaching tertiary care center			
0	20 (19.1)	4 (25.0)	24 (19.8)
1	73 (69.5)	10 (62.5)	83 (68.6)
≥2	12 (11.4)	2 (12.5)	14 (11.6)
	<b>n=85</b>	<b>n=12</b>	<b>n=97</b>
Health center visited before coming to the tertiary care center			
Government	50 (58.8)	9 (75.0)	59 (60.8)
Private	35 (41.2)	3 (25.0)	38 (39.2)
	<b>n=89</b>	<b>n=12</b>	<b>n=101</b>
Type of health center visited before tertiary care center			
Hospital	69 (77.5)	12 (100.0)	81 (80.2)
Clinic	10 (11.2)	0 (0.0)	10 (9.9)
Traditional Healer	9 (10.1)	0 (0.0)	9 (8.9)
Others	1 (1.1)	0 (0.0)	1 (0.9)
	<b>n=32</b>	<b>n=12</b>	<b>n=44</b>
Type of health center visited after tertiary care center			
Hospital	22 (68.8)	11 (91.7)	33 (75.0)
Clinic	5 (15.6)	0 (0.0)	5 (11.4)
Traditional healer	5 (15.6)	1 (8.3)	6 (13.6)
	<b>n=26</b>	<b>n=11</b>	<b>n=37</b>
Reasons for visiting other hospitals after discharge			
Referred from [NIMHANS]	5 (19.2)	5 (45.4)	10 (27.0)
Was not confident with the treatment received	5 (19.3)	3 (27.3)	8 (21.6)
Place is closer to home	16 (61.5)	3 (27.3)	19 (51.4)

HCF=healthcare facility; others=nursing home

We included both patients who reported to the outpatient department (OPD) and emergency, whereas other studies included in-patients or emergency patients who are likely to experience higher mortality compared to outpatients.

The association of age and male predominance of stroke observed in our study is consistent with previous research.<sup>[12]</sup> Although age is a known predictor of stroke outcomes,<sup>[13]</sup> differences in lifestyle factors such as smoking and alcohol consumption and hormonal factors might influence the difference in outcomes by gender.<sup>[14]</sup> In line with existing evidence, the study results confirm that hypertension

and diabetes are the most common co-morbidities for stroke.<sup>[15]</sup> Hypertension accompanied by other systemic diseases exacerbates the risk of stroke.<sup>[16]</sup> Diabetes increases the risk of stroke by inducing pathological changes in blood vessels, including those in the brain.<sup>[15]</sup> A small proportion (6.6%) of stroke patients were not aware of their hypertension or diabetes previously, highlighting the importance of early detection and appropriate management of stroke and reducing consequent disability.<sup>[17]</sup> In our study, we found that almost one-fifth of fatal stroke cases had cardiac problems (18.8%), emphasizing the importance of careful management of cardiac problems.<sup>[18]</sup> The observed low proportion of obesity (3.3%) could be due

to the method of data collection (telephonic calls), which did not involve actual measurement.

Nearly 30% of stroke patients reported to have ever-smoked tobacco products and alcohol use. Smoking and alcohol use are known risk factors for stroke<sup>[19]</sup> with a positive dose–response relationship.<sup>[20]</sup> Contrary to available evidence, in our study, the majority of stroke patients did not have a family history of stroke.<sup>[21]</sup> Other non-communicable diseases (NCDs), such as hypertension or diabetes within the family may serve as mediators for the pathway between genetic factors and stroke. Eliciting the history of such NCDs could have provided valuable input into this hypothesis that was not sought in the current study. This is a limitation of the study. Alternatively, a family history of stroke may increase awareness of risk factors and make them adopt preventive measures to reduce their risk in contrast to those without a family history. However, this needs further exploration.

The mRs is a commonly used tool to measure the degree of functional outcomes attributable to stroke alone<sup>[22]</sup> rather than any pre-existing disabilities. This may result in lower mRs scores for patients with pre-existing disabilities. Subjects with higher age having a lower proportion of severe disability in our study may be due to this reason as older patients are more prone to pre-existing disabilities.

The study findings underscore the effect of socioeconomic status on stroke outcomes (disability)<sup>[23]</sup> highlighting the need for effective stroke rehabilitation strategies, particularly in low- and middle-income nations with high economic barriers and inadequate access to care. Ensuring universal access to quality care and health insurance, improving outcomes for stroke survivors, and reducing the economic burden on caregivers leading to significant public health implications.

Among stroke patients, a 3-month period is considered the period for maximum functional recovery. In our study, over two-thirds of patients experienced slight to severe disability. It is reported that patients with bilateral hemiparesis tend to have better functional outcomes than those with unilateral hemiparesis.<sup>[24]</sup> However, the lack of proper rehabilitation services may be affecting our study results. Rehabilitation services play a vital role in helping patients achieve optimal recovery outcomes. Individualized rehabilitation plans including physical rehabilitation, and emotional and psychological support are essential for optimal recovery.

About 40% of patients had moderate to severe disability highlighting the significant impact on an individual's ability to perform daily activities and subsequent quality of life. This iterates the need for early rehabilitation therapy and rehabilitation plans post-discharge for stroke patients to regain functionality and improve their quality of life.<sup>[25]</sup> However, this does not eliminate the need for such rehabilitation services for those with slight disability, as they may experience challenges with daily activities that can impact their independence and overall well-being. This also reduces the burden on caregivers by reducing the need for long-term care.

Patients managed at a tertiary care center are expected to have better outcomes (survival, disability, and quality of life). However, significant disability is observed in our study. Conventionally, any treatment outcome depends mostly on the care services provided, time to treatment, complications, and comorbidities the patient might have. There was a significant proportion of patients with comorbidities (use of substances, hypertension, and diabetes) among our patients with some detected with comorbidities after stroke. There was an indirect hint that the time to treatment was higher with the proportion of patients/caregivers reporting transportation and distance as problems in accessing care. The study site was a tertiary care neuro-specialty center with adequate standards of management. It is unlikely that these disabilities are due to care-related issues. However, information related to time to treatment and severity would have thrown more light on the reasons for residual disability.

The study found that patients face multiple barriers in receiving care and support after stroke, including patients preferring to manage their health on their own, not seeking assistance, and lack of awareness on where to get help or how to access care. This finding highlights the need for increased patient and/or caregiver education and awareness on the importance of seeking assistance and to ensure that stroke patients are aware of the resources available to them.

Distance and transportation were identified as the main barriers to accessing healthcare services consistent with previous research. The hub and spoke model, which centralizes specialized services at a hub location, with satellite clinics in the surrounding areas, addresses the issue of distance as a barrier to accessing healthcare services.<sup>[26]</sup>

Our study identified a range of needs for patients post-stroke. A majority of them perceived the need for follow-up visits and compliance with stroke medicine, which is consistent with previous studies.<sup>[27]</sup> It is concerning that a significant proportion of perceived needs were unmet, particularly with regard to tobacco and alcohol de-addiction, social security, and vocational training. These needs were not perceived as important by some patients, whereas some patients were detected with hypertension post-stroke, which underlines the need for education and awareness campaigns. This would ensure early detection and appropriate management of hypertension and diabetes, especially in the backdrop of stroke as a serious complication. Many stroke patients perceived the need for cognitive training and emotional support; however, not all of them received these services. This is concerning, as cognitive deficits and emotional disturbances are common after stroke and can have a significant impact on a patient's quality of life.<sup>[28]</sup>

We found that a significant proportion of patients first visit a healthcare center before being referred to a tertiary care center for further treatment, emphasizing the importance of primary healthcare centers equipped in identifying stroke patients and ensuring they receive appropriate care and referral to

specialized centers when necessary. The majority of patients visited hospitals before reaching the tertiary care center, with a smaller proportion seeking care from clinics or traditional healers. Although it is heartening to note that most patients visit hospitals, there is a need for training clinicians and traditional healers on the identification and referral of stroke patients. Almost half of patients sought care at healthcare facilities closer to their home, after treatment at a tertiary care center. This suggests that there is a need for improved coordination between different levels of health care to ensure that patients receive continuous and comprehensive care throughout the stroke care pathway.

Patient satisfaction is a key indicator of quality of care and is associated with better health outcomes (Jenkinson *et al.*, 2002; Sofaer and Firminger, 2005).<sup>[30]</sup> In this study, some patients reported a lack of confidence in the treatment received and sought treatment at another hospital. This might seem to be a matter of concern. However, the study site being a tertiary care neuro-specialty center, the standardized triage and discharge procedures (triage, treatment, and transfer) used by such centers explain this observation.<sup>[29]</sup> In addition, the referral of non-emergency patients to secondary-level hospitals might contribute to patient dissatisfaction. Patients might perceive this as a lack of continuity of care or feel that their needs are not being fully addressed by the tertiary care center. To address these issues, it is helpful to implement strategies that focus on improving patient satisfaction and engagement. This includes enhancing communication with patients and their families, providing access to support services and resources, and creating a more patient-centered hospital environment.<sup>[30]</sup>

Our study has many strengths. It provides valuable insights into the experiences and outcomes of stroke patients in India, covering factors such as survival, disability, perceived needs, barriers, and post-hospitalized care at 3 months. The use of CT scans for accurate stroke diagnosis minimizes the risk of misdiagnosis. Data collection through telephonic interviews from participants outside of Bengaluru provides a comprehensive understanding of stroke outcomes across different regions. The study generates hypotheses that can guide future research on stroke prevention, management, and outcomes, including factors such as age, co-morbidities, substance use, socioeconomic factors, and unmet needs. Improving access to essential services and addressing transportation barriers through a hub and spoke model of stroke management can improve stroke outcomes.

The study has some limitations, including the use of telephone interviews, which may result in non-response bias and a lack of nonverbal cues or physical assessments. A family history of hypertension and diabetes was not collected, potentially affecting the results. Social desirability bias and potential influence from caregivers of severely disabled patients may have affected data accuracy. However, these are the only

known ways to gather information from those who were severely disabled.

## CONCLUSION

Stroke remains a significant cause of fatality and disability, emphasizing the need for increased prevention efforts and access to post-stroke care and support services. Stroke survivors also require follow-up and compliance to medication, along with various unmet needs such as de-addiction services, vocational training, and emotional support. A network-based multi-disciplinary approach, along with a comprehensive hub and spoke model of stroke management services, could help address these challenges and improve patient outcomes.

## Key messages

This study provides valuable insights into the experiences and outcomes of stroke (survival, disability, perceived needs and barriers for care among patients and their quality of life) 3 months post-discharge. Our results may aid in bridging the treatment gap, improve treatment outcomes, and strengthen healthcare delivery for stroke in India.

## Financial support and sponsorship

Nil.

## Conflicts of interest

There are no conflicts of interest.

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