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ABSTRACT:

Introduction: The ability to use one's arms is vital for daily tasks, social interactions, and quality of life. However, 33% to 66% of stroke survivors fail to regain upper limb function within six months, hindering rehabilitation and reintegration. Self-perception evaluations show minimal influence from the WHO's ICF domains, emphasizing the need for a patient-centered approach. Participatory Action Research (PAR), widely used in community health, offers a collaborative framework for rehabilitation. However, research on Indian stroke patients' attitudes and recovery goals is limited, highlighting the need for tailored strategies addressing their expectations and challenges.

Objectives: This study's core objective is to examine stroke survivors' perspectives on their diminished arm and hand capabilities, emphasizing their inclination to utilize assistive technologies for upper limb functional recovery.

Methods: Ethical committee approval was obtained from the institute before starting the study. The procedure was explained to patients, and consent was obtained orally and in writing. A translated version of a 69-item survey questionnaire, developed by Sullivan et al., was used with permission. The questionnaire was translated into Marathi, and its reliability and validity were tested among stroke patients in Aurangabad. Initially, 112 participants were screened, and 96 meeting inclusion criteria were included. Participants completed the survey through personal interviews or telephonic conversations.

Results: Mean perceived strength, recovery, and function scores for arm/grip strength were considerably lower than desired ratings (p 0.01). Participants' mean perceived functional tasks were significantly less than desired function, household tasks ratings (p<0.01). All participants (100%) showed readiness to employ an assistive device to improve arm and hand function. Important device characteristics were addressed in survey items 60 to 65. Participants considered the weight, size, home usability, cost, functional improvement after training, and independent use capacity as most essential device aspects. The main obstacles to rehabilitation were discomfort, home assistance, transportation, and device cost.

Conclusions: The research findings indicated that stroke survivors experienced considerably lower arm/hand strength, functionality, and overall recovery than anticipated. Surprisingly, socioeconomic factors were found to pose greater challenges to arm rehabilitation than physical limitations such as weakness and stiffness. The majority of participants demonstrated significant interest in arm/hand training devices, with a primary focus on functional improvement. These results emphasize the need to address both physical impairments and external obstacles when developing comprehensive rehabilitation strategies for stroke survivors.

KEYWORDS: - Stroke, Upper-limb impairments, Arm function, Participatory Action Research

Introduction: -

Stroke is a leading cause of mortality and disability in India. Recent demographic studies show an incidence rate ranging from 119 to 145 per 100,0001,2. Strokes are the second leading cause of death and disability worldwide, following ischemic heart disease3. Stroke rates are disproportionately higher in low- and middle-income countries4. In India, stroke ranks as the fifth most common cause of years lived with disability5. In 2016, India had 6.5 million stroke cases, accounting for 7.1% of all fatalities6. Stroke, often referred to as a brain attack, results in sensory, neurological, and cognitive impairments7. Stroke survivors may require short-or long-term assistance, which has profound social and economic impacts8. Research conducted in developing settings highlights that stroke survivors face challenges with mobility, mood, education, and employment9,10.



The 75th Round of the National Sample Survey reports cardiovascular disorders as the leading cause of inpatient stays (18.1%) and outpatient visits (32%) among the elderly in India11. From a public health perspective, it is vital to understand the prevalence and causes of stroke to develop effective prevention and treatment strategies12,13. More than 50% of stroke survivors face long-term difficulties with physical functioning, including mobility and falling13. Furthermore, a significant portion experiences progressive physical decline post-stroke. Within the first year, more than 25% of stroke survivors lose physical function, and this loss peaks at 40% within the first three years14. Therefore, preventing further physical decline in the early stages after a stroke is crucial14.

Risk factors for stroke include high blood pressure, diabetes, high cholesterol, unhealthy habits (such as smoking and binge drinking), a sedentary lifestyle, obesity, and ongoing stress. Lifestyle modifications can prevent and significantly reduce stroke risk15. Studies have shown that motor impairment in the ipsilesional upper limb appears within three months after a stroke, hindering physical function and self-reliant daily tasks16. Only 20% of subacute stroke patients regain normal arm function17, and after six months, 33% to 66% of patients fail to restore upper limb function18. Arm use is critical for performing basic everyday tasks18-20, and bimanual activity performance is essential in rehabilitation since most daily activities involve both hands18-20. Enhanced arm and hand function promotes social engagement and improves health-related quality of life19,20. Impaired hand function and arm motor dysfunction are significant predictors of recovery21. Upper extremity retraining within the first six months post-stroke is crucial, as functioning and ADL recovery typically deteriorate thereafter22.

Compared to healthy individuals, stroke patients tend to avoid using bilateral motor patterns in daily tasks23. Relearning bimanual tasks is critical for stroke patients, as tasks like driving, dressing, and using towels require both hands24-30. However, many stroke rehabilitation approaches overlook engaging the less-affected arm and focus mainly on strengthening the contralesional arm30. A multidisciplinary approach to stroke research broadens the lens through which recovery is perceived, offering a framework for interdisciplinary dialogue31. Holistic care is essential, as addressing only the cognitive, emotional, or physical aspects in isolation slows the healing process and undermines the effects of treatments32,33. Comprehensive rehabilitation is provided by a team consisting of physiotherapists, allied health professionals, speech-language pathologists, psychologists, social workers, and rehabilitative physicians30,31,32. Various tools are available for assessing upper limb function in stroke rehabilitation34. Although most instruments require an observer, self-reports are encouraged as they provide valuable insights into a patient's ability to use the affected upper limb in meaningful activities outside the rehabilitation context35,36,37. Commonly used and validated measures include the Action Research Arm Test (ARAT)38, the Box and Block Test (BBT)39, and the Wolf Motor Function Test (WMFT)40, which evaluate a patient's ability to perform activities of daily life in clinical settings. These tests align with the International Classification of Functioning, Disability, and Health (ICF)41.

Self-perception assessments for upper limb function are independent of WHO-level ICFs of participation and activity42. These assessments, such as the Motor Activity Log (MAL) or the Hand domain of the Stroke Impact Scale (SIS-Hand)43,44,45, focus on the extent to which the affected upper limb is used in daily activities, the types of movements involved, and the complexities of its use. They provide insight into the patient's perspective on their functional capabilities 46.47. Participatory Action Research (PAR) has been widely applied in local and public health programs and could be an effective method for addressing complex public health issues47,48. PAR is a systematic, collaborative, and empowering process aimed at improving practices. It is a qualitative approach that emphasizes the roles of both participants and researchers49,50. According to Joy Hammel et al., PAR can facilitate system changes by analyzing the barriers to communal living and inclusion post-stroke. However, research on post-stroke needs and recovery goals among Indian patients is limited51. Furthermore, there is a scarcity of PAR studies focusing on stroke patients' perspectives on improving upper limb function in India. This study aims to evaluate post-stroke patients' perceptions of their impaired arm and hand function and their willingness to use devices to restore upper limb function. It also seeks to understand the needs and challenges faced by stroke survivors in rehabilitating their arm and hand function. By exploring these factors, the study hopes to contribute valuable insights for enhancing arm intervention research and developing more effective devices in the Indian context.

Methods: -

The study encompassed 96 stroke patients, a sample size chosen to align with the research objectives and anticipated prevalence of functional impairments related to stroke in the target population. Conducted across various hospitals in Aurangabad, including MGM Hospital, the study invited eligible patients to take part. Selection criteria for participants were specific. Individuals had to be willing to join the study and provide verbal or written consent. Eligibility required a stroke diagnosis, regardless of stage, with at least one year post-stroke. The age range for both male and female patients was 30 to 75 years, with a focus on those who had experienced a middle cerebral artery (MCA) stroke. Exclusion criteria encompassed patients with contractures in both upper and lower limbs, inability to follow instructions, presence of other neurological conditions like

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Parkinson's disease or multiple sclerosis, or emotional or behavioral issues that could hinder participation. The study utilized materials such as a consent form, data collection sheet, mobile phone, and pen. Adult stroke patients over 30 years old were recruited from MGM Hospital and other Aurangabad hospitals. Those who provided informed consent, either written or verbal, were included. A study team member maintained phone contact with participants, conducting personal interviews when necessary. The research team, consisting of the primary investigator, an assistant physical therapy student, and the researcher, underwent training to ensure consistent communication with participants. Before participation, patients were briefed on the study's objectives and methodology. Upon agreeing to participate, they could choose to complete the survey immediately via phone or through a personal interview.

The main outcome measures were obtained from a translated version of a 69-item survey questionnaire, initially created by Jane E. Sullivan, Justin Drogos, Carolina Carmona, and Jun Yao. This survey explored various crucial areas: demographic information, stroke and comorbidity details, pre- and post-stroke activity and exercise habits, post-stroke arm and hand functionality, and the perceived necessity for arm/hand function improvement training. It also evaluated the readiness to utilize an arm/hand exercise device and the essential features of such devices. Furthermore, the Stroke Impact Scale 3.0 was employed to evaluate seven questions on arm/hand-related activities of daily living (ADLs), two questions on arm/grip strength, five questions on hand function, and one question on recovery. Arm/hand strength, hand function, and recovery barriers or goals were rated using a 5-point Likert scale, with recovery items measured from 1 to 100%. To ensure accuracy and consistency with the original English version, a back translation of the Marathi version was conducted. The survey's content validity was assessed by two stakeholder groups. The first group comprised five physical therapists experienced in stroke patient treatment and familiar with Marathi. The second group consisted of ten stroke survivors. These stakeholders examined the questionnaire and offered feedback on its clarity, relevance, comprehensiveness, grammar, and potential additional items. Their recommendations were incorporated into the revised survey version. Items were rated using a 5-point Likert scale, and reviewers were encouraged to provide narrative feedback for further improvements. The reliability of the translated Marathi questionnaire version was evaluated using Cronbach's alpha coefficient, with a value of 0.7 or higher considered indicative of acceptable internal consistency. The translated version's Cronbach's alpha value was 0.748, demonstrating acceptable reliability.

The original authors granted permission to use the questionnaire in the study. Data collection was performed through phone or in-person interviews, based on participant preference. The research team ensured all participants fully comprehended the study objectives and procedures before participation, and informed consent was obtained. Participant data were securely stored and analyzed to address the study's aims. This methodology provides a comprehensive framework for understanding stroke survivors' rehabilitation needs and perceptions, emphasizing the role of assistive devices in enhancing post-stroke upper limb function.

RESULT

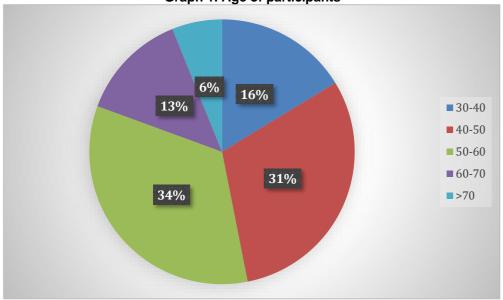
Table 1. The characteristics of the participants

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Characteristics		Frequency	Percentage		
AGE	30-40	16	16.3		
	41-50	30	30.6		
	51-60	33	33.7		
	61-70	13	13.3		
	>71	6	6.1		
GENDER	MALE	89	90.8		
	FEMALE	9	9.2		
DOMINANT	LEFT	3	3.1		
SIDE	RIGHT	95	96.9		
AFFECTED	LEFT	11	11.2		
SIDE	RIGHT	87	88.8		

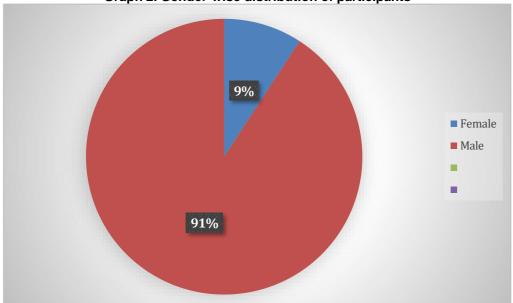
The age group of 51-60 showed more incidence of stroke which was 33.7% followed by the age group of 41-50 which was 30.6%. The male population was more affected than the female population i.e., 90.8% and 9.2% respectively.



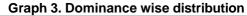
Graph 1. Age of participants

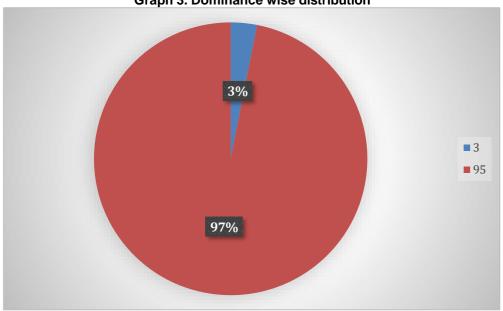


Graph 2. Gender-wise distribution of participants









Graph 4. Affected side-wise distribution

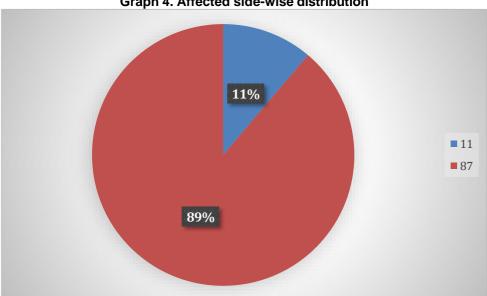


Table 2: Perceived and desired strength, recovery, and function scores of study group subjects.

Components	Survey items	Perceived Mean±SD	Desired Mean±SD	Mean difference	p-value
Arm Strength	17 perceived 36 Desired	2.60±0.8	3.18±0.9	0.58	0.001
Grip Strength	18 perceived 37 Desired	2.38±0.868	3.17±0.931	0.79	0.001
Arm recovery	32 perceived 34 Desired	27.70±21.708	27.70±21.708	0	
Hand Recovery	33 perceived 35 Desired	27.70±21.708	27.70±21.708	0	

The mean arm/grip strength ratings given by participants were considerably lower than their targeted strength ratings (p<0.01).

The hand and arm recovery were measured on a scale from 0 to 100%. Strength, function, and restoration as "perceived" relate to answers to survey questions with the item stem: On a scale from 0 to 100, where 100



corresponds to full recovery and 0 corresponds to no recovery, how much of YOUR ARM (or hand or hand function) has recovered after your stroke?

The stem of survey questions the "desired" strength, function, and recovery were assessed using a "scale from 0-100, with 100 reflecting full recovery and 0 representing no recovery," or "think that concentrating on improving its functioning was advantageous"?

Ratings of arm and grip strength were made using a 1–5 scale, with the results as follows: 1 = No Strength; 2 = Minimal Strength 3 = Some Little Strength 4 has a lot of strength. 5 indicates great strength

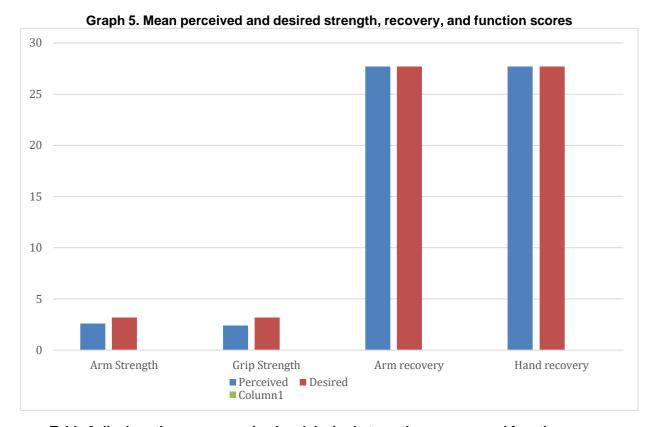


Table 3 displays the mean perceived and desired strength, recovery, and function scores

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Hand Function	Survey items		Desired Mean±SD	Mean differences	P value
Carry heavy objects	26 Perceived 45 Desired	2.38±0.868	3.36±0.815	0.98	0.001
	27 Perceived 46 Desired	2.38±0.868	4.02±0.688	1.64	0.001
Open a can or jar	28 Perceived 47 Desired	2.38±0.868	2.78±0.793	0.39	0.001
llie a	29 Perceived 48 Desired	2.38±0.868	2.69±0.779	0.31	0.001
Pick up a coin	30Perceived 49 Desired	2.38±0.868	3.34±0.773	0.95	0.001

Mean perceived strength scores for participants' arm/grip strength ratings were significantly lower than their targeted strength ratings (p 0.001).

On a scale from 0 to 100%, the hand and arm recovery were calculated. Survey responses to the question: How much has YOUR ARM (or hand or hand function) recovered after your stroke, on a scale from 0 to 100, with 100 signaling full recovery and 0 showing no recovery?



In response to a survey's stem question, "How much improvement would you need to observe to feel that arm and hand training was worth your time and effort?" the "desired" strength, function, and recovery were calculated using a "scale from 0-100, with 100 indicating full recovery and 0 representing no recovery." or "believe it was better to focus on enhancing its functionality"?

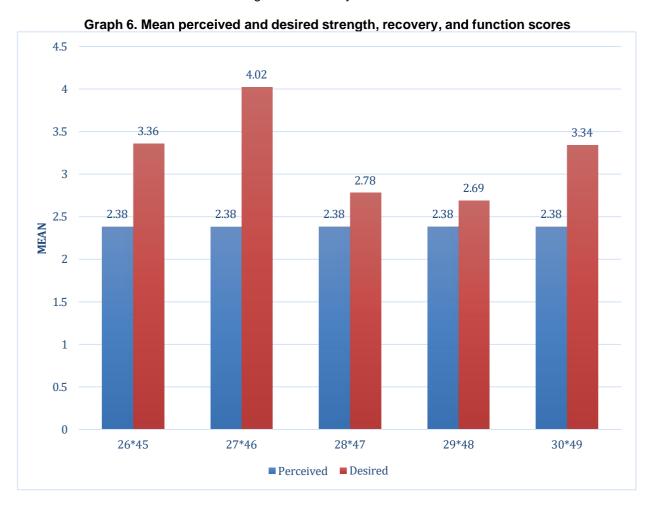
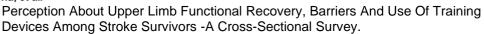


Table 4. Displays Perceived and Desired scores for Functional Tasks

Components			Desired Mean±SD	Mean differences	P value
	19 Perceived 38 Desired	2.16±0.858	3.63±0.830	1.46	0.001 (S)
Dressing	20 Perceived 39 Desired	2.38±0.868	3.18±0.923	0.806	0.001 (S)
Bathing	21 Perceived 40 Desired	2.38±0.868	3.17±0.931	0.79	0.001 (S)
Shopping	22 Perceived 41 Desired	2.38±0.868	3.18±0.829	0.806	0.001 (S)
Light household chores	23 Perceived 42 Desired	2.38±0.868	3.67±0.715	1.29	0.001 (S)
Heavy household chores	24 Perceived 43Desired	2.38±0.868	2.59±0.744	0.21	0.001 (S)
Cooking	25 Perceived 44 Desired	2.38±0.868	4.15±0.751	1.77	0.001 (S)
	26 Perceived 45 Desired	2.38±0.868	3.36±0.815	0.98	0.001 (S)
	27 Perceived 46 Desired	2.38±0.868	4.02±0.688	1.64	0.001 (S)

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Open a can or jar	28Perceived 47 Desired	2.38±0.868	2.78±0.793	0.39	0.001 (S)
Tie a shoelace		2.38±0.868	2.69±0.779	0.31	0.001 (S)
Pick up a coin	30 Perceived 49 Desired	2.38±0.868	3.34±0.773	0.95	0.001 (S)

Mean ratings of intended functional activities by participants were significantly higher than mean ratings of perceived functional tasks (p 0.01).

Based on the average desired rating, the tasks are ranked. Perceived ratings, which reflect participants' assessments of their present status, and wanted ratings, which reflect participants' ratings of their planned objectives or states, have been used to categorize the ratings of participants' arm function while participating in activities.

The stem for the items, which served as the foundation for scoring, questioned, "How difficult was it to use the hand that was most affected by your stroke to... in the preceding two weeks?" Then, ask, "How difficult should it be to...," using the scale below.

1/5 - Completely Incapable 2/5 -Very Difficult 3/5 - Moderately Difficult 4/5 -It's a little difficult, 5/5 - Not at all challenging

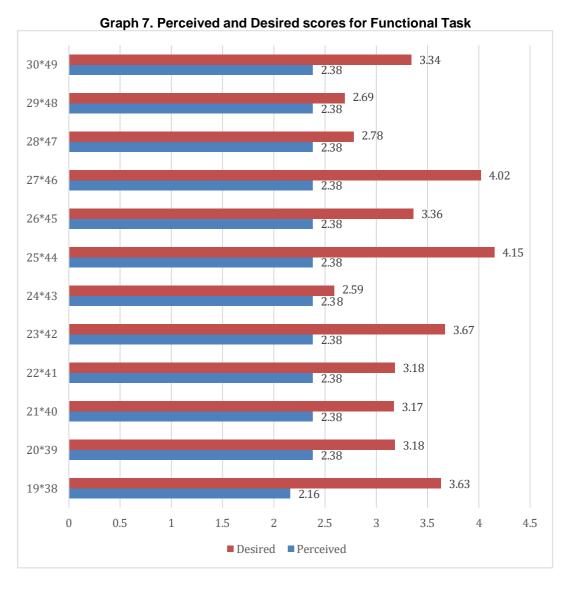




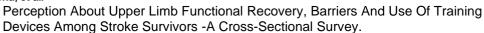
Table 5. Summarizes participants' identification of barriers to arm recovery

Possible barriers	% of participants rated the item as a significant barrier or barrier (score 1-2/5)	% of participants rated the item as neutral to no barrier (score 3-5)
Time	14.2%	85.6%
Cost	75.5%	24.5%
Access to therapy	21.4%	78.6%
Assistance at home	35.7%	64.4%
Transportation	32.6%	67.4%
Ability to use arm/hand during daily activities	25.5%	74.5%
Weakness	15.3%	84.7%
Spasticity	25.7%	74.3%
Pain	46.9%	53.1%

The percentage of participants who assessed each problem as a "barrier" (2/5) or "major obstacle" (1/5) indicates how significant it is to arm/hand rehabilitation.

The following is how the items were scored: 1/5 = A major impediment 2/5 = Barrier 3/5 = Uncertain <math>4 = A Slight Obstacle 5/5 = Definitely Not a Barrier

Graph 8. Barriers to arm and hand recovery





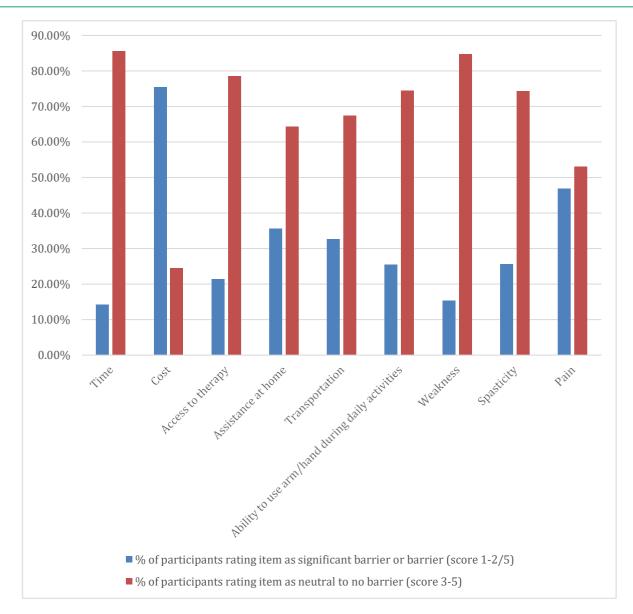


Table 6. Summarizes participants' identification of the importance of device characteristics.

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Device	% of participants	% of participants	% of participants	
Characteristics	rating very important	rated somewhat to	rated little to not	
	(5/5)	quite important (3-4/5)	important (1-2/5)	
Coot	0		44.9	
Cost	U	55.1	44.9	
Functional gain	7.1	80.7	12.2	
following device-				
assisted training				
	10.0	00.4	10.1	
Device weight	12.2	68.4	19.4	
Device size	2	69.4	28.6	
Able to use at home	37.8	62.2	0	
Able to use at nome	37.0	02.2	0	
Increased arm	35.7	63.3	1	
function while using				
the device				
Low risk of side	25.5	74.4	0	
effects	20.0	,	ľ	
CHECIS				



Use independently	30.6	68.4	1
Use the device for ≤2 hours	23.5	65.3	11.2

Here is a list of the top device features, ordered by the proportion of respondents who gave each one a score of 5 out of 5.

The following is how the items were scored: 1/5 = A major impediment 2/5 = Barrier 3/5 = Uncertain <math>4 = A Slight Obstacle 5/5 = Definitely Not a Barrier

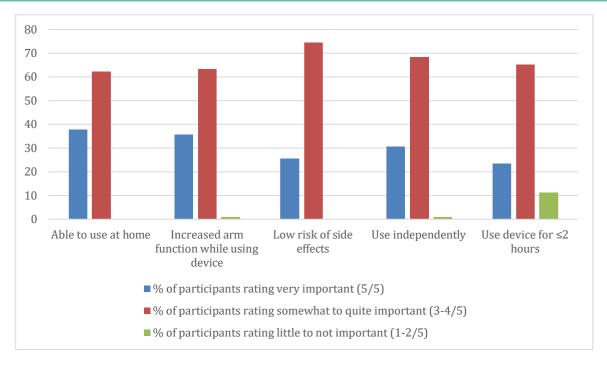
90 80 70 60 50 40 30 20 10 0 Cost Functional gain following Device weight Device size device assisted training ■ % of participants rating very important (5/5) ■% of participants rating somewhat to quite important (3-4/5) ■ % of participants rating little to not important (1-2/5)

Graph 9. Importance of device characteristics: Cost, Functional gain, Device weight, device size

Graph 10. Importance of device characteristics: Ability to use at home, increased arm function with device use, low risk of side effects, independent use, use for ≤2 hours

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DISCUSSION

The undertaken study aims to understand the perception of upper limb functional recovery, barriers, and use of training devices among stroke survivors in the Indian population. Almost one of those who experience a stroke are severely handicapped and reliant on others for daily living activities (ADLs) and call for some rehabilitation techniques. Upper limb impairment is troublesome, resulting in an impact on many ADLS, namely dressing and feeding⁷⁶. A unique kind of bimanual function is presented by coordinated hand motions. They vary from other bimanual operations in that they demand both hands to move in synchrony in addition to acting simultaneously. For instance, while opening a bottle, the action of one hand is complemented by the equivalent counteraction of the other⁵³.

The current study employs PAR to better understand participants' perceptions of and desires for their functional recovery of the upper limb, as well as their opinions on the usage of assistive devices and potential recovery roadblocks. The definition of PAR is "a systematic investigation, incorporating individuals impacted by the subject being analyzed, with the objectives of education and action, or promoting social change.⁵⁴" The fundamental principles of PAR, according to Israel et al., include that it is participatory and encourages "collaborative, fair collaboration throughout the qualitative research^{55,56}. Underpinning PAR and related approaches are a shift in power from academic institutions to communities, where participants are treated as more than just research subjects and outsiders are encouraged to value "the experience and partnership of individuals we typically are contented simply to quantify.^{57,58}" Existing PAR in stroke has mainly been undertaken to either investigate experiences of the participants with stroke or to explore satisfaction after participants finished an intervention or used an equipment⁵⁹.

In our study, analysis was done at the baseline which showed that the age group of 51-60 showed more incidence of stroke which was 33.7% followed by the age group of 41-50 which was 30.6% which was similar to the findings of **Kaur P**, **Verma SJ**, **et al.**, who showed that the mean age of those with stroke was 62.2 years. We also observed that the male population was more affected than the female population i.e., 90.8% and 9.2% respectively⁶⁰. These results showed a resemblance with a prevalence study conducted by **Stephanie P Jones, Kamran Baqai, et al.** which reported the epidemiology of stroke in India⁶¹.

The perceived, desired, and actual levels of recovery, strength, and function in our participants' damaged arms and hands were significantly different from one other. In addition, we discovered that even though the perceived levels of recovery at the hand are substantially lower than those at the arm (p = 0.001), and when comparing the perceived levels of recovery at the hand or arm to the overall recovery, there is no difference between the desired levels of recovery for the arm and hand. These findings emphasize the opportunity for clinicians and researchers to assist patients in achieving their objectives for arm/hand recovery by showing that even in a chronic stroke sample, participants seek higher hand/arm recovery, strength, and function than they have attained.

The Stroke Impact Scale (SIS 3.0) subscale was used to generate survey questions 26–30 (perceived) and 45–49 (desired). Mean scores for desired and perceived hand function were 11.9 and 16.19 respectively. The discrepancy between the desired and perceived scores was 24.337. The survey recovery questions (32-35)



were modified from SIS 3.0 item 9, which requests respondents to score overall recovery on a scale of 0 to 100%. These questions and the survey's hand and arm recovery items have a statistically significant positive connection, indicating they may be reliable instruments for measuring stroke recovery in the arm and hand. To improve their arm and hand function, all participants (100%) had shown readiness to employ an assistive device, emphasizing that this is a high key priority for assistive device development. Important device characteristics were addressed in survey items 60 to 65. The weight and size of the device, the ability to use it at home, the cost, the functional improvement after device training, and the capacity to use it independently were the device aspects that our participants thought were most essential. The main obstacles to rehabilitation, according to our participants, are discomfort, home assistance, transportation, and the device's cost. The design of devices and therapies for people with persistent arm paresis as a result of stroke should be shaped by considering these aspects into account. In a low-resource setting like India, stroke units and rehabilitation facilities are virtually absent in the Government sector, and those in the private sector are inaccessible to the semi-urban and rural population⁶².

It has been discovered that a stroke unit's organized caregiving increases the proportion of patients who survive, go home, and regain functional independence in daily activities⁶³. In low- and middle-income nations, particularly in places like India with scarce resources for rehabilitation, effective implementation of such systematic treatment for stroke is, however, restricted and insufficient⁶⁴. Owing to rising stroke incidence and very little social support, a similar situation is anticipated in India.

Contrarily, prior PAR research by **Wyller TB, Sveen U, et al.** revealed that limited arm movements were the main obstacle to the participants' rehabilitation⁶⁵. Although spasticity, weakness, and inhibited arm/hand mobility were less frequently recognized as impediments to recovery, therapists should take into account that these remain the primary factors that stand in the way of recovering as prolonged impairment of the arm and hand caused by hemiparesis, which has a major influence on performance in daily living tasks, is one of the most typical disabilities following stroke as stated by **Johan Anton Franck et al**⁶⁶.

In a recent systematic review by **Luker J, Lynch L, et al.**, the authors argued that participants' experiences and preferences should be taken into account by stroke researchers⁶⁷, and prior research by **Reker DM**, **Duncan PW**, **et al.**, indicates that patient adherence to recommended treatment regimens is linked to both higher user satisfaction and better results⁶⁸. According to **I.F. Groeneveld**, **et al.**, clinical improvement persisted up to a year following the stroke, and participation, adherence, and response rates for a comprehensive database of Patient Related Outcome Measures (PROMS) for patients with stroke in rehabilitation were moderate to good⁶⁹. Participants in our study ranked functional improvements, cost of the training device, its weight, and size, and autonomous, an at-home device used as the major five aspects of arm training devices that are "extremely essential." Researchers and device designers have to take into account these user objectives in the development of arm function devices and the design of interventions.

CONCLUSION:

Participants reported much less than anticipated levels of arm/hand strength, function, and overall stroke recovery. Impairment-level elements such as socioeconomic factors are more of a hindrance to arm healing than weakness and stiffness. Most stroke survivors are interested in utilizing arm/hand training devices and cite functional progress as the most crucial device feature.

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CONFLICT OF INTEREST: The authors report no conflict of interest in this work.

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