

Rehabilitation of Stroke Patients in India: An Exploratory Study from a National-Level Survey Data

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Abstract

Background: Stroke is one of the significant public health challenges and one of the critical causes of disability. It has been forecasted that globally age group 60 and above will outnumber children under age 14 in 2047. With the increasing rate of survival, the burden of stroke is going to increase continuously. Currently, old age people suffer from stroke, which limits their activities of daily living. This study explores the determinants of stroke survivors seeking rehabilitation services and the factors affecting them.

Methods: In this study, first wave of Longitudinal aging study in India (LASI) data has been used. The data was collected from all the States and Union Territories across India in 2017-2018. A total number of 72,265 individuals (45 years and above) participated in this study. Subjects who have been ever diagnosed with stroke by any health care professionals were considered as the study population. Subjects were categorized into two groups based on accessing rehabilitation services. For the data analysis, survey-weighted tools have been applied for descriptive statistics and multivariable logistic regression model. The data analysis used R version 4 using R studio.

Results and Discussion: The prevalence of stroke is 1.8% in India. Nearly 40% of them visited Physical therapy or Occupational therapy services for their rehabilitation. Household economical condition, gender, residence, requirement of additional help for daily activities and availability of health insurance are strongly determining visiting rehabilitation services. The summary of this will help to develop our understanding of, why people are not availing of rehabilitation services despite having multiple problems.

Keywords: *Activities of daily living, Physical therapy, Occupational therapy, Stroke rehabilitation, After care.*

Introduction

Worldwide stroke is the second leading cause of mortality ^[1] and one of the significant public health challenges resulting in disability. A study conducted in India by Global Burden of Disease revealed 9.4 million

deaths were only from stroke and 28.5 million lost Disability-Adjusted Life Years (DALYs), which is six times more than malaria ^[2,3]. The incidence and prevalence of stroke in India vary extensively due to variation in dietary intake, vitamin levels, the air pollution level, cultural and genetic variance ^[4,5]. Despite availability of various intervention techniques, still Stroke is one of the major reason for the disability worldwide ^[6]. It has been forecasted that globally people age 60 years and above will outnumber children under age 14 in 2047 ^[7]. This shows that with the increasing rate of survival, the burden of stroke will increase continuously ^[6]. Stroke is a complex condition that includes collecting symptoms

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like sensorimotor, cognitive, perceptual, behavioural and motor impairments^[1,8,9].

The after-effects of stroke will limit the independence and activity level of stroke survivors not only in activities of daily living (ADL) but also in instrumental activities of daily living (IADL), affecting behavioural and social roles^[1]. We should understand the needs of stroke survivors in their participation in daily activities, both ADL and IADL, maintain the socialization, money management and other simple cognitive functions^[10]. Here comes the role of a rehabilitation professional, who help the stroke survivors to return to the previous activity level. After stroke, the prominent role of rehabilitation professionals is to focus on overall improvement in motor control and hand function to regain independence in ADL and IADL. Stroke rehabilitation is a multidisciplinary and interdisciplinary approach. Physical Therapists (PT) and Occupational Therapists (OT) play a pivotal role in stroke management^[11]. They conduct a detailed assessment of motor functions and other areas like perceptual, cognitive, memory, executive function, participation in the community, work environment, home modifications, physical and task performance like self-care tasks, including bathing, dressing, undressing, toileting, grooming, eating, and domestic or instrumental tasks like meal preparation, shopping, cleaning, laundry, financial and medicines management^[7]. Their interdisciplinary roles help in the holistic development of the patient. There is evidence showing that rehabilitated patients after stroke are better in functioning and performance than others^[7]. The rehabilitation regime focuses on the essential motor function, teaching compensatory techniques, and includes retraining in other areas like perceptual, cognitive, and visual by graded activities. Moreover, they also focus on training to caregivers, proper handling techniques etc., which eventually minimizes further complications. Treatment overall helps patients regain confidence, perform daily tasks, return to work, and mainstream society like being with their peers. Retraining stroke individuals is a complex task, and the rehabilitation programs help in neurological recovery, teaching ADL and IADL activities through compensatory techniques, social skills and psychological support^[12]. A non-discriminatory and equitable health care access is the goal of any health care

program globally^[13]. However, certain salient features are key to rehabilitation service, for instance, use of a supportive device or aids like a wheelchair, caregiver who can accompany them for rehabilitation service, health insurance to cover their expenditure (financial barriers) etc.

This study explores the landscape of the burden of stroke, access to therapeutic services to stroke patients in India, and its implications. This study aims 1) To find out the self-reported prevalence of stroke in India for the year 2018, stratified by location, gender, and other sociodemographic factors 2) To estimate the proportion of stroke survivors who availed PT/OT services for their rehabilitation. 3) To explore the range of different forms of disability, including physical, psychological, cognitive, speech, and vision. 4) To estimate the burden of mobility-related impairment in stroke survivors. 5) Evaluate the level of independence in performing ADL/IADL 6) To explore the use of various types of supportive devices and 7) To understand the requirement of external help in the form of caregivers for their day-to-day performance.

Material and Methods

Cross-sectional data were collected in 2017-18 from a nationally representative Longitudinal Ageing Study in India (LASI) Wave-1^[14]. Household and individual Interviews, physical measurement and biomarker data were collected from individuals aged 45 years and above and their spouses, regardless of age, in a household survey. Details of the sampling strategy have been described elsewhere^[14]. The study was approved by the Indian Council of Medical Research (ICMR) Ethics Committee, and written informed consent was obtained from participants^[14]. The data was collected from all the States and Union Territories across India in 2017 – 2018. A total number of 72,265 individuals participated in this study. This study used unit level first wave of LASI data.

For this study, we have used variables from the Health module of the Individual level questionnaire. Subjects who have been ever diagnosed with stroke by any health care professionals were considered the study population. Eleven relevant questions had been asked to explore the range of problems within that

population. Subjects diagnosed with stroke were again sub-categorized to avail rehabilitation services PT/OT for stroke or its complications. The questions related to our interest are due to stroke any types of physical disability like weakness in arms and legs or their ability to use them, difficulty in speaking, swallowing, vision, thinking or finding the right words to say. There is another module of functional limitations and helpers within individual questionnaires where questions related to physical, or health problems have been asked. The range of questions includes mobility-related impairments (both upper limb lower limb), ADL/ IADL, supportive devices, any types of external help in the form of caregivers for daily activities. Monthly per capita expenditure variable has been used as proxy for the financial status of the household.

For the data analysis, survey-weighted tools have been applied for descriptive statistics and multivariable logistic regression model. The data analysis used R version 4 using R studio. P value less than 0.05 taken as statistically significant for all the results.

Results

A total number of 72,265 individuals participated in this study, out of which 1,220 individuals reported being diagnosed as stroke survivors across India for 2017-2018. The self-reported prevalence of stroke from this study was 1.8% among older adults (45 and above) in India. The prevalence of stroke in rural India was 1.7 %, whereas in urban counterpart was 2%. The male proportion stands at 2.5%, which is nearly double the rate of females (1.3%). Across the 45-59 age group, the proportion was 1%, whereas, in the 60+ age group population, the burden was 2.7%. The mean age of stroke in India stands at 58.5 ± 11.1 years and the median age 65 (Range 31-98 and IQR 57-72 years). Among stroke survivors, 94% of them have been diagnosed by the mainstream healthcare system (MBBS and above), whereas only 4.2 % were diagnosed by AYUSH (Ayurvedic/Unani/ Homeopathic/ Siddha) system practitioners. A small proportion of 1.7% was diagnosed by others, including Auxiliary Nurse Midwife (ANM), health workers, nurses, private clinics, quack, and registered medical practitioners (RMP) doctors. Nearly a quarter of the subjects have more than one episode of

stroke within their lifetime.

To understand the variability among those who visit therapeutic services for stroke rehabilitation from non-visitors, the following tables have been stratified by the factor of whether anyone visits PT/OT services or not. Of the 1220 individuals with ever diagnosed stroke, 469 (40.1%) availed PT/OT services for their treatment, whereas 749 had not availed PT/OT with two missing information. Table 1 describes demographic variables and their association with PT/OT services. As seen in the table 1, the proportion of stroke survivors is higher in the 60+ age group than the 45-60 age group. Also, there is a significant difference of around 17% between males and females to access the professional rehabilitation services in India for stroke. Similarly, place of residence, having health insurance, dependency on external support and supportive devices are other variables that play a significant role in accessing those services. Despite the difference in accessing rehabilitation services for caste, marital status, education, occupation, and diagnosis by medical professionals, these parameters are found to be not statistically significant.

A stroke results in multiple types of disabilities; table 2 explored the proportion of range of disabilities after stroke. Movement-related problems was the highest among different problems, with nearly 90% of the stroke survivors followed by speech and cognitive problems. There was a variation of these impairments among those who visited PT/OT services for their rehabilitation. As described above mobility-related issues are a significant burden for stroke survivors; following analysis has been emphasized on gross motor function and fine motor activities, respectively.

Among different types of movement-related impairments, stair climbing, and kneeling were maximally affected activities. The proportion of activity related to hand function (picking up a coin from the table) was the least for the stroke survivors (Figure 1).

As presented in the figure 2, most outdoor activities such as gardening, money management while shopping, and finding a new address among stroke survivors are more affected than other basic activities such as eating, bathing, etc.

Table 3 describes the use of various forms of supportive devices to compliment the independence in ADL/IADL. More than half of the stroke survivors using any form of supporting devices for performing gross activities, among which using a walker or walking stick is the most frequently used device. For their daily activities, nearly 46% depend on external help such as family members' professional help from outside or others.

The multivariate logistic regression analysis has been done to decide who is visiting therapeutic services for the rehabilitation after stroke in India. We found residence, occupation, monthly per capita expenditure, availability of health insurance, use of supportive devices, and need for external help were statistically significant differences in groups who visited PT/OT

services from those who never visited for rehabilitation in India independently. The persons with rural, unemployed, poor economic status, lack of financial security, user of supportive devices, using external help are in disadvantageous position compared to others. After putting these variables for multivariate logistic regression following models have been evolved along with other critical demographic variables following three models have been evolved. Model-1 shows that the richest quintiles, external help, and occupation were significant contributing factors after adjusting for other demographic and other variables. Model-2 describes Economic status as the critical factor to decide, whereas model-3 shows residence, gender and external help requirement are the essential parameters to determine whether anyone will visit for PT/OT services or not for stroke rehabilitation.

Table 1 Demographic variable and its association with stroke survivors

Determinant	Response	Availing PT/OT services		Total n (%)
		Yes n(%)	No n(%)	
Age group (In years)	31-44	7 (1.4)	18 (2.6)	25 (2.1)
	45-59	123 (27.5)	229 (29.3)	353 (28.7)
	60+	338 (71)	499 (68)	838 (69.1)
Gender	Male	288 (64.4)	430 (54.6)	720 (58.6)
	Female	181 (35.6)	319 (45.4)	500 (41.4)
Place of residence	Rural	250 (56)	460 (69.6)	712 (64.3)
	Urban	219 (44)	289 (30.4)	508 (35.7)
Caste	Scheduled caste	80 (17.1)	136 (26)	217 (22.4)
	Scheduled tribe	54 (4.2)	110 (6.5)	164 (5.6)
	Other Backward Class	175(48.3)	249 (39.1)	425 (43)
	General	138 (30.3)	218 (28.3)	356 (29)
Marriage	Married	339 (69.4)	536 (70.5)	876 (70.1)
	Widowed	119 (29.1)	195 (28)	315 (28.4)
	Others	11 (1.4)	18 (1.5)	29 (1.4)
Ever attended school	Yes	281 (53.6)	424 (52.6)	706 (53)
	No	188 (46.4)	325 (47.4)	514 (47)

Cont... Table 1 Demographic variable and its association with stroke survivors

Occupation	Employed with primary work#	135 (28.8)	234 (31.2)	370 (30.3)
	Unemployed	205 (43.7)	351 (46.9)	557 (45.7)
	Others	129 (27.5)	164 (21.9)	293 (24)
Health insurance	Yes	82 (13.8)	172 (21.6)	254 (18.5)
	No	381 (86.2)	573 (78.4)	956 (81.5)
Use of supportive device	Yes	285 (63.7)	405 (52.1)	691 (56.9)
	No	183 (36.3)	344 (47.8)	528 (43.1)
External help for ADL / IADL*	Yes	196 (59.6)	190 (36.5)	386 (46.5)
	No	146 (40.4)	287 (63.4)	434 (53.5)
Who first diagnosed with stroke	A doctor with MBBS@	453 (96.4)	713 (92.4)	1167 (94)
	AYUSH\$	13 (2.9)	25 (5.2)	38 (4.3)
	Others	3 (0.7)	11 (2.4)	14 (1.7)

@MBBS- Bachelor of Medicine, Bachelor of surgery, *ADL – Activities of daily living, IADL- Instrumental activities of daily living, \$AYUSH- Ayurvedic/Unani/ Homeopathic/ Siddha, #Employed for primary work: Agri/ fishery/ elementary occupation

Table 2 Burden of types of disabilities among stroke survivors stratified by availing PT/OT services.

	Response	Availing PT/OT services		Total n(%)
		Yes n(%)	No n(%)	
Physical disabilities\$	Yes	272(93.6)	289(85.8)	562(89.6)
	No	25(6.3)	50(14.9)	75(10.3)
Speaking or swallowing problems	Yes	169(60.1)	183(57.3)	352(58.4)
	No	128(39.9)	156(42.6)	285(41.6)
Difficulty in thinking or finding the right words to say	Yes	169(59.9)	175(52)	345(56)
	No	128(40.1)	164(48)	292(44)
Difficulty with vision	Yes	137(44.7)	152(48.3)	289(46.4)
	No	160(55.3)	187(51.7)	348(53.6)

\$Physical disabilities: Weakness in your arms and legs or decreased ability to move or use them

Table 3 Use of supportive devices by stroke survivors

		Availing PT/OT services		Total n(%)
		Yes n(%)	No n(%)	
Using any aid or supportive devices	Yes	285(63.7)	405(52.1)	691(56.8)
	No	183(36.3)	344(47.9)	528(43.1)
Walker/Walking sticks	Yes	100(43.1)	118(27.2)	218(34.2)
	No	185(56.8)	287(72.7)	473(65.7)
Wheelchairs	Yes	17(4.3)	8(.3)	25(2)
	No	268(95.7)	397(99.7)	666(98)
Adjustable shower stools / Commodes	Yes	27(18)	23(3.5)	50(10.2)
	No	258(82)	382(96.5)	641(89.8)
Back/neck collar	Yes	9(2.1)	2(0.4)	11(1.2)
	No	276(97.9)	403(99.6)	680(98.8)
Orthosis/prosthesis	Yes	9(4.8)	8(1.8)	17(3.1)
	No	276(95.2)	397(98.2)	674(96.8)

Table 4 Multivariate logistic regression models describing variables deciding access to rehabilitation services for stroke in India

	Model-1			Model-2			Model 3		
	Est.	2.50%	97.50%	Est.	2.50%	97.50%	Est.	2.50%	97.50%
(Intercept)	2.26	0.08	4.44	2.12	-0.12	4.36	1.71	-0.5	3.92
Age groups-45-59	-0.93	-2.91	1.05	-0.91	-2.96	1.13	-0.92	-2.98	1.14
Agegroups-60+	-1.03	-3.01	0.95	-1.18	-3.22	0.85	-1.26	-3.31	0.78
Gender-Female	0.43	-0.05	0.91	0.35	-0.08	0.78	0.48	0.06	0.9
Residence-Urban	-0.39	-0.88	0.1	-0.4	-0.85	0.05	-0.51	-0.95	-0.07
Poorer	-0.43	-1.14	0.29	-0.41	-1.12	0.3	-0.41	-1.1	0.27
Middle	-0.39	-1.06	0.29	-0.6	-1.24	0.05	-0.58	-1.22	0.07
Richer	-0.63	-1.33	0.07	-0.84	-1.51	-0.17	-0.83	-1.5	-0.16
Richest	-1.02	-1.71	-0.32	-1.04	-1.69	-0.4	-1.08	-1.71	-0.44
Human help No	0.82	0.38	1.25	0.78	0.35	1.2	0.78	0.36	1.2
Health Insurance No	-0.45	-0.99	0.08	-0.36	-0.87	0.15			
Occupation-Others	-0.74	-1.32	-0.15	-0.52	-1.07	0.04			
Occupation -unemployed	-0.05	-0.58	0.47	-0.03	-0.53	0.48			
Scheduled tribe	0.07	-0.74	0.87						
Other backward class	-0.24	-0.79	0.3						
General	-0.16	-0.76	0.44						
AYUSH	0.65	-0.5	1.79						
Others	0.24	-1.47	1.96						
Aids/assistive devices No	-0.1	-0.53	0.33						
Educated No	-0.26	-0.74	0.22						

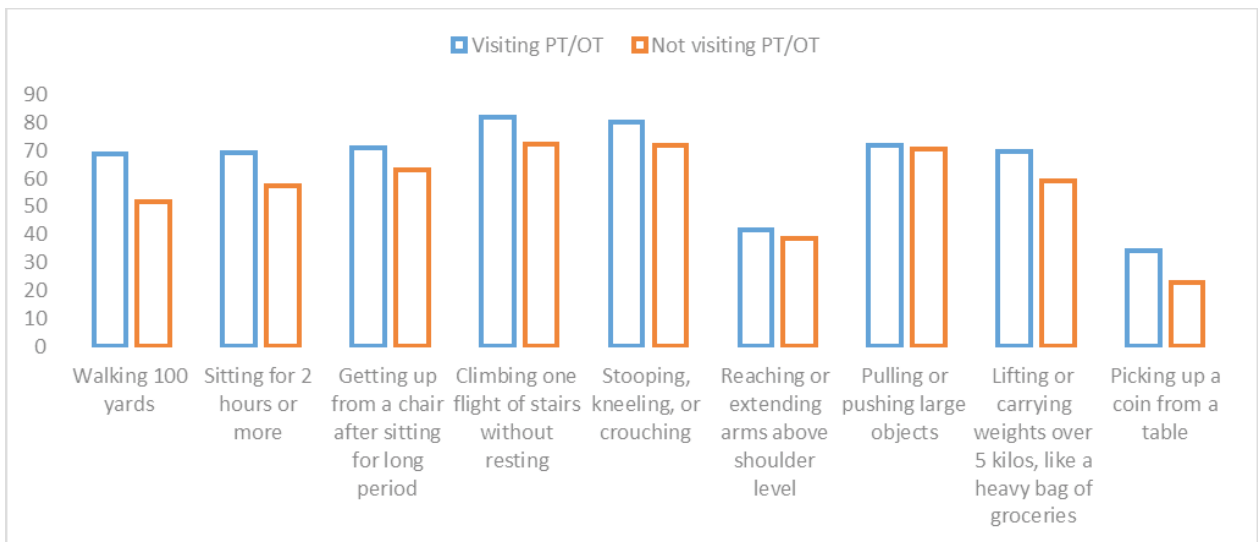


Figure 1 Problem with gross motor function among stroke survivors

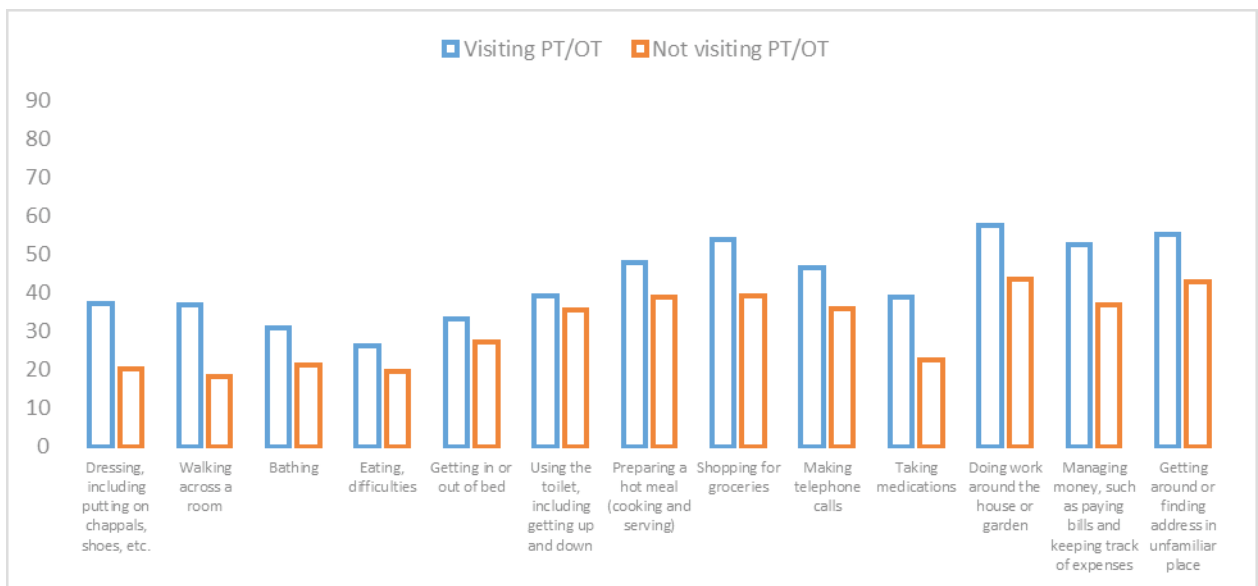


Figure 2 Problem in performing ADL/IADL among stroke survivors

Discussion

Developing countries have reported an extensive burden of impairments and disabilities in association with stroke [15,16]. We found a prevalence of 1.8 % of older adults (45 years and above) in India are suffering from stroke. Other studies have illustrated an increased incidence rate from 56/100,000 person-years during 1970-1979 to 117/100,000 person-years during the period 2000-2008 in low, middle-income countries (LMICs) [8]. 60% of the people either die post stroke, disabled or dependent on their ADL/IADL [17]. Studies

shows that stroke is more prevalent in older adults, with males affected more than females [15] which can be reflected in our results. Most stroke survivors result in hemiparesis, for years resulting in functional limitation [18]. Early rehabilitation leads to early motor control which needs professional services to mainstream in daily activities and socialization. Our study states nearly two-fifth are only visiting rehabilitation professionals post stroke.

For the first time, based on our knowledge, a Nationalized survey asked a question related to

receiving PT/OT services for stroke survivors. Physical rehabilitation professionals include mainly PT/OT in India [9]. Several factors decide receiving therapeutic services like demographic, socioeconomic status, residence, occupation, health insurance coverage etc. The result shows the proportion of males receiving this service is higher than females. The reason might be lack of gender empowerment [19], cultural barrier, educational status, health literacy and gender preference. As nearly three fourth of the population of India still resides in rural area, the health care infrastructure is limited to primary care [20,21]. Rehabilitation is a luxury rather than a necessary service in rural India, multiple factors come into play to avail the service. There are barriers like availability, accessibility, affordability, acceptability, difficult geographic terrain etc. [13] for visiting a health care facility. Our study shows that irrespective of educational attainment, there is no statistical difference in availing rehabilitation services, similarly, caste, marital status, occupation affect availing services. However, use of aid and supportive device, dependency on caregiver, having a health insurance has a substantial impact in accessing rehabilitation care.

Among stroke survivors, four salient kinds of difficulty in activities have been assessed like mobility, speaking or swallowing, vision and thinking. In our study, nearly 90% of the stroke survivors reported any form of movement impairments in their upper or lower extremity, which needs professional intervention. Therapeutic methods have shown an effect on improvement in both upper and lower extremities, resulting in improved motor function and hand function [22,23]. Problems like motor function have day-to-day implications in a patient's life in contrast to other impairments like swallowing, thinking, and difficult vision. Therefore, patients visit a therapist primarily to regain motor function. Apart from motor impairment, other difficulties like speech, recreational etc., also need health care professionals. Rehabilitation is a multidisciplinary approach, so along with PT/OT, other rehab professionals also play a pivotal role in regaining their independence in daily living [9,24]. Policymakers have also realized the essence of teamwork; their skills and knowledge have benefited in overall patient improvement leading to quality of life [9].

Motor impairments can be broadly classified into gross motor and fine motor functions. In this survey, gross motor includes walking 100 yards, sitting for two hours, getting up from a chair, sitting for an extended period, stooping, kneeling, reaching, or extending arm above shoulder level, pulling or pushing a large object, lifting or carrying weight above five kg and picking up a coin from a table. Among these activities, our result shows stair climbing, independent walking, kneeling is more affected than other activities. Studies show that 50 to 70 % of the patients reverse their functional independence [12]. In India, more than 50% of stroke survivors have these motor problems, but are not availing PT/OT services, which is a matter of concern. Within ADL/ IADL, activities like dressing, walking across a room, bathing, eating, using the toilet, cooking, shopping, using telephone, taking medications, household chores, gardening, money management and getting around or finding an address in unfamiliar places are asked. Our result shows outdoor functions are severely affected than others. This is not only restricting the individual independence but also the overall family quality of life [25]. In last decade, government policies tried to provide rehabilitation services in all facilities. Hand is always required in day-to-day activities like eating, picking up an object, handwriting, manipulating objects etc. Hand function is directly related to independence and quality of life. There are specific hand therapy principles in Occupational Therapy that improve gross and fine hand function that ultimately helps in ADL/ IADL functions [26].

Besides visiting health care professionals use of supportive devices also plays a major role in the rehabilitation of stroke survivors. In this survey, there is a submodule collecting information about five categories of supportive devices like using walker, or walking sticks, wheelchair, adjustable shower stools or commodes, back or neck collar and use of orthosis or prosthesis. More than half of the stroke survivors using any form of supportive devices. The use of supportive devices is more prevalent who are visiting PT/OT. Wheelchair use among stroke survivors was found to be highly restricted (2%) in our study. The reason might be lack of a barrier-free environment, lack of assessment of an Occupational therapist for home modifications,

acceptance and affording a wheelchair in lower- and middle-income countries like India compared to the developed world. Moreover, there might be another reason, lack of adequate motor function to propel the wheelchair, as most are not attending PT/OT.

As India is progressing towards demographic and epidemiological transition, this prevalence of stroke will increase by manifolds [27]. The risk factors for stroke can be grossly divided into preventable and non-preventable. Low physical activity, high sedentary behaviour, obesity, conditions can lead to stroke in the short term and long term. The journey from the acute stroke phase to the maintenance of routine day-to-day life requires therapeutic services. This rehabilitation process in India is always dependant on several external factors like knowledge of the existence of a mode of therapy, financial strength, availability of health care professionals, referral mechanism, adherence and motivation towards rehabilitation, and trust in available health care professionals [28]. Within the last decade, the government has mainstreamed rehab professionals in health care services to avail the facility with zero out-of-pocket expenditure [29]. Previously only physiotherapists were appointed in government facilities, but nowadays, more emphasis is given to the quality of life, and occupational therapists are also appointed. For the first time, LASI has emphasized rehabilitation care and collected data on the facilities availed by patients. This is a welcome step but can be generalized to other chronic conditions, such as other neurological disorders.

Conclusion

Stroke is a significant public health issue affecting 1.8 % of the Indian population. Gender, financial status of the family, residential area, availability of health insurance, and external help are critical socio-demographic factors that decide whether any person will visit Physical Therapy and Occupational Therapy services for stroke rehabilitation—nearly two-third of the stroke survivors still unable to visit these facilities resulting in poor quality of life. Policy level initiatives should be taken to improve accessing rehabilitation services in India.

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