International Journal of Science and Research (IJSR)
ISSN (Online): 2319-7064
Index Copernicus Value (2015): 78.96 | Impact Factor (2015): 6.391

Perceived Environmental Barriers to Community Participation in Stroke Patients

Isha Akulwar[1], Nivedita Shahane[2]

Abstract: ***Aim**: To determine the environmental barriers to community participation perceived by stroke patients **Objective**: To identify the physical and non-physical environmental factors perceived as barriers to community participation by stroke patients. **Design**: Observational and **Prospective. Setting**: Tertiary care centre. **Participants**: 20 stroke patients with hemiplegia, ambulatory (with/without assistive devices) and community-dwelling voluntarily participated. Patients with severe cognitive, visual, perceptual and communication deficits were excluded. Convenience sampling was used. Main outcome measure: A questionnaire was designed based on the domains of International Classification of Functioning and Disability; and included elements of physical and social environments. This was administered through a semi-structured interview. **Result**: Among the various factors identified, mobility barriers community (e.g., uneven sidewalks, unavailability of lifts) and at home (e.g., stairs or doors) have been implicated to limit community participation by majority of subjects (95% & 85%) followed by lack of accessibility of roads (95%), lack of accessibility of restrooms (55%) and lack of accessibility of transport (45%). Lack of services, systems and policies was perceived as a barrier and inappropriate attitude and lack of support of family and friends by 25% and 20% subjects respectively. **Conclusion**: Environmental factors are crucial determinants of community participation in stroke patients. Along with physical environmental factors, social and attitudinal aspects of environment also have an impact on community participation by stroke patients. **Clinical Implications**: Knowledge of these findings will assist rehabilitation of stroke patients by overcoming barriers and enhancing facilitators through environmental modification in community for easy accessibility, training in community/in a simulated environment and policy changes e.g. changes in regulations, insurance, etc.*

Keywords: environmental barriers, community participation, stroke

1. Introduction

Stroke is the leading cause of disability in adults[1]. More than half of stroke survivors are discharged to their homes, with more or less severe, persistent neurological symptoms and impairments in terms of functional limitations and disability[2]. According to the WHO (2009), there are **6,398,000 DALYs (Disability adjusted life year) lost due to stroke in India.**

In developing countries like India, people with stroke after receiving medical treatment from the acute care setup are directly discharged to their homes. Relatively few rehabilitation centres exists and due to lack of access to facilities in the community, patients with stroke find it difficult to continue with therapy services. This in turn affects the outcome of stroke survivors.

Survivors of stroke rate the ability to "get out and about" and into the community as "essential" or "very important"[3]. Independent ambulation within the community is an important goal for the patient with stroke[4]. Community ambulation refers to the ability to walk with or without gait aid to destinations important for participation in community life[5]. This includes independent mobility outside home which includes the ability to confidently negotiate uneven terrain, private venues, shopping centres and other public venues. People with stroke are affected in their walking ability. This affects their ability to participate in social life for functioning.

The International Classification of Functioning and Disability (2001) is an amalgam of the medical and social models and brings into focus the interaction of the body's structure and function, activities, and participation in life situations. The contextual factors representing the individual's life and living are divided into environmental and personal domains[6, 7].

Environmental factors are hypothesized to be crucial determinants of people's participation in daily activities[8].The environmental domain of the ICF comprises the physical environment and non physical environment such as social and attitudinal factors, which comprised the lived environment. The impact of the physical environment is highly relevant when assessing community ambulation. The ICF enumerates the impact of the physical environment on the activity of walking with subsections that include variable distances, different terrains, obstacles and different locations[7]. As the physical environment include various safety hazards, access problems and home or workplace design difficulties, they can act as barriers for community participation. The social and attitudinal aspects of the environmental domain include family and friends, services such as non-profit organizations, and government agencies and systems such as rules and regulations within communities and facilities. The attitude and support of peers and family, the provision of assistive devices or modification to the work place environment to facilitate a return to work may have as great an impact as any impairment on an individual's achievement of personal goals and the attainment of a reasonable quality of life[9, 10]. All of these factors are external to the individual.

It is necessary for health professionals to acknowledge many physical and non physical factors that can facilitate or limit an individual's participation in society. Therefore in order to effectively retrain stroke patients to ambulate in their community, health professionals must understand the impact of local environment and use this knowledge to assist a client's rehabilitation programme[5]. One should focus on overcoming barriers and enhancing facilitators through modifications in environment[8]. Thus, this study was

undertaken to identify the environmental factors perceived by the stroke patients as barriers to community participation.

2. Methodology

A questionnaire (Appendix) was designed based on the domains of ICF and included elements of physical and social environments. The questionnaire was administered through a semi-structured interview. Stroke patients with hemiplegic involvement, duration of onset $\geq$ 3 months, ambulatory (with/ without assistive devices), mini mental scale score of $\geq$ 24 and community-dwelling were selected. The study criterion of 'community-dwelling' was appropriately chosen to ensure that the stroke subjects participate in social activities and are exposed to environmental barriers. Stroke patients with severe cognitive, visual, perceptual and communication deficits were excluded. 20 stroke patients attending a tertiary care hospital for Physiotherapy voluntarily participated. Informed consent was obtained from all the participants. The procedures followed protocol and accord with the ethical standards of the institutional review board. Data analysis was done using descriptive statistics.

3. Results and Discussion

20 stroke patients with a mean age of 54.6 years $\pm$ 9.67 and duration since stroke mean $\pm$ SD (17.95 months $\pm$ 25.67) participated in the study. 45 % of patients required assistive device for community ambulation and 15 % required assistive device while 10% required help at home for ambulation. Among the various environmental factors identified, *mobility barriers at home and surroundings* were reported by 85% of stroke patients and were implicated for limiting their community participation. In home and surroundings, *stairs (number, unavailability of rails, height), floor (uneven, slippery), lifts (unavailability)* and *doors (raised threshold)* were perceived as barriers in 94.12 %, 47.05%, 35.29% and 23.52% of stroke patients respectively. *Mobility barriers in community* were reported in 95% of stroke patients and were implicated for limiting community participation. In community, *stairs (number, unavailability of rails, height), lifts (unavailability), floors (uneven, slippery) and ramps (unavailability)* were perceived as barriers in 89.47%, 73.68%, 21.05% and 10.52% of stroke patients respectively. *Lack of restroom accessibility* was perceived as a barrier in 55% of stroke patients and *unavailability of rails, inadequate space to move, floors (slippery)* and *entrance (narrow)* were implicated in 90.91%, 54.55%, 54.55% and 45.46% of stroke patients respectively. *Lack of accessibility of roads* was perceived as a barrier in 95% of stroke patients in which the factors such as *pathways (uneven), crowd, sidewalks* and *crossing* were perceived as barriers in 89.47%, 68.42%, 57.89%, and 52.63% of stroke patients respectively. *Lack of public transport* was perceived as a barrier by 45% of stroke patients. In natural environmental features limiting community participation, 70% perceived *rain* while 40% perceived *light (darkness at night, clouds)* as a barrier.

In non-physical factors, *attitude of family members and friends* was perceived as a barrier in community participation by 20% of stroke patients, *lack of support from family* was perceived as a barrier in community participation by 20% of stroke patients and *services, systems and policies* were perceived as a barrier in 25% of stroke patients.

There was also significantly lower rate of participation with variety of environmental barriers such as architectural, discrimination, social attitudes, cost of services or programs, inaccessible facilities[14, 15].

Few researchers have attempted to explore the factors acting as barriers and facilitators in environmental as well as personal context in stroke patient's ambulatory activities in community.[11, 12, 13] However, all these studies have been done abroad and have emphasized on personal factors of stroke patients. To the best of our knowledge, this is the first Indian study in which an attempt was made to explore the environmental barriers to community participation in stroke patients. We ensured that the questionnaire designed includes all the factors in the local environment and is applicable to community participation for a patient with stroke. Also, an important aspect of the present study is that the environmental barriers were identified from the patient's perspective.

4. Conclusion

Environmental factors are crucial determinants of community participation in stroke patients. Apart from physical environmental factors, social and attitudinal aspects of environment also have an impact on community participation by stroke patients.

Limitations: This study has several limitations which could have affected the results of the study. Impact of physical impairments on community participation was not considered in the study. Individuals with communication or cognition problems were excluded from the study; therefore, the sample may only represent a group of individuals with no significant communication or cognition problems post-stroke while the excluded group might have different experiences. Due to relatively small sample, findings of this study cannot be generalized to other stroke survivors from different socioeconomic strata and other geographical area.

Nevertheless, findings of this study indicate a need for similar studies to be conducted on a larger scale in stroke patients and a need to develop objective tools for assessment of environmental factors which are applicable to Indian setup.

5. Clinical Implications

In order to retrain the individual with stroke to his/her previous activities and community participation, knowledge of environmental barriers is very important. Findings of this study have important clinical implications and will assist in rehabilitation of stroke patients by overcoming the barriers and enhancing the facilitators through environmental modification for easy accessibility; training stroke patients in the community or in a stimulated environment; and policy changes in regulations, insurance, etc. We also recommend

that similar studies can be conducted in people with different disability conditions.

6. Acknowledgement

I would like to thank Mrs. Veena Krishnanand (Principal of K. J. Somaiya college of Physiotherapy, Mumbai) for her valuable support.

References

[1] Sridharan SE, Unnikrishnan JP, Sukumaran S, Sylaja PN, Nayak SD, Sankara Sarma P, Radhakrishnan K. Incidence, Types, Risk factors and outcome of stroke in a developing country: The Trivandrum stroke Registry. *Stroke* 2009 Feb 19; 40: 1212 – 1218.
[2] Andersen HE, Schultz-Larsen K, Kreiner S, Forchhammer BH, Eriksen K, Brown A. Can readmission after stroke be prevented? Results of randomized clinical study: A post discharge follow up service for stroke survivors. *Stroke* 2000; 31: 1038-1045.
[3] Lord SE, McPherson K, McNaughton et al. Community ambulation after stroke: how important and obtainable is it and what measures appear predictive? *Arch Phys Med Rehabil*. 2004; 85:234–239.
[4] Hill K, Ellis P, Bernhardt J, Maggs P, Hull S. Balance and mobility outcomes for stroke patients: A comprehensive audit. *Austral J Physiotherapy* 1997; 43(3): 173-180.
[5] Corrigan R, Mcburney H. Community ambulation, Environmental impacts and assessment inadequacies. *Disability and Rehabilitation* 2008; 30(19): 1411-1419.
[6] Haley SM, Langmuir L. How do current post-acute functional assessments compare with the activity dimension of the International classification of functioning and disability (ICIDH-2)? *J of rehabil measures* 2000; 4(4): 51-56.
[7] World Health Organization. International Classification of functioning, Disability and Health 2001 June 22.
[8] Keysor JJ, Jette AM, Coster W, Bettger JP, Haley SM. Association of Environmental factors with levels of home and community participation in an adult rehabilitation cohort. *Arch of phys med rehabil* 2006; 87: 1566-75.
[9] Whiteneck GG, Gerhart K A, Cusick CP. Identifying environmental factors that influence the outcomes of people with traumatic brain injury. *J head trauma rehabil* 2004; 19(3): 191-204.
[10] Whiteneck GG, Harrison- Felix CL, Mellick DC, Brooks CA, Charlifue SB, Gerhart KA. Quantifying Environmental factors: a measure of physical, attitudinal service, productivity and policy Barriers. *Arch of phys med rehabil* 2005; 85: 1324-35.
[11] Wee J, Lysaght R. Factors affecting measures of activities and participation in persons with mobility impairment in persons with mobility impairment. *Arch of Phys med Rehabil* 2009; 31(20): 1633-1642.
[12] Rochette A, Desrosiers J, Noreau L. Association between personal and environmental factors and the occurrence of handicap situations following a stroke . *Disability and Rehabilitation* 2001; 23(13): 559-569.
[13] Robinson, Cynthia A. *Identifying personal factors associated with participation in community walking following stroke.* Doctor of philosophy. University of Washington; 2010
[14] Belanger L, Bolduc M, Noel M. Relative importance of after-effects, environment and socio-economic factors on the social integration of stroke victims. *Int. J. Rehab. Research* 1988; 11(3): 251-260.
[15] Rimmer JH, Wang E, Smith D. Barriers associated with exercise and community access for individuals with stroke. *Journal of rehabilitation research and development* 2008; 45(2): 315-322.

Appendix

Questionnaire
Name:
Age and Sex:
Address:
Occupation:
Date of assessment:
Dominance:
Affection seen on MRI/ CT Scan:
Onset of stroke:
Side of involvement: ¤Right ¤ Left
Current customary mode of mobility:
- At home: ¤Assistance ¤Standby ¤Independent
- Community: ¤Assistance ¤Standby ¤Independent

1. a) Do you use any mobility device? Yes/ no
   b) If yes, then please specify ¤ Walker ¤ Crutches ¤ Straight cane ¤Quad cane ¤Any other -----
   c) How often do you use this device when participating in your community? ¤ Always ¤ Often ¤ Sometimes ¤ Never
   d) How does it influence your participation in community activities? ¤ Helps a lot ¤ Helps some ¤Does not influence ¤ Limits some ¤ Limits a lot

2. How often do you leave home? ¤Same as before stroke ¤More often ¤Less often

3. Do the following features at your home and surroundings limit your participation in community activities?
- Stairs (width, height, rails, number) ¤Yes ¤No
- Doors (narrow doorway, heavy, raised threshold) ¤Yes ¤No
- Door locks (height) ¤Yes ¤No
- Floors (slippery, uneven) ¤Yes ¤No
- Entrance (narrow, obstacles) ¤Yes ¤No
- Ramps (unavailability) ¤Yes ¤No
- Lifts (unavailability, automatic, cramped, width of opening) ¤Yes ¤No
- Any other----------

4. i. The buildings and places that you used to visit in the community before stroke:
¤ Workplace ¤ Theatre ¤ Temple ¤ Clubs ¤ Library ¤ Restaurants/hotels ¤Shopping area ¤ Sports grounds ¤ Garden ¤ Any other------

ii. The buildings and places that you visit in the community after stroke:
¤ Workplace ¤ Theatre ¤ Temples ¤ Clubs ¤ Library ¤ Restaurants/hotels ¤ Hospital or rehabilitation centre ¤Shopping area ¤ Sports grounds ¤ Garden ¤ Any other------

iii. Does the lack of physical accessibility of these sites limit your participation in the community? ¤Yes ¤No

iv. Which of the following factors limit the physical accessibility at these sites?

- Ramps (unavailability) ¤Yes ¤No
- Lifts (unavailability, automatic, cramped, width of door opening, height of control buttons) ¤Yes ¤No
- Stairs (width of the stairway, unavailability of railings on one side/ both the sides, height of the steps, number of steps) ¤Yes ¤No
- Doorways (narrow, uneven) ¤Yes ¤No
- Floors (slippery, uneven) ¤Yes ¤No
- Seating arrangements (inadequate space to move) ¤Yes ¤No
- Any other ----------

v. Does the inaccessibility of restrooms at these sites limit your participation in the community? ¤Yes ¤No

vi. If yes, which of the following factors limit the restroom accessibility at these sites?
- Entrance (narrow)
- Floors (uneven, slippery)
- Inadequate space to move
- Unavailability of railings on one side /both the sides
- Any other----------

5. i. Which mode of public transport you use most often? Train, car, taxi, bus, auto rickshaw
ii. Does the inaccessibility of public transport limit your participation in the community? ¤Yes ¤No

6. i. Does the inaccessibility of roads limit your participation in the community?¤Yes ¤No
ii. If yes, which of the following factors limit the accessibility of roads?
- Pathways (stones, potholes, gravel, uneven, paved surfaces)
- Crowd
- Sidewalks (paved, uneven, slippery)
- Curb cuts (narrow turns, inadequate space to take a turn)
- Intersection (crossing access)
- Any other----------

7. How does the attitude of other people towards you influence your participation in the community?
- Immediate family members ¤Helps ¤Does not influence ¤Limits
- Friends, colleagues, neighbors ¤Helps ¤Does not influence ¤Limits
- community members ¤Helps ¤Does not influence ¤Limits
- Personal attendants ¤Helps ¤Does not influence ¤Limits
- Health professionals ¤Helps ¤Does not influence ¤Limits

8. How does the support you receive from family, friends and colleagues influence your participation in community?
¤Helps ¤Does not influence ¤Limits

9. i. Do you use any service, system or policy? ¤Yes ¤No
ii. If yes, please specify.----------
¤Public or private insurance programs
¤Financial compensation programs or institutions services
¤Socio-economic services
¤Transportation services and systems
¤ Any other----------

iii. How do the services, systems or policies influence your participation in the community? ¤ Helps ¤ Does not influence ¤ Limits

10. Do the following features of the environment limit your participation in community?
Noise ¤Yes ¤No
Light ¤Yes ¤No
Rain ¤Yes ¤No
Any other----------

11. What are the other factors that restrict you going out in community?----------

12. What are your expectations from community that can facilitate you to go out in community? ----------