Review Article

Rehabilitation of Stroke Survivors with Disabilities in Low- and Middle-Income Countries: Barriers and Opportunities

Md. Shahidur Rahman¹

Received: 5 January 2022 Accepted: 27 July 2022 doi: https://doi.org/10.3329/jemc.v12i3.78558

Abstract

Globally, stroke is a leading cause of mortality and disability and there are substantial economic costs for post-stroke care. Barriers to the rehabilitation of stroke survivors with disabilities in low- and middle-income countries are many. There are enormous challenges in overcoming the barriers. The socioeconomic impacts of disabilities are high. Developing and delivering costeffective rehabilitation services to stroke survivors with disabilities are daunting challenges to low- and middle-income countries. The barriers and unmet needs for rehabilitation treatments are high. These challenges are amplified by resource constraints like infrastructural facilities for rehabilitation management, and an inadequately trained healthcare workforce in low- and middle-income countries (LMICs). Multidisciplinary team care management led by physicians, therapists, rehabilitation nurses, and community health workers need to be strengthened. Threats to the outcomes of stroke care in resource-poor settings are the non-availability of cost-effective team care at the hospital and at the community level. Long-term medical and rehabilitation care needs organizational and financial support. The future challenge is to identify what elements of organized stroke care can be implemented to make the largest gain. Simple interventions such as swallowing assessments, bowel and bladder care, mobility assessments, and consistent secondary prevention can prove to be key elements to improving post-discharge morbidity and mortality. Recognition of the importance of stroke rehabilitation by WHO and global health leaders are new opportunities for LIMCs to fight back the stroke-related disabilities. Successful rehabilitation of stroke survivors with disabilities is a paramount challenge in LIMCs. But opportunities are coming up as there is increased awareness about stroke among general people. Task shifting of the rehabilitation health workforce to caregivers at the home or community level can help augment disability-adjusted life years. Proper Caregivers Training is coming out as a good prognostic indicator in stroke survivors in low resource settings. Structured training of caregivers is essentially needed at the low resource outset in developing countries and should be emphasized in stroke rehabilitation protocol. Universal health coverage should be extended to poor stroke survivors with disability. The burden of stroke will further increase until effective stroke prevention strategies are more widely implemented. The objective of this review article is to highlight the elements of health system behavior that affect barriers and opportunities in addressing stroke survivors with disabilities.

J Enam Med Col 2022; 12(3): 148–154

^{1.} Former Professor, Department of Physical Medicine and Rehabilitation Bangabandhu Sheikh Mujib Medical University, Dhaka

Introduction

Stroke has emerged as an important global health problem and is now the third leading cause of death and disability. Decreases in the cause-specific mortality rate reduced the effect of population growth for all but three causes: substance use disorders, neurological disorders, and skin and subcutaneous diseases. Although age-standardized mortality rates have decreased sharply from 1990 to 2016, the decrease in age-standardized incidence has been less steep, indicating that the burden of stroke is likely to remain high. 3

A stroke can produce long term disability and negative impacts on the patient's quality of life as well as reduced disability-adjusted life years (DALY). Most stroke survivors suffer from serious and disabling healthcare problems and medical rehabilitation is a major part of patient care. Potentially beneficial treatment options for motor recovery of the arm include constraint-induced movement therapy and robotics. Promising interventions that could be beneficial to improve aspects of gait include fitness training, high-intensity therapy, and repetitive-task training.⁴

Rehabilitation is a process of active change by which a person who has become disabled acquires the knowledge and skills needed for an optimum physical, psychological, and social function. The first Stroke Recovery and Rehabilitation Roundtable established a game-changing set of new standards for stroke recovery research.⁵ The World Stroke Organization recommends that after a stroke, patients should have access to rehabilitation specialists, including physiotherapists, occupational therapists, and speech and language therapists.⁶

Stroke survivors and the global burden of disease

The huge number of stroke survivors with disability and the lack of adequate rehabilitation management in LIMCs is enhancing the global burden of disease. In a study examining only physical rehabilitation needs using Global Burden of Disease data from 2017, years

lived with disability data for neurological diseases, including stroke, were inversely proportional to a country's income. The greatest increase in physical rehabilitation needs was found in low income countries with the least rehabilitation infrastructure.⁷

Weakness and barriers in resource-poor settings

Weaknesses in stroke rehabilitation are the lack of service development and infrastructural support that made stroke management difficult at all levels, especially in LIMCs. Those in the resource-poor settings are unable to afford rehabilitation care. The global challenge to integrate rehabilitation into universal health coverage as part of the WHO's Sustainable Development Goals (SDG) is spearheaded by the WHO Rehabilitation 2030 action plan.⁸

Barriers to stroke rehabilitation in LIMCs at low resource outset are many. Poor understanding among clinical leaders, health planners, and patients about the role of rehabilitation interventions on impairment, activity, and participation (e.g. return to work) are major obstacles to evaluating the need for rehabilitation delivery in service planning.⁹

Other major barriers include misleading cultural beliefs about stroke and the use of traditional medicine. which might include some traditional practices. Rehabilitation interventions are ignored in many standards of care, clinical practice guidelines, and care pathways and protocols. There are insufficiently skilled workforces to deliver rehabilitation services and difficult access to standardized stroke educational programs. Inadequate access to skilled services results in the often sporadic, non-specific, and short-lived provision of rehabilitation interventions. There is a lack of dedicated stroke units and stroke rehabilitation services in LIMCs. Often there are long delays between stroke onsets and accessing rehabilitation services. 10,11 Insufficient health insurance or financial support for rehabilitation services and the high cost of available services are common constraints. 12,13

Strengthening rehabilitation works

To strengthen rehabilitation works we need to increase the multidisciplinary rehabilitation health workforce. Capacity building of the rehabilitation health workforce should be a priority plan. We should work to develop and implement financing and procurement policies that ensure assistive devices and products to all who need them and ensure adequate training about their use. We should acknowledge and address financial corruption in the health sector as well.^{14,15}

For removing the barriers and illuminating the optimism we need to integrate rehabilitation into health system policy and practice. We should integrate rehabilitation services into all levels of health care delivery systems, and expand and decentralize service delivery strategies. Financial aid should be extended to poor and complicated patients. Hospitals should be enriched with specialized units for inpatients with complex needs. Expanding the use of affordable technologies and devices (e. g., wheel chairs, orthotics) and ensuring adequate training in their use are integral components of interventions. Developing good practice guidelines and expanding research programs are equally important.¹⁶

Task shifting to community health workers, families, or caregivers

The rehabilitation health workforce may not be available at the community level. So, shifting tasks to community health workers or caregivers is an important part of medical rehabilitation. Task shifting isparticularly of vital importance to LIMCs where continued expert services are not available or affordable. One study aims to develop and implement a simplified stroke rehabilitation program that utilizes nurses and family caregivers for service delivery, and evaluate its feasibility and effectiveness in rural China was found to generate initial high-quality evidence to improve stroke care in resource-scarce settings. Awareness will be enhanced when community health workers or family members are involved in stroke care. Mild to moderate cases of stroke result

in a smoother transition from hospital to home.^{20,21} Delegating rehabilitation work loads to care givers may not be as effective as standard care, even with intensive training of caregivers or health workers.²²

Task shifting requires intensive training for community health workers and family caregivers to achieve effective results. Regular and periodic supervision by therapists and trained community health workers will be more remunerative. There is very low- to moderate-quality evidence that caregivermediated exercises may be a valuable intervention to augment the pallet of therapeutic options for stroke rehabilitation.²³⁻²⁹ Family members and caregivers of people with stroke assist patients with mobility, wheel chair activities, balance and self-care, and speech and language. In Africa, caregivers of people with stroke report being confronted by contextual challenges including having little access to transport, inadequate income, and having to manage a complex mix of life roles including employment, home duties, and caring for the stroke survivors.³⁰ Structured training of caregivers provided during discharge of hospital admitted stroke patients have a positive effect on the outcome of the survivors.31

Rehabilitation services if not accessible to the sufferers may exacerbate the problem and can result in avoidable complications that place a further strain on the already under resourced healthcare systems.^{32,33}

Family members or less skilled workers when taking responsibility for the delivery of rehabilitation services requires careful consideration. High-quality trials were done in Asia that showed a model of task shifting had no additional benefit over usual care. Energy should be invested in developing effective models for educating the stroke healthcare workforce as a whole and should include tools for families and caregivers that help them to support stroke survivors in their recovery.³⁴

Building stroke research capacity

Building stroke research capacity in low- and middleincome countries will be useful in improving health

and reducing the huge burden of stroke in these countries. Efforts to implement and test new stroke rehabilitation service models, and new education and information systems to support recovery, are increasing.35 Global and regional efforts from the World Stroke Organization, the European Stroke Organization, and their stroke support organizations and networks, and WHO are working to build effective collaborations to support leaders in LMICs to lobby for and implement stroke services and share their learning. The Stroke Recovery and Rehabilitation Roundtable (SRRR) meetings bring together an international group of preclinical and clinical researchers along with statisticians, methodologists, funders, and consumers, working to accelerate the development of effective treatments for stroke recovery. However, the progress is slow, and rehabilitation and recovery are often given lower priority than establishing primary stroke centers. Global collaborations are emerging that drive changes in how and what is researched and implemented for stroke recovery and rehabilitation, and these groups welcome clinicians and researchers from LMICs. But more efforts need to be done. 36, 37

Stroke survivors with disability

Age-standardized death rates from stroke have decreased in all regions from 1990 to 2016 in most regions. The number of stroke survivors with disabilities is increasing. As a result, there is a higher prevalence of chronic stroke as well as disabilities. Successful rehabilitation and prevention strategies including addressing the risk factors can reduce the stroke-related burden of diseases in society. The high burden of stroke worldwide suggests that primary prevention strategies are either not widely implemented or not sufficiently effective.³⁸ Over the past 10 years, there has been growing collaboration between HICs and LMICs in research and education, including HIC grant-awarding bodies supporting research efforts and training in less well-resourced countries. New global alliances have formed, for stroke generally and for stroke recovery and rehabilitation, and are gaining motion.39,40

Identification of cost-effective ways to rehabilitate people with disability is an important challenge. There is a growing emphasis on using technology to provide patients with information to enable easier access to self-evaluation and self-management strategies. These strategies can be used in areas where large distances or poor accessibility are barriers to access.⁴¹

Crisis and opportunities

Bangladesh perspective: Initiatives taken to rehabilitate stroke survivors are not enough to meet the crisis. Bangladesh is no exception. We have weaknesses in the infrastructural development of rehabilitation services as well as training of the rehabilitation health workforce. There is no stroke rehabilitation unit in the existing hospitals. Wellcoordinated multidisciplinary stroke units need to be set up at least in all district hospitals to achieve the optimum outcome. Most of the patients remain untreated or partially treated cumulating the burden on the family as well to society. Team management facilities should be established in all hospitals. Caregiver's training should be enriched in resourcepoor settings. Increased numbers of rehabilitation health workforces need to be employed to provide rehabilitation services at the grass-root level.

Conclusion

Successful rehabilitation of stroke survivors is a paramount challenge in LIMCs. There are enormous barriers which include resource constraints, lack of trained healthcare workers, and inadequate rehabilitation set up in hospitals and at the community level. Universal health coverage should be extended to poor stroke survivors with disability. Task shifting of the rehabilitation health workforce to caregivers at the home or community level can help improve the DALYs. The burden of stroke will further increase until effective stroke prevention strategies are more widely implemented. Enrichment of quality of stroke rehabilitation and eliminating the barriers to successful rehabilitation for millions of stroke survivors globally and particularly for patients with

stroke in LMICs is a towering challenge of global healthcare burdens. But opportunities are coming up as there is increased awareness about stroke among general people. Governments of LIMCs should give more attention to removing barriers to rehabilitation services. Stroke rehabilitation units in tertiary care hospitals with ample amenities can help reduce the burden of the disease.

References

- Kyu HH, Abate D, Abate KH, Abay SM. Global, regional, and national disability-adjusted life-years (DALYs) for 359 diseases and injuries and healthy life expectancy (HALE) for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet 2018; 392: 1859–1922.
- Roth GA, Afshin A, Agesa KM, Alam T, Ballesteros KE, Bannick MS et al. Global, regional, and national age-sex-specific mortality for 282 causes of death in 195 countries and territories, 1980–2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet 2018; 392: 1736–1788.
- Johnson CO, Nguyen M, Roth GA, Nichols E, Alam T, Abate D et al. Global, regional, and national burden of stroke, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet Neurol 2019; 18: 439–58.
- 4. Langhorne P, Bernhardt J, Kwakkel G. Stroke rehabilitation. Lancet 2011; 377: 1693–1702.
- Bernhardt J, Hayward KS, Kwakkel G, Ward NS, Wolf SL, Borschmann K et al. Agreed definitions and a shared vision for new standards in stroke recovery research: The Stroke Recovery and Rehabilitation Roundtable taskforce. Int J Stroke 2017; 12: 444–450.
- Lindsay P, Furie KL, Davis SM, Donnan GA, Norrving B. World Stroke Organization global stroke services guidelines and action plan. Int J Stroke 2014; 9 (suppl A100): 4–13.
- 7. Jesus TS, Landry MD, Hoenig H. Global need for

- physical rehabilitation: systematic analysis from the Global Burden of Disease Study 2017. Int J Environ Res Public Health 2019; 16: E980.
- 8. Gimigliano F, Negrini S. The World Health Organization "Rehabilitation 2030: a call for action". Eur J Phys Rehabil Med 2017; 53: 155–168.
- Khan F, Owolabi MO, Amatya B, Hamzat TK, Ogunniyi A, Oshinowo H et al. Challenges and barriers for implementation of the World Health Organization Global Disability Action Plan in low and middle income countries. J Rehabil Med 2018; 50: 367–376.
- Chimatiro GL, Rhoda AJ. Scoping review of acute stroke care management and rehabilitation in low and middle income countries. BMC Health Serv Res 2019; 19: 789.
- 11. Yan LL, Li C, Chen J, Miranda J, Luo R, Bettger J et al. Prevention, management, and rehabilitation of stroke in low and middle income countries. E-Neurological Sci 2016; 2: 21–30.
- 12. Mendis S. Prevention and care of stroke in low and middle-income countries; the need for a public health perspective. Int J Stroke 2010; 5: 86–91.
- 13. Olaleye OA, Hamzat TK, Akinrinsade MA. Satisfaction of Nigerian stroke survivors with outpatient physiotherapy care. Physiother Theory Pract 2017; 33: 41–51.
- WHO. Rehabilitation in health systems.
 2017. Available at: https://www.who. int/disabilities/brochure_EN_2.pdf?ua=1. Accessed February 2020.
- 15. Onwujekwe O, Agwu P, Orjiakor C, Mckee M, Hutchinson E, Mbachu C et al. Corruption in Anglophone west Africa health systems: a systematic review of its different variants and the factors that sustain them. Health Policy Plan 2019; 34: 529–543.
- World report on disability 2011. 1. Disabled persons statistics and numerical data. ... Purchased from WHO Press, World Health Organization, 20 Avenue Appia, 1211 Geneva.

- 17. Ochieng B, Akunja E, Edwards N, Mombo D, Marende L, Kaseje DC. Perceptions of health stakeholders on task shifting and motivation of community health workers in different socio demographic contexts in Kenya (nomadic, periurban and rural agrarian). BMC Health Serv Res 2014; 14 (suppl 1) S 4.
- The ATTEND Collaborative Group, Family-led rehabilitation after stroke in India: a randomized controlled trial. Lancet 2017; 390(10094): 588–589.
- 19. Yan LL, Chen S, Zhou B, Zhang J, Xie B, Luo R et al. A randomized controlled trial on rehabilitation through caregiver delivered nurse organized service programs for disabled stroke patients in rural China (the RECOVER trial): design and rationale. Int J Stroke 2016; 11: 823–830.
- Simpson LA, Eng JJ, Chan M. HGRASP: the feasibility of an upper limb home exercise program monitored by phone for individuals post stroke. Disabil Rehabil 2017; 39: 874–882.
- 21. Vloothuis JDM, Mulder M, Nijland RHM, Guedhart QS, Konijnenbelt M, Mulder H et al. Caregiver mediated exercises with health support for early supported discharge after stroke (CARE4 STROKE): a randomized controlled trial. PLoS One 2019; Available at: https://doi.org/10.1371/journal.pone.0214241. Accessesd December 2021.
- Pitthayapong S, Thiangtam W, Powwattana A, Leelacharas S, Waters CM. A community-based program for family caregivers for post stroke survivors in Thailand. Asian Nurs Res (Korean Soc Nurs Sci) 2017; 11: 150–157.
- 23. Warner G, Packer T, Villeneuve M, Audulv A, Versnel J. A systematic review of the effectiveness of stroke self-management programs for improving function and participation outcomes: self-management programs for stroke survivors Disabil Rehabil 2015; 37(23): 2141–2163.
- 24. Liu H, Lindley R, Alim M, Felix C, Gandhi DB,

- Verma SJ et al. Family led rehabilitation in India (ATTEND)—findings from the process evaluation of a randomized controlled trial. Int J Stroke 2019; 14: 53–60.
- 25. Song HY, Nam KA. Effectiveness of a stroke risk selfmanagement intervention for adults with prehypertension. Asian Nurs Res (Korean Soc Nurs Sci) 2015; 9: 328–335.
- Simpson LA, Eng JJ, Chan M. HGRASP: the feasibility of an upper limb home exercise program monitored by phone for individuals post stroke. Disabil Rehabil 2017; 39: 874–882.
- 27. Vloothuis JDM, Mulder M, Nijland RHM, Goedhart QS, Konijnenbelt M, Mulder H et al. Caregivermediated exercises with ehealth support for early supported discharge after stroke (CARE4STROKE): a randomized controlled trial. PLoS One 2019; 14: e0214241.
- Pitthayapong S, Thiangtam W, Powwattana A, Leelacharas S, Waters CM. A community based program for family caregivers for post stroke survivors in Thailand. Asian Nurs Res (Korean Soc Nurs Sci) 2017; 11: 150–57.
- Vloothuis JD, Mulder M, Veerbeek JM, Konijnenbelt M, Visser-Meily JM, Ket JC et al. Caregiver mediated exercises for improving outcomes after stroke. Cochrane Database Syst Rev 2016; 12: CD011058.
- Hassan S, Visagie S, Mji G. Strain experienced by caregivers of stroke survivors in the Western Cape. S Afr J Physiother 2011; 67: 4–8.
- 31. Rahman MS, Salek AKH. Training of caregiver for home care management of stroke survivor at low resource setting. Bangabandhu Sheikh Mujib Medical University J 2016; 9: 193–195.
- 32. Peters GO, Buni SG, Oyeyemi AY, Hamzat TK. Determinants of return to work among Nigerian stroke survivors. Disabil Rehabil 2013; 35: 455–459.
- 33. Kamalakannan S, Gudlavalleti Venkata M, Prost A,

Natarajan S, Pant H, Chitalurri N et al. Rehabilitation needs of stroke survivors after discharge from hospital in India. Arch Phys Med Rehabil 2016; 97(9): 1526–1532.

- 34. Bettger JP, Liu C, Gandhi DBC, Sylaja PN, Jayaram N, Pandian JD. Emerging areas of stroke rehabilitation research in low and middle-income countries: a scoping review. Stroke 2019; 50: 3307–3313.
- Pandian JD, Liu H, Gandhi DB, Lindley RI.
 Clinical stroke research in resource limited settings:
 Tips and hints Int J Stroke 2018; 13(2): 129–137.
- Bernhardt J, Borschmann KN, Kwakkel G, Burridge JH, Eng JJ, Walker MF et al. Setting the scene for the second Stroke Recovery and Rehabilitation Roundtable. Int J Stroke 2019; 14: 450–456.
- 37. Dee M, Lennon O, O'Sullivan C. A systematic review of physical rehabilitation interventions for stroke in low and lowermiddle income countries. Disabil

- Rehabil 2020; 42: 473-501.
- 38. Johnson CO, Feigin VL. GBD 2016 Stroke Collaborators. Global, regional, and national burden of stroke, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet Neurol 2019; 18(5): 439–458.
- 39. Bernhardt J, Urimubenshi G, Gandhi DBC, Eng JJ. Stroke rehabilitation in low-income and middle-income countries: a call to action; Lancet 2020; 396: 1452–1462.
- Bernhardt J, Borschmann KN, Kwakkel G, Burridge JH, Eng JJ, Walker MF et al. Setting the scene for the second Stroke Recovery and Rehabilitation Roundtable. Int J Stroke 2019; 14: 450–456.
- 41. Pandian JD, Kalkonde Y, Sebastian IA, Felix C, Urimubenshi G, Bosch J. Stroke systems of care in low-income and middle-income countries: challenges and opportunities. Lancet 2020; 396: 1443–1451.