

Prioritizing Neuro-rehabilitation Services in Low-and Middle-income countries: Needs, Challenges and Possible Solutions

INTRODUCTION

Disability is the loss of functional capacity due to organ impairment resulting in an inability to perform activities considered normal for human beings.^[1] This inability to perform basic activities of daily living (mobility and transfers, self-care, hygiene, feeding, safety, and awareness) often results in dependency on caregivers. People living with disability are more vulnerable compared to the general population, have poorer quality of life, and a poorer self-perceived quality of care and support.^[2] Rehabilitation encompasses various interventions that aim to reduce disability, activity limitation, and participation restriction among individuals with health conditions in interaction with their environment.^[3] Studies have shown that rehabilitation services improve functional outcomes among disabled individuals and are cost-effective, even in resource-limited settings.^[4-6] However, rehabilitation services are still wrongly perceived as a last resort after the failure of therapeutic curative interventions and are often neglected. The need for rehabilitation services becomes even greater in neurological disorders, some of which are incurable and/or may lead to permanent sequelae. Thus, the strengthening of neurorehabilitation services may be of paramount importance in ensuring equitable access to high-quality health care services.

POPULATION DEMOGRAPHICS AND UNMET NEEDS FOR NEURO-REHABILITATION

According to a recent study, 2.41 billion individuals globally suffer from health conditions that would benefit from access to rehabilitation services as of 2019. Thus, one in every three individuals would require rehabilitation at some point in time.^[7] Furthermore, there were 1.29 million incident cases of stroke, 106,600 cases of multiple sclerosis, 771,000 cases of Parkinson's disease, 25,000 cases of motor neuron disease, 49,300 cases of brain and CNS cancer, and 7.6 million cases of traumatic brain and spinal cord injury in India in 2019.^[8] Hence, the burden of neurological disorders requiring rehabilitation services in India is huge.

However, there is a glaring lack of rehabilitation services in the health care system, especially among low- and middle-income countries (LMICs). According to WHO estimates, only 5%–15% of disabled individuals in LMICs have access to assistive devices.^[9] In addition, neurorehabilitation services are still in their infancy with only a limited number of qualified professionals offering these services in LMICs such as India. There are roughly 40,265 rehabilitation professionals, 3,263 audiology/speech-language pathology specialists, 2,500

neurologists, 1,800 neurosurgeons, and 200 palliative care physicians in India that cater to a population of 1.38 billion individuals.^[10] These figures illustrate the huge unmet need for quality neurorehabilitation services that exist among LMICs.

CHALLENGES AND BARRIERS IN PROVISION OF NEURO-REHABILITATION SERVICES IN LMICs

The barriers to accessing neurorehabilitation services in the health care system among LMICs may be due to logistical factors (distance to service, lack or cost of transport), poverty and nonaffordability, lack of knowledge regarding the existence of services, limited health care workforce dedicated towards rehabilitation (<1 rehabilitation professional/100,000 population), lack of funding, and lack of political will.^[11]

Despite the huge unmet need among LMICs, neurorehabilitation services are fragmented and delivered only at selected levels in the health system. In India, the majority of health care delivery (80%) is via private providers with an unclear zigzag referral pathway.^[12] The problem is compounded by the fact that centers offering neurorehabilitation services are primarily limited to urban cities. Furthermore, primary or district-level health centers that form initial points of contact with public health care systems do not focus on rehabilitation services due to limited resources and workforce. This results in a lack of continuity of care with regards to neurorehabilitation and poor delivery of services. As a result, neurorehabilitation services become limited to tertiary care referral centers or large private super-specialty centers.

LACUNAE IN REPORTING OF SERVICE NEED, PROVISION, AND OUTCOME MONITORING

A recent systematic review of 77 studies showed the overall poor coverage of rehabilitation services among LMICs with regard to various disabilities.^[11] The challenges in measuring coverage and access to rehabilitation (including neuro-rehabilitation services) among LMICs stem from a lack of uniform definitions regarding outcome measures that may overestimate coverage, variation in patient-reported disabilities (curative ailments vs chronic progressive disorders), variability in rehabilitation interventions being studied (hospital/community-based, physical/occupational therapy, assistive devices, etc.), and inadequacy of data collection and record-keeping, particularly at the primary health care level.

The majority of the studies assessing the need or provision of rehabilitation services have focussed on the percentage of

the health care workforce dedicated towards rehabilitation and the proportion of disabled individuals receiving services or assistive devices. However, studies have not focussed on certain patient-specific outcome measures post-rehabilitation. Data on outcomes such as the proportion of patients improving completely/partially with rehabilitation services, the proportion of patients achieving functional independence, and community integration/participation have not been studied. Furthermore, equitable distribution of rehabilitation services across various levels of health care among LMICs has not been studied. Thus, the paucity of data regarding these indicators requires addressal in order to gauge the distribution of services and the efficiency of neuro-rehabilitation service systems in LMICs.

ACCELERATING AND EXPANDING DELIVERY OF NEUROREHABILITATION SERVICES IN LMICs

For equitable delivery of neurorehabilitation services, integration across various levels of health care is required. This would result in the delivery of services according to the degree of disability and maintain a continuum of care across various levels. Delivery of neuro-rehabilitation services can be at an institutional level (district, subnational or national, or private hospitals) or the level of the community. An effective way for equitable delivery of services in the community among LMICs could be via community-based rehabilitation (CBR) services. Community-based neuro-rehabilitation programs can facilitate early coordinated inpatient discharge, maintain continuity of rehabilitation services among disabled neurological patients, and provide rehabilitation to neurological patients who may not require intensive hospital-based rehabilitation.^[13] Community-based rehabilitation (CBR) has been found to increase uptake of exercise programs and improve outcomes and quality of care among Parkinson's disease patients as well.^[14,15] CBR can be especially useful among LMICs where health care workforce is limited, and active community participation by various stakeholders (example community-based health workers, general practitioners, caregivers, neurologists, community-based nurses, psychologists, and trained physiotherapists/occupational therapists) in terms of identifying disabled individuals, education and counseling, spreading knowledge regarding rehabilitation services, physical therapy, and vocational training, and provision of assistive devices could be of vital importance in integrating neurorehabilitation services at the primary and district level. Furthermore, up to 1/3rd of disabled patients can be managed only by CBR, which would help in decreasing patient load on overburdened health systems and reducing health care costs. One such example is an integrated care pathway for stroke care where community-based occupational or physiotherapists, nurses, and family physicians play an integral part in poststroke rehabilitation.^[16] However, this needs linking with a district or higher referral centers so that patients whose needs remain unfulfilled are taken care of.^[17] Thus, multi-disciplinary neuro-rehabilitation services at tertiary care levels would

remain reserved for severely disabled patients that require greater resources.

Establishing professional organizations at the global and national level such as the World Federation of Neurorehabilitation (WFNR) and the Indian Federation of Neurorehabilitation (IFNR) can aid in expanding the workforce, spreading education, developing of guidelines, training and capacity building, and advocacy at the professional level.

In order to assess the unmet need for rehabilitation services, the WHO undertook a stakeholder meeting in 2017, Rehabilitation 2030: A Call to Action. The meeting emphasized the need for integrating rehabilitation services at all levels in order to achieve universal health coverage.^[18] To address this, India's National Health Policy of 2017 declares the expansion of quality rehabilitative services in the public sector as a Policy Objective with an aim to improve health status that includes it in the comprehensive primary health care package and recognizes the need for collaboration with the private sector for providing rehabilitation care services. Furthermore, the policy stresses a comprehensive primary health care package in the form of "Health and Wellness Centers," which would include rehabilitative, geriatric, and palliative care services. In order to ensure equitable access to this package, health cards linking families to a primary health care facility usable throughout the country have been proposed. This would ensure greater uptake of services amongst the poorest of the poor. In addition, linkage of these wellness centers with district and tertiary levels of health care through digital health would ensure a continuum of care at the primary level where neurorehabilitation services would otherwise reach seldom.^[19]

STRENGTHENING PRIMARY AND DISTRICT HOSPITALS: THE WEAKEST LINK

In order to help nations strengthen rehabilitation services, the WHO has outlined a guide having four phases with 12 steps. The four phases deal with Systematic Assessment of Rehabilitation Situation (STARS), Guidance for a Rehabilitation Strategic Plan (GRASP), Framework for Rehabilitation Monitoring and Evaluation (FRAME), and Action on Rehabilitation (ACTOR).^[20] These phases may be useful in strengthening rehabilitation services in India, particularly at the primary level. Furthermore, the WHO Global Cooperation On Assistive Technology (GATE) initiative advocates the provision of high-quality, affordable, and culturally and socially appropriate assistive devices.^[21]

Some steps to ensure adequate delivery of quality neurorehabilitation services at the primary and district levels in LMICs could be as follows: capacity building of the workforce involved in neurorehabilitation, promoting courses/programs for training in neurorehabilitation, strengthening community-based neurorehabilitation (CBNR) services and linking it with tertiary hospitals, well-defined referral systems

for neurorehabilitation services across levels of health care, insurance coverage for neurorehabilitation services and assistive devices for neurologically disabled patients, greater fund allocation, stronger political will, and collaboration between different government stakeholders (health, social welfare, and education).

STRENGTHENING OF TELE-NEUROREHABILITATION SERVICES IN LMICs

Telemedicine can be an important tool that may bridge geographical discrepancies in availing rehabilitation services among resource-poor countries. Smartphone-based assistive technologies have been shown to improve functionality among patients with stroke even at the primary level in resource-poor countries.^[22,23] Video conferencing systems connecting rehabilitation specialists with nurses in rural hospitals have been found useful to deliver stroke rehabilitation services.^[24] Tele-neurorehabilitation services have also been useful for providing continuous rehabilitation services during the period of the COVID-19 pandemic, particularly among neurodegenerative disorders like Parkinson's Disease.^[25,26] Hence, tele-neurorehabilitation may be a cost-effective option for ensuring delivery of services even in remote areas, especially among LMICs. However, due to the lack of organized systems for tele-neurorehabilitation, the IFNR has advocated for greater budget allocation, scaling up of technology in the health care system at all levels, and a sector-wide approach for strengthening tele-neurorehabilitation services.^[27]

CONCLUSIONS

Thus, strengthening neurorehabilitation services in India and other LMICs at the primary as well as district level would help to greater uptake of these services across all strata of society and lead to better functional outcomes and quality of life among patients living with neurological disorders in these countries. To have the greatest effect on population health, careful attention needs to be given to the systems that deliver these services, the training and skills of the neurorehabilitation workforce, and monitoring of neurorehabilitation delivery. Even though rehabilitation plays a critical role in optimizing health outcomes, advances in this field have been found lagging. Recognizing neurorehabilitation's contribution to improving functioning and the quality of life among patients with neurological illnesses, and its importance to the effectiveness of other health interventions, is fundamental to correcting this disparity.

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