

# CHALLENGES & BARRIERS FOR NEURO REHABILITATION IN DEVELOPING COUNTRIES

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## ABSTRACT

**Background & Objective:** People with disabilities especially neurological disabilities have many unmet health and rehabilitation needs, face barriers in accessing mainstream health-care services, and consequently have poor health. There are not sufficient epidemiological studies from Pakistan which assess barriers to neurorehabilitation and ways to counter it.

**Objectives:** The objective of the study was to determine the challenges and to evaluate the barriers for neuro-rehabilitation services in developing countries.

**Methods:** This is Exploratory sequential qualitative study based on the Panel discussion forum in International rehabilitation sciences congress and national rehabilitation conference 2017. Panel group discussion has been conducted in February 2017 with a sample size of eight professionals including Rehabilitation medicine Physician, Physical Therapist, Speech Language therapist, Occupational Therapist, Clinical Psychologist and rehabilitation nurse working in multidisciplinary/Interdisciplinary team. A comprehensive audio-videography have been developed, recorded, transcribed and documented. Data was transcribed and thematic analysis along with characteristics was drawn manually. Data verification was done with the help of two separate coders.

**Results:** After extraction of two separate coders following results are emerged. General category themes are disease profile, demographic profile, training and education, research, barriers, governance, global funding, informal care, resources and cultural beliefs and public awareness. Barriers identified at the level are high cost, stigma, lengthy course of recovery. Hospital related barriers are lack of social support and individually tailored goal setting processes. Organizational barriers identified are lack of basic diagnostic facilities, lack of funding and human resources. Recommendations given by panelists were investment in education, capacity building, infrastructure, governance support, strategies to promote communication and realistic goals.

**Conclusion:** It is concluded that neurorehabilitation in developing countries need attention in following categories i.e. disease profile, demographic profile, training and education, research, barriers, governance, global funding, informal care, resources and cultural beliefs and public awareness. This study also revealed barriers at the level of patient, hospital, organization. Recommendations were also given by panelists.

**Keywords:** disability, neurorehabilitation, telerehabilitation

**INTRODUCTION:** Neurorehabilitation is the delivery of a coordinated interdisciplinary care program comprising a set of measures that assist individuals who experience disability to achieve and maintain optimal function in interaction with their environment<sup>6</sup>, for maximum independence and social reintegration.<sup>8,9</sup>

A neurological disorder is a disorder of the body's nervous system. Structural, biochemical or electrical abnormalities in the brain, spinal cord, or in the nerves leading to or from them, can result in symptoms such as paralysis, muscle weakness, poor coordination, loss of sensation, seizures, confusion, pain and altered

levels of consciousness.<sup>1</sup> Neurological disorders can create serious obstacles to community reintegration.<sup>2</sup>

The World Report on Disability estimates over one billion people with disabilities globally, which equates to 15% of world population or 1 in 7 people (based on 2010 global population estimates)<sup>6</sup>. Of these 110-190 million have significant difficulties, such as inability to walk, perform self-care, or communicate, or to participate in education or employment.<sup>1</sup> The prevalence of disability is significantly higher in low-income than in high-income countries, with an estimated 80% persons with disability living in low-income countries. Disability prevalence rates are also associated with poverty and personal wealth, with 20.7% of persons with disabilities in the lowest-wealth compared with 11.0% in the highest-wealth quintile.<sup>6,7</sup>

The socio demographic and epidemiological transition in developing countries has changed the morbidity and mortality pattern among communities. This has brought non-communicable diseases to the forefront of the health-care delivery system. Within this group, neurological disorder constitute a significant proportion affecting morbidity, mortality, disability and quality of life.<sup>3,4</sup> However, neurological services are slowly expanding in India and given the vast population, there is an urgent need for reorganization of the services with optimal utilization of existing specialized manpower.

The majority of persons with disabilities are economically deprived and experience difficulties in accessing basic health services (including rehabilitation).<sup>10</sup> Only 3% of individuals who need rehabilitation globally receive the service<sup>11</sup>, and this is significantly higher for persons with disability in low-income compared with high-income countries.

Pakistan is a low-middle income country with relatively under-developed and varied health care system between the rural and the urban areas. It is ranked 146th in Human development Index, with Gross National Income per capita of US \$ 2,880. In recent years there is increased awareness about non-communicable diseases and physical disabilities. There are currently over 188,000 doctors (8.3 physicians/10,000 people) registered with the Pakistan Medical and Dental Council, and 170 trained neurologist -majority based in urban areas. Rehabilitation Medicine is in infancy in Pakistan and confused with 'physiotherapy and exercises' alone by many health care professionals of and general public. In 1997 College of Physicians and Surgeon of Pakistan (CPSP) recognized Physical Medicine and Rehabilitation (PM&R) as a specialty and started the 4-year Fellowship training program. To date 48

physicians have successfully qualified the PM&R Fellowship, and majority (30) are working in the military facilities; while only 15 PM&R physicians in the private and public health sector for majority of the PWDs in Pakistan. Many medical schools and hospitals do not have specialized rehabilitation departments; and there is limited undergraduate teaching of rehabilitation medicine. Currently, there are estimated 1700 Physiotherapists in Pakistan and 1300 expected to graduate within one year. There are less than 200 trained occupational therapists, 250 speech and language therapists and no formally trained nurses in neuro-rehabilitation. Data regarding disability and burden of neurological diseases is sparse and mostly comes from hospital-based studies conducted in tertiary care medical institutes/hospitals located in major cities. There is no national registry for stroke, neurological disorders or physical disabilities.

There is no central body for the oversight and coordination, resulting in frequent duplication of effort. There is lack of funding not only for comprehensive management of neurological conditions, but for overall disability management and minimal awareness regarding neurorehabilitation amongst the public and health care professionals, who still practice traditional medical model rather than rehabilitation model for functional restoration and improvement in quality of life. Other barriers include lack of awareness and the perception of neurological disability as an end-of life situation.<sup>13</sup>

A study by Sekaran et al in rural South India showed that there is decline in community reintegration of spinal cord injured patients in rural south India. Architectural and environmental barriers, poor socioeconomic status and comorbidities significantly affected the level of community participation.<sup>5</sup>

A study by Fary Khan et al in Nigeria reported that despite differences in the healthcare system and practice, the challenges were similar to those in other low- and middle-income countries, at both macro (governmental/policymakers) and micro levels (community/social/individual).<sup>14</sup>

Another study conducted on stroke patients concluded that there is unavailability of long term rehabilitation services due to multi-factorial barriers and an urgent need for the establishment of community-based stroke rehabilitation centers was highlighted by discussion groups.<sup>15</sup>

This study is to determine the challenges for neuro-rehabilitation services in developing countries and to evaluate the barriers for neuro-rehabilitation services in developing countries.

## Results

S#	Theme	Characteristics
1	Disease Profile	Adequate Medical rehabilitation is woefully lacking, Incidence of Stroke, Trauma, Dementia, Parkinson's, multiple sclerosis is increasing. Spinal Cord injuries and related disabilities, On-going armed conflicts and wars
2	Demographic Profile	When available, is usually in Urban centers, inaccessible to many due to costs and/or geographical distance
3	Training and Education	Lack of Neuro rehab professionals, (Neurologists, Neuro rehabilitation specialists, Neurophysiotherapist, Neuro occupational therapist), PT have widely variable levels of training, OT, ST, Neuropsychologist, rehab nurses are rare, Limited training centers, No clinical training and clinical degree
4	Research	Different level of education, scopes of practice and practice patterns between rehabilitation professionals in developed and developing countries, Limited Multi-disciplinary team approach, Lack of statistical research or data
5	Barriers	Lack of entrepreneurship, Lack of rehab centers, Lack of social services
6	Governance (Political/Law)	Not priority, "Brain Drain" – Rehabilitation Professionals emigrate to developed countries to seek greater economic opportunities, No medical insurance system, lack of health service structure, Lack of disability in health policy, Lack of community based rehabilitation
7	Global Funding (Government/NGOs/Self Help)	No financial support from Govt/other sectors, Lack of specialized health care reforms, Non-governmental organizations to get more active with the National Societies rather than working alone
8	Informal care	Managing the cost of long-term care, Need to train professional care giver, need to develop visiting rehab nurses care, Lack of follow up issues, Lack of primary rehabilitation health care services, Better acute care leads for need of better Rehabilitation
9	Resources & Cultural beliefs	Spiritual norms, no need for treatment, It will recover with the passage of time, poor community, Non affordability, not available at primary level care
10	Public awareness	A systematic approach to deal with situation, local specialist to get trained, their integration with national society who in collaboration with organization and local neuro societies to improve the services, National Policies with local politician and Authority to deal the situation

Patient Related Barriers	
1	Widespread stigma and discrimination often because of non-biologic concepts and cultural perception of disabilities
2	The cost of access to neurorehabilitation services.
3	Lack of mistrust among Patients for medical practitioners in some cultures is still prevalent, particularly in rural areas, where first preference is to seek help from religious healers and traditional herbal medicine.
4	High cost of extended programs
5	Lengthy courses of recovery
Hospital Staff Related Barriers	
1	The difficulty of precisely determining brain lesion and problems of accurately matching groups.
2	Absence role models, and an understanding of the need
3	Individually tailored goal-setting processes
4	Lack of social support services
Organizational/Hospital level barriers	
1	Data regarding disability and burden of neurological diseases is sparse and mostly comes from hospital-based studies conducted in tertiary care medical institutes/hospitals located in major cities. There is no national registry for stroke, neurological disorders or physical disabilities.
2	Scarcity of qualified rehabilitation medicine physicians in the country (58) and the induction of mere 2-3 trainees per year cannot possibly cater for the increasing burden of disability. Only (2) physiotherapist with higher study and training in neuro-physiotherapy from abroad.
3	Lack of funding and human resources
4	Lack of precise, sensitive measures of outcome
5	No systems of appropriate referral mechanism for neurological illnesses at provincial or national level.
6	In many high-income countries the services are provided by national health care systems, through rehabilitation services, insurance companies, charities and Non-governmental organizations. However, in many low-income countries there is still large gap in service provision of these essential disability services.
7	Lack of comprehensive multidisciplinary rehabilitation centres
9	Inadequate health information systems and communication strategies across health care sectors and between providers (notably between primary and secondary care)
9	Absence of basic diagnostic facilities
10	The need for rehabilitation services in developing countries is not well defined in terms of type, settings, and intensity/duration due to lack of disability-disaggregated data within general statistics of the health and social sectors.

1	Investment in education and skill-development of neurorehabilitation professionals.
2	Capacity building for a strong interdisciplinary workforce for neurorehabilitation.
3	Infrastructure and IT support for sustainable health care for neurorehabilitation to drive economic growth and support health security.
4	Governance support for strengthening neurorehabilitation health care systems through logistics, surveillance and service delivery.
5	strategies to promote communication and understanding
6	strategies to avoid disappointment and unrealistic goals
7	Experience, skill, and engagement with goal-setting could be either a barrier or a facilitator, become more scientific while maintaining its humanity and patient-oriented focus
8	There is a need to build on this momentum and enhance cooperation among different stakeholders to develop neurorehabilitation in Pakistan
9	The residency training programs in neurology must include a mandatory rotation in rehabilitation medicine/Neuro Rehabilitation
10	There is a need to develop local guidelines for common neurological disabilities considering the resources and expertise available here.
11	Establishment of national registry on stroke, spinal injuries, cerebral palsy and multiple sclerosis will help in estimating the true burden of disability and making a strategy accordingly.
12	New partnerships, strategic collaboration; provision of technical assistance, research and development
13	Capacity-building for a strong interdisciplinary workforce
14	Governance for strengthening health care systems through logistics, surveillance and service delivery; and adequate scaling.
15	Build horizontal health care systems/Comprehensive primary health care that are sustainable and responsive

## Discussion

International evidence shows that people with disabilities have many unmet health and rehabilitation needs, face barriers in accessing mainstream health-care services, and consequently have poor health. This study reports potential barriers and challenges for neurorehabilitation in developing countries. It is reported that despite differences in the healthcare system and practice, the challenges were similar to those in other low- and middle-income countries, at both macro (governmental/policymakers) and micro levels (community/social/individual). Common challenges identified were: limited knowledge of disability services, limited Physical Medicine and Rehabilitation workforce, guidelines and accreditation standards; coordination amongst healthcare sectors; social issues; data and research; legislation and political commitment. Common potential facilitators included: need for strong leadership; advocacy of disability-inclusive development; investment in infrastructure/human resources; coordination/partnerships in healthcare sector; and research. Results showed that addressing specific impairments is secondary to ensuring that health systems provide adequately for all people with disabilities.

One of the barriers to neurorehabilitation is that existing policies are under-funded, there is lag in implementation of policies and overall delivery of such services, as well as lack of coordination and collaboration amongst different sectors. Key barriers in healthcare service provision include lack of political commitment and inadequate funding. Despite availability of policies on rehabilitation in some countries, there is lag in implementation of these

policies and/or overall delivery of the rehabilitation service.<sup>16</sup>

There is lack of strong leadership and a central body for developing governance. The implementation of health policies & enforcement of the legislation policy for employment/education/health for persons with disability is not proper. The coordination/collaboration among different government sectors & ministries and healthcare agencies is poor. The health priority more driven towards acute sector & communicable diseases. The coordination/collaboration among different healthcare sectors (hospitals (private, public), primary, Charity & Community organizations, international non-governmental organization and non-governmental organization is limited which is a big challenge.

Many persons with disabilities require specialized, efficient management and health services, which are often limited or lacking in developing countries. There is a shortage of allied health professionals (OTs, speech therapists, prosthetics, etc.) and few educational/training facilities for PM&R capacity building. There is limited or lack of modern equipment therapeutic and diagnostic, which hinders the provision of service delivery. In many developing countries, rehabilitation professional shortage is a real concern and poses a challenge to the healthcare system.<sup>17</sup> Woo and colleagues<sup>18</sup>, in a study of three rehabilitation hospitals, reported a significant reduction in function among stroke survivors when the number of hospital staffs was reduced over a ten year period. In Malaysia, taking physiotherapist as an example; the most recent statistics on human resources in healthcare shows that currently, there are less than 900 registered physiotherapists available in public hospitals in the country.<sup>19</sup>

The cost of access to PM&R services is a significant barrier, as most services are available only as an out-of-pocket payment. The majority of persons with disabilities is economically deprived and experience difficulties in accessing basic health services including rehabilitation. There is lack of universal health insurance systems and many private health insurance systems do not cover rehabilitation. This results in financial hardship and inequity in utilization of healthcare services.<sup>20,21</sup> There are limited PM&R services in rural areas, access to such facilities in urban areas is often costly, time-consuming and difficult.<sup>22</sup> A study conducted by Hirdesh Kumar et al concluded that financial problem was the major barrier for neurological rehabilitation followed by lack of awareness, family negligence and transportation problem.<sup>23</sup>

A potential, low-cost approach for expanding resources available for rehabilitation is to involve family members in conducting specific therapies at home. Findings from a qualitative study by Galvin and colleagues<sup>24</sup> strengthened the view that the family has a role to play in the delivery of therapy. These ideas were tested in a randomized controlled trial of a family-mediated exercise programme involving forty stroke patients, and it was found that family members can successfully implement therapy when training is provided by a qualified therapist.<sup>25</sup> Our findings support these studies; they indicate the potential of family-assisted therapy at home as a solution to enable continued care for long term stroke patients, especially following discharge from hospital rehabilitation.

Another barrier is that there is poor awareness amongst healthcare professionals about disability & PM&R. The evidence-base guidelines & disability centered measures are lacking. There are limited undergraduate courses in PM&R in medical institutions, professional courses/training programmes. There is no staff development or appraisal systems in hospitals or community settings. There is need to develop continuous medical education programmes for PM&R professionals, skill training & education and also Collaboration with international partners for staff education/training.

Another barrier to neurorehab is that the current guidelines for the management and rehabilitation of common neurological disabilities like stroke, spinal cord injury and cerebral palsy are written and published by the authors based in the developed world. Many of them have little relevance to the unique health care structure and limited resources available here. There is a need to develop local guidelines for common neurological disabilities considering the resources and expertise available here.

Another big challenge is that an appropriate referral mechanism for PWD is lacking at many levels. This results in gaps in appropriate services and the care continuum in the community for PWD. Therefore, many people miss appropriate services and/or care continuum in the community, after discharged from an acute facility. An effective referral system is required to ensure a close relationship/coordination between all levels of the health system to ensure those with neurological disorders, receive the best possible care and regular follow-up.<sup>26</sup> This will build capacity and enhance access to better quality care and provide cost-effective use of hospital, community and primary health care services.

While the referral system is one of the major challenges of the health system in the future,<sup>27</sup> just few qualitative studies has evaluated the barriers to the referral system in the process of health care provision in rural areas. A study by M Eskandari concluded that one category, “ineffective referral system”, and five subcategories, i.e. being far from the ideal referral system, lack of adequate governmental referral system, lack of connection between different levels of the referral system, self-referential and bypassing the referral system, and insufficient knowledge about the referral system.<sup>28</sup> Admission without referral forms is common and approximately there is no reference among patients with referral forms and without referral forms.<sup>29</sup> Likewise, Nasrollahpour Shiravani et al. showed that many of the referral system’s rules are not respected.<sup>30,31</sup>

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