WFNR

World Federation for NeuroRehabilitation

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NEUROREHABILITATION IN DEVELOPING COUNTRIES TIME FOR ACTION

WORLD FEDERATION FOR NEUROREHABILITATION

The World Federation for Neurological Rehabilitation (WFNR) was established in 1996. Its objectives are to advance the development and improve the quality of neurological rehabilitation across the world, to stimulate collaboration between clinicians and others with an interest in neurological rehabilitation, and to facilitate exchange of knowledge and scientific research between clinicians and others with an interest in neurological rehabilitation.

The WFNR is calling for:

- Long-term, coordinated efforts by governments, non-governmental organisations, international organisations and other interested partners to facilitate investment in, and the provision of, rehabilitation equipment and the funding of education and training programmes for health professionals
- The development of a core set of standards to constitute minimum requirements for the establishment of credible neurorehabilitation units
- Implementation of community-based rehabilitation services with tailored and culturally sensitive education for families and carers

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OVERVIEW

More than 80 percent of the world's population live in over 100 developing countries. National and regional life expectancies have improved in these countries as a result of medical technology, and the development of, and better access to, public health services. However, increasing life expectancy has not been accompanied by corresponding improvement in their economic status e.g. in Sub-Saharan Africa, life expectancy is about 50 years but Gross National Product per capita is still less than £300. The result is an increasing prevalence of age-related health problems, most of which are neurological disorders with associated functional impairment and disability.

According to the United Nations Development Programme, approximately 800 million people in the developing countries live with disabilities; women in particular with disability are hugely disadvantaged, experiencing exclusion from society. Neurological disorders represent a huge burden in terms of economic and social cost to developing countries, and the rate of increase is set to accelerate with a major impact on the functioning and quality of life of patients.

The delivery of neurorehabilitation in developing countries depends on the needs and resources of the country. Overall the availability of neurorehabilitation services is at best inadequate, mostly lacking, with access to up-to-date technology limited; 60 percent of the developing countries have no neurorehabilitation services. The availability of trained professionals is grossly insufficient. The task of managing patients with neurological impairments is often devolved to generic therapists and inadequately trained nursing and medical staff. The overall effect is that treatments are being provided by less than adequate professionals, possibly delivering outcomes for patients that fall short of their potential. Even in those developing countries where some neurorehabilitation service is provided, the quality is rarely good enough, due to a lack of a well-structured neurorehabilitation system which can provide comprehensive rehabilitation services. More often than not treatment is not provided.

WHAT IS NEUROREHABILITATION?

Neurorehabilitation is a complex medical process of diagnosis, assessment, acute and long-term management of people with complex neurological disabilities – physical, psychological and/or cognitive. It aims to aid recovery from an injury to the nervous system and to minimise and/or compensate for any functional alterations resulting from it. The individual is supported to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living. It is a patient-centred, iterative, goal-focused learning process to

optimise functional recovery, disability management and adaptation to loss and change.

Neurorehabilitation requires an interdisciplinary team of experts comprising clinicians trained in rehabilitation medicine, nurses, physiotherapists, speech and language therapists, occupational therapists and clinical psychologists.

CONDITIONS COMMONLY REQUIRING NEUROREHABILITATION MANAGEMENT

The conditions commonly treated by neurorehabilitation include stroke recovery, brain injury, cerebral palsy, Parkinson's disease, multiple sclerosis, post-polio syndrome as well as the late effects of acute poliomyelitis and Guillian-Barré syndrome. In addition many spinal cord disorders and peripheral neuropathies also require rehabilitation.

Stroke

Stroke is the leading cause of neurological disability particularly in developing countries where, due to epidemiological and demographic transition, there is a current epidemic of cardiovascular risk factors including hypertension, obesity and diabetes mellitus. WHO estimates from 2001 indicate that low and middle income countries accounted for 86 per cent of global stroke deaths. In terms of total disability adjusted life years, the burden for low and middle income countries was almost seven times higher than for high income ones. To some extent this imbalance reflects the disproportionate share of the global population living in low and middle income countries, as well as the increasing burden of cardiovascular risk factors in these countries. While the incidence of stroke has declined in high income countries over the last two decades, it has increased by 12 per cent in low and middle income countries. If the current trends in stroke incidence and aging of the population continue, deaths from stroke in developing countries will increase over the next decade by 20 per cent, and the overall burden of stroke may soon become unbearable for the economy of these countries.

Traumatic brain injury

According to the World Health Organisation (WHO), Traumatic Brain Injury (TBI) will surpass many diseases as the major cause of death and disability by the year 2020.

TBI is an urgent public health and medical issue with an estimated 10 million people annually affected with the resultant mortality and morbidity burden. The burden is predominantly manifest in the developing countries due to the higher incidence of risk factors for the causes of TBI, e.g. in India road traffic accidents (RTAs) and falls

account for 45-60 per cent and 20-30 per cent of TBI respectively, and in Eastern China 61 per cent of TBIs are due to RTAs.

Latin America and Sub Saharan Africa have a TBI incidence rate varying from 150 - 170 per 100,000 respectively, compared to a global rate of 106 per 100,000.

Cerebral palsy

With 80 per cent of children with disabilities living in resource-poor settings, it is likely that there is a high prevalence of cerebral palsy (CP) and neurological impairment in these settings. However, the prevalence and incidence rates of disability, in particular of children with CP in resource-poor settings, are difficult to access and clarify.

Parkinson's disease

According to available statistics, an estimated 6.3 million people have Parkinson's disease (PD) worldwide and this is increasing annually with the greatest growth predicted to occur in developing countries in Asia. By 2030, an estimated five million people in China will have the disease. Drugs for the management of PD are available in most developing countries, but not all patients can afford the cost of long-term treatment.

There is also very limited infrastructure in place to diagnose individuals in the developing countries, much less address their medical needs or the societal impact.

Multiple sclerosis

Globally, the median estimated prevalence of Multiple Sclerosis (MS) is 30 per 100 000; 2.8 for Asia and 0.3 for Africa. However, the unequal distribution of important diagnostic tools such as Magnetic Resonance Imaging scanners is likely to result in under-recording of MS in many low-income countries. This effect is also likely to be reinforced by either ignorance among professionals or the belief, in some of those countries that MS does not occur.

MS in the developing countries, as elsewhere, affects the young with an average age of onset around 25-30 years and is more common in women than men.

Post-polio syndrome

Up to 20 million polio survivors around the world face the threat of new disabilities 15 to 40 years after their original illness, which could leave them using wheelchairs or ventilators for the rest of their lives. The WHO estimates that 10 to 20 million polio survivors are alive worldwide, and some estimates suggest that 4 to 8 million of them may get Post-Polio Syndrome (PPS). In developing countries, where polio outbreaks still occur or have ended much more recently, medical systems will be

facing PPS for decades into the future and have little knowledge or understanding of the condition.

Guillian-Barré syndrome
Guillian-Barré syndrome (GBS) is the most frequent cause of acute flaccid paralysis. Approximately 95% of new HIV infections occur in developing nations and HIV infection is a common cause of GBS in African countries. A recent review reported that the best estimate of the global incidence of GBS in children <15 years of age is 0.6 cases per 100,000 population per year, but reports on incidence rates in developing countries are scarce.

WHY IS ACCESS TO NEUROREHABILITATION INADEQUATE?

The reasons for inadequate access to neurorehabilition in the developing countries include:

Poverty
Not only is poverty a major contributor to the causes of disability, but it is also the primary reason for inadequate rehabilitation services. Even if a service exists, patients often do not have the money to pay for their treatment.

Large population
More than 80 per cent of the world's population lives in over 100 developing countries with 800 million people living with disability. This is a huge patient population to manage.

Apathetic governments
Most developing world governments are apathetic towards neurorehabilitation. The issue of disability does not win votes.

Health priorities
In recent years, a great deal of resources and energy has been focused on confronting infectious diseases such as HIV, malaria, and tuberculosis. This is highlighted by high-profile private investments in these areas by organisations such as the Gates Foundation. However, while infectious diseases have attracted the greatest attention from international donors, it is non-communicable chronic diseases that represent a far greater burden in terms of economic and social cost to developing nations.

Lack of awareness
Awareness of, and the need for, rehabilitation is dismally poor amongst the general population, healthcare providers and governments.

Lack of understanding
Rehabilitation is often confused with physiotherapy, rather than the concept of an interdisciplinary approach.

Chronic illness is not a priority
The priority tends to be to treat the acute illness rather than its consequences. However, these patients are living long-term with the consequences of their disability so short-term management is not acceptable.

Lack of expertise
There is an inadequate number of skilled and trained rehabilitation medicine clinicians. Many go to developed countries to be trained and practice their skills, and this impedes the scope and speed of service development. The essential expert interdisciplinary teams are lacking, even in large cities. The number of neurologically trained physical therapists, occupational therapists, speech and language therapists and neuropsychologists is extremely limited, and places a huge obstacle on the development of services. Developing countries that are financially strong can import expertise, and whilst this generates rapid establishment of the required services, the continuity and consistent development is adversely affected due to a rapid turnover of staff and lack of stake holding.

Lack of equipment
There is restricted access to appropriate and up to date equipment.

Lack of knowledge
The required training programmes in all disciplines for health professionals have not been widely introduced. The rehabilitation programmes that do exist vary from country to country and are not uniform in providing a service to patients.

Poverty breeds illiteracy, and patients have no knowledge of what rehabilitation they need.

WHAT IS NEEDED TO ADDRESS THE SITUATION?

It is imperative that governments, non-governmental organisations, international organisations and other interested partners work together immediately to co-ordinate the training and education of health professionals throughout developing countries.

Investment in, and the provision of, rehabilitation equipment is required and neurorehabilitation units need to be established according to agreed standards.

Whereas hospital-based interdisciplinary neurorehabilitation care is often required as

a first line service to facilitate rapid recovery after neurological injury, community-based or domiciliary services are appropriate for community re-integration in the recovery phase when the trajectory towards maximal quality of life and achievement of purpose in life has been determined. Community-based rehabilitation services are the most appropriate way forward in developing countries, with tailored and culturally sensitive education for the family, to help them participate in the rehabilitation of the patient. Family-based rehabilitation needs to be considered as a viable option; a family can be trained by a therapist, or via the web, to deliver a rehabilitation progamme for a family member.

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