Assessment of Neuro-rehabilitation Services in Delhi/NCR

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Abstract

The quality of life of a person can be greatly affected by a brain or spinal cord injury, or a medical condition, which affects the mobility, cognitive functions, or other physical or psychological processes that have been affected by changes in the nervous system. Neuro-rehabilitation, the case specific processes focus on helping a person to live a normal, active, and independent life by way of combating those changes and improve quality of life by various therapies. A large number of neurological diseases lead to severe lasting disabilities and hence it is very important that specialist rehabilitation centers are developed and nurtured. The scope of rehabilitative services has increased with therapies like Botulinum Toxin and will widen further with computer assisted and robotic devices also known as assistive technology. In this study primarily 25 rehab centers are surveyed for their adequacy and timely delivery of services to deal with the raising neuro problems & disability. In this study an effort has been made to study the population ratio served by these centers, their bed capacity etc.

Keywords: Neuro-rehabilitation services, Disability , Neuro-epidemiologic Surveys, Rehabilitation centers, Types of neuro-rehabilitation.

Introduction

Neurology is the medical specialty encompassing diseases, conditions and infections of the nervous system including the brain, spinal cord and peripheral nerves. There are some basic symptoms that are common among all neurological conditions. These symptoms include differences in speech patterns, loss of balance and coordination, numbness in a single extremity, weakness, memory loss, difficulty moving, tremors, rigid muscles and difficulty swallowing. There may also be an inability to perform tasks such as swinging the arms, blinking or other acts that are normally involuntary.

Neuro rehabilitation forms an integral component of neurology services since disability due to neurological disorders, unlike other diseases, is a major issue. The disabilities are categorized as affecting mobility, disturbance of cognition and behavior, causing pain, disturbance of consciousness and function. Further, a specific neurological disability may result from a combination of different impairments or a single impairment may lead to multiple disabilities. At present there are approximately 1100 qualified clinical neurologists working in India. Out of these, over 400 work in four large metro cities of India. Thus, many districts and rural parts of India have to be covered by single neurologists. Nearly 80 students are registered for neurology courses every year throughout the country but still multidisciplinary team are not available to cater neuro-patients customized healthcare needs. A proportion of new graduates leave India for greener pastures and organized life. Thus, the neurology fraternity is growing very slowly and is grossly inadequate to cater to the large population of India. As a result of this disparity, only a small proportion of neurological cases can find their way to the neurologists and it is believed that over 90 per cent of the neurology is handled by internal medicine specialists.

The neuro rehabilitation works with the skills and attitudes of the disabled person and their family. It promotes their skills to work at the highest level of independence and encourages them to rebuild self-esteem with positive mood. Thus, they can adapt to the new situation and become empowered for successful and committed community reintegration. However, families of patients are of the view that all inclusive care plans should be launched by the Government to ease economic burden. They also observed the lack of trusting relationship as doctors treating patients are not informing patient’s family about the treatment plan. Families also expect to include adequate human & material resources for efficiently resolving patient’s problems.

Neuro Epidemiologic Surveys

Population-based neuro-epidemiologic surveys during the last 15 years, using standardized WHO questionnaire with modifications, in different regions of the country have shown the prevalence rate of neurological disorders to vary from 967 to 4070 per 100000 population. The Parsis, a distinct ethnic group, have an unusually high prevalence rate, but they do not represent the general population of the country. In these surveys, infections of the nervous system and traumatic injuries of brain, spinal cord and peripheral nerves have not been included and therefore it would be an underestimate of the total burden of neurological disorders. All age groups are affected with peaking in the elderly above 60 years of age.

In India according to the 2001 census there are 77 million people above the age of 60 years and it is expected that by 2025 there will be a huge increase to 177 million with
consequent significant rise in age-related disorders such as cerebrovascular disorders, Parkinson's disease and dementia. Contradicting the perception of the policy-makers and administrators that neurological disorders are seen mostly in the urban population, the prevalence in the rural population is significantly higher than in the urban population. In a large community-based survey in Bangalore of a population of 10,2557 comprising an urban population of 5,1502 and rural population of 5,1055, the prevalence rates were 2,190 and 4,070, respectively, with a ratio of 1:1.85. This fact is critical for planning infrastructure and trained manpower for providing equitable neurology care in the country.

Based on the prevalence studies, it is estimated that in India there are 20 to 30 million people with neurological disorders and the common disorders include epilepsy (6 to 8 million), headache (10 to 12 million), and strokes (1 to 2 million). The actual burden of cerebrovascular disorders will be higher than these projected figures. Special mention needs to be made regarding care of people with epilepsy in view of the associated stigma, the myths and misconceptions about the nature of the disorder and the consequent burden to the patients and their family members, factors which are not considered while determining the Disability Adjusted Life Years (DALYS). Some of the crucial factors leading to a wide treatment gap of 38 to 80% in the country are stigma associated with epilepsy preventing patients seeking medical advice, lack of awareness that epilepsy is a brain disorder and that it can be treated. It is therefore important to move forward from descriptive neuro-epidemiologic studies to interventional strategies for prevention and treatment of neurological disorders.

Of its 1.8 billion strong population 70% resides in rural areas and 30% are below the poverty line which limited access to modern amenities of health care. While the majority of the urban population has access to private medical services, the large proportion of rural poor have nothing but public health institutions to fall back on. This paradox of amenities and opportunities has led to unique healthcare system in India which draws on both public and private institutions in varying proportions. In this system modern traditional and alternative medicine working together, largely driven and facilitated by the disproportionate number of trained professionals vis-a-vis the giant population. For example there are only 1200 neurologists, 400 physiatrists, a few hundred therapists and a dozen neuropsychologists catering to the entire population. From the organizational perspective there is a rehabilitation council in place as well as an articulated national policy on the disabled and rehabilitation with stringent provisions but the infrastructure to execute provisions of the Disability Act is scarce. As such India spends only 3% of its GDP on health care.

Epilepsy: Recent community-based surveys have shown that epidemiological indices of epilepsy in India are comparable to those from developed countries, with a prevalence rate of 5 per 1000 and incidence rate of ~50 per 100,000. While the pattern of epilepsy seen in India is comparable to that in the other parts of the world, epilepsies related to neuroinfections, trauma and perinatal difficulties seem to be more prevalent in local situation. Due to the shortage of neurologists and physicians in rural India, large numbers of epilepsy patient either do not receive therapy at all or tend to receive polypharmacy in irrational formats.

In the context of the whole country, the treatment gap [percentage of individuals who are treated] is still very large being about 70%. The discontinuation rate is also very high. On the other hand, there are encouraging aspects to the epilepsy care in India. The epilepsy Society of India, with its wide networking, has helped increasing the awareness of epilepsy in the society and thereby, to an extent, has reduced the stigma. A wide variety of antiepileptic drugs are available to us in India and hence the choices are comparable to those on the international scene. As many of these drugs are manufactured in our own country, the costs are favorable to the patients.

With the frequent use of CT scan and MRI scan, Lesions are being diagnosed earlier and therefore the outcomes have improved. A number of centers have now developed epilepsy surgery programs and pre-and peri operative evaluation has improved. Lesional epilepsy surgeries are gaining more popularity and are being offered earlier, as the results keep improving.

Strokes: Stroke is a major health problem in India. The average annual incidence rate of strokes in a recent study was 145 per 100,000 populations in comparison with the developed countries. Stroke burden has been rising in India as compared to the developed countries where it has reached plateau or decreased. Overall, ischemic strokes account for about 80% of all strokes in India and intracranial atherosclerosis tends to be commoner in Indian people.

Parkinson’s disease and other movement disorders: The prevalence of Parkinson’s disease in Indians is generally believed to lower than people of European origin. A recent epidemiological study showed a low prevalence (Crude Prevalence: 45.8 and Age Adjusted Prevalence: 71.6 per 100,000) of Parkinsonism. While idiopathic Parkinson’s disease is the most common, a small proportion of genetic forms have been identified in hospital-based studies in India. Manganese related toxic Parkinsonism is also reported from India. With the aging of the Indian population, Parkinson’s disease will probably be seen more frequently in neurological clinics in India.

The movement disorder clinics have now become an integral part of large neurology centers, classifying and characterizing the Parkinsonian syndromes. Social organizations for Parkinson’s disease and movement disorders are also active in helping the patient groups. In addition to a variety of dopaminergic medications, with conventional and novel delivery approaches, surgeries like deep brain stimulation, thalamotomy and pallidotomy are being performed in the specialty centers. Recently, yoga therapy has been studied in association with physical therapy. Other movement disorders like chorea, dystonia, tremor and myoclonus are seen regularly. Rheumatic chorea still remains the most common cause of chorea in India.

Economic Aspects: The economic aspects of the burden of neurological disorders include direct cost of outpatient care, drugs, emergency admissions, in-patient care and expenses for transport, particularly from remote areas to centers of healthcare and hospitals. Indirect costs are
unemployment, under-employment, income lost by family members, disability-associated issues and excess mortality. Intangible costs are attributable to pain, disability and suffering. Economic burden of neurological disorders, with the exception of epilepsy, has not been determined in India. In a well-designed study conducted in six medical centers, one each from six states including Andhra Pradesh, Gujarat, Kerala, Karnataka, Maharashtra and Tamil Nadu, the annual cost of epilepsy per patient was Rs 13755. Based on this data and the number of people with epilepsy in the country, the economic burden was estimated to be Rs. 68.75 billion. An important issue emanating from this study was that the indirect costs of travel expenses to the hospital situated at a considerable distance and the consequent loss of productivity amounted to 14% of the total annual cost.

**Types of Neuro-rehabilitation**

The ultimate goal for neuro rehabilitation patients is to improve their quality of life and allow them the most independent life possible for their condition. In order to do so, many therapies are needed to help the individual and his family to adjust to their new ways of life. The most important therapies are those that help people live their everyday lives. These include occupational therapy, psychological therapy, Ultrasonic neuro-modulation, Laser, Hydro Therapy, Cam Therapy, speech and language therapy, etc. Therapies focused on daily function and community re-integration. A particular focus is given to improving mobility and strength.

**Materials and Method**

Primary research was conducted at 25 neuro-rehabilitation centers in Delhi/NCR that catered to rehabilitation services for neurological disorders. The list was prepared of centers providing exclusive services along with their registered names and addresses, the population ratio served, bed capacity, average waiting period for a patient for availing the services, common causes for the disorders and the doctor-patient ratios respectively. The analysis was carried out by descriptive statistical methods.

The results of analysis are discussed in the result and analysis section...

**Rehabilitation centers for the study:** The various departments where survey was conducted include - Laser, Physiotherapy, Occupational therapy, Ultrasonic Neuron-modulation, Rehab psychologist, Independent living units, Vocational training, Hydro therapy, Cam therapy and Assistive technology.

**Operations of neuro-rehabilitation centers:** Keeping in view all aspects of any person well being, neuro rehabilitation offers a series of therapies from the psychological to occupational, teaching or re-training patients on mobility skills, communication processes, and other aspects of that person’s daily routine. Neuro rehabilitation also provides focuses on nutrition, psychological, and creative parts of a person’s recovery.

Many neuro rehabilitation programs, whether offered by hospitals or at private, specialized clinics, have a wide variety of specialists in many different fields to provide the most well rounded treatment of patients. These treatments, over a period of time, and often over the lifetime of a person, allow that individual and his family to live the most normal, independent life possible.

While the field of neuro rehabilitation is relatively new, many therapies are controversial, and while some are considered cutting edge technology. Neuro rehabilitation is the culmination of many different fields to provide the best care and education for patients with injuries or diseases affecting their nervous system.

**Results and Discussions**

As shown in Fig. 1, it may be infer that people still are not aware of the fact that timely treatment given to the patients at rehabilitation centers can improve patient’s life. It may due to very less exposure or may be due to pure antagonistic nature. People tend to oppose the fact that even brain injuries are treatable with impactful change.

![Fig 1: Timely Treatment Awareness](image_url)
Respondents who were accompanying patients during the treatment at rehab centers, majorly elderly people of age group 51 - 60, do believe that if timely intervention of rehabilitation is provided then patients can lead near to normal life.

- As per Physiotherapists the following conditions commonly treated by Neuro- Rehabilitation are as under:
  - Stroke recovery 40%
  - Cerebral palsy 20%
  - Parkinson’s disease 15%
  - Brain injury 15%
  - Multiple sclerosis 10%

For example, 40% physiotherapists indicates that Stroke affected patients shows quick recovery when given timely & regular treatment in the rehabilitation centers, whereas 20% believe that even cerebral palsy can be treated with the timely intervention of rehab centers.

- A survey result shows that certain therapies such as occupational therapy, psychological therapy, speech and language therapy, and therapies focused on daily function and community re-integration help patients to improve mobility and regain strength

- While there have been tremendous advances in imaging and neurological techniques, respondent doctors believe more than 80% of patients are deprived of even basic neurological facilities due to poor awareness, poor accessibility, and lack of funds.

- Therapeutic activities under neurological rehabilitation program offered by neuro-rehabilitation centers are as follows:
  - Activities to improve mobility, coordination and balance.
  - Exercises and splinting to manage spasticity and pain or increase ROM.
  - Retraining in activities of daily living such as grooming, bathing, feeding, handwriting, meal preparation and basic housekeeping.
  - Activities to improve cognitive function, specifically problems such as perceptual deficits, loss of memory, decreased attention span, lack of concentration or altered judgment.
  - Activities to assure safety.
  - Pain management activities.
  - Recommendations for assistive devices that promote independence.

- Neuro rehabilitation centers have identify following the vocational need for patients:
  - Routine vocational needs by health and social care practitioner
  - Provision of information or referral to relevant information sources
  - Avoidance of premature judgment about fitness to work without specialist’s advice
  - First hour of a brain injury is considered the ‘golden hour’ as the first responder can save the life of the victim and also prevent the person from a severe traumatic injury.
  - If public is trained to give the most basic care to a road accident victim. Nearly 50 percent of brain-injury deaths caused by road accidents can be reduced.
  - Rehabilitation centers focus on all aspects of a person's well being, and offer a series of therapies from the psychological to occupational, teaching or re-training patients on mobility skills, communication processes, and other aspects of that person's daily routine. Neuro-rehabilitation also focuses on nutrition, psychological, and creative parts of a person’s recovery

Recommendations

- Neuro rehabilitation should be:
  - Holistic approach to cater the physical, cognitive, psychological, social and cultural dimensions of the personality, stage of progress and lifestyle of both the patient and their family.
  - Patient’s centric health care strategies should be developed.
  - Inclusive care-plans should be designed and implemented by multidisciplinary and highly qualified and motivated practitioners.
  - The patient and family must be well informed and a trusting relationship with the multidisciplinary team must be built.
  - Sparing treatment must aim for empowering the patient to maximize independence
  - Approach of physiotherapy plan has to reduce physical impairment & reliance on mobility aids.
  - Patient’s various needs throughout their life must be catered by ensuring continuity of care by all means from injury onset to the highest possible level of recovery of function. This may include addressing medical complications of the injury or illness later in life.
  - Resolving Treatment has to include adequate human and material resources for efficiently resolving each patient’s problems as they arise.

Conclusion

It has been observed that the diagnostic and therapeutic abilities of neurological physicians have gradually increasing. Compared to earlier times, the amount of facilities and technologies available in India has improved but still for better disease management human & material resources for efficiently resolving patients problems. If this trend continues in the near future more improvement may be made in this field. The potential therapies of neurological disorders are largely available to Indian physicians although there are certain restraints like the shortage of neurology
workforce, it’s uneven distribution, costs of neurology care are some of the hindrances in providing the available facilities to the common Indian patients.

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