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Role of neuropsychology in continuum of health care in neurological conditions

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A review on global burden of neurological illness shows that neurological disorders remain a public health challenge (PHC). There is ample evidence that shows that neurological disorders are one of the greatest threats to public health. There are several gaps in the understanding of the numerous issues that are related to neurological disorders, but experts already know enough about their nature and treatment to be able to shape effective policy responses to some of the most prevalent disorders among them. The PHC is related to the fact that there are increasing global public health problems pertaining to all neurological conditions, including diseases by faulty genes, degenerative diseases, diseases of blood vessels that supply the brain, injuries to the spinal cord and brain, seizure disorders, cancers, brain tumours, infections such as meningitis as well as developmental disorders.^[1] All of these conditions have a huge neuropsychological, psychosocial and quality-of-life impact. The lack of access to evidence-based treatment and care for psychological health has reached a critical point and a concerted national effort is needed to address this public health crisis.

Recently, these neurological conditions have been listed under the World Health Organization (WHO) Mental Health Atlas-2017 under different country profiles and published on 21 January 2019 by Patel *et al.* This is a concerted effort to deal with the mental health issues associated with neurological conditions.^[1] Hence, the role of neuropsychology had assumed great importance in the present era.

The Neurological Disorders Collaborator Group (GBD 2016) published a report in 2016, wherein comparable data on the global and country-specific burden of neurological disorders and their trends were studied.^[2] The role of this data in being crucial for health-care planning

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and resource allocation has been emphasized. The Global Burden of Diseases, Injuries, and Risk Factors (GBD) Study provides such information but does not routinely aggregate results that are of interest to clinicians specializing in neurological conditions. Globally, the burden of neurological disorders has increased over the past 25 years because of expanding population numbers and ageing, despite a substantial decrease in the mortality rates from stroke and communicable neurological disorders being seen. The number of patients who will need care by clinicians with expertise in neurological conditions will continue to grow in the coming decades. Policy makers and health-care providers should be aware of these trends in order to augment their resources to provide adequate services.

A recent study on the brain and central nervous system (CNS) cancers focuses attention on how treatment of such conditions require extensive resource allocation and sophisticated diagnostic and therapeutic technology. The finding of this study also shows that the top three countries with the highest number of incident cases were from China, USA, and India. CNS cancers were responsible for 7.7 million (95% uncertainty interval [UI] 6.9 to 8.3) disability adjusted life years (DALYs) patients globally, a non-significant change from the age-standardized DALY rate of -10.0% (range: -16.4 to 2.6) that was assessed between 1990 and 2016. The age-standardized DALY rate decreased in the high socio-demographic index (SDI) quintile (-10.0% [-27.1 to -0.1]) and high-middle SDI quintile (-10.5% [range: -18.4 to -1.4]) over time but increased in the low SDI quintile (22.5% [11.2 to 50.5]).^[2]

Burden of Mental Health

According to the National Mental Health Survey (NHMS, 2016), mental disorders, including that accompanying neurological

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conditions, contribute to a significant load of morbidity and disability, even though few conditions account for an increasing mortality.^[3] As per Global Burden of Disease report, mental disorders accounts for 13% of total DALYs lost for Years Lived with Disability (YLD), with depression being the leading cause.^[2] Previous reviews, meta-analysis, studies, and independent reports have indicated that nearly 100 million persons in India are in need of systematic care based on data that are a few decades old and have serious methodological limitations.

By the most conservative estimates, at least 5% of the Indian population lives with psychological health problems, a figure that translates to over 50 million people. These numbers have a close bearing with the rate of suicides, cardiovascular health issues, and several days of productivity lost. The impact of inadequate mental health treatment can be estimated—though not entirely correlated—by its effect on suicide rates. The WHO statistics states that the average suicide rate in India is 10.9 for every 100,000 people due to mental health problems.

Psychology plays a major role in different aspects, e.g., in diagnosing mental disorders and in therapeutic intervention in difficult-to-deal-with patients as well as in managing those patients who have a higher likelihood to institute litigation against medical doctors. To deal with this problem, assessment, psycho-education, and counseling of these patients has a major role to play in alleviating these disorders.

Burden of Neurological Conditions

The report on global, regional, and national burden of brain and other central nervous system (CNS) cancers, 1990–2016,^[2] gives recommendations for action to health care professionals and planners. These reports provide them the opportunity to assess the burden caused by neurological disorders in their respective countries and to take appropriate action. All the recommendations need to be implemented across a wide range of sectors and disciplines if they are to achieve success. They are not a universal blueprint, however, and will have to be adapted to the local conditions and capacities of the indigenous population of that area.

According to the report, the actions recommended can be beneficial directly, by decreasing the mortality, morbidity and disability caused by neurological disorders; and indirectly, by improving the functioning and quality of life of patients and their families (which fall within the realm of neuropsychology services). Surprisingly, the report by Patel *et al.*,^[2] shows that in certain low- and middle-income countries with limited human resources, it may be difficult for governments to apply some of these recommendations on their own. On the contrary, there is no dearth of availability of manpower in India. There are many core professions related to the realm of psychology. Members of these groups would be happy to serve and help their patients and get due recognition for their efforts.

Patel *et al.*,^[2] recommend efforts to increase the public and professional awareness. Public and professional awareness of public health aspects of neurological disorders need to be raised through the launch of global and local campaigns and initiatives that target health professionals, general practitioners

and primary care physicians, specialists in public health, neurologists, health planners, health economists, the media, and the general public. All of these tasks can be performed by neuropsychologists. According to Patel *et al.*,^[2] another path of sensitization is the development of educational programs in public health aspects of neurology (including the amalgamation of local practices and traditions), and their inclusion in the teaching and training curriculum of all institutions where neurology is taught. Self-help groups, patient information programs, and basic educational and training interventions for caregivers, should be encouraged and facilitated. Patients, their families, and caregivers should be represented and optimally involved in the development and implementation of policies and services for individuals with neurological concerns.

Stigma and Discrimination Associated with Most of these Disorders

According to the WHO Mental Health Atlas-2017 country profiles, the stigma often associated with neurological disorders adds to the social and economic burden of a family and society.^[1] According to the report, one of the most damaging results of stigmatization is that the affected individuals or those responsible for their care may not seek treatment, hoping to avoid the negative social consequences of the diagnosis, despite being acutely aware of the psychological need of their patients to seek treatment for their ailment. Indeed, in some communities, the stigma leads to the denial of basic human rights. The stigma aggravates the vicious cycle of illness and the negative social reaction and leads to social exclusion and discrimination. Epilepsy, one of the most common neurological conditions, is well understood in many societies but its psychological sequel is not so well accepted.^[4]

Thus, in developing countries, in particular, epilepsy is considered as contagious or the sign of a curse or possession, with the blame for the condition attached to the family as well as to the patient. The direct and indirect discriminatory behavior and factual choices by the society causes substantial reduction in societal opportunities such as education, marriage or work, or may result in these patients being excluded from community activities. Fortunately, the stigma and its negative effect on the quality of life can be substantially reduced by better seizure control, highlighting the need for effective treatment (which falls within the realm of neurology services under the curative model) and sensitizing the public. Cost-effective interventions are available for many of the neurological disorders. There are inexpensive but effective interventions that could be applied on a large-scale basis through primary care intervention (which falls within the realm of neuropsychology services). A number of strategies implemented at the policy level by governments through legislation (such as the WHO Mental Health Atlas-2017 country profiles), as well as the tax or financial incentives, can reduce the risks to health.^[1] For example, in the effective implementation of road safety, a significant number of people might not choose to drive safely or to use seatbelts or motorcycle helmets, but governmental action can encourage them to do so, thereby preventing injuries to themselves and to other people. The ultimate goal of such efforts should be to prevent the isolation of patients with neurological disorders and their families and to encourage their social integration. The dignity of individuals with neurological

disorders needs to be preserved and an improvement in their quality of life should be initiated.^[4] The approach of the intervention needed to mitigate the stigma varies with the condition. For example, efforts to alleviate the stigma of epilepsy needs to focus on helping individuals acknowledge their treatable disease and adjusting to the life with it in a large number of cases.^[4] This again highlights the major role of neuropsychology. Information, education and communication, and social marketing campaigns need to increase compassion and reduce blame. Legislation represents an important route in dealing with these problems and challenges. Governments can facilitate the efforts by implementing laws that protect people with brain disorders and their families from abusive practices and prevent their discrimination in education, employment, housing, and other opportunities.

Since primary care teams work in the community, they are well placed to recognize factors such as the prevalence of social stigma, family problems, and cultural factors that hamper the treatment of neurological disorders. Thus, primary care is the logical setting in which neurological disorders and related stigma need to be dealt with, in a robust neuropsychological and psychosocial care model. The important role of primary care is founded on the principle that decisions in primary care also take into account the patient-related factors, the medical history of the family and the patient's individual expectations and values. The continuity and long-term relationships provided by the primary care workers generates awareness, while promoting trust and satisfaction among patients.

What is required is an approach that provides continuing and seamless care to handle the long-term nature of neurological disorders and the persistent requirement of ongoing care. These factors enhance the role of neuropsychology in dealing with neuropsychological disorders. Incorporating rehabilitation into the core strategies (all existing therapies including neuropsychological therapies) is also an immensely effective strategy. Rehabilitation complements the other core strategies that focus on the promotion, prevention and treatment of the primary disease. While prevention involves targeting of the risk factors of the disease and treatment deals with health conditions of the patient, rehabilitation targets their individual functioning during and following their effective treatment.

Mental health as well as psychological rehabilitation are also relevant strategies that brings together other sectors such as education, labor and social affairs. These two, therefore, form most relevant strategies within the community. There are wide ranges of rehabilitation interventions, programs and services that have been shown to be effective in contributing to optimal functioning of people with neurological conditions. Rehabilitation services need to be made available to all patients with disabilities, and this includes people with disabilities attributable to neurological disorders. Multidisciplinary rehabilitation is considered to be beneficial in the early recovery of stroke and traumatic brain injury patients; although options for treatment of multiple sclerosis are relatively limited, sufferers can gain significant improvement in their quality of life with neurorehabilitation.

As community-based rehabilitation programs are a low-cost means to coordinate medical guidance and community

resources in the rehabilitation of disabled individuals, they need to be encouraged. The programs should be linked to and supported by institutional and hospital-based care, where appropriate, thus creating a comprehensive rehabilitation service. Developing national capacity and international collaboration in these newer avenues of disease management are mandatory. The international implications of dealing with neurological disorders in the low- and middle-income countries are reported to be similar to those for a variety of other health concerns. Building capacity in these countries to reduce the burden of neurological disorders would require international contributions in terms of expertise and resources. Examples of such collaboration are the global campaigns against epilepsy and headache disorders, which have been launched by the WHO, in partnership with leading international non-governmental organizations working in these areas. According to the report, the donor community urgently needs to dedicate more of its resources to help low- and middle-income countries improve their services for the prevention and management of neurological disorders. For the same task, the services of neuropsychologists may also be used.

Non-governmental organizations have an important role to play in this regard, and the government should be encouraged to give greater support to their initiatives. Collaborative efforts of health policymakers, health-care providers and people affected by neurological disorders and their advocacy groups might be the best vehicles for determining and bringing about the changes that individuals with neurological disorders need, as per this report by Patel *et al.*^[2]

The report by Patel *et al.*, also defines the priorities for research.^[2] The report gives a view that no research can be complete without assessing outcome related to a person's cognition and behavior. Hence, there is a need for using a trained personal in neuropsychology for issues dealing with neurological conditions. One of the research agendas for developing countries is operational research, which needs to be focused upon to gain a better understanding of the problem so that appropriate responses can be developed and evaluated. Specific areas for research and development could include conducting population-based epidemiological studies in developing countries where insufficient data limit evidence-based planning.^[2] It is also necessary to develop and evaluate simple models of care for management of different neurological disorders by existing community-based health-care providers.

After all, the adage "one size fits all" would not be the right approach for treatment. Many currently available medications have significant side-effects and are too expensive for most patients in developing countries. Multi-center epidemiological studies and trials of novel treatments should be facilitated through better funding, multidisciplinary approaches, and international collaboration. Endeavours to contribute to the knowledge base regarding public health aspects of neurological disorders should also become a priority.

Research and funds should be directed at identifying what gaps in knowledge matter the most to patients, care-providers, and health professionals. Stages, such as gathering of treatment

uncertainties, checking of existing research evidence, interim prioritization to identify the priorities of relevant individuals and stakeholder groups, and a final consensus meeting to reach an agreement should be the priorities in research.^[5] In the management and rehabilitation of neurological conditions, neuropsychology has an important role to play to develop such a model, wherein contributions in the identification, management, and long-term maintenance of quality of life can be ensured.

A comprehensive national strategy thus combining prevention, community-based health promotion and access to treatment can substantially decrease the burden associated with cardiovascular and neurological diseases. The disability consequent to neurological disorders can be decreased by rehabilitation programs and policies. For the implementation of all of these policies, neuropsychology has an important role to play.

How it can be Dealt with through Psychological Measures

To enumerate more on this aspect, let us start from the grass root level: Central Board of School Education (CBSE), India, has introduced the subject, psychology, in standard eleven in school, approximately since the year 2000, identifying its importance. This introduction gives opportunity to the students to choose this discipline as a core program or as a non-core program.

Background

Psychology training is a core model course as per the University Grants Commission (UGC) Report, 2016 (by the UGC Expert Committee on Model Courses in Psychology-2016),^[6] which starts at the undergraduate level with the Bachelors degree being given. Subsequently, a Masters Degree (including extensive hours of practical lab work and training), followed by an M. Phil Degree/Postgraduate Diploma (in guidance and counseling), and PhD degree (clinical/applied) are also available. The entire educational curriculum tenure involves a vigorous 7–10 year program, with extensive focus on the theories and systems of human psychology, besides exposure to other subsections. These years of training focus on the practical laboratory training throughout the program. Hence, nuances in the identification of behavioral/cognitive/psychological issues are the focus of this program, besides practical training in assessing human behavior.

Core psychology services are being used in the training and education of various core and allied health services, namely the military services, forensic science, nursing, speech therapy, occupational therapy, physical therapy, social work, etc.

Empirical Role of Neuropsychological Science in Healthcare and Policy Making

Neuropsychology is a study of brain and behavior and represents a new approach to studying the brain. According to Daryl Bruce, the term was first used in an early-twentieth-century textbook, which was the standard medical reference of the

times. It later (in 1949) appeared as a subtitle to the Canadian psychologist Donald O. Hebb's treatise on brain function, wherein Hebb defined it as a multidisciplinary focus of scientists who believed that an understanding of the human brain function was central to understanding human behavior.

Today, we define neuropsychology as the study of the relation between human brain function and behavior. Although neuropsychology draws information from many disciplines—for example, anatomy, biology, biophysics, ethology, pharmacology, physiology, physiological psychology, and philosophy—its central focus is the development of a science of human behavior based on the function of the human brain.^[7]

As such, it is distinct from neurology, which is the subject that provides a diagnosis of nervous system disease and injury by physicians who are specialists in nervous system diseases; it is distinct from neuroscience, which is the study of the molecular basis of nervous system function by scientists who mainly use non-human animals; and, from psychology, which is the study of behavior more generally. Neuropsychology is strongly influenced by two traditional foci of experimental and theoretical investigations into the brain function: the brain hypothesis, the idea that the brain is the source of behavior; and, the neuron hypothesis, the idea that the unit of brain structure and function is the neuron.^[7]

Role of Neuropsychology in the Continuum of Health Care

The “neuropsychology continuum of health care model for neurological conditions” can typically focus on service delivery with the special focus and concern on achieving a long-term care. The preventive aspects should include prevention through a careful identification of the problem by conducting epidemiological research and by identifying stages where the problems are occurring, thus helping in providing a holistic psychological care (counseling and behavioral modification); in the promotive aspect that includes supporting or actively encouraging, counselling, psycho-educating and developing a psycho-social model to deal with the idiosyncrasies of each neurological condition; the conservative approach using auto-suggestions/meditation/breathing exercises/stress management teams/visualization programs; the curative-medical aspect that becomes functional while the patient is undergoing treatment (either clinical or surgical) and ideally should include all neuropsychological standards of care as a part of the core aspect (e.g., treatment of dementia, stroke, epilepsy, head injury, movement related disorders, etc.); the neuropsychological rehabilitative aspect that should ideally be included because it has a strong role to play in bringing back normalcy in the patients', the care givers', the community's and the family's work and life; and the palliative aspect that should focus upon the quality of life issues, the methods to provide comfort during and after treatment, the methods to address the end-of-life decisions and the means to provide supportive counselling. Another important aspect besides the factors enumerated above is the assessment of neuropsychological disability based upon the mental health care model.

There are certain known uses of neuropsychological assessment, i.e., it helps in supporting a clinical diagnosis,

as seen in patients suffering from dementia. The patients' return to normalcy will depend on the confirmation by their neuropsychological assessment; such assessments are also required to monitor the course and outcome of treatment. Neuropsychological rehabilitation cannot be formulated without adequate and formal neuropsychological assessment. A neuropsychological assessment is also needed prior to fitness assessment. Neuropsychological changes often occur even before structural changes are seen; hence a great deal of importance is attached to it. A neuropsychological assessment also helps in formulating decisions for neurosurgical strategies. The cognitive profile in functional psychoses can be best assessed using neuropsychological tests. Neuropsychology helps in the management/intervention in patients with epilepsy, in counselling, in stress reduction, in the improvement of cognitive deficits, and in alleviating prejudice and ridicule that may be causing stress to the patient. It also helps in eliciting diagnostic signs and in suggesting procedures which can treat behavioral disorders. It also helps in developing neuropsychological tools for different neurological conditions.

Unavailability of appropriate, evidence-based mental health care is a major impediment to recovery for a vast majority of patients of various disorders leading to their increased global burden.^[1,8] As stated earlier, the report by Patel *et al.*, shows that in certain low- and middle-income countries with limited human resources, it may be difficult for governments to apply some of these recommendations on their own.^[2] On the contrary, there is no dearth of availability of trained manpower pertaining to psychology in India.^[8]

Future Directions

The care-givers' burden is an important aspect of health care, which is a public health challenge. In the Indian set up, most of the patients belonging to the economically weaker sections of the society are not able to come to a hospital set-up for care as it causes immense financial burden on these patients and their care givers. The concepts of health care delivery pertinent to other countries cannot be used in our health care system and these concepts, therefore, need modifications to suit the Indian settings.^[8]

The usefulness and outcome of digitization in neurological conditions is a subject of further research. At present, personal psychological services including an eye contact, a touch, and a personal contact are known to work well in personal therapies, which also helps in catharsis. These methods are well-established but do not take the help of digital data for their sustenance and propagation.^[9,10]

Another important aspect in health care delivery is the assessment of disability in the cases with impairment of neurological conditions. To obtain a proper assessment of one's neuropsychological disability is a fundamental right of the patient. Again, this assessment is not possible without proper training. There are techniques that are a part of the training, that elicit evidence related to malingering or the associated soft signs of behavioral oddity using objective scientific psychological tools/techniques/testing measures or other neuropsychological measures developed by qualified

and trained psychology personnel having knowledge of psychometric properties.

Neuropsychology is an integral aspect of continuum of health care in neurological conditions and a precursor to determine the course of cognitive and psychosocial well-being of the patients. It helps not just in diagnostics, but also to understand the curative or rehabilitative course for each patient, thereby, making it a specialized science for studying brain and behavior interactions, requiring years of specialized, supervised, and robust training.

Future Needs of Neuropsychology

These include the need to have an independent psychology council in India under the Ministry of Health; to be identified as a core discipline; to start a formal training program in psychology for students even in the rural set up; to lay down norms for clinical practice, certification, and licensure; and, to create a nationalized scientific journal where the novel ideas of neuropsychologists from different parts of India may be collated. Thus, neuropsychology should be identified as a core discipline of medicine and be made an integral part of the specialized services provided for different neurological conditions.

References

1. Mental Health Atlas 2017. Geneva, Switzerland: World Health Organization; 2018. Available from: https://www.who.int/mental_health/evidence/atlas/mental_health_atlas_2017/en/. [Last accessed on 2019 Apr 07].
2. Patel AP, Fisher JL, Nichols E, Abd-Allah F, Abdela J, Abdelalim A, *et al.* GBD 2016 Brain and other CNS cancer collaborators. Global, regional, and national burden of brain and other CNS cancer, 1990-2016: A systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol* 2019;18:376-93.
3. National Mental Health Survey of India 2016. Prevalence, pattern and outcomes. Ministry of Health and Family Welfare Government of India and National Institute of Mental Health and Neuro Sciences Bengaluru 2015-16. Available from: <http://www.nimhans.ac.in/sites/default/files/u197/NMHS%20Report%20%28Prevalence%20patterns%20and%20outcomes%29%201.pdf>. [Last accessed on 2019 Apr 07].
4. Nehra A, Singla S, Bajpai S, Malviya S, Padma V, Tripathi, M. Inverse relationship between stigma and quality of life: Is epilepsy a disabling neurological condition? *Epilepsy Behav* 2014;39:116-25.
5. Pollock A, St George B, Fenton M, Firkins L. Top 10 research priorities relating to life after stroke--consensus from stroke survivors, caregivers, and health professionals. *Int J Stroke* 2014;9:313-20.
6. UGC Expert Committee on Model Courses in Psychology 2016. Available from: https://www.ugc.ac.in/pdfnews/6918481_Psychology_Final-Report-24-Nov-16.pdf. [Last accessed on 2019 Apr 03].
7. Kolb B, Gibb R. Brain plasticity in the developing brain. Changing brain. Applying brain plasticity to advance and recover human ability. *Prog Brain Res* 2013. doi: 10.1016/B978-0-444-63327-9.00005-9.
8. National commission on macroeconomics and health. Burden of disease in India. New Delhi: Ministry of Health and Family Welfare; 2005. Available from: <https://www.who.int/macrohealth/action/Report%20of%20the%20National%20Commission.pdf>. [Last

accessed on 2019 Apr 07].

9. Khan MAR, Karapetrovic S. An ISO 10002:2004-based feedback-handling system for the emergency and inpatients care. *European Accounting and Management Review* 2014;1: Available from: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2532477. [Last accessed on 2019 Apr 07].
10. Healthcare Information and Management Systems Society (HIMSS). *Continuum of Care 2019*. Available from: <https://www.himssconference.org/session/enabling-data-interoperability-across-continuum-care>. [Last accessed on 2019 Apr 07].

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