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Neurodevelopmental Disorders: The Journey, the Dreams and their Realization

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ABSTRACT

Neuro Developmental Disorders (NDDs) are associated with significant morbidity. This involves early identification of the disorder, the correct management of the disorder and associated disabilities. In India, the paucity of trained personnel and lack of knowledge about these disorders has been instrumental in inadequate management and recognition of these NDDs. The Child Neurology Division, Department of Pediatrics at All India Institute of Medical Sciences has made few noteworthy and meaningful contributions in these aspects: devising a DM curriculum for pediatric neurology, developing indigenous tools for diagnosing these NDDs and performing relevant research. These endeavors would go a long way in serving the children with NDDs.

Keywords: Neurodevelopmental disorders, autism, cerebral palsy, attention deficit hyperactivity disorder.

Introduction

Neuro Developmental Disorders (NDDs) constitute a significant proportion of morbidity handled by pediatric health care services. These include cerebral palsy, autism, attention deficit hyperactivity disorder (ADHD) and intellectual disability, epilepsy, autoimmune disorders including autoimmune encephalitis and neuromuscular disorders (including muscular dystrophy). A recent study estimated prevalence of 'any NDD' in 2–9 year old children in India to be 12.0% (95% CI: 10.9–13.2%), and 21.8% of these had more than one NDD (unpublished data). Thus, neurological disorders represent a significant cause of morbidity among children.

In addition, there has been a paucity of physicians trained in pediatric neurology and also, inadequate research focusing on disorders specific to our nation, which has further compromised care of these children. Hence, to overcome these lacunas, the Child Neurology Division, All India Institute of Medical Sciences has taken enormous steps over the past several years. These have been highlighted in subsequent sections.

DM Pediatric Neurology

In order to overcome the scarcity of physicians trained in Pediatric Neurology in our country, Pediatric Neurology program was

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initiated in 2004, at All India Institute of Medical Sciences, under the Child Neurology Division as a part of Department of Pediatrics. Over the past 12 years, twenty-five residents have qualified as DM Pediatric Neurology. These residents are subjected to rigorous training under all aspects of clinical care as well as neuroradiology, neuropathology and other clinical and rehabilitative aspects of child neurology. The DM program at AIIMS has contributed to trained manpower not only in our country, but has also trained fellows from other SAARC nations, United States of America, France, and United Kingdom.

Research

There has been scarcity of research in pediatric neurological disorders from our country. Numerous national and international research projects have been undertaken at the Child Neurology Division, AIIMS, which contributed to the arena of epilepsy, autism, other NDD (like cerebral palsy), and autoimmune disorders. The division has been a pioneer in the country in developing dietary therapies for drug resistant epilepsy (1). The children whose epilepsy fails to be adequately controlled despite two antiepileptic drugs are defined to have drug resistant epilepsy (2). The

therapeutic options for these children include epilepsy surgery or dietary therapy. The division has demonstrated the efficacy of these dietary therapies in drug resistant epilepsies using ketogenic diet, modified Atkins diet, and low glycemic index dietary therapy (3-7). In addition, it has contributed to the development of 2.5:1 ketogenic diet and proved its efficacy in institutional research (3). The division also, has been the frontrunner in diagnosing, managing and optimizing the treatment for autoimmune encephalitis (8), leukodystrophies (9), and acquired demyelinating disorders of CNS (10). Also, the research focusing on domiciliary management of intranasal and buccal midazolam has helped to standardize the management protocols for seizures at home (11). These researches have been instrumental in developing various therapeutic guidelines, and have also paved the way for various national programs including Rashtriya Bal Swasthya Karyakram (RBSK) (12).

Public Health Initiatives

Educating the parents and children and the society at large is an important aspect about management of any disease. The Child Neurology Division has played a pivotal role in educating the society about NDDs (Fig. 1),



Fig. 1: Neurodevelopmental Disorders workshop was organized in December 2014. The picture shows the different events during the workshop.



Fig. 2 : The building of AIIMS, New Delhi being lit blue on 30 Apr 2015 to commemorate Autism Day.



Fig. 3 : Autism-related patient information booklets launched by Child Neurology Division, Department of Pediatrics, AIIMS

autism (Fig. 2 to 4), and epilepsy by organizing regular public health lectures, television and radio shows/ interviews, newspaper interviews and information materials. In addition, the division has published patient educational booklets on all the common pediatric neurological disorders. These are freely downloadable from http://www.aiims.edu/en/2014-12-24-07-16-28/neurology_educatio.html (Fig. 3) (13). Also the division has launched a helpline (with mobile number 9868399037 and email: autismhelp.pedsaiims@gmail.com, pedneuroaiims@yahoo.com) to facilitate help to parents of sick children.

Assisting Government Initiatives

The division was part of the INCLEN Collaborative study (with me being the Network Coordinator and Site PI), which estimated the prevalence of various neurological disorders across the country (14-17). This was instrumental in developing the convergence framework of RBSK (12). Also, the division has worked in close liaison with the Government of India for the certification of autism as a disability

and issue of certificate for this disorder. The division in close collaboration with Ministry of Social Justice & Empowerment, Government of India, organized the workshop for training the master trainers for diagnosis of autism across the country in August- September 2016. This was aimed at formulating a uniform instrument for diagnosis of autism, and training health care professionals to use that tool and spreading awareness about the certification process.

Innovation

The division has been significantly contributed to several decisive innovations. These include use of skin biopsy to diagnose muscular dystrophy (especially collagen 6 related disorders) (18-20). Also, the division has revolutionized telephonic follow-up for disorders like neurocysticercosis, Lennox-Gastaut Syndrome, and Duchenne Muscular Dystrophy.

The division has also been pivotal in developmental of tools for diagnosis of various NDDs. Initially these tools were developed in collaboration with INCLEN (14-17). The tools

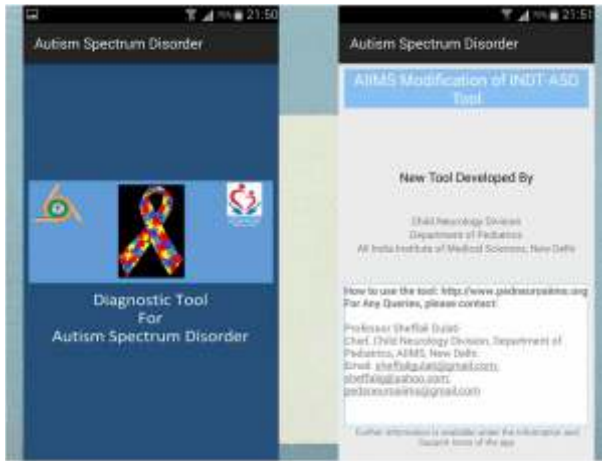


Fig. 4 : Snapshot of mobile app on Autism launched by Child Neurology Division, Department of Pediatrics, AIIMS on 28 Apr 2016



Fig. 5 : Snapshot of microsite, with autism related information, launched by Child Neurology Division, Department of Pediatrics, AIIMS

were later updated as per the latest guidelines. These AIIMS modified INDT tools for diagnosis of epilepsy, neuromuscular impairment, ADHD, and autism have been validated in institutional research. The tools for Autism Spectrum Disorder (<https://play.google.com/store/apps/details?id=app.autism.sanyakhurana.diagnostictoolforautismspectrumdisorder> and <https://itunes.apple.com/us/app/autism-spectrum-disorder-diagnostic/id1151524697?mt=8>) and epilepsy (<https://play.google.com/store/apps/details?id=com.weboutsourcing.childhoodepilepsy.childhoodepilepsydiagnostictool&hl=en> and <https://itunes.apple.com/in/app/childhood-epilepsy-diagnostic/id1078173463?mt=8>) have been converted into a mobile application (Fig. 4) which is downloadable free of cost, while applications for other tools are under development.

Microsite

The Child Neurology Division of Department of Pediatrics at AIIMS launched a mobile-based website (m.nddworkshop2014.org) on 03-December-2014. This microsite was renamed as m.pedneuroaiims.org, in Dec 2015. This microsite deals in NDD including ADHD, Autism Spectrum Disorders, Intellectual Disability, Epilepsy, Learning Disability, Neuromuscular Disorders, Cerebral Palsy, Speech and Language Disorders, Hearing, and Vision Impairment. The microsite has various educational materials including videos, for doctors for clinical applications and for parents for home-based intervention (Fig. 5).

Future

The various initiatives mentioned above have laid the foundation for a healthier child neurology environment, where we can expect evidence-based management of neurological disorders among children. To build on these foundations, it is planned to perform high quality research covering all domains of neurology in collaboration with international leaders.

Conclusion

Neurological disorders are an enormous burden in terms of associated disabilities. In association most of these disorders are chronic and require patience and expertise for management. Various measures including

training physicians, research, innovations and public health initiatives will immensely contribute in improving the management of these children individually and also educate the society about the rights of these disabled children.

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