

# Psychology and Psychiatry: Open access

## Extended Abstract

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### Epilepsy and Disability- Unknown Devil

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#### Epilepsy and Burden of Disease

Epilepsy is a central (neurological) nervous system disorder where brain activity becomes abnormal, causing seizures or periods of unusual behavior, sensations and sometimes loss of consciousness. Epilepsy is a global public health issue that affects people of every race, caste, religion, and gender worldwide. Close to 50 million people worldwide are estimated to be living with epilepsy. Seizures of epilepsy are broadly classified into Focal onset, Generalized onset & Unknown onset. Developed & developing countries often have people dealing with epilepsy, and the stigma of epilepsy still affects developing countries most. This is due to the financial burden facing the individual with epilepsy, and the economy faces this financial burden as well. The number of patients and qualified practitioners in these countries is a discrepancy that leads to a treatment gap of over 60%. Epilepsy, if diagnosed early, is treatable.

In developing countries, the life-time prevalence rate for epilepsy ranges from 1.5-14 per 1000 in Asia, 5.1-57.0 per 1000 in Latin America and 5.2-74.4 per 1000 in sub-Saharan Africa. Disability is known as any limitation or incapacity resulting from impairments to perform an activity in a manner or within the range considered normal for the human being. Neuro-disability defines a category of congenital or acquired long-term disorders due to brain & /or neuromuscular system dysfunction that creating functional limitations. Neuro disability is poorly characterized and global estimates are highly likely to underestimate its prevalence in developing countries, given the high frequency of risk factors, fast-growing population, and high mortality in children with severe neuro disability. This increase in prevalence can be attributed to an increase in the incidence of birth trauma, brain injuries and infections affecting the nervous system, leading primarily to hypoxic and scarring, leading to abnormal electrical activity.

Literature shows that 30-35 % of people with epilepsy have severe neurological co-morbidities and 30% have moderate neurological co-morbidities on average. Cerebral palsy, autism, attention deficit hyperkinetic disorders, cerebrovascular accident, traumatic brain injury & infectious encephalitis are the commonest conditions associated with epilepsy. Epilepsy is misdiagnosed in developing countries because of myths and treatments with quacks and the patient receives actual neurological attention at the later stage of the disease. People with epilepsy have physical, cognitive, speech and communicative disorders which may go undiagnosed in the earlier stages or if not assessed by a trained, expert multi disciplinary team. The physical disabilities include hemi paresis, ataxia, dystonia, Global developmental delays, spasticity or tremors. Cognitive disabilities include intellectual disabilities, autism, Attention deficit hyper or non hyper disorders. Speech and communicative disorders such as slurred speech, wernickes aphasia, brocas aphasia, global aphasia, apraxia are also seen.

Psychological problems such as depression, anxiety, disorientation, panic etc are also seen in people living with epilepsy. Few studies have 30-40% children with epilepsy have intellectual disabilities; 7-20% children have autism spectrum disorders. Literature has shown the more serious the neurological co-morbidity, higher the incidence of epilepsy and greater the chances of secondary disability. Epilepsy in developed countries has various myths, taboos and misunderstandings associated with epilepsy which leads to stigmatization of epilepsy, thus people with epilepsy have social and psychological co morbidities such as social withdrawal, discrimination & depression. Each Condition, disability needs to be addressed separately along with Epilepsy. Hence multi disciplinary comprehensive epilepsy is needed to provide a holistic approach of care. The psychological or social co morbidities secondary to epilepsy can pose a greater challenge to treat than the primary condition i.e Epilepsy itself.

#### Epilepsy Foundation

Epilepsy Foundation is an NGO created in 2009 that provides comprehensive epilepsy care in Maharashtra state. The NGO has been in public-private collaboration with Maharashtra's National Health Mission Government since 2011; this relationship has helped uncover this mysterious demon of epileptic neuro-disability. Free epilepsy diagnosis & treatment camps are conducted once a month in all Maharashtra districts. A team of neurologists, neurosurgeons, pediatricians, physiotherapists, occupational therapists, speech and language pathologists, clinical psychologists, cognitive therapists, social workers are involved in this training camp for epilepsy identification and care. We saw a total of 31,655 patients with epilepsy in 88 camps from 2011 to 2020. A total of 2149 patients had physiotherapist-treated co-morbidities, 3324 patients had cognitive and behavioral co-morbidities treated by occupational therapists and cognitive therapists, 3131 patients had speech and swallowing co-morbidities treated by speech and language pathologists and 2363 patients had psychological co-morbidities treated. The main reason for this may be the lack of awareness of epilepsy and mental illness, poverty, high illiteracy rates, fear, stress, addiction, stigma and poor medical facilities Education and early identification and timely intervention helps in reducing the burden of neuro disability. Epilepsy Foundation aims at reducing this burden by providing education and awareness about epilepsy by the medium of street plays, banners, social gatherings and awareness lectures. A few of the disabilities are permanent, in India Epilepsy is covered in the disability act of 2016. The Patient is assessed periodically and is provided by a disability certificate which entitles them to various benefits for living the life with dignity in the society. We recommend that when a child is suspected to have epilepsy, they should be referred to an epilepsy professional without delay, children with epilepsy need a comprehensive multidisciplinary assessment, including input from pediatricians, child neurologists, psychologists,

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speech and language pathologist, physiotherapists, occupational therapist and special educators, parents need to be made aware and give accurate information about the condition, assessment should include all domains including sleep and integration of family in rehabilitation is of utmost importance. More research is needed to identify how to support caregivers, especially mothers, who may be experiencing

significant mental health problems. Research is also needed on how to identify neuro disability at early stage and how to intervene early along with this how is neuro disability affecting siblings of these patients also needs to be studied and addressed.

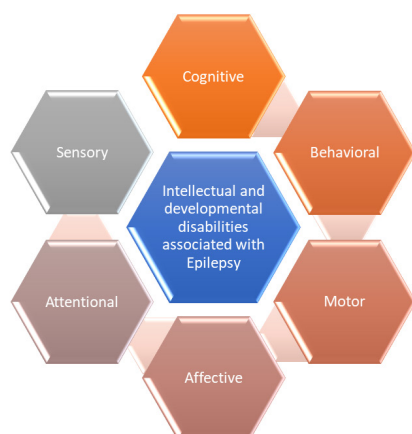


Fig. 1. Intellectual and Development Disabilities

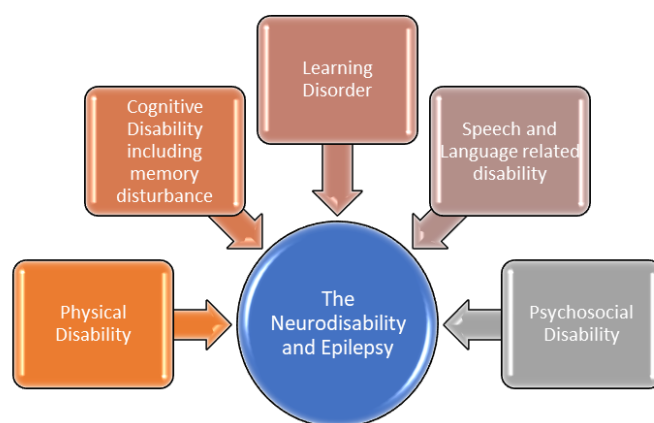


Fig. 2. Neurodisability in Epilepsy