

Epilepsy, Behavioral Problems, and Intellectual Disability among Children in India: Conundrums and Challenges

A research paper, “Behavioral problems and IQ changes in pediatric epilepsy: A case-control study”^[1] included in this volume attracts attention to the association between epilepsy and behavioral problems, and its impact on intelligent quotient (IQ) among young children in India. Does epilepsy have an association with IQ? Does epilepsy have an association with behavioral problems? Do behavioral problems, epilepsy, and low IQ interact with each other? These are some of the many questions that need to be closely examined.

Worldwide, 70 million people suffer from epilepsy.^[2] About 33 million children with epilepsy suffer from various types of behavioral problems, and from these 90% of the children reside in developing countries.^[3] Over 12 million people are estimated to have some form of epilepsy in India.^[2] Disability-adjusted life years lost due to epilepsy from a study in India in 2007–2008 placed it at 846.96/100,000.^[4] In a study conducted among poor rural population in India, over 23.7% of the children with intellectual disability were found to have some type of epilepsy, and 80.7% behavioral problems coexisted.^[5] In developing countries, very few studies have been conducted on the relationship between epilepsy, IQ, and behavioral problems.^[6,7]

While research continues to investigate prevalence related interconnections between pediatric epilepsy with the typology of behavioral problems and its negative impact on IQ, we should be cognizant about the larger research lacunae that confront us at the national level in India on this topic. For example, we do not have estimates of the prevalence of epilepsy, behavioral problems, and intellectual disability together from a nationally representative sample. Further, there is lack of prevalence data of epilepsy, behavioral problems, and IQ levels respective to factors such as severity, age, gender, place of living, etc., An association between IQ, behavioral problems, and epilepsy has been suggested in some studies from developed countries.^[8-10] A complex interconnection of neurological, psychological, educational, and social pathology behind these disorders presents a serious challenge for developing effectual interventions. A strong disabling stigma attached separately with epilepsy, behavioral problems, and lower levels of IQ further complicate interventional efforts at all levels.

Among people with intellectual disability of genetic etiology, the stereotype, self-injurious, aggressive,

or destructive behaviors may be a manifestation of unrecognized seizure activity.^[11] Most behavioral problems among children with intellectual disability can be treated with behavior modification approaches, and in a few cases, in combination with pharmacological therapies. By treating behavioral problems among this population, can we reduce the risk of epilepsy and a lowering effect on IQ; such questions warrant further explorative research.

Full Scale Intelligence Quotient scale has shown to make significantly lower estimates of intellectual ability in people with epilepsy.^[12] Hence, a word of caution is mandatory, when introducing IQ as a factor into intellectual disability and behavioral functioning. Changing behaviors assume some level of intelligence, to receive information, process it, and make decisions that result in adaptive behavior. Research studies show that IQ tests seem to be biased in both the tester and the tested.^[13] Thus, the tools themselves pose a challenge. Therefore, looking at IQ as a determinant among the intellectually disabled may be problematic.

While we do not have a clear understanding of the prevalence of children suffering from epilepsy, behavioral problems, and low IQ combined, but it is generally accepted that the prevalence is high enough to label it as a significant public health concern for the nation. Stigma and resultant psychological issues are hindrances for children with epilepsy^[14,15] intellectual disability, and behavioral problems^[16,17] to actively participate in many activities in their lives and adversely affect their quality of life.^[9] The social and physical isolation and discrimination due to stigma not only limit their chances of learning new skills and mastering learned skills but also limit the opportunity of recovering and improving in their lives. Issues related with stigma and isolation are rarely addressed in current medical and rehabilitation practices in India.^[14] More research is needed to develop public health models and strategies to combat the social stigma and its negative impact on the condition.

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