

Improving Diagnosis of Epilepsy in India – How Difficult is it?

PEDIATRIC NEUROLOGIST'S PERSPECTIVE

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Misdiagnosis of seizures and epilepsy is rampant. There are several paroxysmal non-epileptic events (NEE) – like syncope, non-epileptic attacks (earlier called psychogenic or pseudo-seizures), paroxysmal movement disorders, migraine equivalents, parasomnias, non-epileptic staring – which can mimic seizures and confuse even the experienced observer [1,2]. In a prospective study of first 'seizures', 39% had NEE [2]; interestingly even when the referring physician was certain of the diagnosis of seizures, more than one-third had NEE. In retrospective studies of first events, syncopal attacks outnumber seizures and the diagnosis remains unclear even after investigations in about one-sixths of all referrals [3].

Why is the diagnosis of epilepsy so difficult? Even in the 21st century diagnosis of epilepsy is based almost exclusively on the description of the episode given by an eyewitness or sometimes by the child him/herself if he/she is old enough. The art of history taking is unfortunately dying in this era of technology. Often the actual witness may not be available in the clinic or may not be a good observer, especially during the stressful time of an event. Who evaluates the patient first also seems to matter. In a study [4], referrals from neurologists were more likely to be accurate in comparison to referrals from family physicians. In another study, where videos of true seizures and NEE were shown to doctors with different expertise, neurologists were more accurate than non-specialists and junior doctors in correctly identifying the event as a seizure or NEE [5]. This is not surprising as practical epilepsy training hardly figures in the medical curriculum at both graduate and post-graduate levels. As seizure/epilepsy is mainly handled by general practitioners, alternative medicine practitioners and pediatricians/internists in India (India has only about 1500 neurologists), misdiagnosis abounds. Even among pediatric neurologists, agreement on whether an event is a seizure is only modest [6].

The other factor contributing to the misdiagnosis of epilepsy in India is the overdependence on the EEG as a diagnostic tool. It is generally accepted that only about 40-50% of children with definite epilepsy have epileptiform abnormalities on a single inter-ictal EEG recording, and up to 3.5% of children who do not have epileptic seizures have epileptiform abnormalities on inter-ictal EEG [7]. Also the quality of EEG recordings is often questionable in a country with only a handful of training courses for EEG technologists. Interpretation which needs years of apprenticeship and practice are done by persons of varied training like neurologists, psychiatrists and sometimes even by EEG technologists who often miss the subtleties of EEG reporting, more so in children. Hence, most non-specialists rely on dubious EEG reports to make life-altering treatment decisions.

The study by Konanki, *et al.* [8] in this issue of *Indian Pediatrics* has tried to validate a diagnostic tool – the INCLN Diagnostic Tool for Epilepsy (INDT-EPI) – for primary care physicians to help them make an accurate clinical diagnosis of epilepsy in the community. The authors designed a questionnaire using common seizure semiology characteristics and other questions relating to the circumstances around the episode. This was then used by a graduate physician to arrive at a diagnosis of epilepsy or no epilepsy and compared with the diagnosis reached by a group of expert child neurologists who had access to all investigations. The results showed a surprisingly high sensitivity of 86% and an even higher specificity of 95% with no patients in the indeterminate category. This excellent concordance might have been helped by certain factors. As the setting was tertiary pediatric neurology clinics, most patients would already have an established diagnosis of epilepsy rather than a first event where most of the diagnostic confusion arises. Also, the graduate physicians were trained for several hours before they applied the diagnostic tool, a scenario unlikely to happen in a community setting. Though the authors need to be

lauded for designing a well thought out tool, certain deficiencies stand out. For example, many of the criteria for a convulsive seizure also apply to convulsive syncope where similar symptoms are seen in upto 90% of patients [3]. The diagnostic tool would have been more discriminatory between seizures and NEE had signs like open eyes in seizures and closed eyes in NEE, been included [9].

The diagnosis of epilepsy is not a trivial one to make. Besides the ensuing family stress and anxiety, restrictions in activities and overprotection by parents lead to unacceptable social consequences. Chronic exposure to unnecessary anti-epileptic drugs (AEDs) with their wide range of adverse effects especially on behavior and sleep could be often detrimental to school performance. This is worsened by the ease with which AEDs are prescribed because of the prevalent belief that seizures are dangerous and brain damaging and that lack of treatment would somehow perpetuate epilepsy. This view is no longer tenable as it has been demonstrated that long-term outcome is similar whether treatment is immediate or deferred [10].

In summary, misdiagnosis of epilepsy is common. To improve diagnostic accuracy of epilepsy, one would need to improve training of physicians not only during service but also by increasing exposure to subject of epilepsy in pre-service curriculum. Diagnostic tools like the INDT-EPI would further help this cause.

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Diagnostic Questionnaire and its Validation

BIostatistician's PERSPECTIVE

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Epilepsy is a complex disease to diagnose in some cases because seizures occur in a variety of conditions. Fever, central nervous system (CNS) infections, head trauma or systemic illnesses can cause seizures, and seizures also mimic breath holding spells and syncopal attacks. Differentiation of symptomatic from epileptic seizures, and of seizures from disturbance due to other transient neurological conditions may be difficult [1]. Reports

suggest that misdiagnosis and missed diagnosis among pediatricians can occur in nearly one-third of cases [1,2]. In addition to expertise, neuroimaging and electroencephalography are often needed to confirm or exclude the disease. Would it not be nice if the diagnosis can be made by asking a few searching questions? No need of any examination, no need of any investigation – just binary yes/no type answer to a series of questions. If