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Although more than once we were told, “Good news—it’s not epilepsy,” we didn’t see it that way. It meant that because my daughter’s case didn’t meet strict diagnostic criteria, we’d be sent on our way without any diagnosis of epilepsy or plans for follow-up. Her seizures are evoked by environmental stimuli. Did that mean they qualify as unprovoked events? Although reflex epilepsy was already known to be a type of epilepsy, the previous diagnostic criteria allowed uncertainty among clinicians as to whether reflex epilepsy could be diagnosed in someone with no other seizure types. Clinicians were more concerned about the risks of overdiagnosis than about the ramifications for patients of underdiagnosis.

It is therefore a most welcome step by the International League Against Epilepsy (ILAE) to broaden and refine the operational definition of epilepsy to make it more relevant and responsive to clinical care. The manner in which the authors present their reasoning demonstrates both flexible thinking and respect for the lives that may be affected by these changes. The new clinical definition addresses the need to consider more of the patient’s circumstances, and it encourages a more nuanced analysis of the patient’s history and seizure syndrome. By adapting the legalistic diagnostic criteria used in research, the authors of this practical definition have produced common sense–infused guidelines for clinicians. In addition, they have anticipated economic, psychological, and social challenges that the redefinition may introduce for patients.

The task force has carefully considered the perspective of patients and families while also respecting and encouraging the independent judgment of clinicians. Although epilepsy should be a clinical diagnosis, in the absence of a practical clinical definition, some clinicians may not have felt free to interpret and temper the classic diagnostic criteria to make allowances for the particulars of a given case. When daily realities do not precisely fit the conceptual criteria, conceptual definitions can feel arbitrary, not terribly useful, and even alienating, because patients feel their own experiences and perspectives devalued.

Of the specific changes in the new definition, the most significant for my family is the clarification that reflex epilepsy “counts” as a bona fide expression of the disease. The ILAE task force quite correctly describes patients with only this type of seizure as disenfranchised by prior definitions. In our experience, approaching specialists about my daughter’s repeated reflex seizures typically led to the presenting complaint being set aside until unprovoked seizures could be confirmed (which in her case was not so straightforward).

The new clinical definition should help remove a longstanding bias whereby reflex seizures are considered a medical curiosity¹ and a freakish rarity that deserve little serious attention. Despite a 2005 consensus report² identifying photic seizures as a public health risk, the marginalizing of photosensitive epilepsy among epilepsy specialists and very low awareness in other clinical fields persist, thereby delaying diagnosis. Moreover, ubiquitous audiovisual technologies in daily life are ever more liable to activate symptoms in those with latent photosensitivity; according to most researchers studying photic seizures, that population segment is likely larger than previous estimates. The ILAE’s operational clinical definition should now bring wider attention to this seizure type, and encourage neurologists and their clinical colleagues in all areas of medicine to be mindful regarding photic seizures, even in individuals with no seizure history.

DISCLOSURE

The author has no conflicts of interest to disclose. I confirm that I have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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