



# Epilepsy or a Seizure Disorder? Parental Knowledge and Misconceptions About Terminology

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**Objective** To assess primary caregiver understanding of the term epilepsy.

**Study design** A cross-sectional telephone survey evaluated understanding of the term epilepsy among primary caregivers of children diagnosed with epilepsy at an urban referral center during a 24-month period. Three measures of primary caregiver understanding were used: (1) identifying if their child had a seizure disorder, epilepsy, or both; (2) providing an open-ended definition of epilepsy; and (3) selecting from a multiple-choice definition of epilepsy. Caregivers with 3 correct answers were assigned the greatest knowledge score. Associations with possible predictor variables were analyzed.

**Results** Caregivers for 75 of 116 eligible patients were contacted successfully. Of those, 55 of 75 met eligibility criteria; 45 of the eligible caregivers completed the survey. Twenty-six of 45 caregivers (58%) identified that their child had both a seizure disorder and epilepsy, 5 of 45 (11%) provided a correct open-ended definition of epilepsy, and 16 of 45 (36%) selected the correct multiple-choice definition. Fifteen caregivers (33%) had no correct answers. Seventeen (38%) answered 1, 9 (20%) answered 2, and 4 (9%) answered all 3 measures correctly. Caregivers with greater self-rated understanding had greater epilepsy knowledge scores ( $P = .008$ ). Having a child neurologist as the first person to discuss the diagnosis with the caregiver also predicted a greater epilepsy knowledge score ( $P = .04$ ).

**Conclusions** Most primary caregivers of children with epilepsy have a poor understanding of the term epilepsy. Changes are needed in how we educate caregivers about the meaning of this term. (*J Pediatr* 2017;191:197-203).

See editorial, p 8

Epilepsy is one of the most common childhood neurologic disorders, with a prevalence of 0.5%-1% in children 16 years and younger.<sup>1</sup> Each year in the US, 20 000-45 000 children are newly diagnosed with epilepsy.<sup>1,2</sup> The definition of epilepsy is evolving. Most healthcare providers continue to use the definition of 2 or more unprovoked seizures occurring at least 24 hours apart.<sup>3,4</sup> The International League Against Epilepsy (ILAE) revised the definition in 2014 to include individuals who have had only one unprovoked seizure but who have additional features putting them at a similar risk of recurrence as those who have had 2 unprovoked seizures.<sup>4</sup>

Medical terms are understood poorly by the lay public.<sup>5-10</sup> The term epilepsy, in particular, has long been associated with misconceptions and stigma,<sup>11-16</sup> even among those affected by the disorder.<sup>17-22</sup> Various terms, such as fits, spells, turns, or attacks, may be used by the public. At present, opinions differ about how best to explain the diagnosis of epilepsy to patients and patient caregivers.<sup>23</sup> Healthcare providers frequently use the term seizures or seizure disorder instead of the term epilepsy when referring to a child with recurrent seizures. Such alternate terms are perhaps gentler, but their use limits caregiver exposure to the term epilepsy.

We hypothesized that many parents of children with epilepsy have a poor understanding of the term epilepsy. Our study was designed to evaluate how well primary caregivers of children with epilepsy understand that term. Our aim was to optimize communication between healthcare providers and primary caregivers to improve caregiver understanding of the term epilepsy.

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ILAE International League Against Epilepsy  
SILS Single-Item Literacy Screener

**Methods**

This was a cross-sectional study to assess understanding of the term epilepsy among primary caregivers of children with epilepsy. Approval was granted by the institutional review board of Boston University School of Medicine. Data were collected between August 2014 and June 2015.

Eligible patients were children 15 years and younger who had been evaluated by a physician at our institution and who had received a new diagnosis of epilepsy within the preceding 24 months. Eligible caregivers were the patient’s primary caregiver (person “who cares for the child most of the time”). Caregivers were excluded if they were: (1) non-English speaking, (2) younger than 18 years old, or (3) not present at relevant healthcare visits. Only one eligible caregiver per eligible patient participated.

The hospital’s electronic medical record was queried for patients diagnosed with epilepsy and recurrent seizures (*The International Classification of Diseases, Ninth Revision* code 345.X) or other convulsions (*The International Classification of Diseases, Ninth Revision* code 780.39) within the specified time period. Eligibility was confirmed by chart review. Recruitment letters were mailed to caregivers of eligible patients, followed by up to 3 attempts to reach the caregivers by telephone. These caregivers were screened for eligibility and

ability to complete a telephone survey in English. Verbal consent was obtained. Participants were not provided compensation.

Participating primary caregivers completed a 28-question, interviewer-administered telephone survey (Figure 1; available at [www.jpeds.com](http://www.jpeds.com)). Questions were developed by the authors and were screened for simplicity, clarity, and content by a focus group of parents of children with epilepsy and by a group of general pediatricians. Surveys were conducted by trained interviewers by using a script written at a fifth-grade level. Usual completion time was 20 minutes. Responses were deidentified.

Participants were asked what term they use for their children’s seizures. This term was used in question stems to prevent bias. Data regarding the type of healthcare provider who first explained the child’s diagnosis, the terminology used by the child’s healthcare providers, and the caregiver’s sociodemographics were collected. Caregivers self-rated their understanding of the term epilepsy using a 5-point scale (poor to excellent). General health literacy was assessed with the Single-Item Literacy Screener (SILS), which consists of one question: “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?” Responses range from “1” (never) to “5” (always), with scores of “2” or greater capturing patients who may have low health literacy.<sup>24</sup> Level of understanding of the term epilepsy was assessed by 3 measures (Figure 2).

Measure 1	
Survey Question	Answer Choices
1a. Does your child have a seizure disorder?*	Yes, No, or Not sure
1b. Does your child have epilepsy?*	Yes, No, or Not sure
<i>Correct response:</i> Caregiver answered ‘yes’ to both parts (1a.) and (1b.), indicating he/she understood both terms applied to the child’s diagnosis.	
Measure 2	
Survey Question	Answer Choice
2. What is the definition of epilepsy?	Open-ended response
<i>Correct response:</i> Credit was given to answers that described the occurrence of two or more seizures (eg, multiple, recurrent, etc), with no incorrect information included.	
Measure 3	
Survey Question	Answer Choices
3. What is the definition of epilepsy?	A. A seizure caused by fever B. Two or more unprovoked seizures C. A seizure disorder that requires medication D. A seizure that causes loss of consciousness and shaking of the arms and legs
<i>Correct response:</i> B. Two or more unprovoked seizures <sup>†‡</sup>	
*Parents were instructed that both answers could be correct. †The accepted definition of epilepsy during the time period when eligible patients received their diagnosis. ‡If clarification was needed, unprovoked was described as “no apparent trigger or cause.”	

**Figure 2.** Measures to assess primary caregiver’s knowledge of epilepsy.

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