



Children with new onset seizures: A prospective study of parent variables, child behavior problems, and seizure occurrence



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ABSTRACT

Objective: Parent variables (stigma, mood, unmet needs for information and support, and worry) are associated with behavioral difficulties in children with seizures; however, it is not known how this relationship is influenced by additional seizures. This study followed children (ages 4–14 years) and their parents over a 24-month period (with data collected at baseline and 6, 12, and 24 months) and investigated the effect of an additional seizure on the relationship between parenting variables and child behavior difficulties.

Methods: The sample was parents of 196 children (104 girls and 92 boys) with a first seizure within the past 6 weeks. Child mean age at baseline was 8 years, 3 months (SD 3 years). Data were analyzed using *t*-tests, chi-square tests, and repeated measures analyses of covariance.

Results: Relationships between parent variables, additional seizures, and child behavior problems were consistent across time. Several associations between parent variables and child behavior problems were stronger in the additional seizure group than in the no additional seizure group.

Conclusions: Findings suggest that interventions that assist families to respond constructively to the reactions of others regarding their child's seizure condition and to address their needs for information and support could help families of children with continuing seizures to have an improved quality of life.

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1. Introduction

Children with epilepsy have long been known to have higher rates of behavior problems than healthy children or children with other chronic health conditions [1–3]. Early studies showed that children with epilepsy have more dependency and peer relationship problems than children with either diabetes or cardiac conditions [4] and more quality-of-life problems than children with asthma [5]. In childhood epilepsy, behavior problems can be more obvious and pervasive than the manifestations of actual seizures, add to stigma, and increase the likelihood of child and/or family isolation. These behavioral problems experienced by children with epilepsy disorders often present unique challenges to their parents.

Studies investigating relationships between parenting variables and child behavior problems in children with epilepsy show that parent perceptions are associated with child functioning [6,7]. In one of the earliest studies, Mitchell et al. [8] found that negative parental attitudes were associated with child behavior problems. Cross-sectional studies exploring parental perceptions of stigma in parents of children with epilepsy also

showed relationships with behavior problems. In studies of children with chronic epilepsy, Carlton-Ford et al. [9] found that parental perceptions of stigma were related to child behavior problems, and Dunn et al. [10] found that greater parental perception of epilepsy-related stigma was associated with relatively more child depression symptoms.

There are few prospective, longitudinal studies investigating parental perceptions and child behavior problems. Ostrom et al. [2,11] investigated parent and child adaptations, including child behavior problems, in a sample of children with newly diagnosed epilepsy and a comparison group of children without a health condition. A major finding was that disruption of usual parenting practices from the onset of seizures in the child and family trouble (such as divorce) were associated with more behavior problems in the children. Children who had behavior problems before the onset of seizures were at the highest risk for behavior problems during the first year after epilepsy onset. A limitation of this study was the measurement of the family variables, which were categorized in a yes/no fashion (e.g., presence or absence of family trouble).

Studies investigating relationships between parent variables and child behavior problems over time have shown an association between parenting variables and child behavior problems [2,8]. According to Akay et al. [12], high levels of anxiety and depression found in mothers

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of children with epilepsy might adversely influence their attitudes toward their children. In addition, a 24-month investigation of 337 children with new onset epilepsy showed that maternal depressive syndrome had a negative effect on child's quality of life [13]. Parental need for emotional support was found to contribute to later internalizing behavior problems in children with new onset seizures [14]. However, no reported prospective study has explored the association of parent variables and child behavior problems in a sample of children with a first seizure and also explored the effect of an additional seizure on that relationship.

The current prospective study builds on earlier work by measuring the effect of at least one additional seizure on the association of parent variables and child behavior problems in a sample of children with new onset seizures over a 24-month period. The purpose of this study was to describe the associations over time between parent perceptions (stigma, mood, worry, need for information and support) and child behavior problems (total, internalizing, and externalizing) and determine the influence of an additional seizure on the relationship.

We compared parents whose child experienced additional seizures with those parents whose children had no additional seizures after the initial unprovoked seizure because we have found that children with recurrent seizures had more behavior problems in our past research [15]. Specifically, we investigated potential effects of seizure group (additional seizure vs. no additional seizure) and time since seizure onset (baseline and 6, 12, and 24 months) by exploring interaction effects of group and/or time with parent variables. In addition, we controlled for research site and race as well as other demographic variables that have been related to child behavior problems in past research such as child age, child gender, and socioeconomic status [16–18].

2. Method

2.1. Sample

This study was part of a larger study of 224 children with new onset seizures and their primary caregivers [14,15]. The larger study was approved by the institutional review boards at Indiana University and the University of Tennessee, Memphis. Of the 224 children, additional seizure information was available for 196 (88%); thus, the subjects in this study were 196 children (104 girls and 92 boys) with new onset seizures and their primary caregiver. The 28 families not providing seizure information did not significantly differ from the 196 on child age, child sex, type of seizure, medication use at baseline, or education of caregiver. They did significantly differ on race ($p < 0.0001$). African-Americans were less likely to remain in the study than Caucasians (32.7% vs. 7.1%). At enrollment, the children were between 4 and 14 years of age ($M = 8$ years, 3 months; $SD = 3$ years) and within 6 weeks of their first recognized seizure ($M = 35$ days). Subjects were recruited through electroencephalogram (EEG) laboratories, emergency departments, and pediatric neurologists in two large children's hospitals (Indianapolis and Memphis) and from practices of private pediatric neurologists in Indianapolis.

Exclusion criteria for the larger study were: a comorbid chronic physical disorder, intellectual disability (based on either clinic records or parent report), a sibling with a chronic condition, or seizures precipitated by an acute event (e.g., intracranial infection, metabolic derangement, and recent head injury). Children who had had two or more febrile seizures or who were placed on daily antiepileptic drug (AED) after a febrile seizure were also excluded. The rationale for this latter exclusion was that the AED might influence behavioral, emotional, or cognitive response to new onset seizures. Parental informed consent and child assent were obtained prior to data collection. The study was approved by the institutional review boards overseeing investigations at the facilities described above.

Data were collected four times: baseline and 6, 12, and 24 months. Baseline data, which were collected within 6 weeks of the first recognized

seizure, were retrospective to provide information about the 6 months prior to the seizure. Data were collected using computer-assisted, structured telephone interviews with the primary caregiver, who was the mother with very few exceptions. During the 2-year period of the study, 110 of the children had at least one additional seizure. Demographics for the children and information on AEDs are presented by the two seizure groups (no additional seizure and at least one additional seizure) in Table 1.

2.2. Instrumentation

Variables measured were: child behavior problems (total, internalizing, and externalizing) and parent variables (stigma, positive mood, unmet needs for support and information, and worry). Child behavior problems were measured at baseline and 6, 12, and 24 months. Parent variables were measured at 6, 12, and 24 months, but not at baseline because some of the items on these scales pertained to seizures and the baseline data collection reflected the period before the first seizure.

2.2.1. Child behavior problems

The Child Behavior Checklist (CBCL) [19] was completed by the parent to measure the child's behavior problems during the past 6 months. The CBCL has 118 items describing behaviors that are rated using 3-point scales of 0 (*not true*), 1 (*somewhat or sometimes true*), and 2 (*very true or often true*). Parents were specifically instructed to exclude any behaviors that might have been actual seizure activity or any behaviors that occurred immediately prior to, or after, a seizure episode. The reliability and validity of the CBCL as well as norms based on age and gender have been established in past research [19]. The three scores used in this study were the *T*-scores for total behavior problems, internalizing problems, and externalizing problems. These *T*-scores are normed for age and gender. The internalizing problems score includes syndrome scale scores of anxious/depressed, withdrawn, and somatic complaints, and the externalizing problems score includes the syndrome scale scores of delinquent behavior and aggression. Social, thought, and attention problems scores are included in the total problems score in addition to internalizing and externalizing problems scores.

2.2.2. Parent variables

Stigma was measured using a 5-item scale developed for the study [20]. Parents rated their perceptions of stigma related to their child's seizure condition on 7-point scales of 1 (*strongly disagree*) to 7 (*strongly*

Table 1
Demographic and clinical characteristics at baseline.

Baseline characteristics	No additional seizure (n = 86)		Additional seizure (n = 110)		p-Value
	Mean	SD	Mean	SD	
Child age (years)	8.13	3.09	8.36	2.90	0.6068
Caregiver education (years)	13.93	2.50	13.84	2.66	0.8017
Gender—% female	53.5%		52.7%		0.9156
Race					
% Caucasian	86.0%		75.5%		0.1074
% African-American	10.5%		21.8%		
% Other	3.5%		2.7%		
Main seizure type					
% Generalized: tonic-clonic	44.2%		34.5%		0.2318
% Generalized: absence	4.7%		13.6%		
% Simple partial	9.3%		6.4%		
% Complex partial	22.1%		27.3%		
% Generalized: atonic, akinetic, myoclonic	0.0%		0.9%		
% Partial seizures evolving to secondarily generalized	18.6%		14.5%		
% Unclassified	1.2%		2.7%		
Medication usage—% taking AEDs	59.3%		50.9%		0.2415

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