

Research Paper

Functional difficulties and school limitations of children with epilepsy: Findings from the 2009–2010 National Survey of Children with Special Health Care Needs

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Abstract

Background: Epilepsy is a common serious neurologic disorder in children. However, most studies of children's functional difficulties and school limitations have used samples from tertiary care or other clinical settings.

Objective: To compare functional difficulties and school limitations of a national sample of US children with special health care needs (CSHCN) with and without epilepsy.

Methods: Data from the 2009–2010 National Survey of CSHCN for 31,897 children aged 6–17 years with and without epilepsy were analyzed for CSHCN in two groups: 1) CSHCN with selected comorbid conditions (intellectual disability, cerebral palsy, autism, or traumatic brain injury) and 2) CSHCN without these conditions. Functional difficulties and school limitations, adjusted for the effect of socio-demographic characteristics, were examined by epilepsy and comorbid conditions.

Results: Three percent of CSHCN had epilepsy. Among CSHCN with epilepsy 53% had comorbid conditions. Overall CSHCN with epilepsy, both with and without comorbid conditions, had more functional difficulties than CSHCN without epilepsy. For example, after adjustment for sociodemographic characteristics a higher percentage of children with epilepsy, compared to children without epilepsy, had difficulty with communication (with conditions: 53% vs. 37%, without conditions: 13% vs. 5%). Results for school limitations were similar. After adjustment, a higher percentage of children with epilepsy, compared to children without epilepsy, missed 11 + school days in the past year (with conditions: 36% vs. 18%, without conditions: 21% vs. 15%).

Conclusion: CSHCN with epilepsy, compared to CSHCN without epilepsy, were more likely to have functional difficulties and limitations in school attendance regardless of comorbid conditions. Published by Elsevier Inc.

Keywords: Epilepsy; Disability; Comorbid conditions

Epilepsy is among the most common serious neurologic disorders in children and comprises a broad spectrum of disease. The prevalence of current epilepsy or seizure disorder among US children has recently been estimated to

be 6.3/1000.¹ Many studies, based primarily on children recruited from tertiary care or other clinical settings, have described higher rates of functional difficulties of children with epilepsy compared to children without epilepsy.^{2–6} Several population-based studies of the prevalence of epilepsy in US children also reported higher rates of functional difficulties and academic problems among children with epilepsy compared to children without epilepsy.^{7,8} Clinical studies have compared the functional difficulties of children with epilepsy to children with specific comorbid conditions such as intellectual disability.⁹ However, recent population-based studies have not compared functional difficulties and school limitations of children with epilepsy to children with other chronic health conditions. A specific research implication identified by the 2012 Institute of Medicine Report, *Epilepsy across the Spectrum: Promoting*

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Abbreviations: CSHCN, children with special health care needs; NS-CSHCN, National Survey of Children with Special Health Care Needs.

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Health and Understanding was the need for more information about the particular functional impairments and educational problems of children with epilepsy.^{10,11} Studies of the academic problems experienced by children with epilepsy suggest that early detection and intervention may prevent many of these problems.^{12,13}

Among children identified as currently having “epilepsy or seizure disorder” in the 2011 National Survey of Children’s Health, nearly 95% were also reported to have a special health care need (unpublished data, 2011 National Survey of Children’s Health). Children with special health care needs (CSHCN) have been defined by the US Maternal and Child Health Bureau of the Health Resources Services Administration — as children who “require health and related services of a type or amount beyond that required by children generally.”¹⁴ As a result, the National Survey of Children with Special Health Care Needs (NS-CSHCN) presents a unique opportunity to study the functional difficulties and school limitations of children with epilepsy using nationally representative data for a large sample of CSHCN. The aim of this study is to compare the demographic characteristics, special health care needs, functional difficulties, and school limitations of CSHCN with epilepsy to CSHCN without epilepsy. Because epilepsy is often associated with comorbid conditions which have been shown to affect the functioning of children and their ability to participate in school activities, the analysis has been stratified by selected comorbid conditions.^{1,8} The specific objectives of this study are the following:

1. Estimate the prevalence of epilepsy and selected comorbid conditions among CSHCN,
2. Describe the sociodemographic characteristics of children with and without epilepsy who do and do not have selected comorbid conditions, and
3. Examine the association between epilepsy and functional difficulties and epilepsy and school limitations after stratifying for the presence of selected comorbid conditions and adjusting for sociodemographic characteristics.

Methods

Data source

The 2009–2010 NS-CSHCN is a nationally representative periodic survey designed to examine the health, functional status, and health care of CSHCN ages 0–17 in the US. In the 2009–2010 NS-CSHCN, a random-digit dial (RDD) sample of landline telephone numbers supplemented by a RDD sample of cell-phone numbers was used to identify households with children less than 18 years of age. A parent or guardian was the proxy respondent for each child. A screening interview (screener) consisting of five questions was used to determine if a child had a special health care need.¹⁵ Parents were asked if a child: 1) needs/

uses prescription medications; 2) needs/uses more medical, mental health, or educational services than are usual for most children of the same age; 3) has limitations in the ability to perform activities that other children of the same age can perform; 4) needs/gets specialized therapies; or 5) needs/gets treatment or counseling for an emotional, developmental, or behavioral problem. Parents were also asked if these needs were attributable to a medical, behavioral, or other health condition that had lasted or could be expected to last for 12 months or longer. A “yes” response to any of the five screener questions qualified a child to be a CSHCN. If the household had more than one CSHCN, then one child was randomly selected to be in the sample. More than 372,000 children were screened for special health care needs and detailed interviews were completed for 40,242 CSHCN. The weighted national response rate for special-needs interviews in 2009–2010 was 43.7% for the landline sample, 15.2% for the cell-phone sample, and 25.5% for the combined sample.¹⁶ Analyses of the results from the 2009–2010 NS-CSHCN has not shown evidence of significant bias in the estimates for selected variables¹⁷; however, given the low response rate bias cannot be ruled out.

Measures of Special Health Care Needs (SHCN), epilepsy, and comorbid conditions

Children were identified as having current epilepsy by a yes response to the following two questions: “Has a doctor or other health care provider ever told you that [child’s name] had epilepsy or seizure disorder?” and “Does [child’s name] currently have epilepsy or seizure disorder?” To better evaluate the association between epilepsy and children’s functional difficulties, children were categorized into two groups: 1) children who currently had one or more of the following selected comorbid conditions: intellectual disability/mental retardation; cerebral palsy; autism (which includes children with a diagnosis of Asperger’s Disorder, pervasive developmental disorder, or other autism spectrum disorder); or traumatic brain injury/concussion and 2) children who did not currently have any of these conditions. These conditions were selected because of the strong association between these conditions and both epilepsy and functioning. Additionally, clinical studies have shown that children with these conditions and epilepsy tend to have more functional difficulties than similar children without epilepsy.^{18–21} In order to better identify the effect of epilepsy on children’s functioning, the analysis was stratified by the presence of these comorbid conditions.

Measures of functional difficulty

In regard to variables related to the child’s basic functional difficulties, parents were asked “Compared to other children of the same age, would you say that your child has a lot, a little, or no difficulties with the following areas: 1)

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