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Adaptive functioning in children with seizures: Impact of maternal anxiety about epilepsy

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Abstract

This study evaluated the impact of maternal anxiety about a child's epilepsy on parental overprotection and the child's adaptive functioning. Specific maternal and family characteristics that contribute to elevated maternal anxiety about epilepsy were also studied over a year's time in a group of 56 mothers with children recently diagnosed with epilepsy. Overall, the primary predictor of maternal anxiety about epilepsy was the mother's level of coping resources, although family stress aggravated anxiety at the initial time point. Maternal anxiety about epilepsy was associated with overprotective and overly directive parenting styles, but it was the anxiety level itself that was most strongly related to the child's adaptive functioning. Maternal anxiety about epilepsy decreased over time, as did the relationship of maternal anxiety to the child's adaptive functioning. Nonetheless, after a year had elapsed, maternal anxiety was still associated with poorer adaptive skills.

Keywords: Epilepsy; Child; Parenting; Psychosocial; Adaptive skills

1. Introduction

Children with epilepsy are at risk for problems with behavioral and social adjustment. Undoubtedly, multiple underlying factors are responsible for abnormalities of development in this group of children—some of them medical and some social [1]. Results from a number of studies have indicated that the child's emotional and behavioral status has a direct relationship to the child's seizure characteristics and cognitive abilities [2–5], whereas other studies have clearly demonstrated the importance of parent and family characteristics to the child's behavioral adjustment [6–8]. In addition, there may be effects of epilepsy on a child's development that are indirect rather than direct. Parents' reaction to their child's medical condition may distort their interactions with their child and that, in turn, may interfere with normal social development.

Fear of one's own seizures appears to a have a negative effect on social and vocational adjustment for adults with epilepsy [9]. In the case of children with epilepsy, parental anxiety about their child's seizures may be a more significant factor. Williams et al. [10] have shown that generalized parental anxiety is related to diminished quality of life for children with epilepsy. Many parents have specific fears about their child's seizures [11–13], and there is evidence that maternal anxiety about seizures is associated with behavioral disturbance in this group of children [12]. A particular concern for children

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with epilepsy is dependency [14]. From his review of the literature, Bornstein [15] concluded that the roots of dependent personalities in the general population can be found in overprotective, authoritarian parenting styles. Parental anxiety about seizures may increase the likelihood of an overprotective parenting style, thereby impeding the child's development of independence.

The present study had a number of goals. The first was to identify maternal factors, including generalized anxiety, that place mothers at risk for elevated anxiety about their child's epilepsy. The second goal was to test the hypothesis that maternal anxiety about epilepsy is associated with an overprotective parenting style. The third goal was to assess the relative impact of maternal anxiety about seizures, maternal factors that contribute to anxiety about seizures, and parenting style on the child's adaptive functioning. Specifically, it was predicted that a mother's fear of seizures would have a negative impact on her child's adaptive functioning by contributing to an overprotective parenting style. Finally, the stability of these relationships was examined over time.

2. Methods

Maternal fear of seizures and its relationship to maternal and child characteristics were studied by following a group of mothers with children with newly diagnosed epilepsy over the course of 1 year. As a part of this project the Parental Anxiety about Epilepsy Questionnaire was developed. The study was approved by the Institutional Review Board at Baylor College of Medicine.

2.1. Subjects

Subjects were 56 mothers and one of their children who had been diagnosed with epilepsy in the previous 6 months. Eighty percent of the subjects were recruited from local schools and the rest were recruited from the practices of pediatric neurologists. In addition to the inclusion criteria that all children participating in this study be diagnosed with epilepsy within the previous 6 months, children were required to be between 6 and 12 years old, and the families were required to be English-speaking. Children whose seizures were secondary to another neurological condition, for example, tuberous sclerosis or encephalitis, were excluded. Although not specifically excluded, no children in this study were diagnosed with a major behavioral disorder such as autism or mental retardation. The average age of children at the time of the first visit was 8.6 years. The sample was composed of 36% girls and 64% boys. Socioeconomic status (SES) was assessed with the Hollingshead Four Factor Index of Social Status [16]. The Hollingshead yields a score ranging from 0 to 60 on the basis of educational and occupational levels of both parents. Average SES was in the middle class range (mean = 40.30), but ranged broadly between 11 and 60. Grouping by ethnicity indicated that 75% of subjects were Caucasian, 14% were Hispanic, and 11% were African-American.

Seizure types included: generalized tonic–clonic ($n = 16$), complex partial ($n = 11$), complex partial with secondary generalization ($n = 15$), and absence ($n = 14$). The children who participated in this study had generally well-controlled seizures. With the exclusion of those who had absence seizures, 80% had experienced only two seizures and 20% had experienced only three seizures. All subjects were taking a single antiepileptic drug. At the time of the second visit, 66% of the subjects had experienced no seizures during the previous year, 30% had relatively good control (4 or fewer seizures), and 4% had experienced 10 or more seizures. Eleven percent of the families had a member of the immediate family with a history of seizures, and, in one case, that family member was the sibling of the child participating in the study.

Forty-two families returned for the second visit, for an attrition rate of 25%. Differences between those families who did and did not return were assessed with either a χ^2 or a t test. There were no significant differences between the two groups with respect to SES, race, age or gender of child, seizure type, maternal trait anxiety, or initial level of anxiety about seizures.

2.2. Procedure

Medical information was collected from medical records, and each mother provided demographic information. Mothers completed questionnaires while their children completed tests of cognitive and academic functioning. Each mother was given a seizure calendar and asked to keep a record of her child's seizures over the following year. The families returned a year later and the same questionnaires were administered.

2.3. Instruments

2.3.1. Parental Anxiety about Epilepsy Questionnaire (PAE)

Items were generated from interviews with parents of children with seizure disorders and professionals who see children with epilepsy as part of their clinical practice. Items were then read by a small group of parents to ensure clarity. The resulting questionnaire contained 14 items with a 5-point Likert scale. To assess the psychometric properties of the Parental Fear of Seizures Questionnaire, it was administered to 152 parents of children with epilepsy who, in addition to those participating in the longitudinal study, were recruited through a pediatric neurology practice and educational events