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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

hosted by the Houston/Gulf Coast Epilepsy Foundation. The questionnaire was found to have excellent internal consistency with a Chronbach α of 0.91. A principal-component factor analysis was conducted to evaluate the factor structure. The initial factor solution revealed only one factor with an eigenvalue equal to or more than 1.0. This factor explained 49% of the variance. The questionnaire and item factor loadings are presented in the Appendix A.

2.3.2. Family Inventory of Life Events and Changes (FILE)

The FILE is a 71-item self-report measure designed to assess the accumulation of normative and nonnormative life events and changes experienced by the family, such as parenting strains, marital strains and illness [17]. The respondent indicates whether or not his or her family has experienced each event. The total score is calculated by summing the "yes" responses so that higher scores indicate more potentially stressful events. Chronbach's α was assessed to be 0.81 in the normative sample, and the total score has been positively correlated with family dysfunction. The average score reported for families who were a part of the normative sample was 8.8 (5.87).

2.3.3. Coping Resources Inventory (CRI)

The CRI is a 60-item questionnaire with a 4-point scale that assesses the individual's resources for coping with stress [18]. Resource domains include Cognitive (degree to which individuals maintain a positive outlook), Social (degree to which individuals have supportive social network), Emotional (degree to which individuals accept and express a wide range of affect), Spiritual/Philosophical (degree to which individuals' actions are guided by stable and consistent values), and Physical (degree to which individuals engage in health-promoting behavior). Coefficient α for the total scale, computed for the normative sample, is 0.91. Higher scores from the CRI are associated with more coping resources and have been shown to have an inverse relationship with symptoms of stress. The overall standard score, which has a mean of 50 and a SD of 10, rather than individual domain scores, was used in the analyses.

2.3.4. State–Trait Anxiety Inventory for Adults (STAI)

The STAI is a 20-item questionnaire with a 4-point scale on which higher scores are related to increased anxiety [19]. The STAI correlates well with other measures of anxiety. Only the Trait Anxiety Scale was used for these analyses because it provides a measure of characteristic rather than transient or situation-specific anxiety. The STAI has been found to correlate well with other measures of anxiety and the median coefficient α is 0.90. A standard score with a mean of 50 and a SD of 10 was used in the analyses.

2.3.5. Maternal protectiveness and directiveness questionnaires

Maternal overprotection was assessed with two questionnaires developed by Hardy et al. [20]. The 12-item Parental Protectiveness Scale yields a single-factor protectiveness score that reflects parental attempts to protect children from physical harm (e.g., "If my child hurt himself at a friend's house I would not let him go back there to play") and from failure (e.g., "I think that it is important that my child does not get involved in activities or tasks where he or she may potentially fail"). Coefficient α for this scale has been assessed to be 0.76. The Parental Directiveness Scale from the Parental Problem-Solving Directiveness Questionnaire is a six-item scale that assesses parental attempts to prevent child failure through high levels of parental involvement in the child's schoolwork and daily activities (e.g., "I help my child with tasks he is having trouble with in order to prevent him from getting frustrated"). Coefficient α for this scale was assessed to be 0.64. Both scales use a 6-point scale, with higher scores associated with higher levels of parent intervention. Maternal responses on both scales have predicted children's self-reported coping styles, optimism, and depressive symptoms [20,21].

2.3.6. The Vineland Adaptive Behavior Scales

The Vineland is a semistructured interview that is administered to parents to assess their child's adaptive functioning or capacities for personal and social self-sufficiency in real-life situations [22]. The Vineland assesses the capacity for self-sufficiency in Communication (receptive, expressive, and written language), Daily Living Skills (personal, domestic, and community), and Socialization (interpersonal relationships, play, and leisure time). An age-based standard score is computed for each behavioral domain, with higher scores reflecting higher levels of adaptive functioning. Median α coefficients for the Communication, Daily Living Skills, and Socialization scales are 0.89, 0.90, and 0.86, respectively.

2.4. Statistics

A number of analyses were completed using data from each visit. Individual relationships between variables were assessed with product–moment correlations. Stepwise multiple regression analyses were used to evaluate the relative contributions of maternal and family characteristics to maternal fear of seizures and the relative contributions of fear of seizures, parenting style, and other maternal characteristics to the child's adaptive functioning. Change in level of fear of seizures between the first and second visits was assessed with a correlated-group t test. Stability was assessed with a simple correlation.

3. Results

3.1. Prediction of maternal anxiety about epilepsy from maternal and family characteristics

Means and SDs for measures of maternal characteristics at each time point are listed in Table 1. At the time of the first visit, higher levels of maternal anxiety about epilepsy were associated with lower SES ($r = -0.31$, $P < 0.02$), more family stress ($r = 0.38$, $P < 0.01$), higher generalized anxiety ($r = 0.43$, $P < 0.001$), and fewer coping resources ($r = -0.46$, $P < 0.001$). The relative contributions of these variables to maternal anxiety about epilepsy were evaluated in a multiple regression analysis. The results are summarized in Table 2. Maternal anxiety about epilepsy was predicted by fewer coping resources (lower CRI scores) and, to a lesser extent, more family stresses (higher FILE scores). No other variables remained in the model.

At the time of the second visit, higher levels of maternal anxiety about epilepsy were associated with lower SES ($r = -0.43$, $P < 0.01$), higher generalized anxiety ($r = 0.31$, $P < 0.05$), and fewer coping resources ($r = -0.42$, $P < 0.01$). The relative contributions of these variables to maternal anxiety about epilepsy were evaluated with multiple regression, and the results are summarized in Table 2. At this time point, only coping resources (CRI) remained in the model.

3.2. The relationship between maternal fear of seizures and parenting style

Correlations between maternal anxiety about epilepsy and parenting style are summarized in Table 3. At the first time point, maternal fear of seizures was associated with increased parental protectiveness and, to a lesser extent, with increased parental direction in problem solving. At the time of the second visit, maternal anxiety about epilepsy was again significantly correlated with both parental protectiveness and parental directiveness in problem solving.

Table 1
Maternal characteristics

	First visit		Second visit	
	M	SD	*M*	SD
STAI	53.18	11.11	55.70	12.30
CRI	48.54	10.54	46.13	11.24
FILE	11.56	6.30	11.58	6.76
PAE	33.67	12.81	27.31	10.87

Table 2
Maternal and family characteristics associated with maternal anxiety about epilepsy

Predictor variable	R^2 increment	*P*
First visit		
CRI	0.25	<0.001
FILE	0.06	<0.04
Second visit		
CRI	0.18	<0.01

Table 3
Association of maternal anxiety about epilepsy with parenting style

Parenting style	*r*	*P*
First visit		
Parental protectiveness	0.60	<0.0001
Parental directiveness	0.33	<0.02
Second visit		
Parental protectiveness	0.54	<0.0002
Parental directiveness	0.55	<0.0002

3.3. The association of maternal fear of seizures, parenting style, and maternal characteristics with the child's adaptive functioning

Mean and SDs for the Vineland domain scores at each time point are listed in Table 4. As maternal anxiety about epilepsy was hypothesized to impact children's adaptive functioning by an overprotective parenting style, simple correlations were initially computed between the two parenting questionnaires and adaptive functioning in each of the Vineland behavioral domains at each time point. The Directiveness Scale did not have a significant relationship with adaptive functioning in any of the behavioral domains at either time point. The Protectiveness Scale, however, had significant inverse correlations at the first time point with adaptive functioning in the Daily Living Skills domain ($r = -0.26$, $P < 0.05$) and the Socialization domain ($r = -0.28$, $P < 0.05$). There were also significant inverse correlations at the second time point with the adaptive functioning in the Daily Living Skills domain ($r = -0.27$, $P < 0.05$) and in the Socialization domain ($r = -0.25$, $P < 0.05$). Scores from the Parental Protectiveness Scale were not significantly correlated with the scores on the Vineland Communication Scale at either time point. Therefore, only the score from the Protectiveness Scale was entered into the multiple regression

Table 4
Vineland domain scores

Vineland domain	First visit			Second visit		
	M	SD	% <85[a]	*M*	SD	% <85[a]
Communication	90.55	15.35	37	89.07	15.51	36
Daily Living Skills	87.11	13.89	36	84.62	16.10	48
Socialization	85.04	14.89	39	80.04	15.23	57

[a] Percentage of scores more than 1 SD below the mean of the normative sample.

Table 5
Prediction of Vineland domain scores by maternal anxiety about epilepsy, parenting style, and maternal characteristics

Predictor variable	R^2 Increment	P
First visit		
Communication		
PAE	0.11	<0.02
FILE	0.08	<0.03
Daily Living Skills		
PAE	0.26	<0.0001
Socialization		
PAE	0.25	<0.0001
Second visit		
Communication		
PAE	0.10	<0.04
Daily Living Skills		
CRI	0.14	<0.02
Socialization		
PAE	0.13	<0.02

models predicting Daily Living Skills and Socialization at each time point.

The results of the analyses assessing the relationship between maternal variables and the children's adaptive functioning are summarized in Table 5. At the first time point, scores from the PAE, the FILE, and the CRI were entered into a multiple regression equation to predict adaptive functioning in the Communication domain. The analyses revealed that higher levels of maternal anxiety about epilepsy and more family stress were associated with lower levels of adaptive functioning in the Communication domain. The score from the Parental Protectiveness Scale was also entered into the equation to predict adaptive functioning in the Daily Living Skills and Socialization domains. Only increased anxiety about epilepsy was associated with lower levels of adaptive functioning in the Daily Living Skills and Socializations domains. No other variables remained in the models.

At the second time point, increased anxiety about epilepsy was associated with lower levels of adaptive functioning in the Communication and Socialization domains, while fewer maternal coping resources were associated with more poorly developed adaptive skills in the Daily Living Skills domain. No other variables remained in any of the models.

3.4. Stability and change in maternal anxiety about epilepsy from first to second visit

To assess the stability of maternal fear of seizures, a correlation was computed between the scores from the first and second visits, and the results indicated a high level of stability, $r = 0.77$, $P < 0.0001$. Nonetheless, a t test for correlated groups revealed a significant decline in the group means for those mothers who returned for the second visit, $t = 4.97$, $P < 0.0001$.

The relationship between changes in maternal anxiety about epilepsy and changes in the children's adaptive skills was examined by creating change scores for both the PAE and each of the Vineland domain scores. Correlations were computed between the change score for the PAE and the change score for each of the Vineland domains. Correlations between changes in maternal anxiety about epilepsy and adaptive functioning in the Communication and Daily Living Skills domains were not statistically significant, $P > 0.50$. The analysis of the relationship between changes in maternal anxiety about epilepsy and adaptive functioning in the Socialization domain yielded a correlation coefficient of 0.24. This coefficient was not significantly different from zero, $P = 0.06$.

4. Discussion

A mother's anxiety about her child's epilepsy appears to be an emotion that underlies a variety of specific fears. Even though the Parental Anxiety about Epilepsy Questionnaire, the instrument developed for this study, included items about both social and health-related concerns, only one factor accounted for a significant proportion of the variance in responses. Individual differences in level of maternal anxiety about epilepsy were stable over a year's time for this group of mothers whose children had recently been diagnosed with epilepsy, although the group as a whole became less anxious. The children of the mothers participating in this study, however, had relatively well-controlled seizures. Other mothers with children who have intractable seizures may maintain a more elevated level of anxiety.

Some mothers appear to be more likely to experience heightened anxiety about their child's epilepsy. Unsurprisingly, the results of this study indicate that mothers with higher levels of generalized anxiety are more anxious about their child's epilepsy, a relationship that may explain the association between maternal anxiety and quality of life for children with epilepsy demonstrated in the Williams et al. study [10]. The mothers of lower socioeconomic status in the present study were also more likely to report elevated anxiety about their children's medical condition. Their lower level of education may have made it more difficult for them to take advantage of information they received about epilepsy, or, perhaps, parents of lower socioeconomic status spend less time with medical staff. The effects of generalized anxiety and SES, however, were entirely mediated by the coping resources available to the mother. The mothers, for example, who had social supports, who were comfortable talking about emotions, or had a spiritual/philosophical outlook on life were less anxious about their child's epilepsy. There was some evidence from this study that family stress may aggravate mater-

nal anxiety about seizures, at least initially, but maternal coping resources were the primary predictor of mothers' responses to their children's medical condition.

As predicted, mothers who expressed more anxiety about their children's epilepsy were more likely to adopt a protective parenting style and to be more involved in solving problems for their children, and these relationships remained stable over time. Only the protective parenting style, however, was found to have a deleterious effect on the child's level of adaptive functioning in social situations and managing the requirements of daily living. The findings from this study suggest that maternal anxiety about epilepsy does have a negative impact on the child's adaptive functioning, but that effect appears to be only partially mediated through an overprotective parenting style. One explanation may be that there are additional paths, such as direct communication of anxiety, through which maternal anxiety impacts the child's adaptive functioning. Another possible explanation is that, because of factors such as the desire to give socially acceptable responses, parental responses to the Parental Protectiveness Scale may only imperfectly reflect the parent's actual parenting practices.

At both time points, maternal anxiety about epilepsy was associated with the child's adaptive functioning in the Communication, Daily Living Skills, and Socialization domains. The strength of these associations, however, diminished over a year's time, and, by the second visit, the impact of maternal anxiety about anxiety on children's daily living skills was entirely mediated by maternal coping resources. The decrease in the strength of these relationships may be due to a statistical artifact. Average anxiety about epilepsy decreased from the first visit to the second, with an associated attenuation in the range of scores. An equally plausible explanation is that, as mothers become less anxious about their child's medical condition, their anxiety plays less of a role in their child's development.

In considering the findings from this study, several limitations should be kept in mind. First, the study employed a measure of parental anxiety about epilepsy that has not been previously used in studies of children with epilepsy. Second, we chose to study mothers because mothers were more able or willing to commit the time required for participation, but fathers may have their own distinctive responses to their children's medical condition and their own contribution to their children's development. Consequently, it would be informative to conduct a similar study of fathers or perhaps a study of both parents. Third, there was a very limited range of seizure frequency represented in the children whose mothers participated in this study, so the impact of seizure frequency on maternal anxiety could not be assessed. Increased seizure frequency may be associated with higher levels of maternal anxiety about their children's epilepsy, and, as a consequence, there may be more pronounced consequences for the parent–child relationship and, ultimately, for the child. Finally, not all mothers returned for the second visit. Nevertheless, 75% of them did return and those who returned could not be differentiated from those who did not.

Despite the limitations noted above, this study provides a valuable longitudinal perspective on adaptive functioning in children with epilepsy and the contribution of maternal characteristics. The findings suggest that a mother's anxiety about her child's epilepsy may have a detrimental effect on her child's social development. The data from this study also suggest that interventions that help mothers develop more resources for coping with stress may mitigate some of the problems with adaptive functioning common in this group of children.

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Appendix A. Parental Anxiety about Epilepsy Questionnaire and item factor loadings

The following are fears that are sometimes expressed by parents of children with epilepsy. Indicate to what degree each is a worry of yours by circling the appropriate number.

1 = This is not a worry of mine.
2 = I am slightly worried about this.
3 = I am moderately worried about this.
4 = I am quite worried about this.
5 = I am extremely worried about this.

1. Individuals with epilepsy do not live as long as other people. 0.65
2. Seizures can cause brain damage. 0.71
3. Individuals with epilepsy do not live normal lives. 0.75
4. Epilepsy is associated with mental illness. 0.71
5. Individuals with epilepsy are never able to live fully independent lives. 0.78
6. Sports are dangerous for children with epilepsy. 0.66
7. Children with epilepsy are often mentally retarded. 0.67
8. My child may die during a seizure. 0.65
9. Children with epilepsy are more often ridiculed or rejected by their peers. 0.58
10. Children with epilepsy have trouble in school. 0.59

11. Children with epilepsy are in danger of hurting themselves if they are not closely watched. 0.72
12. Individuals with epilepsy are denied jobs because of their medical condition. 0.65
13. If my child has a seizure when I am not there, others will not know what to do to keep him or her safe. 0.60
14. Individuals with epilepsy are limited in the kind of work they can do to make a living. 0.71

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