

## Family function in cognitively normal children with epilepsy: Impact on competence and problem behaviors

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### Abstract

A cross-sectional cohort of 82 cognitively normal children with epilepsy attending the pediatric neurology clinic, who were aged 6–17 years and who had a similarly aged sibling without seizures or cognitive delay, were identified. The parent was asked to complete the Family Assessment Measure III (FAM-III) as well as the Child Behavior Checklist (CBCL) for both the child with epilepsy and his or her sibling. The Overall Rating Score on FAM-III did not differ significantly from the normative mean, although families scored significantly better on the Involvement subscale and significantly worse on the Role Performance subscale. Moderate correlations were found between competence and behavior problems and family function in both children with epilepsy and their siblings. In families functioning at the highest level, both cohorts did well. In those at the lowest level, approximately half of the children in either cohort had problems. For average functioning families, behavior and competence issues were more frequent in children with epilepsy than their siblings.

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### 1. Introduction

Family functioning plays a critical role in adaptation of both child and family to chronic illness [1,2]. Deficits in family cohesion, family adaptability, parent–child interactions, family conflict, and family problem-solving skills can be problematic in families of children with chronic illness [2–4]. In addition to the burden of a chronic physical illness, children with epilepsy are known to be at higher risk of behavior problems, which can be further exacerbated by family dysfunction [5–7]. Studies have suggested that families of children with epilepsy generally fare worse

than control groups [8,9]. Effective interventions to improve family functioning might, in turn, diminish behavioral and competence problems and improve well-being of children with epilepsy.

Although previous work has suggested that mental illness [6,10], sleep disorders [11], and stress [12–14] may be more prevalent in families of children with epilepsy, few studies have used standardized and validated scales to measure family function and identify the severity and correlates of family dysfunction in epilepsy [12,15]. The primary goal of this study was to measure family function in children with epilepsy and identify neurological correlates of family dysfunction, and to identify factors that may be important in predicting families at risk of dysfunction. We employed a standardized measure of family function, The Family Assessment Measure III (FAM-III) [16], which provides quantitative indices of family strengths and weaknesses.

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Our secondary goal was to determine whether and to what degree family dysfunction is associated with emotional and behavioral difficulties in children with epilepsy and whether this risk generalizes to nonepileptic siblings. To do so, we analyzed the relationship between family dysfunction and emotional/behavioral difficulties in children with epilepsy and in siblings using a general measure of psychopathology, the Child Behavior Checklist (CBCL) [17].

## 2. Methods

This study was a cross sectional, cohort survey of children with epilepsy attending the pediatric neurology clinic at Alberta Children's Hospital and their nonepileptic siblings. This hospital is the only tertiary care pediatric center in south-central Alberta, and serves a population of approximately 1.5 million.

### 2.1. Identification of cohorts

Two cohorts were identified, the first consisting of children with epilepsy and the second consisting of their nearest-in-age, nonepileptic siblings. Children with epilepsy were identified through the neurology clinic database at Alberta Children's Hospital as per the following inclusion criteria: (1) aged 6–17 years (covering the age range of the CBCL), (2) diagnosed with epilepsy for at least 3 months, (3) seen by a pediatric epileptologist between July 1, 2002, and August 1, 2006, in the neurology clinic at Alberta Children's Hospital, (4) absence of mental handicap (defined as a measured or estimated developmental quotient <70), and (5) living with the parent or primary caregiver for a minimum of 1 year. For children with epilepsy, neurology clinic charts were reviewed for developmental status, and potential cases were excluded if they either had been diagnosed to have mental handicap on a formal psychological assessment (defined as a developmental quotient <70) or were felt to have a mental handicap by the treating neurologist.

The nearest-in-age full or half-sibling of each child with epilepsy, aged 6–17 years, who was not mentally handicapped and who had no history of seizures according to parent report was identified and served in the second cohort.

### 2.2. Completion of surveys

The mother or primary caregiver was mailed a letter outlining the study and then contacted by phone to request participation. Each participant was sent a package containing the Family Assessment Measure III and two Child Behavior Checklists to be completed for both the child with epilepsy and her or his sibling. All questionnaires were completed by the same caregiver.

#### 2.2.1. Family Assessment Measure III

The Family Assessment Measure III (FAM III) 50-item General scale was completed by the mother or primary caregiver. Responses to each statement are divided into "strongly agree," "agree," "disagree," or "strongly disagree." The scale provides a measurement of overall family health and family relationships [16], and, in addition to an Overall Rating score, clinical subscales in seven universal clinical parameters are calculated. These subscales include Task Accomplishment (the achievement of basic, developmental and crisis tasks); Role Performance (the allocation or assignment of specified activities to each family member, the agreement or willingness of family members to assume the assigned roles, and the actual enactment or carrying out of prescribed behaviors); Communication (the achievement of mutual understanding so that the message received is the same as the message intended); Affective Expression (the content, intensity, and timing of feelings); Involvement (the degree and quality of family members' interest in one another); Control (the process by which family members influence each other, i.e., is the family predict-

able vs inconsistent, constructive vs destructive, or responsible vs irresponsible in its management style); and Values and Norms (whether family rules are implicit or explicit, the latitude or scope allowed for family members to determine their own attitudes and behavior, and whether family norms are consistent with the broader cultural context). Two performance scales (Social Desirability and Defensiveness) are also calculated. Family function was divided into three categories, based on the Overall Rating *T* score: Strong (*T* score  $\leq 40$ ), Average (*T* score  $>40$  and  $<60$ ), and Weak (*T* score  $\geq 60$ ). The FAM-III has been demonstrated to have acceptable psychometric properties [16]. Internal consistency measures for the General scale are as follows: Overall Rating ( $\alpha = 0.93$ ), Task Accomplishment ( $\alpha = 0.67$ ), Role Performance ( $\alpha = 0.73$ ), Communication ( $\alpha = 0.73$ ), Affective Expression ( $\alpha = 0.74$ ), Involvement ( $\alpha = 0.78$ ), Control ( $\alpha = 0.71$ ), and Values and Norms ( $\alpha = 0.70$ ). FAM-III can be completed by either the parent or child; however, it requires a reading level of age 10. As we wished to include children as young as 6, we had the parents, rather than the children, complete this form.

#### 2.2.2. The Child Behavior Checklist (CBCL)

The CBCL/6–18 is a parent-completed measure for children aged 6–18 [17]. For this study, the following scales were assessed: (1) Total Competence, which comprises Activities, Social, and School competence; (2) Internalizing Problems, which measures behaviors indicating sadness, anxiety, loneliness, and poor self-esteem; and (3) Externalizing Problems, which measures problem behaviors such as verbal or physical aggression, poor control of temper, and arguing. The *T* scores were used for each variable, and scores were then classified into normal versus borderline clinical or clinical ranges. This questionnaire has been well standardized and is commonly used in pediatric research. Internal consistency is high for both Internalizing Problems ( $\alpha = 0.90$ ) and Externalizing Problems ( $\alpha = 0.94$ ).

### 2.3. Review of neurology clinic charts

Neurology clinic charts of children with epilepsy were reviewed for the following information: seizure type (generalized vs partial), seizure frequency over the past year, number of antiepileptic drugs used at present, age at seizure onset, learning disability (present, absent), intractability (defined as seizures occurring at least every 3 months despite trials of three or more AEDs), and seizure etiology (idiopathic, cryptogenic vs remote symptomatic). Etiology was defined as *idiopathic* if the child fit into one of the accepted benign idiopathic epilepsy syndromes, such as the idiopathic generalized epilepsies or benign focal epilepsies of childhood; as *remote symptomatic* if there was a known brain insult or lesion accounting for the seizures; and as *cryptogenic* if the child was mentally normal, had no underlying lesion or insult, but did not fit into one of the known idiopathic epilepsy syndromes. A learning disability was considered to be present if the child had been previously diagnosed with this condition or required program modification or assistance at school. Details regarding current seizure type(s), frequency, antiepileptic medications, and academic functioning were confirmed with the parent or primary caregiver by phone at the time of study enrollment.

### 2.4. Data analysis

The primary analysis involved assessing family function in children with epilepsy. We determined the mean *T* scores for each FAM-III subscale and the Overall Rating score, and compared the scores from our families with the normative mean using the one-sample *t* test. The proportions of families functioning in each category—Strong, Average, and Weak—were also determined. Based on the normative data, we would expect 16% of families to function in the Strong category, 68% in the Average category, and 16% in the Weak category. To determine if epilepsy variables were predictive of family function, Pearson correlations were conducted between the FAM-III Overall Rating *T* score and epilepsy variables (seizure type, frequency, etiology, number of current AEDs, age at seizure onset, presence of learning disability, and intractability).

Secondary analyses involved identifying the association between family function and competence/behavior in children with epilepsy and their non-epileptic siblings. Pearson correlations were conducted between FAM-III Overall Rating Score and *T* scores for Total Competence, Internalizing Problems, and Externalizing Problems for both children with epilepsy and their non-epileptic siblings. We then divided families into three categories, based on category of function (Strong, Average, or Weak). We identified the prevalence of children with CBCL scores in the borderline clinical or clinical range in both the epilepsy and sibling cohorts. For each category of family function, we compared the proportion of children in the borderline/clinical range in cases versus siblings using  $\chi^2$  analysis.

### 3. Results

One hundred and one children were contacted who met inclusion criteria and had an age-appropriate sibling. Three families refused the study, and packages were sent to the remaining 98 families. Of these, 82 patient–sibling pairs returned completed questionnaires, representing 81% of all pairs who met inclusion criteria. No significant differences were seen in seizure type or proportion with intractable epilepsy between patients who did and did not complete the survey. Mothers completed the questionnaires in all but two cases. Epilepsy characteristics of cases are summarized in Table 1.

There were no significant differences between patients and siblings with respect to age [mean age (SD) of child with epilepsy vs sibling: 12.2 (3.3) vs 12.0 (3.3)] or gender (M:F in children with epilepsy and siblings: 40:42).

Table 1  
Characteristics of epilepsy group

Characteristic	<i>N</i> (%)
Seizure type	
Generalized	31 (38%)
Partial onset	51 (62%)
Seizure etiology	
Idiopathic	37 (45%)
Cryptogenic	32 (39%)
Remote symptomatic	13 (16%)
Seizure frequency	
Seizure-free over past year	35 (43%)
Seizures less than every 3 months	24 (29%)
Seizures every 1–3 months	12 (15%)
Seizures less than weekly to monthly	4 (5%)
Seizures less than daily to weekly	5 (6%)
Seizures at least daily	2 (2%)
Learning disability present	24 (29%)
Current No. of AEDs	
None	14 (17%)
1	52 (63%)
2	12 (15%)
≥3	4 (5%)
Prior epilepsy surgery	7 (8%)
Intractability	8 (10%)
Age at onset of epilepsy	
<3 years	14 (17%)
≥3 years	68 (83%)

### 3.1. Primary analysis: Family function

#### 3.1.1. Family Assessment Measure III

The Overall Rating score and FAM-III subscale scores are given in Table 2. The Overall Rating score in our families did not differ significantly from the normative mean: only 11% of families were considered to have *weak* family functioning. Families with epilepsy had scores on the Involvement subscale that were significantly better than the normative mean ( $P < 0.03$ ). However, scores on the Role Performance subscale were significantly poorer than the normative mean ( $P < 0.04$ ).

#### 3.1.2. Association between epilepsy variable and family function

Epilepsy variables were found to not be significant predictors of family function. No significant correlations were found between Overall Rating score on the FAM-III and seizure type ( $P = 0.22$ ), frequency ( $P = 0.16$ ), etiology ( $P = 0.26$ ), total number of AEDs ( $P = 0.58$ ), age at seizure onset ( $P = 0.51$ ), presence of learning disability ( $P = 0.46$ ), and intractability ( $P = 0.20$ ).

### 3.2. Secondary analyses: Association between family function and emotional/behavioral functioning in children with epilepsy compared with their non-epileptic siblings

Significant correlations were found between the Overall Rating score of the FAM-III and the Total Competence, Internalizing Problems, and Externalizing Problems *T* scores of the CBCL in both children with epilepsy and their non-epileptic siblings (Table 3), indicating a moderate association between extent of family dysfunction and emotional/behavioral difficulties in both groups of children.

Compared with their non-epileptic siblings, children with epilepsy had significantly lower scores in Total Competence [epilepsy mean = 44.63 (SD 9.73), non-epilepsy mean = 49.78 (SD 9.59),  $P < 0.002$ ] and higher scores in Internalizing Problems [epilepsy mean = 56.63 (SD 12.01), non-epilepsy mean = 49.78 (SD 11.04),  $P < 0.001$ ] and Externalizing Problems [epilepsy mean = 51.43 (SD 11.59), non-epilepsy mean = 48.10 (SD 10.43),  $P = 0.05$ ].

Nine (11%) families were functioning in the Strong category, 64 (78%) in the Average category, and 9 (11%) in the Weak category, based on the Overall Rating score on the FAM-III. The proportions of children with epilepsy and their non-epileptic siblings functioning in the borderline/clinical range for Total Competence, Internalizing Problems, and Externalizing Problems, in each family function category, are listed in Table 4. In families with Strong function, outcome was favorable for most children with epilepsy and their non-epileptic siblings. In families with Weak function, significant difficulties were seen in both cohorts of children. In families with Average function, children with epilepsy had a higher prevalence of problems than their non-epileptic siblings in Internalizing Problems ( $P < 0.004$ ) and Externalizing Problems ( $P < 0.05$ ), and

Table 2  
Family Assessment Measure III scores<sup>a</sup>

Scale	Mean	SD	% Strong	% Average	% Weak	<i>P</i> <sup>b</sup>
Overall Rating	49.64	7.72	11.0	78.0	11.0	0.67
Task Accomplishment	48.07	9.91	19.5	72.0	8.5	0.08
Role Performance	52.27	9.69	8.5	68.3	23.2	<0.04
Communication	50.61	9.46	17.1	64.6	18.3	0.56
Affective Expression	48.46	8.80	19.5	72.0	8.5	0.12
Involvement	47.66	9.30	25.6	62.2	12.2	<0.03
Control	51.22	10.12	12.2	69.5	18.3	0.28
Values and Norms	49.15	8.03	14.6	78.0	7.3	0.34
Social Desirability	50.27	7.61	8.5	76.8	14.6	0.75
Defensiveness	49.34	9.62	13.4	73.2	13.4	0.54

<sup>a</sup> Note that lower *T* scores on the FAM-III are indicative of better function.

<sup>b</sup> One-sample *t* test comparing these results with normative mean.

Table 3  
Correlation of Overall Rating score on the FAM-III with Total Competence, Internalizing Problems, and Externalizing Problems *T* scores on the CBCL in children with epilepsy and their nonpileptic siblings

CBCL scale	Children with epilepsy		Nonpileptic siblings	
	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>
Total Competence	−0.329	<0.004	−0.260	<0.03
Internalizing Problems	0.379	<0.001	0.396	<0.001
Externalizing Problems	0.478	<0.001	0.372	<0.002

showed a trend toward greater difficulties in Total Competence (*P* = 0.08).

#### 4. Discussion

Overall, our results indicate that families of cognitively normal children with epilepsy function well, with overall family function not differing significantly from the normative mean. However, two subscales on the FAM-III were notably different. Families in this study scored significantly better on Involvement, a subscale that measures such aspects as empathy, the degree of fulfillment of emotional needs, and nurturing and supportive interactions between family members. Because of their child’s epilepsy, parents may become more involved and nurturing, reflecting a positive impact of epilepsy on the family. A similar finding was noted in studies in children with either cystic fibrosis [18,19] or developmental delay [20]. However, we found families of children with epilepsy scored significantly poorer on the Role Performance subscale, which measures

agreement regarding role definitions and ability to adapt to new roles required in the evolution of the family life cycle. Poorer scores reflect that family members are less clear about what is expected of them and doing their share, and are less effective at getting things done. This finding may be due to a number of reasons. Parents may react differently to a diagnosis of epilepsy in their child, with some perceiving a greater need for close supervision and/or limitation of activities than others. The burden of extra care posed by a child with epilepsy may also not be shared equally among family members, leading to feelings of being overwhelmed or resentment by those carrying the bulk of the burden. In our study, mothers completed 98% of questionnaires and, therefore, may carry the bulk of the caregiver burden. Interestingly, studies looking at family function in children with cystic fibrosis or developmental delay did not note similarly elevated scores in Role Performance.

Previous studies comparing parents of healthy children with those of children with epilepsy have suggested problems with emotional overinvolvement [21]; decreased affection and stimulation [22]; poor limit setting [22,23]; authoritarian parenting [23]; higher rates of depression, anger, guilt, and feelings of frustration and helplessness [10]; lower self-esteem and higher stress [12]; and poorer sleep [11]. However, Hoare and Kerley found no increased risk of psychiatric morbidity or marital difficulties [24,25]. A small number of studies have used formal social science measures of family function to measure family interactions [12,15]. Austin, in a study using the family Adaptation-Partnership-Growth-Affection-Resolve and the Family

Table 4  
Proportion of cases and controls functioning in the borderline/clinical range for Total Competence, Internalizing Problems, and Externalizing Problems, based on family function

	Family function								
	Strong ( <i>N</i> = 9)			Average ( <i>N</i> = 64)			Weak ( <i>N</i> = 9)		
	Epilepsy	Sibling	<i>P</i> value	Epilepsy	Sibling	<i>P</i> value	Epilepsy	Sibling	<i>P</i> value
Competence	11%	11%	1.0	28%	15%	0.08	67%	44%	0.34
Internalizing	11%	0%	0.30	41%	17%	<0.004	56%	56%	1.0
Externalizing	0%	0%	—	20%	8%	<0.05	56%	56%	1.0

Inventory of Resources for Management scale [12], found that families of children with epilepsy had lower levels of communication, family social support, and financial well-being. Only one prior study that used the FAM-III in childhood epilepsy has been reported. Tatzer et al. compared families of children with epilepsy with controls and found signs of family malfunction in 26% of those with epilepsy versus only 6.5% of controls [15]. However, this study was not limited to children who were cognitively normal.

Several studies have also noted that greater epilepsy severity correlates with greater perceived impact on the family unit [26,27]. However, similar to Tatzer and colleagues' study [15], we found that epilepsy variables did not significantly impact family function, although the number of our cases with intractable epilepsy was very small.

Previous work in childhood epilepsy has demonstrated that family function is very important in predicting both adaptive [28,29] and cognitive and behavioral [21,30] function. Compared with those without seizures, children with epilepsy are more predisposed to behavior and competence problems [5,6]. We found that family function correlated moderately with competence and behavior problems in both children with epilepsy and their siblings. In families who were functioning at the highest level, no significant differences were seen between the proportion of children with epilepsy and the proportion of their siblings who scored in the borderline or clinical ranges for Total Competence, Internalizing Problems, and Externalizing Problems, as both groups were doing well. In families functioning at the lowest levels, again, no significant differences were seen between children with epilepsy and their siblings in the prevalence of behavior problems. In these families, approximately half of children in either group scored in the borderline or clinical range. However, the number of families functioning in either the Strong or Weak category was small, so these results are tentative. In average functioning families, behavior and competence issues were seen more often in children with epilepsy than their siblings. These findings can be explained by presuming a balance between family function and biological risk of behavior and competence problems in each child. Strong family function is able to compensate for the higher risk of behavior and competence issues in children with epilepsy, so these are not clinically expressed. Similarly, in families who are functioning poorly, even children with a presumably lower biological risk for behavior and competence problems by virtue of not having epilepsy may express this risk: significant problems are seen in both children with epilepsy and siblings. In these cases, the additional stressor of having a child with epilepsy presumably affects the quality of the parent–child relationship of both the child with epilepsy and his or her sibling, which, in turn, results in increased behavior problems. In families who are functioning in the average range, a significantly higher prevalence of problems is seen in the epilepsy group, as their greater biological predisposition for these

problems may not always be balanced by the presence of healthy family dynamics. However, while we presume that good family function leads to fewer behavior problems in children, it is also possible that well-functioning children may lead to better family function.

We did not specifically address the effects of marital status, family size, socioeconomic status, family stressors, or social supports on family function in our children with epilepsy. However, these may be important variables in determining how a family copes with their child's epilepsy and should be assessed in future studies.

Our results emphasize the importance of providing additional support to most families of children with epilepsy, not just those with markedly maladaptive family relationships. Although families of children with epilepsy do well with respect to Involvement, providing a nurturing and supportive environment for each other, they do less well on Role Performance, agreeing on role definitions and adapting to new roles required in response to family stressors such as illness. Previous work with families of children who have other chronic health conditions suggests that specific interventions targeting this area contribute to improved overall family function and family management, leading to better outcomes [3,31]. Tailoring such interventions to our patient population may well contribute to improved competence and behavior in children with epilepsy and to better family management. Support aimed at siblings is particularly important in families with marked dysfunction.

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