# Parental anxiety and family disruption following a first febrile seizure in childhood

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**OBJECTIVE:** To evaluate the degree of parental anxiety and family disruption following a child's first febrile seizure.

PATIENTS AND METHODS: The families of all children presenting with their first febrile seizure to any of the three emergency departments in the Saskatoon District, Saskatchewan, were invited to participate in a telephone interview to assess the degree of parental anxiety and family dysfunction that was experienced. Parameters measured included cosleeping with the child, parental sleep disturbance, parental fatigue, monitor use, the number of night time checks on a child, child care use, parental outings, parental fear of missing a seizure, parental perception of a child's increased vulnerability and the family's stress level. The interview, which was conducted shortly after presentation at the emergency departments, compared anxiety and dysfunction experienced during the two weeks immediately preceding the visit with that experienced during the two weeks following a febrile seizure. Potential predictors of anxiety and dysfunction, including details of the presenting seizure, past medical illnesses, family history, the family's socioeconomic status and parental perception of the risk of a febrile seizure were queried.

**RESULTS:** Thirty-one (89%) of 35 families who were eligible for the study participated. Parental anxiety and family dysfunction were significantly greater for nearly all of the parameters assessed during the two weeks following a seizure. Socioeconomic factors correlated most closely with anxiety and dysfunction before a febrile seizure; however, socioeconomic factors were less predictive of anxiety and dysfunction during the two weeks following a seizure.

**CONCLUSIONS:** Parental anxiety and family dysfunction are the rule following a child's first febrile seizure. Neither higher socioeconomic status nor an understanding of the low risk of sequelae associated with febrile seizures was strongly predictive of improved coping during the two weeks following a seizure.

Key Words: Febrile seizures; Parental anxiety

### L'anxiété parentale et la perturbation familiale après une première convulsion fébrile chez l'enfant

**OBJECTIF** : Évaluer le degré d'anxiété parentale et de perturbation familiale après une première convulsion fébrile chez l'enfant.

PATIENTS ET MÉTHODOLOGIE : La famille de tous les enfants atteints d'une première convulsion fébrile s'étant présentés à l'un des trois départements d'urgence du district de Saskatoon, en Saskatchewan, a été invitée à participer à une entrevue téléphonique afin d'évaluer le degré d'anxiété parentale et de dysfonction familiale vécues. Les paramètres mesurés incluaient le fait de dormir avec l'enfant, les troubles du sommeil des parents, la fatigue parentale, le recours à un moniteur, le nombre de vérifications de l'enfant pendant la nuit, le recours aux services de garde, les sorties parentales, la peur parentale de rater une convulsion, la perception parentale d'un accroissement de la vulnérabilité de l'enfant et le niveau de stress familial. L'entrevue, menée peu après la visite à l'urgence, permettait de comparer l'anxiété et la dysfonction vécues pendant les deux semaines précédant immédiatement la convulsion à celles vécues pendant les deux semaines suivant cette convulsion. On a évalué les prédicteurs potentiels d'anxiété et de dysfonction, y compris le détail de la convulsion même, les antécédents médicaux et familiaux, le statut socioéconomique de la famille et la perception parentale du risque de convulsion fébrile.

**RÉSULTATS :** Trente et une (89 %) des 35 familles admissibles à l'étude y ont participé. L'anxiété parentale et la dysfonction familiale étaient beaucoup plus élevées dans les deux semaines suivant une convulsion et ce, dans presque tous les paramètres évalués. Les facteurs socioéconomiques étaient les plus corrélés à l'anxiété et à la dysfonction avant une convulsion fébrile. Cependant, ils prédisaient moins bien l'anxiété et la dysfonction dans les deux semaines suivant une convulsion.

**CONCLUSIONS :** L'anxiété parentale et la dysfonction familiale sont la règle après la première convulsion fébrile d'un enfant. Ni un statut socioéconomique élevé ni une compréhension du faible risque de séquelles reliées aux convulsions fébriles ne constituaient un prédicteur important de meilleure adaptation dans les deux semaines suivant la convulsion.

Correspondence: Dr Elaine Wirrell, Department of Pediatrics, Alberta Children's Hospital, 1820 Richmond Road SW, Calgary, Alberta T2T 5C7. Telephone 403-229-7683, fax 403-229-7649, e-mail elaine.wirrell@crha-health.ab.ca A febrile seizure is one of the most common neurological symptoms in the paediatric population, affecting 4% of children between the ages of six months and five years (1). Parents are usually reassured by doctors that these events are benign and that, with the exception of the rare case of prolonged febrile status epilepticus, do not cause brain injury or otherwise harm a child.

However, witnessing a febrile seizure may be very frightening. Baumer et al (2) reported that the majority of parents who witnessed their child's first febrile convulsion believed that the child was dying. Clearly, there is a discordance between the physician's perception that a febrile seizure is a benign phenomenon and most parents' reactions.

We undertook this prospective study to assess the degree of parental anxiety and disruption of routine experienced in families of children presenting with their first febrile seizure to an emergency department.

#### PATIENTS AND METHODS

All children between the ages of six months to five years presenting with their first febrile seizure to the emergency departments of the Royal University Hospital, St Paul's Hospital or Saskatoon City Hospital between January 1 and October 31, 1997, were identified by a review of emergency room records from Saskatoon District Health. These are the only three hospitals in Saskatchewan's Saskatoon district. Ethical approval for the study was received from the University of Saskatchewan Advisory Committee on Ethics in Human Experimentation.

A seizure was considered to be febrile if the rectal temperature was  $38.5^{\circ}$ C or higher, and was defined as complex if it was focal, lasted 15 min or longer, or if the child had more than one seizure within a 24 h period. Children with a previous history of febrile or afebrile seizures, or those with a co-existing intracranial infection were excluded from the study.

Parents were mailed an information sheet that described the study, and were contacted within two weeks of their child's initial presentation to the emergency department to request their participation in a brief telephone interview to collect the following information.

- A. Details about the presenting seizure (complex features, preceding illness or fever) and subsequent seizures since presentation.
- B. The child's past medical history. This included gestational age at birth, neonatal problems (defined as the need for hospitalization beyond seven days, excluding infants hospitalized solely for maternal reasons), previous medical illnesses requiring hospitalization, previous surgeries and developmental history.
- C. Family history. This included the number of parents in the home, the number of siblings,

the patient's birth order, and any previous seizures or hospitalizations of siblings.

- D. Socioeconomic status of the family. The socioeconomic status was assessed by maternal and paternal education levels (no high school, high school only, vocational school, some college or university, graduation from college or university), maternal and paternal occupation (unemployed, househusband or housewife, unskilled labour, clerk or apprentice, middle managerial, upper managerial, professional or other), and gross annual income of the family.
- E. Previous awareness of febrile seizures.
- F. Parental perception of the risks associated with a febrile seizure. This included the risk of epilepsy, death and brain injury with brief febrile seizures, and the risk of recurrence. Information about parental awareness of appropriate first aid measures to be taken in the event of a subsequent febrile seizure was also collected.
- G. Family function and parental anxiety during the two weeks immediately preceding and the two weeks immediately following the febrile seizure. Parents were questioned about co-sleeping with the child (rarely or never versus usually or always), monitor use (rarely or never versus usually or always), parental sleep problems (rare or none versus frequent or always), parental fatigue (rare or none versus frequent or always), frequency of night time checks on the child (up to once per night versus more than once per night), willingness to leave the child with a sitter (willing versus unwilling), parental outings (at least one versus none in a two-week period), persistent fear of missing an event that may harm the child (absent versus present), perception of the child's vulnerability (not increased versus increased) and the family stress level (none, mild, moderate or severe). Mild stress was defined as being equivalent to that experienced after being involved in a minor motor vehicle accident without sustaining personal injury. Moderate stress was defined as being equivalent to that experienced following the loss of a job. Severe stress was defined as being equivalent to that experienced after a life-threatening illness is diagnosed in an immediate family member.

#### Statistical analysis

Data processing and analysis were performed using Epi Info Version 6.0 (Centers for Disease Control, USA) (3). Measures of parental anxiety and family functioning before and after the febrile seizure were compared using risk ra-

Factor assessed	Two weeks before seizure (n=31)	Two weeks after seizure (n=31)	Relative risk (95% Cl)	Р
Co-sleeping with child				
Rarely or never	24	14	2.43	< 0.02
Frequently or always	7	17	(1.18 to 5.02)	
Monitor use during sleep				
Rarely or never	25	22	1.50	0.55
Frequently or always	6	9	(0.61 to 3.71)	
Parental sleep problems				
Rarely or never	29	9	11.00	< 0.001
Frequently or always	2	22	(2.83 to 42.83)	
Parental fatigue				
Rarely or never	18	5	2.00	< 0.002
Frequently or always	13	26	(1.29 to 3.11)	
Average number of night time checks on child			, , , , , , , , , , , , , , , , , , ,	
Un to one/night	18	7	1 85	< 0.01
More than one/night	13	24	(1.17 to 2.91)	-0.01
Willingness to leave child with a sitter			, , , , , , , , , , , , , , , , , , ,	
Willing	24	14	2 43	< 0.02
Unwilling	7	17	(1.18  to  5.02)	-0.02
Parantal outings			(	
At loss one outing in the past two wooks	23	10	2.63	< 0.003
No outings in the past two weeks	8	21	(1.38  to  5.00)	<0.005
Persistent fear of missing an event that will harm the shild	÷		(1100 10 0100)	
No	26	12	3.80	< 0.001
Voc	5	19	(1.62 to 8.89)	<0.001
Percention of child/com/unorability	5		(1102 to 0103)	
Not increased	26	17	2.80	< 0.03
Increased	20	14	(1.15  to  6.83)	~0.05
	3		(1.15 to 0.05)	
Pamily stress level	22	5	3.25	<0.001
Moderate or sovere	23	26	(1.75  to  6.02)	<0.001

tios. A risk ratio greater than 1 indicated a higher likelihood for that specific measure of parental anxiety or family dysfunction following compared with before the febrile seizure. A 95% CI that included 1.0 was not considered significant at P < 0.05.

To determine whether parental anxiety and family function were related to other data collected during the interview, including details of the presenting febrile seizure, the child's past medical history, family history, socioeconomic status of the family, previous parental awareness of febrile seizures and parental perception of the risks associated with febrile seizures (listed in A through F above), an overall Anxiety and Dysfunction Score was calculated. For each of the 10 items that measured parental anxiety or family dysfunction (listed in G above), families were given one point for responses that indicated greater anxiety or dysfunction and no points for responses that indicated less anxiety or dysfunction. The Anxiety and Dysfunction Score was the sum of the score for all of the 10 items. Thus, a score of 10 represented the highest level, and a score of 0 the lowest level of parental anxiety and family dysfunction. Univariate analysis of the

erception ofzure (SD±2, range two to seven weeks). In all cases, thelisted in Aparent who was interviewed had witnessed the seizure.DysfunctionThe study group consisted of 12 boys and 19 girls; the

cant).

RESULTS

(SD±12, range six to 66 months). Eighteen (58%) of 31 children had simple febrile seizures, while 13 children had complex seizures (three focal, one prolonged and nine recurrent within 24 h). The median seizure duration was 2 min (25th to 75th percentile, 1 to 4 min). Twenty-two (71%) children were known to have a fever or had other symptoms of an intercurrent illness before the seizure. Fifteen (48%) families

predictors of the Anxiety and Dysfunction Score was per-

formed using  $\chi^2$  analysis (P<0.05 was considered signifi-

Thirty-one of 35 (89%) families with children present-

ing with their first febrile seizure between January 1 and

October 31, 1997 participated in the study. The remain-

ing four (11%) families could not be contacted. Parents

were interviewed a mean of four weeks following the sei-

mean age of the children at presentation was 19 months

Factor	Number of subjects*	Mean score	Р
Previous medical illness requiring			
hospitalization			
No	24	2.0	< 0.03
Yes	7	3.7	
Paternal education			
Some college or university	18	1.7	< 0.02
No college or university	12	3.3	
Maternal occupation			
Middle or upper management,	11	1.2	< 0.004
None of the above	20	3.1	
	20	5.1	
Paternal occupation Middle or upper management, or professional	12	1.3	< 0.003
None of above	18	3.1	

**TABLE 2:** Factors affecting parental preseizure Anxiety and Dysfunction Score

were aware of febrile seizures before their child's presentation.

Most parents had a reasonable perception of the risks associated with a febrile seizure, although they tended to underestimate the risk of febrile seizure recurrence and overestimate the risk of death or brain injury. The median recurrence rate for febrile seizures given by parents was 25% (25th to 75th percentile, 10% to 50%) and the risk of subsequent epilepsy was given as 5% (25th to 75th percentile, 0% to 10%). The median risk of death with a brief febrile seizure stated by parents was 2% (25th to 75th percentile, 0% to 5%) and for brain injury was 5% (25th to 75th percentile, 2% to 5%). When questioned about how they would manage subsequent febrile seizures, 22 (71%) parents responded appropriately, indicating that they would place their child on his or her side or abdomen, and not attempt to put anything in his or her mouth.

#### Family function and parental anxiety two weeks after compared with immediately preceding a febrile seizure

With the exception of monitor use, significantly greater anxiety and dysfunction for all factors assessed were experienced after a febrile seizure compared with before the seizure (Table 1).

The mean Anxiety and Dysfunction Score was also significantly higher in the two weeks following the febrile seizure (mean score 6.3, SD $\pm$ 2.1, range 2 to 9) than immediately preceding the seizure (mean score 2.4, SD $\pm$ 1.7, range 0 to 6, P<0.01), indicating greater anxiety and more family dysfunction. The preseizure Anxiety and Dysfunction Score was significantly higher in families that had experienced a previous medical illness requiring the hospitalization of a child, had a lower paternal education level, and had lower maternal and paternal occupation levels (Table 2); however, the score was unrelated to other factors in the child's past medical history or family history, the maternal education level or family income.

The Anxiety and Dysfunction Score two weeks after a seizure was related only to a previous medical illness that required hospitalization of the child and paternal occupation. Anxiety and dysfunction were higher in families with a child who had been hospitalized previously (mean score 7.9) versus families that had not experienced a child's previous hospitalization (mean score 5.8, P<0.02). Families with fathers employed in middle or upper management, or professional fields coped better (mean score 5.2) than families with fathers who worked in other fields (mean score 7.0, P<0.03). Anxiety and family dysfunction two weeks after a seizure were unrelated to other factors in the child's past medical history, family history, socioeconomic status, details of the presenting seizure, previous parental awareness of febrile seizures, correct parental interpretation of the event or parental perception of the risks of a febrile seizure.

#### DISCUSSION

Witnessing a child's first febrile seizure is a very frightening experience for most parents. In our study, more than one-quarter of parents – a percentage comparable with previous studies (2,4-6) – did not recognize the event as being a seizure, but instead believed that the child was dying. The extreme fear felt by most parents is in sharp contrast to the physician's perception that most febrile seizures are benign and are associated with a minimal risk of brain injury, death or subsequent epilepsy.

Not surprisingly, we found parental anxiety and family dysfunction to be significantly higher shortly after a child's first febrile seizure compared with before the seizure. Before the febrile seizure, the strongest predictor of parental anxiety and family dysfunction was low socioeconomic status, as measured by the level of parental education and occupation. However, two weeks after a febrile seizure, socioeconomic status was much less predictive of coping ability, with only paternal occupation remaining as a significant predictor of coping ability. Thus, there is no guarantee that families of higher socioeconomic status, who normally function well, cope favourably following their child's first febrile seizure. Previous hospitalization of a child was the only other significant predictor of greater parental anxiety and family dysfunction after a seizure. These families had already suffered through an important medical illness in the child, and may have viewed the child as being more vulnerable to serious medical problems.

Education of parents about the potential risks of febrile seizures has been deemed to be very important in diffusing anxiety because parents often overestimate serious risks such as death, brain damage or subsequent epilepsy associated with simple febrile convulsions (7). Furthermore, discussion of appropriate first aid measures to be taken in the event of subsequent seizures should empower and reassure parents. Surprisingly, we found that parents who correctly perceived the low risks of serious sequelae and knew appropriate first aid did not have a significantly lower level of anxiety or lower degree of family dysfunction following the febrile seizure than parents who did not correctly understand the risks or first aid procedures. Shortly after witnessing a very frightening event such as a febrile seizure, parents may have difficulty conceptualizing the risks, leading to a disparity between what they 'know' and what they 'feel'.

Despite the fact that a febrile seizure is one of the most common neurological symptoms in childhood, few studies have assessed parental reactions associated with febrile seizures. Shuper et al (8) reported high parental anxiety in a prospective study of children presenting to the emergency department with a simple febrile seizure; however, they did not assess other measures of anxiety or family function. Balslev (6) reported increased sleep disturbance and dyspeptic symptoms in parents who witnessed a febrile seizure; however, the predictors of adverse parental reaction were not studied.

The present study is unique in several aspects. No previous study has addressed the predictors of parental anxiety and family dysfunction following febrile seizures; however, Mitchell et al (9) studied the predictors of parental anxiety in children with epilepsy and concluded that socioeconomic factors were the most significant predictors. A second strength of the present study is its populationbased, prospective design. We surveyed emergency departments from the only three hospitals in the Saskatoon area and, therefore, included all children in this region brought to emergency departments with their first febrile seizure. However, the study did not include children who were taken to their family doctors or a walk-in clinic. We interviewed all families within seven weeks of presentation to minimize recall bias.

Several weaknesses of the present study are also evident. We did not assess whether hospitalization of the child at the time of presentation with a febrile seizure or whether the extent of laboratory investigations performed affected parental anxiety or family dysfunction. However, Shuper et al (8) reported that admission to hospital yielded no relief of anxiety for 27% of parents and only some relief for 34% of parents. We also did not assess the effect of counselling and information given to parents during the emergency room visit, nor did we assess whether parents who were taught to administer rectal benzodiazepines in the event of a subsequent febrile seizure coped better. Finally, we measured family function and parental anxiety using a series of variables that were summated into an Anxiety and Dysfunction Score. These variables have not been validated, and the use of a known scale of parental anxiety and family function would have strengthened our results. Finally, our patient numbers were small, which may limit the strength of our results.

#### **CONCLUSIONS**

Family anxiety and dysfunction are the norm following a child's first febrile seizure, even in families with higher socioeconomic status who usually cope well. At the time of a child's presentation, education of the parents about febrile seizures is important but is unlikely to provide adequate reassurance to allow resumption of normal family functioning, particularly when this information is conveyed to highly distraught parents who have just witnessed a febrile seizure. Although it is important for families to be told that these events are generally benign, with a minimal risk of brain damage or subsequent epilepsy, written information should be provided and a routine follow-up visit scheduled one to two weeks after the seizure to review these facts and first aid steps in the event of a subsequent seizure. At the follow-up visit, it can be acknowledged that significant anxiety is a normal reaction and inquiries about current family functioning can be made. Given that febrile seizures are such common occurrences in young children, they should also be discussed at well-baby visits, particularly in children known to be at higher risk for febrile seizures (10).

Further studies using greater patient numbers and validated measures of parental anxiety and family dysfunction are warranted.

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