

Febrile seizures and parental anxiety: does information help?

Tanja Flury^a, Christine Aebi^a, Filippo Donati^{a,b}

^a Children's Hospital Wildermeth, Biel

^b Department of Neurology, University Hospital, Inselspital, Bern, Switzerland

Summary

Aim of the study: To investigate the effect of febrile seizures on the behaviour and emotional situation of parents in order to improve our attitude towards these children and parents in future.

Methods: We analysed 135 questionnaires on parents' behaviour and emotional situation during and after a febrile seizure in their children.

Results: Febrile seizures were unknown to 44% of the parents. 121 parents (91%) reported severe anxiety on witnessing the first febrile seizure. In 69% the anxiety was so strong, that the parents believed their child would die. Severe anxiety was significantly associated with lack of knowledge about febrile seizures: 79% (no knowledge of febrile seizures) versus 59% (with knowledge). The level of anxiety appeared to be associated with low educational level, but not with ethnic background or income.

Conclusions: Our study shows that knowledge

of febrile seizures among concerned parents in our region remains insufficient. The results are ambiguous. On the one hand we found an association between severe anxiety and lack of knowledge on febrile seizures, suggesting that information prior to the first febrile seizure might reduce the anxiety level and thus lead to appropriate reactions in case of recurrence. On the other hand although parents knew about febrile seizures, they still had very high anxiety levels and would react inappropriately in case of recurrence. Therefore if information is provided to parents, it must be specific, especially about which measures are to be taken or avoided respectively. A prospective study to observe positive and negative effects of preventive information is needed.

Key words: febrile seizure; parental anxiety; information

Introduction

When parents witness a febrile seizure in their child, it may provoke strong anxiety and fear [1, 2]. The event may be followed by restrictions on the quality of family life and parents may suffer from anxiety and insecurity for a long period of time whenever their child subsequently develops a fever

[3]. This is in stark contrast to the very good prognosis associated with febrile seizures [4-6].

The aim of the study is to investigate the effect of febrile seizure on the behaviour and emotional situation of parents in order to improve our attitude towards these children and parents in future.

Patients and methods

Using the databank of the Children's Hospital Wildermeth in Biel we were able to identify 213 children with the diagnosis of febrile seizures who were observed in the hospital over at least twenty-four hours in the period between April 1995 and December 1999. Children with previous epileptic seizures without fever and/or children with psychomotor retardation were excluded.

A questionnaire with 115 items in French and German was sent to the parents of these 213 children. The questionnaire, which was anonymous and coded, had previously

been tested by six parents of children with febrile seizures and adjusted to improve comprehension.

The parents were asked about the following topics: knowledge of febrile seizures, measures taken, their thoughts and feelings at the time of the first febrile seizure and their fear of recurrence at the time of the study. Parents were asked to quantify their anxiety at the first febrile seizure on a scale of 1 to 4 (1 = no anxiety, 4 = anxiety, so strong they thought their child was going to die). They also assessed their general anxiety level on a scale of 1 to 5. We also asked

about the quality of the information they had received from physicians, as well as about possible effects of the first febrile seizure on their own behaviour and health (manifestations of nervousness, headache, stomach ache, sleep disturbances). The following baseline characteristics were recorded: income, country of origin and parental education.

The databank was linked to the statements in the coded

questionnaires. Data were evaluated with S-PLUS Professional (Copyright 1998-1999, Math Soft Inc). Univariate analysis was performed with Fisher's Exact Test and Pearson's Chi²-Test with Yates' continuity correction. For multivariate analysis we used a Logistic Regression Model and a Cumulative Regression Model. We chose 95%-probability for confidence interval, with significance above 5%.

Results

Background

Of the 213 questionnaires distributed we received 135 answers about 133 children (response rate 63%). Twenty-eight patients could not be reached due to unknown new addresses. Two of the questionnaires were completed by both parents, duplicate statements were corrected. In 80% of the cases the questions were answered by the mother, in 19% by the father and in one case by the grandmother. All answering persons were witnesses of the febrile seizure. Of the 135 questionnaires, 101 (75%) were fully completed, the maximal missing rate, especially for socio-economic items, was 15%. Eighty-three percent of the parents wished to be informed of the results of the study. Forty-two parents (35%) had received a primary school education only, 50 parents (42%) had attended secondary school and 28 parents (23%) had completed higher education. Ninety-three parents (73%) were of Swiss origin, 19 parents were (15%) of west European and 15 parents (12%) of east European, Asian or Latin American origin. The parent's income was less than 3500 Swiss francs in 20%, between 3500 and 6000 Swiss francs in 50%, above 6000 Swiss francs in 30%.

The mean age of the children at the first febrile seizure was 21.9 ± 15.8 months, 79 children (62%) were younger than 24 months and the sex ratio male to female was 1.04:1.00 (table 1).

According to the parents febrile seizure lasted less than 5 minutes in 70 cases (53%), 5 to 15 minutes in 36 cases (27%), 15 to 30 minutes in 14 cases (11%) and more than 30 minutes in 12 cases (9%). Nineteen children (15%) presented with two or more seizures in 24 hours and 27 children (20%) had siblings or a parent with febrile convulsions.

In 72 children (56%) there had been no recurrence of febrile seizures. At the time of questioning 26 children (20%) had suffered one recurrence, 16 (13%) had had three episodes, six children (5%) had had four febrile seizures, five children (4%) had had five seizures, in two cases there had been six seizures and in one case a total of eight febrile seizures had

occurred. At the time of questioning the average time since the first febrile seizure was 2.3 ± 1.4 years (data from the patient's hospital admission).

Situation during the first febrile seizure

Prior to their child's first febrile seizure, febrile seizures were unknown to 58 parents (44%). During the first febrile seizure, 79 parents (60%) thought, "the child would die or is already dead". Ninety-four parents (72%) "did not know what to do" during the first febrile seizure of their child. Inappropriate measures were often taken: in 22 cases (16%) mouth-to-mouth respiration and in six cases (5%) cardiac massage were performed, 16 children (12%) were hit on their back. Appropriate measures such as placing the child on its side were carried out in 39 cases (29%) and medication to reduce fever was given in 57 cases (42%).

Severe parental anxiety during the first febrile seizure was present in 121 cases (91%) and in 92 cases (69%) parental anxiety was of the highest level (table 2). 64 parents (48%) feared a disturbance in the child's future development due to the febrile seizure.

Severe anxiety was significantly associated with the level of previous information: 79% of those parents with no knowledge of febrile seizure reported maximal anxiety in comparison to 59% of the parents with knowledge about febrile seizures ($p = 0.020$ in multivariate analysis). We found a significant connection between severe parental anxiety and low educational level ($p = 0.033$), but none with further possible factors for anxiety such as differing ethnic background, very anxious personality or low income (table 3).

Situation after the first febrile seizure

Although all parents were verbally informed by the physician following the first febrile seizure of their child, only 101 parents (75%) mentioned that they had received information about the benignity of febrile seizures. 85 parents (65%) judged the information as sufficient, 41 parents (31%) wished more verbal and 45 parents (34%) wished more

Table 1

Data on patients.

		n			n			n		n total
Sex	male	68	51%	female	65	49%				133
Age in months	<12	24	19%	12-24	55	43%	>12	49	38%	128
Number of febrile seizures	1 FS	72	56%	2 FS	26	20%	>2 FS	30	24%	128

n total = all parents that answered this question

written information. 13 parents (10%) requested further investigation. 89 parents (66%) had felt reassured after receiving the information from the physician, but anxiety over a recurrence still existed at the time of questioning in 118 parents (88%), of which 76 parents (56%) presented moderate to very severe fear of recurrence (table 2).

In those parents who in the self-assessment judged themselves to be moderately to very anxious there was a significant association with fear of recurrence in Pearson's Chi²-Test and in multivariate data analysis (p < 0.001). The time elapsed since the first febrile seizure was significantly inversely associated with fear of recurrence (p < 0.001) (table 3).

Fear of recurrence was not associated with the total number of febrile seizures (more than 4), ethnic origin, low educational level or altered perception of the child.

A hundred and twenty-six parents (93%) mentioned having received information as to the measures they should take in case of recurrence. However many parents stated they would still react inappropriately: 13 parents (10%) would perform cardiac massage, 23 parents (18%) would carry out

mouth-to-mouth respiration and 19 parents (15%) would shake their child strongly. Appropriate measures, such as laying the child on its side would be performed in 82 cases (64%), 100 parents (76%) would give medication against fever, 119 (90%) would protect against aspiration and 109 parents (95%) would give diazepam rectal (table 4).

In 99 cases (75%) parents had suffered from sleep disturbances following the febrile seizure in their child, in 35 parents (27%) these persisted for several weeks and in 28 parents (21%) for months. The majority of parents (86%) monitored the child at night, in 62% more than once a night. New symptoms appeared in concerned parents: in 40 cases (30%) nervousness, in 16 cases (12%) headache and in 12 cases (9%) stomach ache were mentioned. Anxiety reappeared in 124 parents (93%) in case of renewed fever in the child. 34 parents (25%) found their child changed after the first febrile seizure. The change noticed persisted for weeks in 8 cases (6%) and for years in 6 cases (5%). The most frequently described changes were: "more anxious, more sleepy, more calm or more lively than before the first febrile seizure".

Table 2
Level of anxiety at the first febrile seizure and fear of recurrence at the time of the study (on average 2.3 ± 1.4 years later).

Level of anxiety	at the first febrile seizure		at the time of the study*	
	n = 134		n = 134	
Very severe	92	69%	18	13%
Severe or moderate* anxiety	29	22%	58	43%
Mild anxiety	8	6%	42	32%
No anxiety	4	3%	16	12%

* Fear of recurrence was measured in 5 levels

Table 3
Factors significantly influencing the anxiety level at the first febrile seizure (a) and at the time of the study (b).

Factors for severe anxiety					P
Knowledge about febrile seizures	knowledge FS	59%	no knowledge FS	79%	0.002
Education	high education	89%	low education	95%	0.033
Very anxious personality	not or lightly anxious	83%	moderate or very anxious	17%	>0.001
Time since the first febrile seizure	x _{max}	5.3 years	x _{min}	0.23 years	-0.001

Table 4
Appropriate and inappropriate measures during the first febrile seizure and in case of recurrence.

	first febrile seizure			in case of recurrence		
	n		n total	n		n total
Side position	39	29%	133	82	64%	128
Medication against fever	57	42%	135	100	76%	132
Inappropriate measures:						
Cardiac massage	6	5%	134	13	10%	127
Mouth-to-mouth respiration	22	16%	135	23	18%	130

n total = all parents who answered this question

Discussion

A large majority of patients wish to be informed in detail about disease and therapy [7]. The present study confirms this desire. The high response rate (63%) to our questionnaire, the very strong wish

(83%) of the parents to be informed about our results and the demand for more written or verbal information in a third of parents, indicate the intense interest of concerned parents. Although the possi-

bilities of obtaining information about diseases have increased tremendously in these last years [8], our study shows that the knowledge of febrile seizures is still insufficient in our region. Febrile seizures were unknown to 44% of the parents in our study as opposed to only 17% in a Scandinavian study [9].

Febrile seizures are a harmless condition with a very good prognosis [4-6], but they may all the same provoke anxiety in concerned parents. Our results show that at the time of the first febrile seizure very severe anxiety appeared in 69% of the parents. Our data are confirmed by other studies showing severe anxiety ("the child is going to die or is already dead") in 47% and 77% of parents [1, 3, 9]. To our knowledge only the study of Shuper et al. demonstrated a significantly lower anxiety (29%) [2]. Severe anxiety at the time of questioning existed in 87% of the parents in comparison with 44% of the parents in Van Stuijvenberg's study [3] and correlated directly with the emotional situation (anxiousness). In our study anxiety decreases significantly with the lapse of time after the first febrile seizure (with or without recurrence). This is in contrast to the study of Balsev et al., which demonstrated a persisting constant level of anxiety [9].

We are aware that our patients form a selected group as we included only those patients admitted for observation for at least 24 hours in the study.

Although better information has been provided in the last years and socio-economic and educational levels have increased, the level of anxiety due to febrile seizures appears to have remained constant at a very high level during the past 20 years [1-3, 9, 10]. In a majority of parents we also observed new psychosomatic disorders such as sleep-disturbances (75%), nervousness (30%) and headache (9%). These disturbances often persisted for months. A quarter of parents claimed that their child was emotionally altered or that its level of activity had changed, confirming a study of Verity et al. [6] demonstrating a significant change in the mothers' perception of their children following febrile seizures. Our study showed a slight but significant reduction of anxiety level in parents with previous knowledge of febrile seizures in comparison with parents without knowledge (59% versus 79% on the highest anxiety level). These results confirm those of two previous studies: Shuper et al. [2] found a significant correlation between anxiety relief and increased medical information and van Stuijvenberg et al. demonstrated that reassuring information was the reason for a calm attitude towards febrile seizures in 21% of the parents [3]. In the present study anxiety did not correlate with the ethnic origin of the parents, in contrast to Van Stuijvenberg's study [3] where a significant correlation between a high anxiety level and non west European background was demonstrated. We did find a low educational level to be associated with anxiety at the first febrile seizure and thus specific and repeated information to these parents might be advantageous.

The inverse correlation between severe anxiety and previous knowledge of febrile seizures leads us to the hypothesis that preventive information about febrile seizures could have a positive effect on the behaviour and the measures taken by the parents as shown by Balsev et al. [9]. Our results are ambiguous on this topic: on the one hand we demonstrated that information provided before the first febrile seizure can significantly reduce the anxiety level of parents and we also observed an increase in the performed appropriate measures in the case of recurrence. On the other hand, although preventive information had been given, we observed a persistent high level of severe anxiety at the time of the study, as well as an increase in performed inappropriate measures in case of recurrence. The high level (28%-66%) of inappropriate measures in case of febrile seizures shown in previous studies [1, 2, 9] as well as our results (paradoxical increase of prevention of inappropriate measures in case of recurrence) must spur us on to improving our information in order to avoid inappropriate, unnecessary and potentially dangerous measures such as cardiac massage or slaps on the back. Preventive medical information may have negative effects on parents in terms of worrying them unnecessarily or, if the information is not sufficiently specific, more incorrect measures might be taken by concerned parents. A prospective study to define the positive and negative effects of preventive information about febrile seizures is needed.

Conclusions

With our study we show that the knowledge of febrile seizures is still insufficient among concerned parents in our region. The results of supplying information are ambiguous; on the one hand we found an association between severe anxiety and knowledge of febrile seizures, which suggests that information before the first febrile seizures reduces the level of parental anxiety thus allowing more appropriate measures to be taken. On the other hand, even if parents were well informed about febrile seizures, they still suffered from very high anxiety and performed more inappropriate measures. If information is provided to parents, it has to be specific, especially as to measures to be taken or avoided during a seizure. We suggest a prospective study to observe the positive and negative effects of preventive information.

Correspondence:

Dr. med. Filippo Donati
Department of Neurology
University Hospital, Inselspital
CH-3010 Bern
e-mail: filippo.donati@insel.ch

References

- 1 Baumer JH, David TJ, Valentine SJ, Roberts JE, Hughes BR. Many parents think their child is dying when having a first febrile convulsion. *Dev Med Child Neurol* 1981;23:462-4.
- 2 Shuper A, Gabbay U, Mimouni M. Parental anxiety in febrile convulsions. *Isr J Med Sci* 1996;32:1282-5.
- 3 van Stuijvenberg M, de Vos S, Tjiang GC, Steyerberg EW, Derksen-Lubsen G, Moll HA. Parents' fear regarding fever and febrile seizures. *Acta Paediatr* 1999;88:618-22.
- 4 Annegers JF, Hauser WA, Shirts SB, Kurland LT. Factors prognostic of unprovoked seizures after febrile convulsions. *N Engl J Med* 1987;316:493-8.
- 5 Nelson KB, Ellenberg JH. Prognosis in children with febrile seizures. *Pediatrics* 1978;61:720-7.
- 6 Verity CM, Greenwood R, Golding J. Long-term intellectual and behavioural outcomes of children with febrile convulsions. *N Engl J Med* 1998;338:1723-8.
- 7 Chaplin JE, Wester A, Tomson T. The perceived rehabilitation needs of a hospital-based outpatient sample of people with epilepsy. *Seizure* 1998;7:329-35.
- 8 Keller M, Gruetter R, Peltenburg M, Fischer JE, Streuer J. Use of the Internet by medical doctors in Switzerland. *Swiss Med Wkly* 2001;131:251-4.
- 9 Balslev T. Parental reactions to a child's first febrile convulsion. A follow-up investigation. *Acta Paediatr Scand* 1991; 80:466-9.
- 10 Rutter N, Metcalfe DH. Febrile convulsions - what do parents do? *Br Med J* 1978;II:1345-6.

The many reasons why you should choose SMW to publish your research

What Swiss Medical Weekly has to offer:

- SMW's impact factor has been steadily rising, to the current 1.537
- Open access to the publication via the Internet, therefore wide audience and impact
- Rapid listing in Medline
- LinkOut-button from PubMed with link to the full text website <http://www.smw.ch> (direct link from each SMW record in PubMed)
- No-nonsense submission – you submit a single copy of your manuscript by e-mail attachment
- Peer review based on a broad spectrum of international academic referees
- Assistance of our professional statistician for every article with statistical analyses
- Fast peer review, by e-mail exchange with the referees
- Prompt decisions based on weekly conferences of the Editorial Board
- Prompt notification on the status of your manuscript by e-mail
- Professional English copy editing
- No page charges and attractive colour offprints at no extra cost

Editorial Board

Prof. Jean-Michel Dayer, Geneva
 Prof. Peter Gehr, Berne
 Prof. André P. Perruchoud, Basel
 Prof. Andreas Schaffner, Zurich
 (Editor in chief)
 Prof. Werner Straub, Berne
 Prof. Ludwig von Segesser, Lausanne

International Advisory Committee

Prof. K. E. Juhani Airaksinen, Turku, Finland
 Prof. Anthony Bayes de Luna, Barcelona, Spain
 Prof. Hubert E. Blum, Freiburg, Germany
 Prof. Walter E. Haefeli, Heidelberg, Germany
 Prof. Nino Kuenzli, Los Angeles, USA
 Prof. René Lutter, Amsterdam, The Netherlands
 Prof. Claude Martin, Marseille, France
 Prof. Josef Patsch, Innsbruck, Austria
 Prof. Luigi Tavazzi, Pavia, Italy

We evaluate manuscripts of broad clinical interest from all specialities, including experimental medicine and clinical investigation.

We look forward to receiving your paper!

Guidelines for authors:

http://www.smw.ch/set_authors.html

Impact factor Swiss Medical Weekly



All manuscripts should be sent in electronic form, to:

EMH Swiss Medical Publishers Ltd.
 SMW Editorial Secretariat
 Farnsburgerstrasse 8
 CH-4132 Muttenz

Manuscripts: submission@smw.ch
 Letters to the editor: letters@smw.ch
 Editorial Board: red@smw.ch
 Internet: <http://www.smw.ch>