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ORIGINAL ARTICLE

Consensus statements on the information to deliver after a febrile seizure

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Abstract

Febrile seizures (FS) are usually self-limiting and cause no morbidity. Nevertheless they represent very traumatic events for families. There is a need to identify key messages that reassure carers and help to prevent inappropriate, anxiety-driven behaviors associated with "fever phobia." No recommendations have been proposed to date regarding the content of such messages. Using a Delphi process, we have established a consensus regarding the information to be shared with families following a FS. Twenty physicians (child neurologists and pediatricians) from five European countries participated in a three-step Delphi process between May 2018 and October 2019. In the first step, each expert was asked to give 10 to 15 free statements about FS. In the second and third steps, statements were scored and selected according to the expert ranking of importance. A list of key messages for families has emerged from this process, which offer reassurance about FS based on epidemiology, underlying mechanisms, and the emergency management of FS should they recur. Interestingly, there was a high level of agreement between child neurologists and general pediatricians.

Conclusion: We propose key messages to be communicated with families in the post-FS clinic setting.

What is Known:
- *Febrile seizures (FS) are traumatic events for families.*
- *No guidelines exist on what information to share with parents following a FS.*

What is New:
- *A Delphi process involving child neurologists and pediatricians provides consensual statement about information to deliver after a febrile seizure.*
- *We propose key messages to be communicated with families in the post-FS clinic setting.*

Keywords Febrile seizure · Fever phobia · Delphi · Antipyretics · Parental reassurance · Consensus

Abbreviations

EEG Electroencephalogram
FS Febrile seizure
MRI Magnetic resonance imaging

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Introduction

Febrile seizures (FS) are defined by the American Academy of Pediatrics as seizures that occur during fever in the absence of intracranial infection[1]. The prognosis is usually excellent with no long-term consequences[2–4]. However, FS are traumatic events for families[5]. Parents frequently describe that at the

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moment their child experienced a FS, they feared their child's imminent death[6]. Thus, there is a high risk of subsequent post-traumatic stress disorder[7, 8]. Recurrence of FS prompts more than half of the parents to modify their parenting behaviour[9] by sleeping in the same room with their child or by measuring body temperature multiple times per day[6]. Most of the parents exhibit sleep disturbance and a high level of anxiety[7, 8]. In this context, the fear of fever may also lead to an overuse of antipyretics that might be harmful[10–13].

These modifications of parenting behaviors are probably motivated by fear[6,14,15,] and erroneous beliefs about FS, for example, that FS can cause brain damage and subsequent intellectual and physical disability[16]. The influence of socio-cultural factors on these flawed beliefs is controversial[16, 17]. However, a systematic review described it as a common world phenomenon[16]. Some studies report that these beliefs are shared and promulgated by poorly informed healthcare professionals when their role is to share accurate information and reassure parents[5, 12].

Recommendations have been published regarding the neurodiagnostic evaluation of a child with a simple FS[18], diagnostic markers, management interventions, and outcome measures of FS [19]. There are also website providing information on FS for parents and caregivers (e.g., NINDS, Mayo clinic). However, no guidelines to date have addressed the question of what information to share with parents following a FS in particular in the emergency setting.

To this end, we conducted a study involving child neurologists and pediatricians from five European countries to achieve a consensus regarding the first key messages to be shared with parents following a FS.

Material and methods

Two groups of 10 physicians (respectively, child neurologists and pediatricians working either in general pediatric department, in the pediatric emergency room, or both) participated in the study from May 2018 to October 2019 with two pairs of specialists per country (France, Germany, Italy, Spain, UK). The rationale of interviewing pediatricians from two different subspecialties was motivated by the idea that these different points of view may be complementary.

Our aims were shared with those experts in a short summary emphasizing that FS are "very emotional events for parents" and could "change the daily life of the whole family as well as the parental attitudes" towards their child(ren).

A three-step Delphi process was undertaken separately for each group of experts. The Delphi is a technique that aims at obtaining consensus on the opinions of "experts." By experts is usually meant "a panel of informed individuals." Consensus is obtained through a multistage process, replies to the first questionnaire being implementing the following, and so on[20, 21]. By contrast to the usual method based on structured questionnaires, in this study, we first collected free statements. First, each expert provided 10 to 15 free statements representing key messages to give to parents following a FS, without more precision. They were free to decide whether to provide messages about simple FS or to provide messages concerning both simple and complex FS. Letting these two alternatives possible was a way to address the question of whether this distinction is relevant to be communicated to parents, or whether it can be seen too complex or stressful. These were collected without any selection. Secondly, participants were asked to rate each statement obtained in the first step from 1 to 10, according to their relevance (1 being less relevant). Participants were encouraged to use the whole scale and to direct statements towards parents rather than healthcare professionals. Twenty statements with the highest relevance scores were selected. In the third step, participants were invited to select their 10 preferred statements from the 20 identified as most relevant and to rank them in order of priority from 1 to 10 (1 being the highest priority).

The study did not require ethical approval. The data was then analyzed quantitatively (i.e., the means of quotations for each proposition was calculated as well as standard deviations) and qualitatively (i.e., the main thematics were extracted from the reading of all propositions and comparisons were made between the information sharing statements that emerged from child neurologists and those from pediatricians).

Results

Child neurologists step 1 (Supplementary material table 1)

A total of 40 proposed information sharing statements were summarized for the first round (Supplementary material table 1). Several statements were proposed by more than one expert. According to a qualitative analysis, they can be gathered in five descriptive categories.

1) The first category focuses on an *epidemiological and definitional theme* where febrile seizures, the population affected, and frequency are described.
2) The second focuses on the *physiological mechanisms*. Several panel members wished to emphasize the concept of an "individual-dependent temperature threshold" which triggers a FS.
3) The third category places FS in a realistic context emphasizing that they are not triggered by every infection and have an excellent prognosis.
4) The fourth category focuses on the emergency care plan for parents to implement in the event that FS recur.

5) The fifth and final category emphasizes that the diagnosis of FS is a clinical one in order to prevent unnecessary investigations.

Child neurologists step 2 (Supplementary material Table 1)

Participants were then asked to score the 40 statements from 1 to 10 according to their respective importance (1 meaning "less important"). Statements showed mean values of 3.2 to 9.5 and standard deviations from 0.8 to 3.8 indicating that participants had scored using the whole scale. The five categories identified in step 1 were found again in the 20 highest scoring statements in step 2 as follows:

- *Category 1:* "FS are common. For every 100 children, between 3 and 5 will experience one or more FS."
- *Category 2/3*: "In most cases, FS cease spontaneously within 2-3 minutes, and do not require any treatment."
- *Category 4*: "In the event of a FS, keep calm, make the environment safe to avoid harm to the child, if possible place the child in the recovery position, do not put anything into mouth or between teeth, note the duration and physical features of the seizure."
- *Category 5*: "The diagnosis of FS is based on history and physical examination. Laboratory tests, electroencephalogram and neuroimaging are not routinely recommended."

Statements rated at the lower end were those providing details about biological mechanisms or about epidemiology. Some statements mentioned risk of recurrence (e.g., "after 24 hours of fever, the risk of appearance of FS is very low") or the genetically determined susceptibility to FS (e.g., "FS affect genetically predisposed individuals: the seizures are not precipitated by fever"). The statements receiving the lowest scores were statements about the risk of epilepsy in the future.

In summary, it is of value to examine the lowest scoring statements in addition to the highest scoring ones as the lower scoring ones may reflect information that physicians would freely share with parents but which may generate anxiety and confusion and generate the risk of fever phobia.

Child neurologists step 3 (Supplementary material Table 2)

Experts then ranked the 20 highest scoring statements from step 2 in order of priority (1= highest priority). Therefore, each participant had to abandon 10 statements judged less important for parents. One participant declined to contribute to step 3 due to objections to the 20 statements selected in step 2. This resulted in the emergence of ten preferred information-sharing statements from the experts (Supplementary material table 2).

We did not observe any obvious association between the relevance score and the propensity to be abandoned, i.e., some propositions were kept by all participants although the relevance score was not very high, and vice versa. For instance, statement 4 relating to the temperature threshold for triggering a FS was abandoned by the majority of child neurologists (7/10), although the 3 who kept this statement scored it as priority. "Degree of temperature is not very important in triggering seizures, sometimes even with a very mild increase of temperature, an event might occur. The highest fever necessary to cause FS is specific to the individual as each child's threshold convulsive temperature varies."

Three statements achieved the greatest consensus in that they were kept by all or almost all participants (associated with only 2, 0, 2, and 1 abandons, respectively):

- "FS are common: for every 100 children aged 6 months-5 years, between 3 and 5 will experience one or more febrile seizures."
- "In the event of a FS: keep calm, make the environment safe, place the child in the recovery position, do not place anything into the mouth or between the teeth, note duration and features of the seizure"
- "In most cases, FS spontaneously cease within 2-3 minutes, and do not require any treatment."
- "Call emergency services if:

- A FS lasts longer than 5 min
- rectal diazepam has been applied
- there are focal features
- there is post-ictal paresis
- the child's general clinical condition seems impaired or symptoms are prolonged (more than 5 min)"

The same three-step procedure was run with pediatricians.

Pediatricians step 1 (Supplementary material table 3)

A total of 55 statements were collected from the first round with the pediatricians. The five previously identified categories were also found in the pediatricians' proposals: FS and epidemiology (mean age of occurrence, percentage of the general population with FS), possible mechanisms of FS, safety measures to take in the event of recurrence, and when to go to the pediatric emergency department. Many statements offered reassurance, emphasizing the "excellent prognosis" of FS, the "short duration of a seizure," and the fact that "children experiencing FS will have normal intelligence."

Pediatricians step 2 (Supplementary material table 3)

The 55 statements were scored in the second round from 1 to 9.3 with standard deviations spreading out from 0.9 to 3.8

indicating the use of the whole scale. The four best-scored statements illustrate how public health messages were at the core of the content of information shared at a clinic following a FS and were as follows:

- "A typical FS does not require an assessment by a neurologist nor any further investigations (electroencephalogram i.e. EEG, Magnetic Resonance Imaging scan i.e. MRI, etc.)"
- "General recommendations for the management of the FS in the family environment: a) keep calm; b) lie the child on the floor and loosen clothing; c) remove any objects nearby; d) if the child is unconscious, put him/her in lateral decubitus (side-lying position); e) do not force opening of the mouth and do not try to put anything inside; f) observe the type and duration of the seizure; g) do not give drugs or fluids orally. If the seizure persists more than 3 minutes administer rectal diazepam, as medical prescription."
- "The number of simple FS does not correlate with the risk of epilepsy nor with the risk of developing cognitive disorders, therefore neither prophylaxis nor intermittent strategies with benzodiazepines nor continuous antiepileptic drugs are usually recommended."
- "The correct explanation on the management of fever is essential to avoid the abuse/overuse of antipyretic drugs or other inappropriate and unnecessary measures of intervention on fever (physical methods such as fanning, cold bathing and tepid sponging). All this is aimed at reducing or removing the intrinsic fear of the fever affecting the family members. Using antipyretic medication can make child feel better when unwell with fever but should not be seen as useful for preventing FS. "

The statements associated with low-relevance score were mostly addressing the risk of recurrence of FS or the risk of epilepsy.

Pediatricians step 3 (Supplementary material table 4)

Unfortunately, incomplete data affected analysis in step 3. One expert did not participate in the last round, and four experts did not perform the scoring appropriately. This resulted in scores from only five pediatricians being available for analysis. Based both on the relevance score and on the propensity to be abandoned, 10 statements emerged from the third step. Statements abandoned by at least 3 experts were not kept in the final selection (Supplementary material table 4). The 10 statements selected emphasized the following (Table 1): FS are common, fever does not systematically cause a FS, FS

Table 1 Key messages on febrile seizure for parents issued from a Delphi process

1-Definition: febrile seizures, also commonly known as febrile convulsions, are epileptic seizures that occur in association with increased temperature. They are not epilepsy, but are rather sensitivity to the child's immature brain at fever.

2-Acknowledging parental stress: FS might appear frightening to observer but are generally harmless.

3-A common phenomenon: febrile seizures are common, up to 2 to 5% of children in the USA and Western Europe, and 6 to 9% of infants and children in Japan, will have experienced at least one febrile seizure, simple or complex, by the age of 5 years.

4-Recurrence: not all illness and episodes of fever will provoke a febrile seizure.

5-In case of FS:

a. Keep calm, secure site that child cannot harm itself during the seizure, apply stable side position, do not apply anything into mouth or between teeth, note time and character of seizure.

b. Most FS spontaneously terminate within 2–3 min, not requiring any treatment.

6-What if the FS lasts longer than 5 minutes? Call emergency if:

a. FS lasts longer than 5 min.

b. Rectal diazepam has been applied.

c. Focal symptoms, post-ictal paresis, general clinical condition is impaired/ symptoms prolonged.

7-Diagnosis of febrile seizure is essentially based on history taking and physical examination. Laboratory tests, EEG, neuroimaging as a routine diagnostic procedure being not recommended.

8-Follow-up: no specialized follow-up is necessary. A consultation with your attending physician is recommended to talk about this event with him.

9-Prognosis: the number of simple FS does not correlate with the risk of epilepsy nor with the risk of developing cognitive disorders; therefore, neither prophylaxis nor intermittent strategies with benzodiazepines nor continuous antiepileptic drugs are usually recommended.

10-Prevention:

a. The number of simple FS does not correlate with the risk of epilepsy nor with the risk of developing cognitive disorders.

b. Therefore, neither prophylaxis nor intermittent strategies with benzodiazepines nor continuous antiepileptic drugs are usually recommended.

c. Using antipyretic medication can make child feel better when unwell with fever but should not be seen as useful for "preventing" FS.

d. Parents should avoid co-sleeping, which is dangerous for their child and will not prevent FS.

generally cease spontaneously, and most FS do not require further investigation.

Discussion

Although fever phobia has negative consequences in terms of public health, recommendations are still lacking with regard to the management of parents and carers following FS and with regard to the management of subsequent episodes. Several studies produced guidelines for physicians[21–24]. Armon et al. used a Delphi process to raise a consensus-based guideline intended for physicians focusing on the management of a child after a seizure[24]. This interdisciplinary and multinational work has used a Delphi process to raise a consensus about what first key messages to share with parents following a FS.

Similar messages were prioritized by both sets of panelists with similar evaluation of relevance; however, the rankings of priority of the messages to parents were slightly different. In the first step of the process, pediatricians delivered more statements about the sequence of clinical signs characterizing a FS. They emphasized that FS should not be perceived as a sign of an infection of the central nervous system. They highlighted the distinction between "simple" versus "complex" FS, while child neurologists did not. They also mentioned differential diagnoses such as Dravet syndrome. Pediatricians gave more details about risk factors of FS (such as having several FS, having a family history of FS) and the risk factors associated with developing epilepsy in the future. Some participants in this group were more "permissive" about the need for investigations (such as MRI), but such statements were not selected in the next rounds of the study. Finally, the pediatricians focused more on the management of parental stress.

Importantly, however, in the later steps, child neurologists and pediatricians converged on the main key messages to share with parents, as summarized in the 10 statements emerging from both groups of panelists (Table 1).

Interestingly, no expert addressed the risk of change in parental behavior that might be adopted after FS, such as co-sleeping[6]. However, both groups of experts described the risks associated with antipyretic and antiseizure medication overuse.

Our study has limitations. Firstly, not all experts completed the three-step process. Secondly, the views from a parent/carer group whose children experienced FS would have added to the consensus reached in this study. Parental views regarding the information they wish to receive as well as the accessibility of the language used, e.g., "simple FS," "immature brain," "focal symptoms," or "post-ictal paresis," would have been helpful. It has been shown that the priorities of healthcare professionals can differ from those of patients and relatives[24]. Third, our study has a limited generalizability, given that it has only been run in five European countries.

Finally, there was consensus between both groups of experts concerning the most important information sharing statements even if the prioritization differed slightly. The next steps will involve parent/carer groups in finalizing the information sharing statements followed by a validation study of the effectiveness of these statements following an episode of FS. The information would be effective if it improved understanding, decreased parental anxiety and post-traumatic stress disorder, and prevented the modification of usual parenting behaviors.

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Code availability Not applicable.

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Declarations

Statement of ethical standards The authors declare appropriate approvals.

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