Febrile Seizures: Perceptions and Knowledge of Parents of Affected and Unaffected Children

Steven Alan Rice

University Hospital for Children and Adolescents

Ruth Melinda Müller

University Hospital for Children and Adolescents

Sarah Jeschke

University Hospital for Children and Adolescents

Birthe Herziger

University Hospital for Children and Adolescents

Thilo Bertsche

Leipzig University and Drug Safety Center, Leipzig University and University Hospital

Martina Patrizia Neininger

University Hospital for Children and Adolescents

Astrid Bertsche (✉ Astrid.Bertsche@medizin.uni-leipzig.de)

University Hospital for Children and Adolescents <https://orcid.org/0000-0003-2832-0156>

Research Article

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Abstract

Febrile seizures (FS) in children are common. Little is known on parents' perceptions and knowledge of FS. We interviewed parents of children aged 6 months to 6 years affected (FS-group, 65 parents) or unaffected by FS (unaffected group, 54 parents). Of the FS-group, 32% said they knew their child had a FS when the first event occurred. Of the FS-group, 89% described fear when the child had a seizure with a median intensity of 10/10 (Q25/Q75: 9/10). Of the FS-group, 77% said they (will) observe their child more carefully since the first seizure had happened, 63% (will) give antipyretics earlier at a median temperature of 38.2°C (100.8°F). Of the FS-group, 62% had not informed themselves about FS before the first event occurred (unaffected group: 54% had not informed themselves about FS so far). Of the FS-group, 20% would put a solid object in the mouth of a child having a seizure (unaffected group 39%), and 92% would administer an available anti-seizure rescue medication (unaffected group 78%). Of the FS-group, 71% stated children with FS might suffocate (unaffected group 70%).

Conclusion: Information about FS and its management should be more widespread to improve parents' coping and patient safety.

What Is Known

- Febrile seizures in children are common.
- The prognosis of children suffering from febrile seizures is usually rather good.

What is new

- Over half of parents had not informed themselves about febrile seizures so far; and only 32% of parents realized their child had a febrile seizure when it occurred.
- Most parents described own fear with a median intensity of 10/10; and 63% (will) give antipyretics earlier at a median temperature of 38.2°C (100.8°F).

Introduction

Febrile seizures in children are common with an incidence of 2–5% in Europe and the United States [6, 10, 26]. They are defined as seizures occurring in children aged 6 months to 5 years with a body temperature >38°C (100.4°F) without an intracranial cause, another definable cause of seizure such as electrolyte imbalance, or a history of an afebrile seizure [16]. The commonest underlying conditions are respiratory tract infections and gastroenteritis [18]. A recent study showed that influenza and coronaviruses cause respiratory tract infections leading to a febrile seizure more often than other respiratory viruses [11]. Frequent fever episodes have been shown to be associated with an increased risk of febrile seizures in the second and third years of life [28]. About one third of children with a first febrile seizure gets at least one recurrent febrile seizure [1]. A lower degree of fever in the initial febrile convulsion is associated with an increased risk of subsequent convulsions [4].

Earlier studies reported insufficient knowledge and high amounts of anxiety in parents witnessing a febrile seizure in their child [5, 13, 15, 23, 29]. To address those problems, it is important to know if parents realize their child has a febrile seizure when the event occurs and how parents perceive the situation. To improve coping and patient safety, it is also necessary to be aware of the current parental' knowledge on febrile seizures. This applies not only to parents of children affected by febrile seizures but also to parents whose children in the age group at risk for febrile seizures have not yet been affected. As data on those aspects are scarce, we performed interviews to explore perceptions of parents whose children experienced a febrile seizure. Additionally, we wanted to learn about knowledge of parents with children affected by febrile seizures in comparison to parents of unaffected children.

Materials And Methods

Setting and patients

After approval of the local ethics committee, we performed this prospective observational study at a German university hospital for children and adolescents from October 2019 to March 2021. We consecutively invited parents of children aged 6 months to 6 years who were admitted to our hospital due to at least one febrile seizure (FS-group) to take part in the interview. We also invited parents of children who were admitted to our hospital for other diagnoses such as infections and had not experienced a febrile seizure so far (unaffected group). Requirements to participate in the study were in-patient treatment, sufficient knowledge of the German language, and intellectual capacity to understand and answer the questions. Participation in this study was voluntary and without any compensation. Written informed consent was gained from all participants.

Data assessment

An expert panel consisting of a neuropediatrician, pharmacists, a child and adolescent psychotherapist, and a medical student with a qualification as emergency medical technician developed a questionnaire as basis for the structured interview. The questionnaire was pretested with 8 persons for comprehensibility and the questions were adjusted accordingly. We addressed the following questions:

Parents' perceptions of febrile seizures in the FS-group

- 1.) Did you realize your child had a febrile seizure? If no, what did you think happened?
- 2.) What was the dominating feeling when your child had a febrile seizure?
- 3.) Who told you your child had a febrile seizure (pre-set answers to choose)?
- 4.) Which issues were addressed in the first consultation about the diagnosis (pre-set answers to choose)?

5.) Changes after the febrile seizure: Were there / will there be any general changes in the handling of your child? Do you / will you take your child's temperature more often? Do you / will you give your child medicine to lower his/her fever earlier? At what temperature would you start giving your child medicine to lower his/her fever? Do you / will you see your pediatrician more often when your child has a fever?

Parents' knowledge of febrile seizures in the FS-group and in the unaffected group

6.) Did you inform yourself on the topic of febrile seizures before your child was affected?

7.) Which measures would you take in case of a febrile seizure (pre-set answers to choose)?

8.) Do you know about possible negative consequences resulting from a febrile seizure (pre-set answers to choose)?

9.) Do you feel adequately prepared for a febrile seizure in your child? What measures would you need to feel better prepared?

At the end of the interview, we asked the parents about sociodemographic data.

Statistics

Frequencies are reported in absolute and relative numbers. Continuous data are described as median with first (25%) and third (75%) quartile (Q25/Q75).

Results

Altogether 119 parents took part in the interview, 65 whose child had at least one febrile seizure (FS-group) and 54 whose had not (unaffected group). Details on sociodemographic data are displayed in Table 1.

Parents' perceptions of febrile seizures in the FS-group

Of the FS-group, 21/65 (32%) said when the first event occurred they knew the child had a febrile seizure, the others had different ideas, for example an epileptic seizure (11/65, 17%) or a life-threatening event (13/65, 20%), but did not realize the specific diagnosis.

Asked about the feelings the event induced in the parents, 58/65 (89%) described fear, 4/65 (6%) said they felt despair, 1 (2%) parent said he/she stayed calm, 1 (2%) did not witness the seizure, 1 (2%) did not answer the question. On a scale from 0 to 10 (highest intensity) the participants who had reported fear described a median intensity of fear of 10 (Q25/Q75: 9/10). Those participants who described despair said the intensity of this feeling was in median 10 (Q25/Q75: 9.5/10).

According to the parents, 56/65 (86%) were informed by a physician about the diagnosis, 6/65 (9%) claimed no one had informed them.

Concerning the consultation after the febrile seizure, 41/65 (63%) parents said they received information about acute measures to be taken in case of another febrile seizure. More information on the topics parents claimed they were informed about is displayed in Table 2.

Of the parents, 50/65 (77%) said that after the febrile seizure there had been/would be general changes in the handling of their child such as closer observation. As a specific change, 41/65 (63%) (will) give antipyretics earlier at a median temperature of 38.2°C (100.8°F). For more details on changes see Table 3.

Parents' knowledge of febrile seizures in the FS-group and in the unaffected group

Of the FS group, 40/65 (62%) had not informed themselves about febrile seizures before the first event happened. Of the unaffected group, 29/54 (54%) had not informed themselves about febrile seizures so far. Asked about measures they would take in case of a febrile seizure, 13/65 (20%) of the FS-group would put a solid object in the mouth of a child having a seizure [unaffected group 21/54 (39%)], 60/65 (92%) would administer an available rescue medication [unaffected group 42/54 (78%)]. More information about measures parents would take in case of a febrile seizure can be found in Table 4. On the question relating to possible negative consequences of febrile seizures, 46/65 (71%) of the FS-group stated children can suffocate [unaffected group 38/54 (70%)], 27/65 (42%) stated children with febrile seizures can develop an epilepsy [unaffected group 26/54 (48%)], 27/65 (42%) stated they can develop a developmental disorder [unaffected group 25/54 (46%)]. Detailed information about assumed consequences of a febrile seizure is displayed in Table 5. On a scale from 1 (not at all) to 5 (definitely), the FS-group described their preparedness for another febrile seizure in median with 4 (Q25/Q75: 2/4); the parents whose children have not yet been affected rated their preparedness for a febrile seizure with 2 (Q25/Q75: 1/3). Asked in an open question what would be necessary for a better preparedness for a febrile seizure, the following answers were given most often: general information on febrile seizures by pediatricians/medical staff before the first event [FS-group 10/65 (13%), unaffected group 40/54 (74%)], training on measures to be taken in case of a febrile seizure / pediatric emergency by pediatricians / medical staff [FS-group 8/65 (10%), unaffected group 24/54 (44%)], information on febrile seizures / pediatric emergencies in doctor's offices [FS-group 5/65 (6%), unaffected group 25/54 (46%)], information about febrile seizures in the internet [FS-group 1 (2%), unaffected group 5 (9%)]. Of the FS-group, 9/65 (14%) said such a situation will always be overwhelming and parents will never be properly prepared [unaffected group 1 (2%)].

Discussion

Parents' perceptions of febrile seizures in the FS-group

Only one third of the parents of the affected children said they knew the child experienced a febrile seizure when the event occurred and most parents in our study expressed a maximum level of anxiety when experiencing their child's febrile seizure. This is in accordance with other studies that also report

high levels of anxiety of parents experiencing a febrile seizure of their child [5, 15, 23, 29]. Lack of parents' knowledge on febrile seizures was also shown in earlier studies and might enhance anxiety and hinder parents from undertaking appropriate actions to manage the seizure [13]. A recent consensus statement on the information that should be delivered when a child has a febrile seizure recommended that definition, parental stress, the commonness of febrile seizures, measures to be taken when a seizure occurs, and prognosis should be addressed [17]. Asked for specific information they got, two thirds of affected parents in our study said they received information about measures to be taken if their child had another febrile seizure. Less than half of the participants said they got information on topics such as frequency of febrile seizures, risk factors for febrile seizures, acute complications of febrile seizures, measures to prevent febrile seizures, and long-term consequences of febrile seizures. We were not able to judge if this information was really not given or if the parents were so emotionally overwhelmed that they were not able to process the given information. Thus, information should be given in a structured way and be repeated regularly. Furthermore, oral information should be supported by written leaflets [20].

In accordance to other studies [29], parents in our study who had experienced a febrile seizure of their child tend to watch their children very carefully and especially take their children's temperature more often and use antipyretics very early at a median temperature of 38.2°C (100.8°F). It is important to tell parents that prophylactic fever medication at low temperatures in most cases cannot prevent febrile seizures. Otherwise they might feel guilty when a febrile seizures occurs. A systematic review published in 2013 found that antipyretics were ineffective in reducing the recurrence rate of febrile seizures [21]. A recent review showed only weak evidence for a possible role of antipyretics for preventing a febrile seizure in the same fever episode and stated that febrile seizures in distant fever episodes clearly cannot be prevented [9].

Parents' knowledge of febrile seizures in the FS-group and in the unaffected group

Many participants said they had not had informed themselves about febrile seizures as long they were not or not yet affected. In addition to enhancing parents' anxiety, this can lead to reduced patient safety. For example, the share who would perform the obsolete action of putting a solid object in their child's mouth during a seizure was twice as high in parents whose children did not have a febrile seizure so far compared to those who did have. As it is not predictable if a child will experience a febrile seizure, all parents should be informed about this possible emergency situation in order to act appropriately. A high share of parents in both groups expressed the willingness to administer an available anti-seizure rescue medication. Earlier studies, however, have shown a high amount of drug-handling errors in parents administering those medications which might reduce effectiveness [14]. Those errors also occurred in parents who had already administered anti-seizure rescue medication in their child. The errors were significantly and sustainably reduced by a one-time intervention consisting of the supervised administration of the medication to a dummy doll [22]. Thus, at least parents whose child already had experienced a febrile seizure should optimally receive such a training. However, the parents should be told that most febrile seizures do not last longer than two to three minutes and do not require any treatment

[17]. For seizures lasting longer than five minutes, an anti-seizure rescue medication should be administered to reduce the risk of a prolonged seizure and its complications [12, 27].

Asked for possible consequences of febrile seizures, more than two-thirds of parents said the child might suffocate. This is probably one of the main reasons for the extremely high level of anxiety of parents whose child had a febrile seizure. It seems important to educate parents on measures to be taken during a seizure such as keeping calm, securing the site, applying stable site position, and not putting anything into the child's mouth [17]. Besides, parents should be assured that suffocation in a febrile seizure is extremely unlikely. Each more than 40% of participants said there is a risk for epilepsy and for developmental disorder. Studies conducted in the 1960s and 1970s found an epilepsy risk for children with febrile seizures of 3% [24] and 2% [19]. A review from 2008 showed a slightly higher risk of later epilepsy after a febrile seizure of between 2.0% and 7.5% [3]. Consequently, the general prognosis is still favorable with more than 90% of children suffering from a febrile seizure not developing an epilepsy. For intellectual and behavioral outcome of children with febrile seizures, a population based study of children born in one week in April 1970 in the United Kingdom found no differences compared to children without febrile seizures [25]. A recent study from Sweden, however, shows that children with early onset of febrile seizures and those with recurrent febrile seizures may be at risk for developing cognitive executive dysfunctions [2]. Nevertheless, the developmental prognosis is usually considered as relatively favorable. As we did not ask for the grade of probability of development of an epilepsy or a developmental disorder, we were not able to judge if the parents interviewed in our study rightly knew about the slightly increased risk or if they overestimated those risks.

Parents who had not experienced a febrile seizure in their child so far felt badly prepared for such an event. Accordingly, they expressed the wish to receive information from their healthcare providers. A previous study had already shown the importance of healthcare professionals' support to handle the situation [29]. In order to provide high quality information, healthcare professionals themselves need to have a good knowledge on fever and its management and on febrile seizures. A recent study from Australia showed gaps in knowledge of fever and its management among nurses, pharmacists, general practitioners, and pediatricians [7]. Similar gaps were shown for German medical and pharmacy students at the end of their university education [8]. Thus, it seems crucial to improve training for healthcare professionals.

Limitations

We did not ask the parents to assume the extent of risk increase for the development of an epilepsy or a developmental disorder. Thus, we were not able to judge if the interviewed parents rightly knew about the slightly increased risks or if they simply overestimated them.

Conclusion

Only one third of parents realized their child had a febrile seizure when the event occurred. Most parents of children with febrile seizures expressed extremely high levels of anxiety. Knowledge of parents of both affected and unaffected children is insufficient. In order to facilitate parents' coping and to improve patient safety, parents should receive more information on this topic. Information can be for example spread by pediatricians' offices.

Abbreviations

FS febrile seizures

Declarations

Funding

This study received no particular funding.

Conflicts of interest

AB reports grants from UCB Pharma GmbH and honoraria for speaking engagements from Biogen GmbH, Desitin Arzneimittel GmbH, Eisai GmbH, GW Pharma GmbH, Shire/Takeda GmbH, UCB Pharma GmbH, and ViroPharma GmbH. The other authors declare they have no conflicts of interest.

Availability of data and material

The data presented in this study are available on request from the corresponding author.

Code availability

Not applicable

Authors' contributions

SAR designed the study protocol, developed the questionnaire, performed the questionnaire survey, the statistical analysis and the interpretation of the data, and wrote the manuscript.

RMM was involved in the design of the study protocol and the development of the questionnaire, performed the questionnaire survey, supported the statistical analysis and the interpretation of the data, and supported the writing of the manuscript.

SJ was involved in the design of the study protocol, the development of the questionnaire and the interpretation of data, and critically reviewed and revised the manuscript.

BH was involved in the design of the study protocol and the development of the questionnaire, and critically reviewed and revised the manuscript.

TB was involved in the development of the study protocol and the questionnaire, and critically reviewed and revised the manuscript.

MPN supported the statistical analysis and the interpretation of data, and critically reviewed and revised the manuscript.

AB designed the study protocol, was involved in the development of the questionnaire, and supervised the questionnaire survey as well as the recruitment of participants and the statistical analysis. She performed the interpretation of data and wrote the manuscript.

Ethics approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study described has been carried out in accordance with above mentioned standards and has been approved by the Ethics Committee of Medical Faculty of Rostock University, Germany (Ethics approval number: A 2019-0145).

Consent to participate

Written informed consent was obtained from all individual participants included in the study.

Consent for publication

Not applicable

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Tables

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