



Parent's Experiences of Their Children Suffering Febrile Seizures



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ABSTRACT

Purpose: To explore parents' experiences of their child suffering febrile seizures.

Design and Method: Seven mothers and four fathers with experience of one or several febrile seizures in their children were interviewed. A qualitative content analysis with an inductive approach was performed.

Result: Five themes emerged; *emotional experiences*, in terms of anxiety and fear, and *need for control, need for support, need for acknowledgement and need for comfort*. Professional assurance and support from healthcare staff was considered important to help parents handle the situation.

Conclusion: Febrile seizure caused anxiety due to parents' lack of comprehension about the event and how to act during the seizure.

Practice Implications: The pediatric nurse plays an important role in gaining the trust of and supporting parents whose children have suffered febrile seizures. They can alleviate concerns that arise, and also generate assured and well informed parents, who are better prepared to deal with recurrent febrile seizures.

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Background

Fever is the main complaint in approximately 30% of patients consulting pediatricians (Hoover, 2012). One reason is the distress of febrile seizure, which causes anxiety among parents (Kolahi & Tahmoorezadeh, 2009; Yilman et al., 2008). Other concerns are fear of death, dehydration, brain injury/stroke and cardiac problems due to increased temperature in fever (Walsh, Edwards, & Fraser, 2007). Febrile seizures are most commonly associated with viral upper respiratory tract infections, but may also occur with virtually any infections and after vaccinations (Kimia, Bachur, Torres, & Harper, 2015; Mittal, 2014). Approximately two to 5% of children, irrespective of gender, have febrile seizures during their first five years, most commonly during their second year of life. Approximately a third of the children will have an additional febrile seizure and approximately 10% suffer three or more (Kimia et al., 2015; Pavlidou, Hagel & Panteliadis, 2013).

A febrile seizure is defined as a seizure that occurs in tandem with a body temperature $> 38^{\circ}\text{C}$ (100.4°F) in the absence of intracranial infection, metabolic disturbance or history of afebrile seizures (American Academy of Pediatrics, 2011). Simple febrile seizures, representing approximately 80% of all cases (Mittal, 2014; Pavlidou et al., 2013), are characterized by a duration of < 15 min, are generalized in nature, and

comprise a single occurrence during a period of 24 h, and are not preceded by neurological problems. A complex febrile seizure has duration of > 15 min, is focal and/or recurs within 24 h (American Academy of Pediatrics, 2011). The causes of febrile seizures are not fully understood (Mittal, 2014). There are suggested risk factors, however, such as developmental delay, discharge from neonatal unit after 28 days, daycare attendance, viral infections, some vaccinations, genetic predisposition, and iron and zinc deficiencies (Graves, Oehler, & Tingle, 2012). Simple febrile seizures are not dangerous and cause no persisting neurological effects. Neither antipyretics nor anticonvulsants are recommended for preventing febrile seizures, due to lack of evidence and, in the latter, the risk of adverse effects (Graves et al., 2012; Mittal, 2014). Despite this, a common conception among caregivers is that a febrile seizure may cause the child developmental disorders or brain damage (Kolahi & Tahmoorezadeh, 2009; Sajadi & Khosravi, 2017; Tamvaki, Papathanassoglou, Matziou, Galetseli, & Giannakopoulou, 2011). 'Fever phobia', defined by Schmitt several years ago, describes the unrealistic concerns about increased body temperature in febrile children (Schmitt, 1980). This phobia, in terms of attitudes toward fever and reliance on antipyretics to reduce it and prevent seizures, also persists among healthcare professionals (Demir & Sekreter, 2012; Greensmith, 2013; Hoover, 2012; Martins & Abecasis, 2016). Considering the fact that pediatricians and pediatric nurses are the primary resource for parents' understanding and ideas about temperature in fever (Chiappini et al., 2012; Dong, Jin, Lu, Jiang, & Shan, 2015), they have an important role in changing current misconceptions and in framing evidence-based management. Hence, the pediatric nurse plays an important role in the emergency setting, not only in caring for the child, but also in

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supporting the parents with an empathic approach, as the febrile seizures may be a daunting experience where parents believe that the child is in mortal danger. The pediatric nurse should give general advice on temperature in fever as well as specific advice on febrile seizures according to current guidelines (Paul, Rogers, Wilkinson, & Paul, 2015; Walsh et al., 2007). In order to better understand and meet parents' need in a Swedish context, the aim of this study was to explore parents' experiences of their child suffering febrile seizures.

Method

Design and Participants

This study applied a qualitative descriptive design, using individual interviews for data collection. Qualitative interviews are an appropriate method when the aim is to gain insight into a person's experiences within a specific area (Kvale & Brinkmann, 2009).

The sample consisted of Swedish-speaking parents to children admitted to a pediatric clinic in southern Sweden due to a febrile seizure. In total, eight mothers and four fathers were interviewed, one of whom was excluded due to the child's seizure deviating from the criteria for simple febrile seizures. Finally, 11 interviews were included in this study. The children whose parents contributed to the study were born between 2007 and 2013, and suffered their first febrile seizure at one and a half years to three years of age. With the exception of two children diagnosed with viral induced wheeze, none of the children had any prior medical conditions. Seven of the children had suffered only one febrile seizure, two had a history of two febrile seizures and one child had suffered three febrile seizures. One of the parents could not recall if the child had experienced three or four febrile seizures. The parents' ages varied between 26 and 49 years of age, mean of 35 years.

Data Collection

Data were collected using semi-structured individual interviews with one of or both of the child's parents. The interview was based on an interview guide that contained open-ended questions about the parents' experiences during and after the febrile seizure. The interviews started with general questions about the family and their child with the purpose of creating a relaxed environment. Then the parents were asked to tell about their experiences of the child having a febrile seizure. Follow-up questions, such as "how did it feel?" and "can you tell me more?" were asked to further explore the parent's experiences.

The data collection took place in two stages. The first stage started in the autumn of 2013, after permission had been obtained from the director of the pediatric clinic. With the assistance of a medical secretary, letters were sent home to parents whose children had been diagnosed with febrile seizures during the period of January–September 2013. In total, there were 37 candidate families, of which 32 families received letters. One child's parents were excluded because they did not speak Swedish and four families were excluded because they did not reside in the county. Of the 32 candidate families, nine parents accepted the request for an interview, six mothers and three fathers. These parents were contacted by the first author and interviews were scheduled. The interviews were performed during October–November 2013 in a location of the parents' choice. Seven of the parents chose to be interviewed in their own home and two at the pediatric clinic at the hospital. In the autumn of 2014, the first author conducted a small number of additional interviews. Therefore, four parents (from two families) whose children had been admitted to the pediatric clinic due to febrile seizures during November–December 2014 were asked to participate in the study by a pediatric nurse during a check-up telephone call. Out of these four parents, three chose to participate in this study. The interviews were carried out during the end of January–beginning of February 2015, all in the parents' homes.

The parents gave consent to the interviews being recorded for later transcription into text. The shortest interview lasted 12 min and the longest 35 min, mean of 22 min and a total of 241 min. During the transcription, all personal data was decoded and the transcripts were tagged with R1–R11. All personal data, recorded interviews and transcripts were stored separately, and only the authors had access to all of the material during the study.

Ethics

The study was conducted in accordance with the Declaration of Helsinki (WMA Declaration of Helsinki, 2013). Participants gave written consent after having received both verbal and written information about the study. Participation was voluntary and the participants could interrupt their involvement at any time. To maintain confidentiality, all data were decoded and locked in a safe, out of reach for anyone but the authors.

Data Analysis

Content analysis is used to interpret texts in order to attain new insights and understandings of a phenomenon. The interviews in this study were analyzed with latent content analysis according to Krippendorff (2013). The interviews were transcribed verbatim by the first author, most often on the same day or the day after the interviews were performed. Upon completion, the texts were read with the study aim in focus to gain a full sense of the content. The meaning units were then identified, i.e., words, sentences or paragraphs that related to the aim of the study (Graneheim & Lundman, 2004). According to Krippendorff (2013), this means the delimitation of an otherwise long and ongoing text. The idea is to leave out irrelevant data and keep together sections that cannot be separated without losing the context. The meaning units were shortened without losing the core content and labeled with codes. Finally, all codes were divided into categories. Categories should be exhaustive and exclusive, meaning that relevant data must be part of a category and cannot be excluded due to not fitting into a category. Nor can any data fit in several categories (Graneheim & Lundman, 2004; Krippendorff, 2013). Finally, in the latent part of the analysis, the interpreted implications were connected in themes. Table 1 illustrates the analysis process.

Results

The data analysis revealed five themes; *emotional experiences, need for control, need for support, need for acknowledgement and need for comfort*, including 15 categories that describe the parents' experiences (Table 2).

Emotional Experiences

When the parents saw their child experiencing a seizure, becoming unresponsive and blue around the lips, the parents experienced feelings of anxiety, fear, panic and even shock.

"Picturing a coffin was close at hand"

[R3]

Many of the parents could not identify what the child suffered from and often thought that it was something serious and in some cases life-threatening, such as suffocation due to choking. Some of the parents recognized it as a seizure and thought their child suffered from epilepsy. Not knowing what it was or how dangerous it might be contributed to the parents' fear. Many of the parents imagined their child dying. Even the parents who identified it as a febrile seizure felt uncertain as to whether it really was just that, and they worried that the seizure would be dangerous, even though they knew it was not.

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