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# BMJ Open

## Parental assessment of disease severity in febrile children under 5 years of age: a qualitative study

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3 **Parental assessment of disease severity in febrile children under 5 years of age: a qualitative**  
4 **study**  
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## **Abstract**

**Objective:** To explore how parents judge disease severity of their febrile child and to identify symptoms they associate with serious illness, minor illness or health.

**Design:** Semi-structured interviews were conducted with parents of children aged 0-5 years with a febrile illness. Interviews were audio taped, transcribed verbatim and analysed thematically.

**Setting:** Participants were recruited at the paediatric ward and the emergency department.

**Results:** Twenty-six interviews were conducted, in which 37 parents participated. Parents described disease severity of their child mainly in terms of changes in their child's normal characteristics (behaviour and physical features). They found it harder to describe specific disease symptoms such as dyspnoea or dehydration. Previous experience with febrile illnesses in their children was of great influence on the number and accuracy of symptoms they reported.

**Conclusion:** Parents used the normal behaviour and physical features of their child as a reference frame for judging disease severity. With a larger deviation from the child's normal characteristics, parents considered the illness more serious. They were less able to describe specific symptoms of disease such as dyspnoea or dehydration. This knowledge is important for clinicians in their communication with parents of children with febrile illness.

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## **Strength and limitations**

- This is the first study to give a profound overview of what parents take into account when assessing disease severity in their child.

- Because of the in-depth interviews, we were able to explore not only alarming symptoms, but also signs that reassure parents.

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3 - The qualitative study design enabled us to explore the parents' perspective thoroughly.  
4  
5 - This study did not examine the correlation between parent-reported symptoms and disease severity  
6  
7 as judged by health professionals and/or diagnostic tests.  
8  
9 - Because this study was performed on the paediatric ED with parents without a severe language  
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11 barrier, its main limitation is the generalizability to other settings such as primary care or parents with  
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13 limited understanding of the Dutch language.  
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## **Introduction**

Febrile illnesses are very common in children. Pre-school children experience almost two infectious diseases per year[1]. In Western Europe, in 20-39% of children with fever a doctor is consulted[2, 3] and about half of the consultations on the paediatric emergency department (ED) are for infections[4]. The majority of these children have a viral infection, which requires little or no medical intervention. Only 10-15% of the children with febrile illness at the ED has a serious bacterial infection[5]. However, it is essential to distinguish serious infections from minor infections to reduce morbidity and mortality. Recognition of disease severity by parents and subsequent healthcare seeking behaviour of parents are the first steps in this process.

Because of the low prevalence of severe disease and abundance of mild disease, diagnosis of serious infections in febrile children is challenging[6]. In the treatment guideline for febrile children at the ED in the Netherlands[7], which is largely based on the NICE guideline for fever, the main factors that are taken into account are the doctors' observations and laboratory tests. However, it would be very useful to acquire a greater understanding of the parental perspective of disease severity assessment as the first step in the diagnostic process. Parents are capable of identifying their child as ill[8, 9] and the parental instinct for disease is an indicator for disease severity[6]. However, what parents take into account exactly while judging disease severity and what symptoms they can recognize in their child, is largely unknown.

Therefore, the aim of this study is to explore how parents judge disease severity in their febrile child. In particular, which signs and symptoms parents associate with severe illness, which conditions they associate with a healthy state and the spectrum in between these limits.

## **Methods**

### **Study design**

We performed a qualitative study with semi-structured interviews in order to explore how parents judged the severity of illness of their febrile child. A topic guide for semi-structured interviews (Supplement 1) was developed based on the study objective, existing literature, clinical experience and the Dutch treatment guideline to assess febrile children in hospital setting[7]. The content and

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2  
3 phrasing of the questions was reviewed by experts in paediatrics and adjusted in accordance with  
4  
5 their remarks.  
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7

## 8 **Recruitment**

9  
10 A purposive sample of parents of children with fever aged 1 month to five years was recruited, in order  
11  
12 to obtain maximum variation within the sample, in terms of patient age and the experience of parents  
13  
14 with diseases in their children. Recruitment took place at the Haga Teaching Hospital, Juliana  
15  
16 Children's Hospital in the Hague (the Netherlands), on both the paediatric ED and the paediatric ward.  
17  
18 Parents were interviewed at times the medical staff did not need to attend the patient, for example  
19  
20 during waiting time for lab results. Both at the ward and at the ED, the average interview duration was  
21  
22 20 minutes. Recruitment was continued until data saturation occurred. Parents with children were  
23  
24 included if fever ( $>38,0$  °C) was reported during the illness episode or if a fever was measured in the  
25  
26 hospital. Parents of patients with a life-threatening condition that needed immediate medical attention  
27  
28 were excluded. Another exclusion criterion was a severe language barrier, defined as parents not  
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30 being able to understand the participant information folder and not able to communicate sufficiently  
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32 with the study team.  
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## 35 **Data collection and analysis**

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37 Semi-structured interviews were conducted in April and May 2019. The interviews with the parent(s)  
38  
39 took place at the patient's room at the ED or ward. Participants were enrolled after providing written  
40  
41 informed consent. Interviews were audio recorded and transcribed verbatim by DK, including non-  
42  
43 verbal information. After 18 interviews, a preliminary analysis took place in the study team, which  
44  
45 guided in-depth questions for the subsequent interviews. Data saturation occurred after 26 interviews.  
46  
47 The accuracy of transcripts was verified by comparing them with the original audio fragments by NB.  
48  
49 Thematic analysis was conducted using MAXQDA data management system[10]. The transcripts were  
50  
51 independently read thoroughly by DK and NB. Thereafter codes were identified inductively by both  
52  
53 investigators in eight transcripts, after which they compared the codes and edited the codes until  
54  
55 consensus was reached. The codes were grouped into themes. Conceptual links were visualized in  
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57 figures by the DK, NB and GD.  
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## Patient involvement

Patients or parents were not involved in the design of this study. However, our study aim and design was completely focused on retrieving their perspective. The results of this study (parent-reported disease severity) can help paediatricians for improving their communication with parents of children with febrile illnesses.

## Results

### Demographics

Twenty-six interviews were conducted, in which 37 parents participated: 24 mothers and 13 fathers. In 11 interviews both parents were present and in 15 interviews only one of them attended. Three eligible parents decided not to participate, out of privacy reasons (one) and lack of time (two). Detailed participant characteristics are presented in Table 1.

### Main themes

The following themes emerged from the data:

- Judgement of disease severity using the child's normal characteristics
- General illness signs recognized by parents
- Difficulty of describing specific symptoms of disease
- Factors influencing parents' ability to assess disease severity

### Judgement of disease severity using the child's normal characteristics

#### *The child as its own reference*

In all interviews, parents reported to recognize disease from their child's characteristics being different from normal. They mentioned subtle differences on various characteristics, including behaviour, like activity level and mood, and physical features, like temperature and appearance. Parents stated to use their child's normal characteristic being the reference for recognizing disease: *"Every day and night we are with the kids. So you know how your child behaves normally. And everything that deviates from that, is an indication [of disease] for me."* (Mother, patient 1 year (y)). Supplement 2 provides an overview of all relevant quotes. Also see Quote 2-3 (Q2-3).

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3 Parents with multiple children described that signs of febrile disease differed greatly between siblings,  
4  
5 which depended on the child's normal characteristics. Every child has specific characteristics which  
6  
7 parents use to recognize (severe) disease: *"He [patient's brother] is always calm and you would see*  
8  
9 *that he becomes more quiet because he is drowsy and passive [...] He becomes quiet with fever,*  
10  
11 *unlike him [patient]. He [brother] would be quiet and sit in a corner and he [patient] would be crying*  
12  
13 *very loudly, like: hey, I'm not feeling well!"* (Father, patient 1 y).

### 14 15 16 *Parental instinct*

17  
18 In 13 of the 26 interviews, parents mentioned to notice that something was wrong with their child  
19  
20 based on their parental instinct. This instinct was regularly expressed in combination with recognizing  
21  
22 that something was abnormal in their child; there seems to be overlap between the parental instinct  
23  
24 and recognizing differences in their child's characteristics: *Father: "Yeah, we just notice it as a parent!*  
25  
26 *I don't know. He's just really a different child [if he's ill]. Maybe it's based on the parent's instinct.*  
27  
28 *Mother: [...] What they normally find interesting, is suddenly not interesting anymore! Then you*  
29  
30 *instantly notice that there is something wrong."* (patient 3 y).

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32  
33 In 6 interviews parents spontaneously reported that the mother's instinct was stronger than the father's  
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35 instinct, and that mothers were therefore better in evaluating the severity of disease. As a reason for  
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37 the mother's instinct being very strong was that mothers said to know their child better. *Father: "And*  
38  
39 *your intuition [to mother] is even stronger than mine. [...] I think that's the widely known mother's*  
40  
41 *instinct. [...] I really keep an eye on him, but what you have... That is just an extra sensor which is*  
42  
43 *turned on!"* (patient 6 mo). Also see Q7, Supplement 2.

### 44 45 46 **General illness signs**

#### 47 48 49 *General signs*

50  
51 Parents mentioned a broad range of signs and symptoms to describe the abnormal state of the child in  
52  
53 case of disease. Table 2 shows reassuring, general and alarming signs of disease from the parents'  
54  
55 perspective on all aspects of their child's characteristics. All signs were present in both children under  
56  
57 one year old and in older children.

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2  
3 In all interviews, parents described their child suffering from febrile illness as being in a less energetic  
4 state, in which the child ate less, drank less, urinated less, played less, and slept more than normal. In  
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7 4 interviews parents described that disease could also be recognized if their child was hyperactive,  
8  
9 irritable, in a bad mood and nagging (Q8-9, Supplement 2). Besides this less energetic mental or  
10  
11 physical state, parents reported to recognize disease from changes in the child's appearance. The  
12  
13 child would be pale, warm and sweaty, or would have red cheeks (with fever). Parents reported also to  
14  
15 recognize disease from 'the look in their eyes' (Q10-11, Supplement 2).  
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### 18 *Alarming signs*

19  
20 Parents described that the less energetic state in case of febrile illness would get worse with  
21  
22 increased disease severity. In severe disease it would alter to a state in which the child barely eats or  
23  
24 drinks, is very weak, and/or barely responds to social stimuli and/or sleeps a lot (Table 2 and Q12-13  
25  
26 in Supplement 2).  
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30 Still, there were major differences in what parents considered alarming, which was linked to their  
31  
32 previous experiences with health and disease. Signs that parents of relatively healthy children  
33  
34 considered alarming, were considered as less alarming by parents of children with a relevant medical  
35  
36 history. For example, there was a parent of a relatively healthy child who appraised being passive as  
37  
38 an alarming sign, whereas a parent of a child with an extensive medical history described being  
39  
40 passive as a general sign to recognize febrile illness. *"Actually she always stays a bit active. If she*  
41  
42 *would get passive, I would worry. I have only experienced that once, maybe."* (Mother, patient 4 y, no  
43  
44 significant medical history); *"Then he gets lethargic or he starts being delirious, he sees things that are*  
45  
46 *not there. But then he really has a high fever. [...] Look, if he has a fever and he is totally 'out', and he*  
47  
48 *is barely moving, being weak... Yeah, then I am really worried."* (Mother, patient 5 y, significant  
49  
50 medical history). Signs that experienced parents considered alarming were extreme weakness,  
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52 lethargy, delirium, not responding well or being unable to wake their child.  
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### Reassuring signs

Parents considered it reassuring if the less energetic state had disappeared or had not occurred at all. They found it reassuring if the child's characteristics (physical features and behaviour) had returned to what was normal for the child (Table 2 and Q16-17 in Supplement 2).

### The complete picture

Parents explained that they assessed disease severity based on the whole picture of alarming and reassuring signs (Q18). For example, in the case of high fever also other aspects of the child's normal characteristics would be assessed to judge disease severity: *"Only if it [fever] is very high, and I see that the kid is not well, then I instantly want to call the GP or out-of-hours services. But if he is playing a lot, eating, drinking, with the fever, then it's no problem if it's 40 degrees. Then I just wait 3 days. [...] I know it when my child is sick or not: I see that he doesn't play, eat, drink or pee anymore, has difficulties with peeing, or has red dots. Or if he is restless, then I know that something is wrong with him."* (Mother, patient 9 mo).

Additionally, symptoms of children with a relevant medical history were interpreted in a different way; parents were more cautious about severe disease (or a relapse of severe disease) in these children depending on previously experienced specific signs or symptoms for this disease *"If [name older brother] has a fever, you think: well, it's only the flu. And he is not sick very often. [...] But look, with [name patient], because of his condition... With him that's the moment to go to the hospital. To [name older brother] I would say: just stay at home, I will put a blanket on you, just wait 'till it's over."* (Mother, patient 5 y).

### Difficulty of describing specific symptoms of disease

Previous experience was important in recognizing specific symptoms. The majority of the interviewed parents had no experience with certain symptoms like dehydration or dyspnoea. These parents found it harder to describe how they could recognize these specific conditions.

Regarding dyspnoea, parents stated in 10 interviews that they did not know what the symptom presentation looked like. 7 of them tried to imagine what it would look like: *"Eh, he has never really*

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3 *had that. But I can imagine: high chest breathing, located here [points high on the chest].*" (Mother,  
4 patient 5 y). See also Q21, Supplement 2. Parents who had recent experience with their child being  
5 short of breath, could describe very precisely how they could recognize this symptom: *"If he is short of*  
6 *breath, then he's only coughing. He becomes red and sweaty. And he breathes very quickly. [...]*  
7 *Sometimes his lungs are also wheezing. A wheezing sound is coming out of them."* (Mother, patient 4  
8 y). See also Q24, Supplement 2.

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16 Regarding dehydration, parents mentioned in 15 interviews that they could recognize dehydration from  
17 the fluid balance in the child's body: a relative higher fluid loss compared to the fluid gains. In 6  
18 interviews, parents had no clue how to recognize it (Q25-26, Supplement 2).

### 23 24 **Factors influencing parents' ability to assess disease severity**

25  
26 Three major factors influence the parents' ability to assess disease severity: previous experience with  
27 signs and symptoms, knowing the child's normal characteristics and the child's ability to speak (see  
28 Figure 1).  
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#### 31 32 33 *Experience with previous illness*

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35 Previous experience with disease influences the parents' capability of recognizing diseases and  
36 judging disease severity (Q27, Supplement 2). Accordingly, the capability of assessing disease  
37 severity increased when parents had more children and when the child got older (Q28, Supplement 2).  
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#### 41 42 43 *Knowing your child*

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45 Parents also described that they had to know their child well to be able to recognize illness signs.  
46 They explained that this was harder in young infants. Knowing the child very well enabled them to  
47 recognize subtle changes in their child's normal characteristics: Mother: *"Especially the first few weeks*  
48 *were quite difficult. Because then you don't understand the different cries well: is she hungry now or is*  
49 *she just tired? You just don't know that well enough. [...]"*. Father: *"At some point just know better*  
50 *what's right and what's wrong. Mother: Yeah, you get to know your child better."* (patient 2 mo).  
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### *Ability to speak*

Parents expressed that assessing disease severity was easier in older children because they were able to talk. Parents felt insecure about their interpretation of the symptoms if the child was not yet able to express him- of herself (Q30-31, Supplement 2).

## **Discussion**

To our knowledge, this is the first study that fully takes the parent's perspective into account regarding judgment of disease severity in their febrile child. Parents mainly used the normal characteristics in terms of behaviour and physical features of their child as a reference frame for interpreting signs and symptoms of disease. Parents could describe alterations in the normal characteristics of their children very precisely, but were less able to describe specific symptoms for disease such as dyspnoea or dehydration if they had no previous experience with these conditions. The variety of illness signs parents described was mainly dependent on their previous experience with disease, as well as the child's ability to speak and how good the parent knew the child's normal characteristics.

A strong point of our study is to provide an overview of how parents assess disease severity in their febrile child. Various studies have described what parents considered alarming signs but there are no studies that showed the complete spectrum from reassuring to alarming signs and symptoms from the parental perspective. The alarming signs described in the literature support our findings, as they are similar to the alarming signs we found[11-20]. All alarming signs were alterations of the normal characteristics of their child, like crying differently, being weak, drinking or eating less. Specifically, *van der Werf et al.*[14] described that parents judged disease as severe based on behavioural changes, whereas clinicians based this mainly on specific symptoms and physical examination. This is supported by our data that parents mainly focused on abnormalities in relation to their child's normal characteristics instead of specific symptoms in disease severity assessment. This also underlines the importance of investigating how parent-reported symptoms could be used in the physician's disease severity assessment and communication with parents.

Some studies have investigated the association between parent-reported disease severity and physician-reported disease severity. The parents' feeling that the ongoing disease episode is different

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3 from common disease episodes is a very strong predicting factor for severe disease[21]. However, the  
4 evidence for the predictive value of other parent-reported symptoms for disease severity is scarce, like  
5 reduced eating or drinking, sleep disturbance or change in cry[22-25] and the evidence of the  
6 predictive value of parent-reported respiratory symptoms like coughing is ambiguous[22, 23].  
7  
8 Interestingly, one of these studies found a poor agreement between observations of parents and  
9 medical staff regarding dyspnoea[23]. This difference can be explained by our observation that most  
10 parents were not able to recognize and describe dyspnoea well, except for parents with previous  
11 experiences with dyspnoea.  
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20 Another strength of this study is the design; the qualitative study design enabled us to explore the  
21 parents' perspective thoroughly. The interview atmosphere was open and the researchers had no  
22 influence on the child's medical care, reducing the risk of social desirability bias. The exclusion of  
23 parents with a severe language barrier could be a limitation of this study, because it could affect the  
24 generalizability of the results. However, parents with a moderate language barrier were included and  
25 overall the participant group was diverse in terms of age, cultural backgrounds and experience with  
26 disease. Additionally, the research was performed in a hospital and ED setting, not in GP setting. In  
27 the Dutch ED, most patients are referred by a GP, which makes the a priori risk of serious infection in  
28 children with fever higher. Therefore, the generalizability of the results is restricted to a hospital  
29 setting.  
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41 Our findings are relevant for clinical practice. Increasing awareness of the way parents recognize  
42 disease severity of their child may improve the communication between parents and physicians.  
43 Physicians should be aware that parents notice minor behaviour changes in their child because they  
44 compare this to the child's normal characteristics. Medical staff would not notice these differences  
45 easily. In contrast, specific symptoms of diseases like dyspnoea or dehydration could be more difficult  
46 to recognize by parents without previous experience with these symptoms. This underlines the  
47 importance of clear discharge instructions, which should be straightforward and unambiguous. During  
48 telephone consultations, in particular, – a frequently used form of follow-up after discharge – all  
49 medical staff should keep in mind that specific disease symptoms could be hard to recognize and  
50 interpret by parents. We suggest to transform our table 2 into a checklist of items to be of use in  
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3 routine practice that parent are able to recognize in his/her child. In the same way clinicians can use  
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5 the list as a basis for post-discharge follow-up.  
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9 The predictive value of parent-reported symptoms in relation to disease severity is still largely  
10  
11 unknown. Further research should therefore explore the diagnostic value and applicability of parent-  
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13 reported symptoms. Next, it is important to prove a correlation between parent-reported symptoms  
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15 and disease severity as judged by health professionals and/or diagnostic tests. If so, parent-reported  
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17 disease severity could be used to predict disease severity in the pre-hospital phase as well as during  
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19 post discharge follow-up of febrile children (safety netting). Parent-reported disease severity should  
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21 ideally be used in the form of a set of questions that is both easy to use, reproducible and reliable. The  
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23 development of such a tool would empower both parents and clinicians, and could bridge to a certain  
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25 extend the communication and knowledge gap between them.  
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## 28 **Conclusion**

29  
30 This is the first study to give a profound overview of what parents take into account when assessing  
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32 disease severity in their child. Parents were very well able to describe disease severity of their children  
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34 in terms of alternations in the child's normal characteristics. We identified a number of reassuring,  
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36 general and alarming signs from the parents' perspective. Specific symptoms of disease like  
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38 dehydration or dyspnoea were less easily described, especially if parents had no previous experience  
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40 with these conditions. Our next step will be to develop and validate a parent-reported disease severity  
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42 tool that can help parents in the pre-hospital phase and during follow-up to predict disease severity  
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44 and guide healthcare seeking behaviour.  
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**Competing interests statement**

None declared.

**Authors' contribution**

All authors helped with the design of this study and approved the final manuscript. DK performed and transcribed the semi-structured interviews. DK and NB independently coded the transcripts. DK wrote the first draft of the manuscript.

**Ethics approval**

This study received approval by the medical research ethics committee Zuidwest Holland and the local board of the Haga Teaching Hospital, Juliana Children's Hospital in the Hague (the Netherlands).

**Data sharing statement**

Data are available upon reasonable request. Please contact dr. G.J.A. Driessen (<https://orcid.org/0000-0002-4566-9547>).

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Table 1. Baseline data of interviewed parents (N=37) and their child with fever (N=26)

Patient's age in years	1,9 (0-5)
Child's sex, male	46% (12)
Country of birth, child	
Netherlands	100% (26)
Parents' age in years	34 (26-48)
Total number of parent's children	2 (1-4)
Education level of the interviewed parents **	
Low	5,4% (2)
Middle	46% (17)
High	49% (18)
Country of birth, interviewed parents	
The Netherlands	65% (24)
Suriname	8,1% (3)
Turkey	5,4% (2)
Morocco	5,4% (2)
Other***	16% (6)
Mother present at interview	92% (24)
Father present at interview	50% (13)
Interviews in acute setting (ED)	46% (12)
Patient admitted after interview at ED	33% (4)
Interviews in non-acute setting (ward)	54% (14)
Number of previous hospital admissions of all of the parent's children*	1 (0-41)
Number of hospital presentations (ED or outpatient clinic) with all of the parent's children	
1 time	12% (3)
2-5 times	42% (11)
>5 times	46% (12)

*Categorical variables are displayed as a number with percentage, continuous variables as a median with range.*

*\* Data not available for 4 children;*

*\*\* Education levels are based on the classification of Statistics Netherlands[26];*

*\*\*\*Netherlands Antilles, Dominican Republic, Syria, Colombia, Pakistan, Germany.*

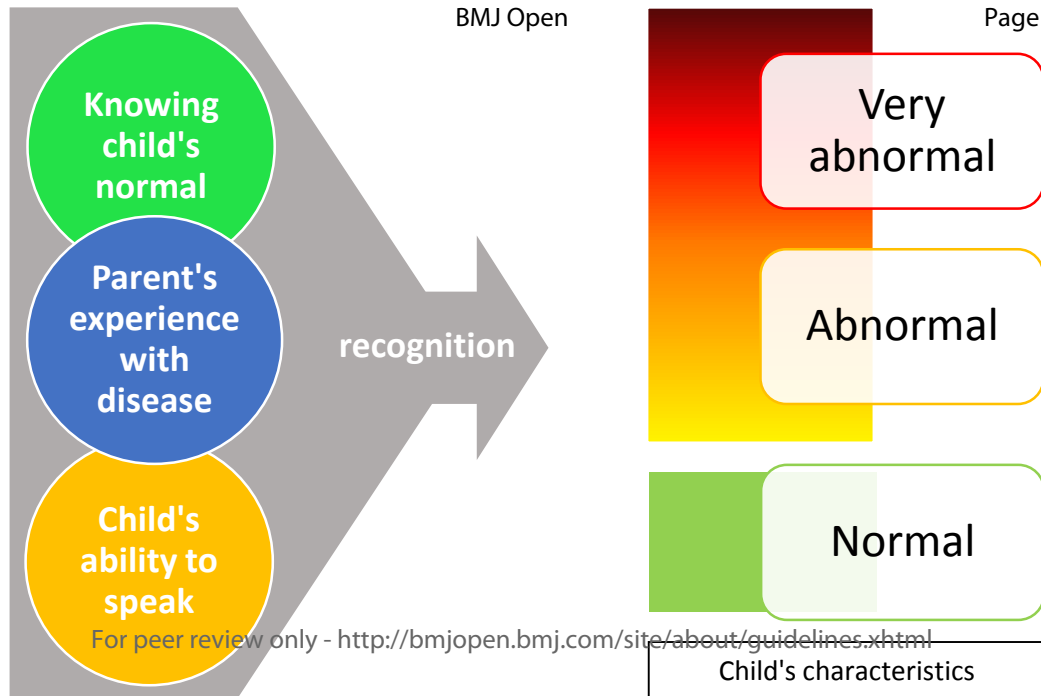
Table 2. Signs and symptoms that are recognized/reported by parents

Characteristic	Reassuring (normal)	General illness (abnormal)	Alarming (very abnormal)
Activity	<b>Walking (crawling), being active</b>	<b>Having less energy, being passive</b>	<b>Not doing anything at all, being very weak</b>
Playing	<b>Playing normally</b>	<b>Playing less</b>	Not playing at all
Eating and drinking	<b>Eating and drinking well</b>	<b>Eating and drinking less</b>	<b>(Almost) not drinking and eating anymore</b>
Sleeping	Sleeping as much as normal	<b>Sleeping more or restlessly</b>	Sleeping extremely much or very restlessly
Consciousness	Alert	Being slow or absent	Not waking up, being delirious
Mood	<b>Happy, smiling</b>	<b>Not smiling, not happy</b>	Crying continually
Talking	Talking (babbling)	Being more quiet	Not talking or babbling anymore
Responding	Responding normally to social cues or recognizing parent	Responding slower or less	(Almost) not responding anymore, not recognizing parent, not making contact
Appearance	Normal appearance	<b>Red cheeks, pale skin, drowsy look in the eyes, feeling warm and sweaty</b>	Extremely pale skin
Temperature	No fever or temperature decreases	Fever (>38 °C)	<b>High fever (&gt;40°C)</b>
Paracetamol	Good effect of paracetamol on temperature and behaviour	-	No effect of paracetamol on temperature and behaviour
Cause of disease	Clear cause, recognizing harmless disease, course of disease like expected	-	<b>Unclear which disease, recognizing serious disease from earlier</b>

Characteristics mentioned in at least 8 interviews are represented in bold. There was some overlap in what parents considered as illness signs and alarming signs. There was no overlap between reassuring signs and illness signs. This is symbolized by the coloured rectangle and arrow.

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For peer review only





## **Supplement 1: Topic list semi-structured interviews**

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### **Overarching questions**

1. How do you notice your child has a fever?
2. What impact does the fever have on you as a parent?
3. How do you judge disease severity?
  - *Reassuring signs*
  - *Alarming signs*
4. How do you classify your child as healthy, ill or extremely ill?
5. How did your ability of judging disease severity develop?
6. What are signs and symptoms that make you decide to seek medical help?

### **In-depth questions judging disease severity**

#### *General appearance*

7. How do you judge skin changes?
  - *Colour*
  - *Rash*

8. How do you notice pain?

#### *Behaviour and consciousness*

9. What do you see from the behaviour of a sick child?
  - *Playing*
  - *Walking / crawling*
  - *Responding*
  - *Being comfortable*
  - *Crying*

10. What is your definition of lethargy?

#### *Breathing*

11. How do you notice shortness of breath / breathing difficulties?
  - *Indrawings*
  - *Sounds*
  - *Respiration rate*

#### *Dehydration*

12. How do you notice that your child is dehydrated?
  - *Crying with tears*
  - *Dry mucous membranes*
  - *Drinking or urinating less*
13. What do you consider as urinating too little?
  - *Gradation: less, severely less*
14. What do you consider as drinking too little?
  - *Gradation: less, severely less*

### **Concluding**

15. Is there anything else you would like to add?

## Supplement 2: Relevant quotes

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6 Q1. "Every day and night we are with the kids. So you know how your child behaves normally. And  
7 everything that deviates from that, is an indication [of disease] for me." (Mother, patient 1 year (y))  
8  
9 Q2. "You look and then you think: yeah, it's just not my child who I'm seeing now." (Mother, patient 4 y)  
10  
11 Q3. "Father: Just like your car. Yeah, you are driving with it every day, and at the moment that you notice  
12 something responds differently than normal, you think: hey, there is something wrong with my car!  
13 That's the same with our kid. [...] If I drive in my car every day... You just know: at the moment that  
14 you hear something, you know; hey, that is different than what I am used to.  
15 Researcher: yes. And sometimes you still don't know exactly what it is...  
16 Father: ... but you know that there is something wrong." (patient 8 months (mo))  
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19 Q4. "He [patient's brother] is always calm and you would see that he becomes more quiet because he is  
20 drowsy and passive [...] He becomes quiet with fever, unlike him [patient]. He [brother] would be quiet  
21 and sit in a corner and he [patient] would be crying very loudly, like: hey, I'm not feeling well!" (Father,  
22 patient 1 y)  
23  
24 Q5. Father: Yeah, we just notice it as a parent! I don't know. He's just really a different child [if he's ill].  
25 Maybe it's based on the parent's instinct.  
26 Mother: [...] What they normally find interesting, is suddenly not interesting anymore! Then you  
27 instantly notice that there is something wrong. (patient 3 y)  
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30 Q6. Father: And your intuition [to mother] is even stronger than mine. [...] I think that's the widely known  
31 mother's instinct. [...] I really keep an eye on him, but what you have... That is just an extra sensor  
32 which is turned on! (patient 6 mo)  
33  
34 Q7. "Mother: He [father] does not feel that. But I do. [...] I think it is just the mother's instinct, that you've  
35 carried him for 9 months. Yeah...  
36 Researcher: That you know him through and through?  
37 Mother: Yes." (patient 8 mo)  
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40 Q8. "She is a very cheerful type, normally. And then she suddenly becomes passive." (Father, patient 9  
41 mo)  
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43 Q9. "It's mostly that she sleeps a lot, is tired quickly, and just wants to lay down and doesn't want to do  
44 anything." (Mother, patient 1 y)  
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46 Q10. "The skin, being pale, having blue circles under the eyes." (Mother, patient 5 y)  
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48 Q11. "Mother: Her neck is warm.  
49 Father: And her eyes look different.  
50 Mother: yeah, a drowsy look in her eyes." (patient 9 mo)  
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53 Q12. "Then he would be very weak, he couldn't be woken up easily, maybe cry a lot. Continuously falling  
54 asleep, just not being alert, not reacting to sounds or so." (Mother, patient 3 mo)  
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56 Q13. "[Regarding last admission:] Really, she could only sleep, she couldn't do anything, because she had  
57 no energy, and she didn't do anything. But most of all: not responding." (Mother, patient 1 y)  
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3 Q14. A mother of a child with no significant medical history stated: *"Actually she always stays a bit active. If she would get passive, I would worry. I have only experienced that once, maybe."* (Mother, patient 4 y)
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6 Q15. A mother of a child with an extensive medical history stated: *"Then he gets lethargic or he starts being delirious, he sees things that are not there. But then he really has a high fever. [...] Look, if he has a fever and he is totally 'out', and he is barely moving, being weak... Yeah, then I am really worried."*
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10 (Mother, patient 5 y)
- 11 Q16. *"If he's like this [you hear the child yelling]: very active, he eats well, he drinks well, he pees well, and he does everything that he would do normally... Then I'm not worried."* (Mother, patient 8 mo)
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14 Q17. *"If he's happy, he is sleeping peacefully, if he is calm when awake, just playing on his own, then we would get the feeling like: everything is fine. And if he finishes his bottles."* (Father, patient 2 mo)
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17 Q18. *"It's everything combined, the whole picture. So: the fever, alertness, whether he has pain somewhere, [...] how long the illness takes, and also how it went over the course of the day."* (Mother, patient 8 mo)
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22 Q19. *"Only if it [fever] is very high, and I see that the kid is not well, then I instantly want to call the GP or out-of-hours services. But if he is playing a lot, eating, drinking, with the fever, then it's no problem if it's 40 degrees. Then I just wait 3 days. [...] I know it when my child is sick or not: I see that he doesn't play, eat, drink or pee anymore, has difficulties with peeing, or has red dots. Or if he is restless, then I know that something is wrong with him."* (Mother, patient 9 mo)
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28 Q20. *"If [name older brother] has a fever, you think: well, it's only the flu. And he is not sick very often. [...] But look, with [name patient], because of his condition... With him that's the moment to go to the hospital. To [name older brother] I would say: just stay at home, I will put a blanket on you, just wait 'till it's over."* (Mother, patient 5 y)
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34 Q21. *"Eh, he has never really had that. But I can imagine: high chest breathing, located here [points high on the chest]."* (Mother, patient 5 y)
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37 Q22. *"When she has a cold, we notice she's breathing less well. [...] But furthermore I have no clue."*
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40 (Father, 8 mo)
- 41 Q23. *"If he is short of breath, then he's only coughing. He becomes red and sweaty. And he breathes very quickly. [...] Sometimes his lungs are also wheezing. A wheezing sound is coming out of them."*
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44 (Mother, patient 4 y)
- 45 Q24. *"The indrawings. And then mainly here [points at neck] and also in his belly, then it's all indrawing. But also the way of breathing. Now he's breathing calmly, but if he's s short of breath it is a sort of... Halve breaths all the time [tries to mimic it, quick and shallow breaths]. No deep breaths."* (Mother, patient 3 y)
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50 Q25. *"I know the basics. I also know there are tricks with the skin, but I think I should have seen that once. But I know that the basis is: if your kid has a fever, pay attention to the nappies and that he drinks enough."* (Mother, patient 8 mo)
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55 Q26. *"He has never had that. So I don't know whether I would recognize it. Maybe I would. That he would get a dryer skin, that kind of stuff. [...] I think you will only see the difference if you have seen it once before."* (Mother, patient 7 mo)
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3 Q27. *"We have never experienced this. So you're going to consider: what have we experienced before, and*  
4 *have we ever encountered such a situation? Well, we had never had such an experience and we*  
5 *thought it looked quite extreme. So we thought, we have to seek help."* (Father, patient 8 mo)  
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7 Q28. *"It is a lot more difficult with your first child than with your second child. [...] We have been worried a*  
8 *lot more with our first one. Just a lack of experience."* (Father, patient 1 y)  
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10 Q29. *"Mother: Especially the first few weeks were quite difficult. Because then you don't understand the*  
11 *different cries well: is she hungry now or is she just tired? You just don't know that well enough. [...]*  
12 *Father: At some point just know better what's right and what's wrong.*  
13 *Mother: Yeah, you get to know your child better."* (patient 2 mo)  
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16 Q30. *"I would be happy if she could say herself: owie ouch, or this, or that. Because you have to judge it*  
17 *yourself and hope you are right."* (Mother, patient 4 mo)  
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19 Q31. *"Father: And now he says it himself, that he is short of breath.*  
20 *Mother: Yeah, that makes a big difference."* (patient 3 y)  
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# Reporting checklist for qualitative study.

Based on the SRQR guidelines.

## Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med.* 2014;89(9):1245-1251.

	Reporting Item	Page Number
<b>Title</b>		
	<a href="#">#1</a> Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
<b>Abstract</b>		
	<a href="#">#2</a> Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
<b>Introduction</b>		
Problem formulation	<a href="#">#3</a> Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4

1	Purpose or research	<a href="#">#4</a>	Purpose of the study and specific objectives or	4
2	question		questions	
3				
4	<b>Methods</b>			
5				
6				
7	Qualitative approach and	<a href="#">#5</a>	Qualitative approach (e.g. ethnography, grounded	4
8	research paradigm		theory, case study, phenomenology, narrative	
9			research) and guiding theory if appropriate; identifying	
10			the research paradigm (e.g. postpositivist,	
11			constructivist / interpretivist) is also recommended;	
12			rationale. The rationale should briefly discuss the	
13			justification for choosing that theory, approach,	
14			method or technique rather than other options	
15			available; the assumptions and limitations implicit in	
16			those choices and how those choices influence study	
17			conclusions and transferability. As appropriate the	
18			rationale for several items might be discussed	
19			together.	
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27	Researcher	<a href="#">#6</a>	Researchers' characteristics that may influence the	5
28	characteristics and		research, including personal attributes, qualifications /	
29	reflexivity		experience, relationship with participants,	
30			assumptions and / or presuppositions; potential or	
31			actual interaction between researchers' characteristics	
32			and the research questions, approach, methods,	
33			results and / or transferability	
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39	Context	<a href="#">#7</a>	Setting / site and salient contextual factors; rationale	5
40				
41	Sampling strategy	<a href="#">#8</a>	How and why research participants, documents, or	5
42			events were selected; criteria for deciding when no	
43			further sampling was necessary (e.g. sampling	
44			saturation); rationale	
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48	Ethical issues pertaining	<a href="#">#9</a>	Documentation of approval by an appropriate ethics	5, 14
49	to human subjects		review board and participant consent, or explanation	
50			for lack thereof; other confidentiality and data security	
51			issues	
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55	Data collection methods	<a href="#">#10</a>	Types of data collected; details of data collection	5
56			procedures including (as appropriate) start and stop	
57			dates of data collection and analysis, iterative	
58				
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1		process, triangulation of sources / methods, and	
2		modification of procedures in response to evolving	
3		study findings; rationale	
4			
5	Data collection	<a href="#">#11</a> Description of instruments (e.g. interview guides,	4,5
6	instruments and	questionnaires) and devices (e.g. audio recorders)	
7	technologies	used for data collection; if / how the instruments(s)	
8		changed over the course of the study	
9			
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12	Units of study	<a href="#">#12</a> Number and relevant characteristics of participants,	5
13		documents, or events included in the study; level of	
14		participation (could be reported in results)	
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17	Data processing	<a href="#">#13</a> Methods for processing data prior to and during	5
18		analysis, including transcription, data entry, data	
19		management and security, verification of data	
20		integrity, data coding, and anonymisation /	
21		deidentification of excerpts	
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26	Data analysis	<a href="#">#14</a> Process by which inferences, themes, etc. were	5
27		identified and developed, including the researchers	
28		involved in data analysis; usually references a specific	
29		paradigm or approach; rationale	
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33	Techniques to enhance	<a href="#">#15</a> Techniques to enhance trustworthiness and credibility	5
34	trustworthiness	of data analysis (e.g. member checking, audit trail,	
35		triangulation); rationale	
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38	<b>Results/findings</b>		
39			
40	Syntheses and	<a href="#">#16</a> Main findings (e.g. interpretations, inferences, and	6-10
41	interpretation	themes); might include development of a theory or	
42		model, or integration with prior research or theory	
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46	Links to empirical data	<a href="#">#17</a> Evidence (e.g. quotes, field notes, text excerpts,	6-10
47		photographs) to substantiate analytic findings	
48			
49			
50	<b>Discussion</b>		
51			
52	Intergration with prior	<a href="#">#18</a> Short summary of main findings; explanation of how	11-13
53	work, implications,	findings and conclusions connect to, support,	
54	transferability and	elaborate on, or challenge conclusions of earlier	
55	contribution(s) to the field	scholarship; discussion of scope of application /	
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generalizability; identification of unique contributions(s) to scholarship in a discipline or field

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4 Limitations [#19](#) Trustworthiness and limitations of findings 12

5  
6 **Other**

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8 Conflicts of interest [#20](#) Potential sources of influence of perceived influence 14  
9 on study conduct and conclusions; how these were  
10 managed  
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12  
13 Funding [#21](#) Sources of funding and other support; role of funders 14  
15 in data collection, interpretation and reporting  
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# BMJ Open

## Parental assessment of disease severity in febrile children under 5 years of age: a qualitative study

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3 **Parental assessment of disease severity in febrile children under 5 years of age: a qualitative**  
4 **study**  
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## **Abstract**

**Objective:** To explore how parents judge disease severity of their febrile child and to identify symptoms they associate with serious illness, minor illness or health.

**Design:** Semi-structured interviews were conducted. Interviews were audio taped, transcribed verbatim and analysed thematically.

**Participants:** Parents of children aged 0-5 years with a febrile illness.

**Setting:** Participants were recruited at the paediatric ward and the emergency department.

**Results:** Twenty-six interviews were conducted, in which 37 parents participated. Parents described disease severity of their child mainly in terms of changes in their child's normal characteristics (behaviour and physical features). They found it harder to describe specific disease symptoms such as dyspnoea or dehydration. Their child being active, eating and drinking well and smiling were perceived as reassuring, whereas high fever, moving very little and uncertainty about the type of infections were mentioned as alarming symptoms. Previous experience with febrile illnesses in their children was of great influence on the number and accuracy of symptoms they reported.

**Conclusion:** Parents used the normal behaviour and physical features of their child as a reference frame for judging disease severity. With a larger deviation from the child's normal characteristics, parents considered the illness more serious. They were less able to describe specific symptoms of disease such as dyspnoea or dehydration. This knowledge is important for clinicians in their communication with parents of children with febrile illness.

Word count abstract: 226 (max 250)

Subject areas: Paediatrics, Emergency Medicine, Community Child Health

Keywords: Paediatric A&E and ambulatory care, Paediatric infectious disease & immunization, qualitative research, paediatrics

## **Strength and limitations**

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3 - This study presents an integral overview of what parents take into account when assessing disease  
4 severity in their child.

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6  
7 - Because of the in-depth interviews, we were able to explore not only alarming symptoms, but also  
8 signs that reassure parents.

9  
10 - The qualitative study design enabled us to explore the parents' perspective thoroughly.

11  
12 - This study did not examine the correlation between parent-reported symptoms and disease severity  
13 as judged by health professionals and/or diagnostic tests.

14  
15  
16 - Because this study was performed on the paediatric ED with parents without a severe language  
17 barrier, its main limitation is the generalizability to other settings such as primary care or parents with  
18 limited understanding of the Dutch language.  
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## **Introduction**

Febrile illnesses are very common in children. Pre-school children experience almost two infectious diseases per year[1]. In Western Europe, in 20-39% of children with fever a doctor is consulted[2, 3] and about half of the consultations on the paediatric emergency department (ED) are for infections[4]. The majority of these children have a viral infection, which requires little or no medical intervention. Only 10-15% of the children with febrile illness at the ED has a serious bacterial infection[5]. However, it is essential to distinguish serious infections from minor infections to reduce morbidity and mortality. Recognition of disease severity by parents and subsequent healthcare seeking behaviour of parents are the first steps in this process.

Because of the low prevalence of severe disease and abundance of mild disease, diagnosis of serious infections in febrile children is challenging[6]. In the treatment guideline for febrile children at the ED in the Netherlands[7], which is largely based on the NICE guideline for fever, the main factors that are taken into account are the doctors' observations and laboratory tests. However, it would be very useful to acquire a greater understanding of the parental perspective of disease severity assessment as the first step in the diagnostic process. Parents are capable of identifying their child as ill[8, 9] and the parental instinct for disease is an indicator for disease severity[6]. However, what parents take into account exactly while judging disease severity and what symptoms they can recognize in their child, is largely unknown.

Therefore, the aim of this study is to explore how parents judge disease severity in their febrile child. In particular, which signs and symptoms parents associate with severe illness, which conditions they associate with a healthy state and the spectrum in between these limits.

## **Methods**

### **Study design**

We performed a qualitative study with semi-structured interviews in order to explore how parents judged the severity of illness of their febrile child. A topic guide for semi-structured interviews (Supplement 1) was developed based on the study objective, existing literature, clinical experience and the Dutch treatment guideline to assess febrile children in hospital setting[7]. The content and

1  
2  
3 phrasing of the questions was reviewed by experts in paediatrics and adjusted in accordance with  
4  
5 their remarks.  
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### 8 9 **Recruitment**

10 A sample of parents of children with fever aged one month to five years was recruited. We aimed to  
11 obtain maximum variation within the sample in terms of patient age and the experience of parents with  
12 diseases in their children. Recruitment took place at the Haga Teaching Hospital, Juliana Children's  
13 Hospital in the Hague (the Netherlands), on both the paediatric ED and the paediatric ward. Parents  
14 were interviewed at times the medical staff did not need to attend the patient, for example during  
15 waiting time for lab results. Both at the ward and at the ED, the average interview duration was 20  
16 minutes. Recruitment was continued until data saturation occurred. Parents with children were  
17 included if fever ( $>38,0$  °C) was reported during the illness episode or if a fever was measured in the  
18 hospital. Parents of patients with a life-threatening condition that needed immediate medical attention  
19 were excluded. Another exclusion criterion was a severe language barrier, defined as parents not  
20 being able to understand the participant information folder and not able to communicate sufficiently  
21 with the study team.  
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### 36 **Data collection and analysis**

37 Semi-structured interviews were conducted in April and May 2019. The interviews with the parent(s)  
38 took place at the patient's room at the ED or ward. Participants were enrolled after providing written  
39 informed consent. Interviews were audio recorded and transcribed verbatim by the first author (DK),  
40 including non-verbal information. After 18 interviews, a preliminary analysis took place in the study  
41 team, which guided in-depth questions for the subsequent interviews. Data saturation occurred after  
42 26 interviews. The accuracy of transcripts was verified by comparing them with the original audio  
43 fragments by NB. Thematic analysis was conducted using MAXQDA data management system[10].  
44 The transcripts were independently read thoroughly by DK and NB. Thereafter codes were identified  
45 inductively by both investigators in eight transcripts, after which they compared the codes and edited  
46 the codes until consensus was reached. The codes were grouped into themes. Conceptual links were  
47 visualized in figures by the DK, NB and GD.  
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## **Patient involvement**

Patients or parents were not involved in the design of this study. However, our study aim and design was completely focused on retrieving their perspective. The results of this study (parent-reported disease severity) can help paediatricians for improving their communication with parents of children with febrile illnesses.

## **Results**

### **Demographics**

Twenty-six interviews were conducted, in which 37 parents participated: 24 mothers and 13 fathers. In 11 interviews both parents were present and in 15 interviews only one of them attended. Three eligible parents decided not to participate, out of privacy reasons (one) and lack of time (two). Detailed participant characteristics are presented in Table 1.

### **Main themes**

The following themes emerged from the data:

- Judgement of disease severity using the child's normal characteristics
- General illness signs recognized by parents
- Difficulty of describing specific symptoms of disease
- Factors influencing parents' ability to assess disease severity

### **Judgement of disease severity using the child's normal characteristics**

#### *The child as its own reference*

In all interviews, parents reported to recognize disease from their child's characteristics being different from normal. They mentioned subtle differences on various characteristics, including behaviour, like activity level and mood, and physical features, like temperature and appearance. Parents stated to use their child's normal characteristic being the reference for recognizing disease: *"Every day and night we are with the kids. So you know how your child behaves normally. And everything that deviates from that, is an indication [of disease] for me."* (Mother, patient 1 year (y)). Supplement 2 provides an overview of all relevant quotes. Also see Quote 2-3 (Q2-3).



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3 Parents with multiple children described that signs of febrile disease differed greatly between siblings,  
4  
5 which depended on the child's normal characteristics. Every child has specific characteristics which  
6  
7 parents use to recognize (severe) disease: *"He [patient's brother] is always calm and you would see*  
8  
9 *that he becomes more quiet because he is drowsy and passive [...] He becomes quiet with fever,*  
10  
11 *unlike him [patient]. He [brother] would be quiet and sit in a corner and he [patient] would be crying*  
12  
13 *very loudly, like: hey, I'm not feeling well!"* (Father, patient 1 y).

### 14 15 16 *Parental instinct*

17  
18 In 13 of the 26 interviews, parents mentioned to notice that something was wrong with their child  
19  
20 based on their parental instinct. This instinct was regularly expressed in combination with recognizing  
21  
22 that something was abnormal in their child; there seems to be overlap between the parental instinct  
23  
24 and recognizing differences in their child's characteristics: *Father: "Yeah, we just notice it as a parent!*  
25  
26 *I don't know. He's just really a different child [if he's ill]. Maybe it's based on the parent's instinct.*  
27  
28 *Mother: [...] What they normally find interesting, is suddenly not interesting anymore! Then you*  
29  
30 *instantly notice that there is something wrong."* (patient 3 y).

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33 In 6 interviews parents spontaneously reported that the mother's instinct was stronger than the father's  
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35 instinct, and that mothers were therefore better in evaluating the severity of disease. As a reason for  
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37 the mother's instinct being very strong was that mothers said to know their child better. *Father: "And*  
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39 *your intuition [to mother] is even stronger than mine. [...] I think that's the widely known mother's*  
40  
41 *instinct. [...] I really keep an eye on him, but what you have... That is just an extra sensor which is*  
42  
43 *turned on!"* (patient 6 mo). Also see Q7, Supplement 2.

### 44 45 46 **General illness signs**

#### 47 48 49 *General signs*

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51 Parents mentioned a broad range of signs and symptoms to describe the abnormal state of the child in  
52  
53 case of disease. Table 2 shows reassuring, general and alarming signs of disease from the parents'  
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55 perspective on all aspects of their child's characteristics. All signs were present in both children under  
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57 one year old and in older children.

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3 In all interviews, parents described their child suffering from febrile illness as being in a less energetic  
4 state, in which the child ate less, drank less, urinated less, played less, and slept more than normal. In  
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7 4 interviews parents described that disease could also be recognized if their child was hyperactive,  
8  
9 irritable, in a bad mood and nagging (Q8-9, Supplement 2). Besides this less energetic mental or  
10  
11 physical state, parents reported to recognize disease from changes in the child's appearance. The  
12  
13 child would be pale, warm and sweaty, or would have red cheeks (with fever). Parents reported also to  
14  
15 recognize disease from 'the look in their eyes' (Q10-11, Supplement 2).  
16  
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### 18 *Alarming signs*

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20 Parents described that the less energetic state in case of febrile illness would get worse with  
21  
22 increased disease severity. In severe disease it would alter to a state in which the child barely eats or  
23  
24 drinks, is very weak, and/or barely responds to social stimuli and/or sleeps a lot (Table 2 and Q12-13  
25  
26 in Supplement 2).  
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29  
30 Still, there were major differences in what parents considered alarming, which was linked to their  
31  
32 previous experiences with health and disease. Signs that parents of relatively healthy children  
33  
34 considered alarming, were considered as less alarming by parents of children with a relevant medical  
35  
36 history. For example, there was a parent of a relatively healthy child who appraised being passive as  
37  
38 an alarming sign, whereas a parent of a child with an extensive medical history described being  
39  
40 passive as a general sign to recognize febrile illness. *"Actually she always stays a bit active. If she*  
41  
42 *would get passive, I would worry. I have only experienced that once, maybe."* (Mother, patient 4 y, no  
43  
44 significant medical history); *"Then he gets lethargic or he starts being delirious, he sees things that are*  
45  
46 *not there. But then he really has a high fever. [...] Look, if he has a fever and he is totally 'out', and he*  
47  
48 *is barely moving, being weak... Yeah, then I am really worried."* (Mother, patient 5 y, significant  
49  
50 medical history). Signs that experienced parents considered alarming were extreme weakness,  
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52 lethargy, delirium, not responding well or being unable to wake their child.  
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### Reassuring signs

Parents considered it reassuring if the less energetic state had disappeared or had not occurred at all. They found it reassuring if the child's characteristics (physical features and behaviour) had returned to what was normal for the child (Table 2 and Q16-17 in Supplement 2).

### The complete picture

Parents explained that they assessed disease severity based on the whole picture of alarming and reassuring signs (Q18). For example, in the case of high fever also other aspects of the child's normal characteristics would be assessed to judge disease severity: *"Only if it [fever] is very high, and I see that the kid is not well, then I instantly want to call the GP or out-of-hours services. But if he is playing a lot, eating, drinking, with the fever, then it's no problem if it's 40 degrees. Then I just wait 3 days. [...] I know it when my child is sick or not: I see that he doesn't play, eat, drink or pee anymore, has difficulties with peeing, or has red dots. Or if he is restless, then I know that something is wrong with him."* (Mother, patient 9 mo).

Additionally, symptoms of children with a relevant medical history were interpreted in a different way; parents were more cautious about severe disease (or a relapse of severe disease) in these children depending on previously experienced specific signs or symptoms for this disease *"If [name older brother] has a fever, you think: well, it's only the flu. And he is not sick very often. [...] But look, with [name patient], because of his condition... With him that's the moment to go to the hospital. To [name older brother] I would say: just stay at home, I will put a blanket on you, just wait 'till it's over."* (Mother, patient 5 y).

### Difficulty of describing specific symptoms of disease

Previous experience was important in recognizing specific symptoms. The majority of the interviewed parents had no experience with certain symptoms like dehydration or dyspnoea. These parents found it harder to describe how they could recognize these specific conditions.

Regarding dyspnoea, parents stated in 10 interviews that they did not know what the symptom presentation looked like. 7 of them tried to imagine what it would look like: *"Eh, he has never really*

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3 *had that. But I can imagine: high chest breathing, located here [points high on the chest].*" (Mother,  
4 patient 5 y). See also Q21, Supplement 2. Parents who had recent experience with their child being  
5 short of breath, could describe very precisely how they could recognize this symptom: *"If he is short of*  
6 *breath, then he's only coughing. He becomes red and sweaty. And he breathes very quickly. [...]*  
7 *Sometimes his lungs are also wheezing. A wheezing sound is coming out of them."* (Mother, patient 4  
8 y). See also Q24, Supplement 2.

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16 Regarding dehydration, parents mentioned in 15 interviews that they could recognize dehydration from  
17 the fluid balance in the child's body: a relative higher fluid loss compared to the fluid gains. In 6  
18 interviews, parents had no clue how to recognize it (Q25-26, Supplement 2).

### 23 24 **Factors influencing parents' ability to assess disease severity**

25  
26 Three major factors influence the parents' ability to assess disease severity: previous experience with  
27 signs and symptoms, knowing the child's normal characteristics and the child's ability to speak (see  
28 Figure 1).  
29  
30

#### 31 32 33 *Experience with previous illness*

34  
35 Previous experience with disease influences the parents' capability of recognizing diseases and  
36 judging disease severity (Q27, Supplement 2). Accordingly, the capability of assessing disease  
37 severity increased when parents had more children and when the child got older (Q28, Supplement 2).  
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#### 41 42 43 *Knowing your child*

44  
45 Parents also described that they had to know their child well to be able to recognize illness signs.  
46 They explained that this was harder in young infants. Knowing the child very well enabled them to  
47 recognize subtle changes in their child's normal characteristics: Mother: *"Especially the first few weeks*  
48 *were quite difficult. Because then you don't understand the different cries well: is she hungry now or is*  
49 *she just tired? You just don't know that well enough. [...]*". Father: *"At some point just know better*  
50 *what's right and what's wrong. Mother: Yeah, you get to know your child better."* (patient 2 mo).  
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### *Ability to speak*

Parents expressed that assessing disease severity was easier in older children because they were able to talk. Parents felt insecure about their interpretation of the symptoms if the child was not yet able to express him- of herself (Q30-31, Supplement 2).

## **Discussion**

This study presents an integral perspective regarding parental judgement of disease severity in their febrile child. Parents mainly used the normal characteristics in terms of behaviour and physical features of their child as a reference frame for interpreting signs and symptoms of disease. Parents could describe alterations in the normal characteristics of their children very precisely, but were less able to describe specific symptoms for disease such as dyspnoea or dehydration if they had no previous experience with these conditions. The variety of illness signs parents described was mainly dependent on their previous experience with disease, as well as the child's ability to speak and how good the parent knew the child's normal characteristics.

A strong point of our study is to provide an overview of how parents assess disease severity in their febrile child. Various studies have described what parents considered alarming signs but there are no studies that showed the complete spectrum from reassuring to alarming signs and symptoms from the parental perspective. The alarming signs described in the literature support our findings, as they are similar to the alarming signs we found[11-20]. All alarming signs were alterations of the normal characteristics of their child, like crying differently, being weak, drinking or eating less. Specifically, *van der Werf et al.*[14] described that parents judged disease as severe based on behavioural changes, whereas clinicians based this mainly on specific symptoms and physical examination. This is supported by our data that parents mainly focused on abnormalities in relation to their child's normal characteristics instead of specific symptoms in disease severity assessment. This also underlines the importance of investigating how parent-reported symptoms could be used in the physician's disease severity assessment and communication with parents.

Some studies have investigated the association between parent-reported disease severity and physician-reported disease severity. The parents' feeling that the ongoing disease episode is different

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3 from common disease episodes is a very strong predicting factor for severe disease[21]. However, the  
4 evidence for the predictive value of other parent-reported symptoms for disease severity is scarce, like  
5 reduced eating or drinking, sleep disturbance or change in cry[22-25] and the evidence of the  
6 predictive value of parent-reported respiratory symptoms like coughing is ambiguous[22, 23].  
7  
8 Interestingly, one of these studies found a poor agreement between observations of parents and  
9 medical staff regarding dyspnoea[23]. This difference can be explained by our observation that most  
10 parents were not able to recognize and describe dyspnoea well, except for parents with previous  
11 experiences with dyspnoea.  
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20 Another strength of this study is the design; the qualitative study design enabled us to explore the  
21 parents' perspective thoroughly. The interview atmosphere was open and the researchers had no  
22 influence on the child's medical care, reducing the risk of social desirability bias. The exclusion of  
23 parents with a severe language barrier could be a limitation of this study, because it could affect the  
24 generalizability of the results. However, parents with a moderate language barrier were included and  
25 overall the participant group was diverse in terms of age, cultural backgrounds and experience with  
26 disease. Parents with a lower SES were under-represented in our study. Additionally, the research  
27 was performed in a hospital and ED setting, not in GP setting. In the Dutch ED, most patients are  
28 referred by a GP, which makes the a priori risk of serious infection in children with fever higher.  
29 Therefore, the generalizability of the results is restricted to a hospital setting.  
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41 Our findings are relevant for clinical practice. Increasing awareness of the way parents recognize  
42 disease severity of their child may improve the communication between parents and physicians.  
43 Physicians should be aware that parents notice minor behaviour changes in their child because they  
44 compare this to the child's normal characteristics. Medical staff would not notice these differences  
45 easily. In contrast, specific symptoms of diseases like dyspnoea or dehydration could be more difficult  
46 to recognize by parents without previous experience with these symptoms. This underlines the  
47 importance of clear discharge instructions, which should be straightforward and unambiguous. During  
48 telephone consultations, in particular, – a frequently used form of follow-up after discharge – all  
49 medical staff should keep in mind that specific disease symptoms could be hard to recognize and  
50 interpret by parents. We suggest to transform our table 2 into a checklist of items to be of use in  
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3 routine practice that parent are able to recognize in his/her child. In the same way clinicians can use  
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5 the list as a basis for post-discharge follow-up.  
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9 The predictive value of parent-reported symptoms in relation to disease severity is still largely  
10  
11 unknown. Further research should therefore explore the diagnostic value and applicability of parent-  
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13 reported symptoms. Next, it is important to prove a correlation between parent-reported symptoms  
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15 and disease severity as judged by health professionals and/or diagnostic tests. If so, parent-reported  
16  
17 disease severity could be used to predict disease severity in the pre-hospital phase as well as during  
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19 post discharge follow-up of febrile children (safety netting). Parent-reported disease severity should  
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21 ideally be used in the form of a set of questions that is both easy to use, reproducible and reliable. The  
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23 development of such a tool would empower both parents and clinicians, and could bridge to a certain  
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25 extend the communication and knowledge gap between them.  
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## 28 **Conclusion**

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30 This study presents an integral overview of what parents take into account when assessing disease  
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32 severity in their child. Parents were very well able to describe disease severity of their children in  
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34 terms of alternations in the child's normal characteristics. We identified a number of reassuring,  
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36 general and alarming signs from the parents' perspective. Specific symptoms of disease like  
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38 dehydration or dyspnoea were less easily described, especially if parents had no previous experience  
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40 with these conditions. Future research should focus on the correlation between parent-reported  
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42 symptoms and disease severity. Therefore, our next step will be to develop and validate a parent-  
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44 reported disease severity tool that can help parents in the pre-hospital phase and during follow-up to  
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46 predict disease severity and guide healthcare seeking behaviour.  
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### **Competing interests statement**

None declared.

### **Authors' contribution**

DK performed and transcribed the semi-structured interviews. DK and NB independently coded the transcripts. DP designed the study and contributed to the logistics. GD designed and supervised the study. JM and RO contributed to the design of the study. DK and GD analysed the data and wrote the manuscript. DP, NB, JM, and RO critically revised the manuscript. All authors approved the final manuscript.

### **Ethics approval**

This study received approval by the medical research ethics committee Zuidwest Holland and the local board of the Haga Teaching Hospital, Juliana Children's Hospital in the Hague (the Netherlands).

### **Data sharing statement**

Data are available upon reasonable request. Please contact dr. G.J.A. Driessen (<https://orcid.org/0000-0002-4566-9547>).

Figure 1. The concept of the parent's ability to recognize symptoms for disease severity assessment.

At the left, we grouped elements that influenced parental ability to describe symptoms. Child's characteristics (as described in table 2) are schematically represented at the right.



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Table 1. Baseline data of interviewed parents (N=37) and their child with fever (N=26)

Patient's age in years	1,9 (0-5)
Child's sex, male	46% (12)
Country of birth, child	
Netherlands	100% (26)
Parents' age in years	34 (26-48)
Total number of parent's children	2 (1-4)
Education level of the interviewed parents **	
Low	5,4% (2)
Middle	46% (17)
High	49% (18)
Country of birth, interviewed parents	
The Netherlands	65% (24)
Suriname	8,1% (3)
Turkey	5,4% (2)
Morocco	5,4% (2)
Other***	16% (6)
Mother present at interview	92% (24)
Father present at interview	50% (13)
Mother and father present at interview	42% (11)
Interviews in acute setting (ED)	46% (12)
Patient admitted after interview at ED	33% (4)
Interviews in non-acute setting (ward)	54% (14)
Number of previous hospital admissions of all of the parent's children*	1 (0-41)
Number of hospital presentations (ED or outpatient clinic) with all of the parent's children	
1 time	12% (3)
2-5 times	42% (11)
>5 times	46% (12)

*Categorical variables are displayed as a number with percentage, continuous variables as a median with range.*

*\* Data not available for 4 children;*

*\*\* Education levels are based on the classification of Statistics Netherlands[26];*

*\*\*\*Netherlands Antilles, Dominican Republic, Syria, Colombia, Pakistan, Germany.*

Table 2. Signs and symptoms that are recognized/reported by parents

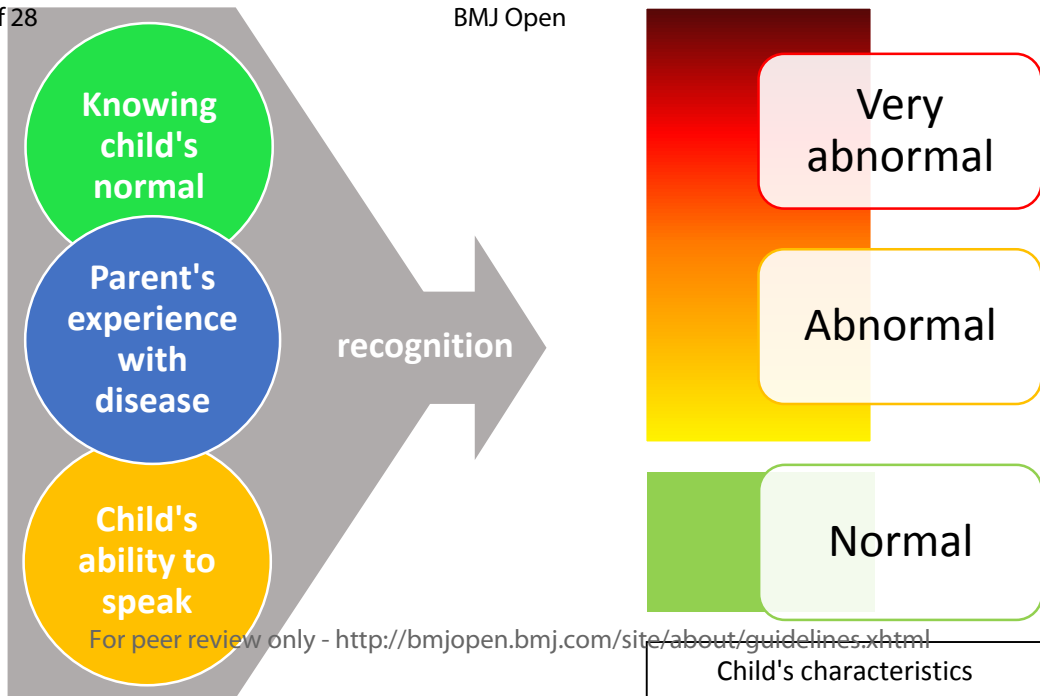
<b>Characteristic</b>	<b>Reassuring (normal)</b>	<b>General illness (abnormal)</b>	<b>Alarming (very abnormal)</b>
<b>Activity</b>	<i>Walking (crawling), being active</i>	<i>Having less energy, being passive</i>	<i>Not doing anything at all, being very weak</i>
<b>Playing</b>	<i>Playing normally</i>	<i>Playing less</i>	<i>Not playing at all</i>
<b>Eating and drinking</b>	<i>Eating and drinking well</i>	<i>Eating and drinking less</i>	<i>(Almost) not drinking and eating anymore</i>
<b>Sleeping</b>	Sleeping as much as normal	<i>Sleeping more or restlessly</i>	Sleeping extremely much or very restlessly
<b>Consciousness</b>	Alert	Being slow or absent	Not waking up, being delirious
<b>Mood</b>	<i>Happy, smiling</i>	<i>Not smiling, not happy</i>	<i>Crying continually</i>
<b>Talking</b>	Talking (babbling)	Being more quiet	Not talking or babbling anymore
<b>Responding</b>	Responding normally to social cues or recognizing parent	Responding slower or less	(Almost) not responding anymore, not recognizing parent, not making contact
<b>Appearance</b>	Normal appearance	<i>Red cheeks, pale skin, drowsy look in the eyes, feeling warm and sweaty</i>	Extremely pale skin
<b>Temperature</b>	No fever or temperature decreases	Fever (>38 °C)	<i>High fever (&gt;40°C)</i>
<b>Paracetamol</b>	Good effect of paracetamol on temperature and behaviour	-	No effect of paracetamol on temperature and behaviour
<b>Cause of disease</b>	Clear cause, recognizing harmless disease, course of disease like expected	-	<i>Unclear which disease, recognizing serious disease from earlier</i>

Characteristics mentioned in at least 8 interviews are represented in italics. There was some overlap in what parents considered as illness signs and alarming signs. There was no overlap between reassuring signs and illness signs. This is symbolized by the coloured rectangle and arrow.

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## **Supplement 1: Topic list semi-structured interviews**

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### **Overarching questions**

1. How do you notice your child has a fever?
2. What impact does the fever have on you as a parent?
3. How do you judge disease severity?
  - *Reassuring signs*
  - *Alarming signs*
4. How do you classify your child as healthy, ill or extremely ill?
5. How did your ability of judging disease severity develop?
6. What are signs and symptoms that make you decide to seek medical help?

### **In-depth questions judging disease severity**

#### *General appearance*

7. How do you judge skin changes?
  - *Colour*
  - *Rash*
8. How do you notice pain?

#### *Behaviour and consciousness*

9. What do you see from the behaviour of a sick child?
  - *Playing*
  - *Walking / crawling*
  - *Responding*
  - *Being comfortable*
  - *Crying*
10. What is your definition of lethargy?

#### *Breathing*

11. How do you notice shortness of breath / breathing difficulties?
  - *Indrawings*
  - *Sounds*
  - *Respiration rate*

#### *Dehydration*

12. How do you notice that your child is dehydrated?
  - *Crying with tears*
  - *Dry mucous membranes*
  - *Drinking or urinating less*
13. What do you consider as urinating too little?
  - *Gradation: less, severely less*
14. What do you consider as drinking too little?
  - *Gradation: less, severely less*

### **Concluding**

15. Is there anything else you would like to add?

## **Supplement 2: Relevant quotes**

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6 Q1. *"Every day and night we are with the kids. So you know how your child behaves normally. And everything that deviates from that, is an indication [of disease] for me."* (Mother, patient 1 year (y))  
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9 Q2. *"You look and then you think: yeah, it's just not my child who I'm seeing now."* (Mother, patient 4 y)  
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11 Q3. *"Father: Just like your car. Yeah, you are driving with it every day, and at the moment that you notice something responds differently than normal, you think: hey, there is something wrong with my car! That's the same with our kid. [...] If I drive in my car every day... You just know: at the moment that you hear something, you know; hey, that is different than what I am used to. Researcher: yes. And sometimes you still don't know exactly what it is... Father: ... but you know that there is something wrong."* (patient 8 months (mo))  
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19 Q4. *"He [patient's brother] is always calm and you would see that he becomes more quiet because he is drowsy and passive [...] He becomes quiet with fever, unlike him [patient]. He [brother] would be quiet and sit in a corner and he [patient] would be crying very loudly, like: hey, I'm not feeling well!"* (Father, patient 1 y)  
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24 Q5. *Father: Yeah, we just notice it as a parent! I don't know. He's just really a different child [if he's ill]. Maybe it's based on the parent's instinct. Mother: [...] What they normally find interesting, is suddenly not interesting anymore! Then you instantly notice that there is something wrong.* (patient 3 y)  
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30 Q6. *Father: And your intuition [to mother] is even stronger than mine. [...] I think that's the widely known mother's instinct. [...] I really keep an eye on him, but what you have... That is just an extra sensor which is turned on!* (patient 6 mo)  
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34 Q7. *"Mother: He [father] does not feel that. But I do. [...] I think it is just the mother's instinct, that you've carried him for 9 months. Yeah... Researcher: That you know him through and through? Mother: Yes."* (patient 8 mo)  
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40 Q8. *"She is a very cheerful type, normally. And then she suddenly becomes passive."* (Father, patient 9 mo)  
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43 Q9. *"It's mostly that she sleeps a lot, is tired quickly, and just wants to lay down and doesn't want to do anything."* (Mother, patient 1 y)  
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46 Q10. *"The skin, being pale, having blue circles under the eyes."* (Mother, patient 5 y)  
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48 Q11. *"Mother: Her neck is warm. Father: And her eyes look different. Mother: yeah, a drowsy look in her eyes."* (patient 9 mo)  
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52 Q12. *"Then he would be very weak, he couldn't be woken up easily, maybe cry a lot. Continuously falling asleep, just not being alert, not reacting to sounds or so."* (Mother, patient 3 mo)  
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56 Q13. *"[Regarding last admission:] Really, she could only sleep, she couldn't do anything, because she had no energy, and she didn't do anything. But most of all: not responding."* (Mother, patient 1 y)  
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3 Q14. A mother of a child with no significant medical history stated: *"Actually she always stays a bit active. If she would get passive, I would worry. I have only experienced that once, maybe."* (Mother, patient 4 y)
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6 Q15. A mother of a child with an extensive medical history stated: *"Then he gets lethargic or he starts being delirious, he sees things that are not there. But then he really has a high fever. [...] Look, if he has a fever and he is totally 'out', and he is barely moving, being weak... Yeah, then I am really worried."* (Mother, patient 5 y)
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11 Q16. *"If he's like this [you hear the child yelling]: very active, he eats well, he drinks well, he pees well, and he does everything that he would do normally... Then I'm not worried."* (Mother, patient 8 mo)
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14 Q17. *"If he's happy, he is sleeping peacefully, if he is calm when awake, just playing on his own, then we would get the feeling like: everything is fine. And if he finishes his bottles."* (Father, patient 2 mo)
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17 Q18. *"It's everything combined, the whole picture. So: the fever, alertness, whether he has pain somewhere, [...] how long the illness takes, and also how it went over the course of the day."* (Mother, patient 8 mo)
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22 Q19. *"Only if it [fever] is very high, and I see that the kid is not well, then I instantly want to call the GP or out-of-hours services. But if he is playing a lot, eating, drinking, with the fever, then it's no problem if it's 40 degrees. Then I just wait 3 days. [...] I know it when my child is sick or not: I see that he doesn't play, eat, drink or pee anymore, has difficulties with peeing, or has red dots. Or if he is restless, then I know that something is wrong with him."* (Mother, patient 9 mo)
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28 Q20. *"If [name older brother] has a fever, you think: well, it's only the flu. And he is not sick very often. [...] But look, with [name patient], because of his condition... With him that's the moment to go to the hospital. To [name older brother] I would say: just stay at home, I will put a blanket on you, just wait 'till it's over."* (Mother, patient 5 y)
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34 Q21. *"Eh, he has never really had that. But I can imagine: high chest breathing, located here [points high on the chest]."* (Mother, patient 5 y)
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37 Q22. *"When she has a cold, we notice she's breathing less well. [...] But furthermore I have no clue."* (Father, 8 mo)
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41 Q23. *"If he is short of breath, then he's only coughing. He becomes red and sweaty. And he breathes very quickly. [...] Sometimes his lungs are also wheezing. A wheezing sound is coming out of them."* (Mother, patient 4 y)
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45 Q24. *"The indrawings. And then mainly here [points at neck] and also in his belly, then it's all indrawing. But also the way of breathing. Now he's breathing calmly, but if he's s short of breath it is a sort of... Halve breaths all the time [tries to mimic it, quick and shallow breaths]. No deep breaths."* (Mother, patient 3 y)
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51 Q25. *"I know the basics. I also know there are tricks with the skin, but I think I should have seen that once. But I know that the basis is: if your kid has a fever, pay attention to the nappies and that he drinks enough."* (Mother, patient 8 mo)
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55 Q26. *"He has never had that. So I don't know whether I would recognize it. Maybe I would. That he would get a dryer skin, that kind of stuff. [...] I think you will only see the difference if you have seen it once before."* (Mother, patient 7 mo)
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3 Q27. *"We have never experienced this. So you're going to consider: what have we experienced before, and*  
4 *have we ever encountered such a situation? Well, we had never had such an experience and we*  
5 *thought it looked quite extreme. So we thought, we have to seek help."* (Father, patient 8 mo)  
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7 Q28. *"It is a lot more difficult with your first child than with your second child. [...] We have been worried a*  
8 *lot more with our first one. Just a lack of experience."* (Father, patient 1 y)  
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10 Q29. *"Mother: Especially the first few weeks were quite difficult. Because then you don't understand the*  
11 *different cries well: is she hungry now or is she just tired? You just don't know that well enough. [...]*  
12 *Father: At some point just know better what's right and what's wrong.*  
13 *Mother: Yeah, you get to know your child better."* (patient 2 mo)  
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16 Q30. *"I would be happy if she could say herself: owie ouch, or this, or that. Because you have to judge it*  
17 *yourself and hope you are right."* (Mother, patient 4 mo)  
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19 Q31. *"Father: And now he says it himself, that he is short of breath.*  
20 *Mother: Yeah, that makes a big difference."* (patient 3 y)  
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# Reporting checklist for qualitative study.

Based on the SRQR guidelines.

## Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med.* 2014;89(9):1245-1251.

	Reporting Item	Page Number
<b>Title</b>		
	<a href="#">#1</a> Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
<b>Abstract</b>		
	<a href="#">#2</a> Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
<b>Introduction</b>		
Problem formulation	<a href="#">#3</a> Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4

1	Purpose or research	<a href="#">#4</a>	Purpose of the study and specific objectives or	4
2	question		questions	
3				
4	<b>Methods</b>			
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7	Qualitative approach and	<a href="#">#5</a>	Qualitative approach (e.g. ethnography, grounded	4
8	research paradigm		theory, case study, phenomenology, narrative	
9			research) and guiding theory if appropriate; identifying	
10			the research paradigm (e.g. postpositivist,	
11			constructivist / interpretivist) is also recommended;	
12			rationale. The rationale should briefly discuss the	
13			justification for choosing that theory, approach,	
14			method or technique rather than other options	
15			available; the assumptions and limitations implicit in	
16			those choices and how those choices influence study	
17			conclusions and transferability. As appropriate the	
18			rationale for several items might be discussed	
19			together.	
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27	Researcher	<a href="#">#6</a>	Researchers' characteristics that may influence the	5
28	characteristics and		research, including personal attributes, qualifications /	
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30			assumptions and / or presuppositions; potential or	
31			actual interaction between researchers' characteristics	
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39	Context	<a href="#">#7</a>	Setting / site and salient contextual factors; rationale	5
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41	Sampling strategy	<a href="#">#8</a>	How and why research participants, documents, or	5
42			events were selected; criteria for deciding when no	
43			further sampling was necessary (e.g. sampling	
44			saturation); rationale	
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48	Ethical issues pertaining	<a href="#">#9</a>	Documentation of approval by an appropriate ethics	5, 14
49	to human subjects		review board and participant consent, or explanation	
50			for lack thereof; other confidentiality and data security	
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55	Data collection methods	<a href="#">#10</a>	Types of data collected; details of data collection	5
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1		process, triangulation of sources / methods, and	
2		modification of procedures in response to evolving	
3		study findings; rationale	
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5	Data collection	<a href="#">#11</a> Description of instruments (e.g. interview guides,	4,5
6	instruments and	questionnaires) and devices (e.g. audio recorders)	
7	technologies	used for data collection; if / how the instruments(s)	
8		changed over the course of the study	
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11	Units of study	<a href="#">#12</a> Number and relevant characteristics of participants,	5
12		documents, or events included in the study; level of	
13		participation (could be reported in results)	
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15	Data processing	<a href="#">#13</a> Methods for processing data prior to and during	5
16		analysis, including transcription, data entry, data	
17		management and security, verification of data	
18		integrity, data coding, and anonymisation /	
19		deidentification of excerpts	
20			
21	Data analysis	<a href="#">#14</a> Process by which inferences, themes, etc. were	5
22		identified and developed, including the researchers	
23		involved in data analysis; usually references a specific	
24		paradigm or approach; rationale	
25			
26	Techniques to enhance	<a href="#">#15</a> Techniques to enhance trustworthiness and credibility	5
27	trustworthiness	of data analysis (e.g. member checking, audit trail,	
28		triangulation); rationale	
29			
30			
31			
32			
33	<b>Results/findings</b>		
34			
35	Syntheses and	<a href="#">#16</a> Main findings (e.g. interpretations, inferences, and	6-10
36	interpretation	themes); might include development of a theory or	
37		model, or integration with prior research or theory	
38			
39	Links to empirical data	<a href="#">#17</a> Evidence (e.g. quotes, field notes, text excerpts,	6-10
40		photographs) to substantiate analytic findings	
41			
42			
43			
44			
45	<b>Discussion</b>		
46			
47	Intergration with prior	<a href="#">#18</a> Short summary of main findings; explanation of how	11-13
48	work, implications,	findings and conclusions connect to, support,	
49	transferability and	elaborate on, or challenge conclusions of earlier	
50	contribution(s) to the field	scholarship; discussion of scope of application /	
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generalizability; identification of unique contributions(s) to scholarship in a discipline or field

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4	Limitations	<a href="#">#19</a>	Trustworthiness and limitations of findings 12
5			
6	<b>Other</b>		
7			
8			
9	Conflicts of interest	<a href="#">#20</a>	Potential sources of influence of perceived influence 14
10			on study conduct and conclusions; how these were
11			managed
12			
13			
14	Funding	<a href="#">#21</a>	Sources of funding and other support; role of funders 14
15			in data collection, interpretation and reporting
16			
17			

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 19 of American Medical Colleges. This checklist can be completed online using  
 20 <https://www.goodreports.org/>, a tool made by the [EQUATOR Network](#) in collaboration with  
 21 [Penelope.ai](#)  
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