

# Suffering in children: opinions from parents and health-care professionals

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**Abstract** Alleviation of suffering is considered to be one of the important goals of medical interventions. Understanding of what constitutes suffering in children admitted to a pediatric intensive care unit (PICU) is lacking. This study aims to assess perceptions by parents, doctors, and nurses of suffering in critically ill children. We interviewed 124 participants (parents, physicians, and PICU nurses) caring for 29 admitted children in a 20-bed level-III PICU and performed a qualitative analysis. We found that most participants made a distinction between physical and existential suffering. Parents considered the child's suffering caused by or associated with visible signs as discomfort. Nurses linked suffering to the

child's state of comfort. Physicians linked them to the intensity and impact of treatment and future perspectives of the child. Various aspects of the child's suffering and admission to a PICU caused suffering in parents.

*Conclusion:* Parents', physicians', and nurses' perceptions of suffering overlap but also show important differences. Differences found seem to be rooted in the relation to and kind of responsibility (parental/professional) for the child. The child's illness, suffering, and hospital admission cause suffering in parents. Health-care professionals in PICUs need to be aware of these phenomena.

**Keywords** Suffering · Pediatric intensive care · Decision-making · Suffering of parents · Physical suffering · Existential suffering

## Abbreviations

PICU Pediatric intensive care unit

## Introduction

The aim of treatment and interventions in medicine is to cure or stop a decline in health status while, at the same time, preventing or relieving suffering [2, 11]. Sometimes medical treatment is considered as only augmenting suffering and, in that sense, causes burden without benefit. In these cases, treatment may not be initiated or may be withdrawn in order to alleviate or prevent suffering. Not initiating or withdrawing treatment can also be seen as good medical practice in cases of a very poor prognostic state of health or lack of possibility for recovery from the disease. The term suffering is used frequently, also in relation to end-of-life decisions in newborn infants [12, 13]. Often, suffering is not clearly defined. Suffering can be divided in "existential" suffering and suffering due to pain

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and discomfort. According to papers on end-of-life decisions in newborn infants, both aspects of suffering have to be taken into account when making decisions. Little has been written about suffering in older children. Most papers describe suffering in children with end-stage cancer and cardiac malformations. In these papers, mainly the physical signs children experience are described, like pain, anxiety, nausea, and discomfort [1, 8, 14–16]. Next to physical signs, non-physical signs might also be an indication of suffering in children. Therapy can relieve symptoms but can also augment or result in (new) symptoms. The non-physical suffering aspects originate from the impact of the disease, the impact of treatment, and fear of possible death. There might be differences in types of suffering between children with end-stage cancer and PICU patients. In end-stage cancer, the unfavorable outcome is sure, while uncertainty about the outcome might be an important cause of suffering in PICU patients. Secondly, the age of PICU patients is usually younger compared to patients with cancer. To what extent existential suffering and pain-related suffering are sources of suffering in children admitted to a PICU is unknown.

Cassell's adage in *The Nature of Suffering and the Goals of Medicine* (1991), which has the status of a seminal work, is "bodies do not suffer, persons do" [5]. Suffering is "experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity" [3]. "What afflicts one part, afflicts the whole and what afflicts the whole afflicts each part." Cassell describes suffering as an attack on a person's integrity. "Most generally," he writes, "suffering can be defined as the state of severe distress associated with events that threaten the intactness of the person" [3–5]. Cassell thus describes suffering as a person- or agent-related experience that results from physical signs, functional losses, and/or lost possibilities. The symptoms and losses, however, are distinct from suffering in the sense that they may be converted into suffering by the meaning the patient attaches to them. And what these signs or losses exactly mean to the patient may depend, for example, on the patient's character, biography, and current (social) situation. According to Cassell, the only way to know whether suffering is present is to ask the person. Only the individual is in the position to say whether or not he or she is suffering. It is the person-related experience of suffering that counts.

Cassell's approach applies to the suffering of adult individuals with personal identities and a "sense of self."

It is obvious that the description of suffering in adults does not fit the situation of the developing child [9]. However, for both children and adults, the experience of suffering as a consequence of a serious disease is multidimensional. In children, however, the suffering has implications for the child itself and for the family as a functional unit [7].

In a pilot study in Groningen, about end-of-life decisions in the pediatric intensive care, we found that the term "suffering" in children was not explicitly mentioned as an argument in making end-of-life decisions. However, it is conceivable that in evaluating the value of starting or continuing therapy, suffering is one of the aspects implicitly taken into account. This is a subject of discussion in the literature about decision-making in severely affected newborns with a hopeless prognosis and severe suffering that cannot be alleviated [12, 13].

Given that the relief of suffering is one of the goals of pediatric medicine, it is important to have a shared understanding of what suffering is and what constitutes suffering. Available literature is scarce. Cassell's approach seems to be the only one available that has been worked out into detail, but it does not fit in the context of the suffering child. Understanding what the perception is of parents and health-care professionals of suffering in critically ill children could improve the quality of care for these children. It could also prevent misunderstandings about suffering between everyone involved in the care of these children, including the parents.

The objective of this study is to describe the perceptions of parents, doctors, and nurses of suffering of critically ill children. What do they consider suffering and do they have a shared assessment of suffering in children?

## Methods

### Patients and family

In the period June 2009 to March 2010, parents of children admitted to the Pediatric Intensive Care of the Beatrix Children's Hospital, University Medical Center Groningen, were invited to participate in the study. Inclusion was performed on different weekdays in order to create a representative sample of children with different underlying diseases and a mix of children admitted electively and non-electively. Children were excluded if discharge or death was expected on the day of admission or if the parents did not speak Dutch. Patients were randomized into groups. The participants were interviewed on the first, seventh, or fourteenth day of admission. We interviewed one of the parents, one of the attending nurses, and one physician of each specialty involved in the care of the child: in all cases, the attending pediatric intensivist was interviewed and, when appropriate, other specialists such as a pediatric cardiologist or oncologist. Parents and health-care professionals were interviewed, independently of each other, in a separate office on the PICU ward.

The study was presented to the Medical Ethics Committee and was determined to be exempted from the approval by the committee. Parents, nurses, and physicians signed a consent form for the recording and use of their verbatim for research purposes. All data were coded.

### Interviews

For our study, we chose a qualitative approach. Qualitative methods are appropriate if relatively little is known about a research topic and the goal is to gain a detailed understanding of participants' beliefs and perspectives [6]. We chose structured interviews as a method, because personal interviews are specifically suitable for exploring the individual participants' perspectives on sensitive topics. A list of topics to be discussed was made before the interviews started, and all these topics were discussed with parents and caregivers. Parents were asked questions about their personal situation (religion, family size, health). Clinical and demographic parameters were recorded for all patients. All participants were asked to describe suffering in general and suffering related to the actual situation of the child. The interviewer asked further questions based on what participants said. At the end of the interview, the researcher checked to assure that all topics had been covered. The interviews were conducted by one researcher (WW). The number of participants was chosen in order to cover the variability in patients admitted to the PICU. At the start of the study, we aimed to include 30 patients and all involved in the care of these children. Older children were not interviewed themselves because they were too ill to be interviewed, as most of them were sedated and intubated. The included population reflects the age range of a PICU population.

### Data analysis

All interviews were recorded and fully transcribed. In this explorative study, we used open coding as described by Straus and Corbin [10]. Examples of codes are symptoms (physical and non-physical), treatment (aggravating), biography, quality of life, age, and suffering of parents. Coding was done in Atlas Ti. One researcher (WW) first carried out the coding process and generated the list of codes. The list of codes was discussed and optimized in cooperation with two other researchers (DT, JJ). These two researchers (DT, JJ) also coded a representative sample of the interviews. The results were discussed, and a general agreement between the researchers was reached.

## Results

### Characteristics of patients and participants

We have interviewed 124 participants related to 29 children (29 parents, 29 nurses, and 66 physicians). Nine children's caregivers were interviewed on day 1, ten on day 7, and ten on day 14. The interviews took place in the period June 2009 to April 2010. The patients had various diseases and had a median age of 1 year (range: 17 days–17.6 years). ICU stay varied from 2 days to 357 days. Other characteristics of the children are summarized in Table 1.

All the nurses who were interviewed worked in the pediatric intensive care unit. The interviewed physicians were pediatric intensivists, pediatric cardiologists, pediatric thoracic surgeons, pediatric gastroenterologists, pediatric oncologists and a general pediatrician, and pediatric surgeon.

### Perceptions of suffering

The perceptions and ideas of the different groups of participants about suffering overlapped on various aspects. Although in different words, parents, physicians,

**Table 1** Characteristics of the children

	No.	Percent
Sex, male	16	55
Diagnosis		
Medical admission	17	58
Surgical admission	12	42
Cardiac surgery	8	
Transplantation	1	
Trauma	1	
Other	2	
Admission, non-elective	17	58
Underlying chronic disease		
Congenital heart disease	9	31
Neuromuscular disease	2	7
Malignancy	2	7
Ex premature	3	10
Chromosomal anomaly	2	7
Mental retardation	2	7
Other	7	24
None	3	10
Death in PICU	1	3
Death after PICU	2	7

and nurses all described the same sort of physical signs of suffering (Box 1)—pain: “pain which cannot be treated” and “unnecessary pain”; all sorts of discomfort: “feeling not comfortable” and “unpleasant, not being well”; hungry, unpleasant: “not being happy” and “something you get a nasty feeling from.” Besides physical aspects, participants from all groups also mentioned non-physical or existential questions as important aspects of suffering: hopelessness, powerlessness, and aspects related to future perspectives; “no vision of the future,” “concerns about the predicted view of a decent quality of life,” and “difficulties in the future.”

In general, parents described suffering using words such as “pain,” “discomfort,” “the inability of the child to understand the disease and the treatment,” or “not being able to do anything.” Parents mentioned a physical and a spiritual or psychological component of suffering. Nurses described suffering as “pain,” “discomfort,” and “hopelessness” as signs of suffering. They emphasized physical and psychological aspects. Physicians used words like “pain,” “quality of life,” “unease,” “handicap,” and “barriers” and focused on physical and psychological aspects.

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#### Box 1: Overlapping perceptions of suffering

Parent: “Suffering to me is a term that indicates physical pain, but it is also psychological, of course. That you’re not yourself anymore, that you no longer feel happy, that you don’t have a vision of the future for yourself. That, to me, is suffering.”

Parent: “Suffering is if a child indicates that he or she is in pain and you can’t treat it. It’s that you can’t do anything about it, that the child can’t do anything about it, that there is nobody who can do anything about it.”

Physician: “A child’s suffering has partly to do with the grief that parents feel, but also with a hopeless situation. That’s what I think about F. Suffering can be very short and powerful. I see it as little sacrifices. You can suffer during the insertion of a drip, but I see that more as a brief moment of suffering. Suffering is more suffering from prolonged pain which can be physical or psychological.”

Physician: “Suffering exists when you have a problem resulting from a disease that changed your daily functioning so that you’re more or less handicapped”. ‘.....’ “Pain or physical suffering can exist, but you can also experience psychological suffering” ‘.....’

Nurse: “Being both physically and psychologically unwell, uncomfortable. Thus, physical pain and discomfort and psychological pain, grief, fear and anxiety”.

Nurse: “It is very difficult and very broad, but when I look at myself, children suffer if they have a lot of pain and will have a very difficult existence in the future”

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#### Parents’ perception of the present and future suffering of the child

Parents described the suffering of their child often in relation to the physical signs shown by their child (Box

2)—for example, pain, state of comfort, and physical symptoms as vomiting, diarrhea, and weakness. They considered the suffering of their child as caused by or associated with visible signs causing discomfort in the child. Another important aspect for the parents was the future perspective of the child and the inability to do anything for their child. Suffering was, in the opinion of the parents, also related to impact, burden, and outcome of treatment

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#### Box 2. Parents’ perspective of suffering of the child

Parent: “He has lots of problems with his intestines and you see him suffer and we give him lactulose and sunflower oil. And you can do nothing and we rub him on his tummy, about 8 h a day, but you can’t do anything for your child, can you?”

Parent: “Sometimes she does suffer and then it’s caused by pain, I think. She can’t do anything about it, she can’t understand why, and you can’t tell her that it is temporary. Eh... and she does have trouble weaning from the sleeping pills and at those moments she suffers, I think.”

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#### Health-care workers’ perceptions of the present and future suffering of the child

Physicians described suffering as discomfort, anxiety, pain, and dyspnea. In their description, the signs of suffering were related to the intensity and impact of the therapy (Box 3). Physicians seemed to have a more long-term perspective on suffering.

Nurses often stated pain and discomfort as signs of suffering. The suffering of the patient they were caring for was associated with the state of comfort of the patient. Nurses were focused on the signs that caused discomfort and on the treatment of this discomfort. Nurses frequently showed a short-term perspective on suffering.

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#### Box 3: Health-care professionals’ perspective

Physician: “We have just discussed that she actually should have chemotherapy, but given her recent suffering in the IC, the question is whether or not we can make her a lot better. She’ll have more disadvantage than benefit from her treatment. The idea is that she has already suffered a lot, and that we would not contribute much more with the last course of chemotherapy. Now, even if the chemotherapy is not very intensive, we believe that we should no longer do it.”

Physician: “You put the potential benefits of the operation, in accordance with the decrease of suffering, against the risks. Look, if a very small profit would mean less suffering, or health, or however you define it, compared to a high risk, we would not do it.”

Nurse: “If she is uncomfortable, I will make sure she gets pain relief and, when she gets restless, I will ask for Temesta or something else for her.”

Nurse: “I think if a patient is really suffering, then I will keep in mind to do things simultaneously and quietly and try to adjust care accordingly. This wasn’t an issue in his situation, but if a child has just had surgery I would give him necessary care, but try to spare him.”

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The two cases in box 4 illustrate the different views of parents and health-care professionals on suffering in two children.

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#### Box 4. Case description

*Day 8: 3-week-old infant with pneumonia on the ventilator. Question: Does the child suffer?*

Parent: “No, not really. She’s sedated, if she is awake she finds the fussing with her tubing irritating and then she gets angry. But that isn’t something she has continuous trouble with. She’s sedated, and that’s why she doesn’t suffer.”

Nurse: “No. You know that this is the standard treatment and that it’s a good treatment. In principle, she only has to get through this and then things will get better. She’s ventilated and sedated, and if she’s comfortable and breathing well, then I don’t think it’s suffering. It’s all for a good cause.”

Physician: “Yes. Because she’s not living her normal life, she isn’t at home with her mummy and daddy.”

*Day 14: 5½-year-old girl with Down syndrome weaning from the ventilator after a critical, life-threatening illness. Question: Does this child suffer?*

Parent: “I think so, I think she feels pain and sometimes she lets us know that, but I don’t think that... I think if it was one of the other children, that he would suffer more, also psychologically like J. If J has nice, cozy surroundings, she enjoys herself and she doesn’t think about suffering.”

Nurse: “I’m not sure what to say, there’s something like suffering there, but, on the other hand, particularly by injections, she gives me the impression that she takes everything as it is, But I think she mostly suffers when her loved ones leave, she finds saying goodbye very difficult and painful. But, besides that, once she’s in her bed I don’t feel that as strongly.”

Physician 1: “Moderately, she’s on a very long trajectory, she’s already been in treatment for the oncology diagnosis for a long time, and she’s still got a very long weaning course. She’s a very happy Down syndrome child, but lets us know now and then that she’s fed up with us. She wants social contact very much and she does get it with various people, but not with the people with whom she should have contact.”

Physician 2: “Yeah, I think there are definitely moments that she’s lonely, and I think that is also suffering. Her parents are there many hours of the day, but she’s not allowed to go wherever she wants, because she’s stuck in her bed and that limits her a great deal. She’s a very happy child with Down syndrome, which gives the impression that she doesn’t mind so much. I do think that there are certainly moments when, for example, she sees lots of people going by but no one there for her, she would like to do things that she can’t.”

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#### Suffering of parents

Many parents mentioned, spontaneously, their own suffering as a consequence of the illness of their child. Seeing their child suffer causes suffering in parents. Parents mentioned various aspects which made them suffer themselves: the uncertain outcome, being uncertain about the recovery of the child, and the uncertain future. The waiting period before their child could be admitted, for example for surgery, also caused stress

and suffering. The feeling of being powerless also made them suffer. The impact of treatment caused stress and discomfort in parents and was difficult to handle. A lot of parents experienced the separation from their child and disturbance of the family as a unit (caused by the hospital admission, often far away from home) as suffering (Box 5). Finally, the inability to help the child caused feelings of suffering.

Physicians and nurses did not spontaneously mention suffering of parents. They interpreted the questions in the interview as applying only to the child they cared for. Loneliness as a sign of suffering was mentioned by physicians and nurses. According to both physicians and nurses, the presence of parents at the bedside in the intensive care unit prevented a child from being lonely.

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#### Box 5. Suffering of parents

Parent: “This is hell. Nobody knows how this will go and it looks really bad right now. You don’t want to lose your child, not ever. And you’re really concerned with what his future will look like. Suppose he survives: Will he have long-term complications? The uncertainty, yes, definitely, the powerlessness.”

Parent: “Yes, for us it is an invasive procedure and gives us a lot of stress and anxiety. So, for us, it is very stressful. Is this the case for her? I think that, in the future for her, it will only be relief that this has happened, otherwise we could have lost her.”

Parent: “And we, we suffer now. We’ve become a different family and we are with our backs against the wall. There is no medicine, no surgery to cure her. You live by the day. But it’s mainly mental suffering. Your family is now disrupted, they sleep at different places and times and sometimes you’re not always there mentally. It will be as it will be and we’ll see later on how sad we will be and what we have experienced. We notice that the boys are pretty quiet right now, they go to school. We talk about how it is going with S at home.”

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#### Discussion

Suffering of critically ill children admitted to a pediatric intensive care unit as described by parents, physicians and nurses can be distinguished in physical and non-physical or psychological signs. Suffering of a child is perceived by parents and health-care professionals as a negative emotion and sensation. Symptoms which cannot adequately be relieved like pain, discomfort and unhappiness were perceived by most caregivers as indications of suffering.

Parents described suffering as evidenced by physical signs of their infant but also based on the future perspective of the child.

Nurses’ descriptions of signs of suffering were mainly associated with the actual state of pain and comfort of the child. They feel responsible for the child they care for and observe every sign of discomfort or pain during their shift.

This may be the cause of their more short-term perspective on suffering. Physicians described signs related to the intensity and impact of therapy. They focused on the harms and benefits of treatment and how this might increase or relieve the child's suffering, not only right away but also in the more distant future. Physicians tend to put suffering in the context of the burden/benefit balance. They interpreted suffering as sign of burden. The future perspective of the child is a very important aspect for physicians with regard to evaluating the present suffering. Physicians had a long-term perspective on suffering, possibly related to their primary responsibility to treat patients the best as they can according to the Hippocratic Oath. As a consequence, physicians have a different perception on the relevance of complications and long-term outcome of their patients compared to nurses, especially when patients were followed in the outpatient clinic and long-term outcome is seen. These differences in opinion about what is considered to be suffering are clearly stated in the cases described in box 4. As suffering can have distinct meanings it is important that when someone uses the word suffering, they must always explain why they feel the patient is suffering. This may prevent important misunderstandings. We hypothesize that the differences in perspectives of the parents and health-care professionals originate from the different kinds of relation they have to the child and the parental or professional responsibility felt for the child.

The assessment of suffering made by parents, nurses, and physicians together almost equal to the concept of suffering as described by Cassell. The three opinions on suffering together form a holistic view of suffering. All aspects of suffering, as described by Cassell, seem to be included. The combined opinion of suffering therefore can be seen as the total suffering of the child.

A number of papers described suffering in children with end-stage cancer. Almost all signs described involved physical symptoms like pain, discomfort, nausea, and dyspnea [8, 14–16]. In these children, the unfavorable outcome was clear. In our group of pediatric intensive care patients, the outcome was not clear. We excluded in our group infants and children that were likely to die on the day of admission. Being uncertain about the outcome constituted an important part of the perceived suffering. The balance between the burden of intensive care and the perceived outcome influenced, especially physicians, their opinion about suffering. A recent study evaluated suffering in children with end-stage cardiac diseases admitted to a PICU. Also in this study, signs of suffering were almost all related to physical signs. A remarkable aspect in this study was that the parents realized rather late in the course of the disease that their child was likely to die. Once they were convinced about this outcome, they indicated that letting their child die in peace was an important part of reducing suffering in the child. The uncertainty about the outcome for the child and the

expected long-term outcome when surviving were important aspects of suffering in our study. There was a high chance for survival in our group, without any reassurance about the future quality of life though. Especially, physicians were influenced by this uncertainty in their opinion about suffering in the children.

A striking and important finding is that parents spontaneously expressed their own suffering. Seeing their child suffer caused suffering in parents. Parents attributed different aspects to the suffering child, for example the clinical condition of the child, the hospital admission of the child, and aspects related to future perspectives that caused suffering of the parents. Parents imagine their child's suffering by seeing the signs, feeling their child's distress, but also by imagining what the child currently feels and experiences. They feel great empathy for the child. Our results indicate that feelings of suffering of the parents are closely connected to the perceived suffering of the child. It is very difficult to separate these feelings. Seeing your child suffer without being able to relieve this suffering causes suffering in parents. Moreover, parents also had their own feelings of suffering, like fear of losing their child and anxiety about the future. Suffering in parents is a combination of both aspects.

Considering a child as a developing individual closely connected to his/her parents supports the concept that in the suffering of children, the suffering of parents has to be taken into account. Cassell stresses the idea that physical pain, signs, and functional losses are not the same as suffering or do not necessarily cause suffering but may be converted into suffering due to the meaning the patient attaches to them [3–5]. We found that critical illness in children may cause suffering in their families through the meaning parents attach to the symptoms of their child. As a result, parents' perceptions of their child's suffering may be a reflection of their own suffering as well. It is important while counseling parents to discuss their feeling towards suffering in their child as well as their own suffering. When evaluating suffering in children admitted to a PICU, one should include both indicators of present suffering like pain and discomfort and also the future life of the child. For both parents and physicians, the future outlook for the child is a very important part of suffering. In treatment decisions, the perspective for the future must have an important role.

#### Strengths and weaknesses of the study

We looked at suffering in children from different perspectives at different moments in time. To our knowledge, this is the first study which included only young children, who are not able to express their opinion about signs of suffering. Obviously, we would have preferred to interview the children themselves. The included population of severely ill, mostly mechanically ventilated patients, and young children made

this impossible. Moreover, we did not include a pediatric neurologist in the group of physicians. It might be possible that this physician would have introduced a different view on suffering in severely ill children.

#### Future study

This study gives an impression of how parents, physicians, and nurses experience suffering of critically ill children. Participants were interviewed at different moments in time. Subject to further study is the importance of the time or moment participants were interviewed and if the opinion about suffering changes over time during the intensive care admission.

#### Conclusion and implications for practice

Parents, physicians, and nurses have partially, but not completely, overlapping ideas about suffering. Differences seem to be rooted in relation to and kind of responsibility (parental or professional) for the child. While evaluating suffering in children admitted to a PICU, one should include both indicators of present suffering like pain and discomfort but also the future life of the child. For both parents and physicians, the future outlook for the child is a very important part of suffering. When making treatment decisions the perspective for the future should have an important role. A child's admission to a PICU and his or her suffering may also cause parental suffering. Health-care professionals in pediatric intensive care units need to be aware of these phenomena in their daily practice.

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