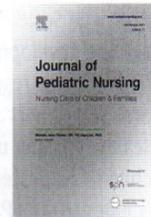




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Parents' perceptions of their child's pain assessment in hospital care: A cross-sectional study



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ABSTRACT

Purpose: A prerequisite for successful pain management is identifying the pain and assessing its intensity. The aim of this study was to describe parents' perceptions of their child's pain assessment in hospital care.

Design and methods: This study was a descriptive cross-sectional study. A questionnaire was completed by parents ($n = 261$) whose child was hospitalized in one of the pediatric units ($n = 6$) of the University Hospital in Finland. Quantitative data were analyzed using statistical methods; open-ended data were analyzed using inductive content analysis.

Results: Parents reported that their children experienced moderate (36%) to severe pain (42%) during hospitalization. The most intense pain experienced by the children was associated with needle-related procedures (41%). A large proportion of parents (83%) were involved in their child's pain assessment. Parents were satisfied with their child's pain assessment but perceived some shortcomings. Parents hoped that a variety of methods would be used to assess their child's pain and that the parents' and child's views on pain would be taken into account.

Conclusions: Most children experience moderate to severe pain during hospitalization. Parents are often involved in pain assessment but are rarely instructed to use pain scales.

Practice implications: Child's pain should be assessed regularly and frequently enough. It is important that the child and parents are involved in shared decision-making about pain assessment and treatment, and they have opportunities to ask questions. Guidance should be offered to parents about the use of pain assessment scales.

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Introduction

Pain is highly prevalent in children receiving hospital care (Manworren & Stinson, 2016). Acute pain is usually associated with medical procedures (Birie et al., 2014) such as blood sampling (Campbell-Yeo et al., 2019), injections (Koller & Goldman, 2012), or surgery (Caixeta et al., 2020), as well as injuries (Clapp et al., 2020; Stillwagon et al., 2020; Zanchi et al., 2020) and acute illness (Delaney et al., 2016). Chronic pain in children is an increasingly recognized clinical problem (Lioffi & Howard, 2016). The most common types of chronic pain in children are headache and abdominal, back, musculoskeletal (King et al., 2011), and disease-related pain (Lioffi & Howard, 2016). Although pain is a common problem in children, it is poorly assessed and managed during hospital care (Birie et al., 2014). Over 60% of children experience moderate or severe pain during

hospitalization (Birie et al., 2014; Taylor et al., 2008) and the worst pain is primarily procedural. This is a significant problem because the pain associated with medical procedures can be alleviated through pain-relieving interventions. Unfortunately, there is evidence that topical anesthetics are underused with child patients (Birie et al., 2014).

Assessment and treatment of pain should be a central part of pediatric care in hospitals. Untreated pain causes unnecessary suffering, can adversely affect emotional functioning and can impose significant economic costs on families and society (Lioffi & Howard, 2016). Accurate pain assessment is the basis for safe and adequate pain management. The evaluation of pain involves determining the underlying type of pain (nociceptive or neuropathic) as well as its location, intensity (Hauer & Jones, 2021), and duration (Manworren & Stinson, 2016). Unfortunately, pain is a complex phenomenon, and the objective assessment of children's pain is challenging for health care professionals (Brudvik et al., 2017; Walther-Larsen et al., 2017). The gold standard method for assessing pain intensity in children involves using validated self-report scales (Birnie et al., 2019; Twycross et al., 2015) such as the Numerical Rating Scale (NRS) (Castarlenas et al., 2017) or the Visual

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Analogue Scale (VAS) (Bailey et al., 2012). Whichever scale is used, the age and development of the child should be taken into account when interpreting its results (Manworren & Stinson, 2016). There are also several self-report scales for determining the location of pain. These scales typically use graphical representations of the body on which a child or adolescent is asked to color areas where they feel pain (Hauer & Jones, 2021). Pain assessment is especially challenging when dealing with children who cannot use self-report scales because they are unable to communicate, such as infants and nonverbal, cognitively impaired, or sedated children (Manworren & Stinson, 2016). In such cases, pain assessment scales based on behavioral and physiological indicators should be used (Manworren & Stinson, 2016; von Baeyer & Spagrud, 2007).

Staying in hospital and being separated from parents are a stressful and distressing experience for children (Çamur & Sarıkaya Karabudak, 2021). Many hospitals implement the principles of family-centered care, which include parental involvement and shared responsibility for the child's care (Kokorelias et al., 2019). Parents can be involved in their child's care by preparing the child for medical procedures, sharing important information with the child and helping the child deal with the experiences of treatment and procedures (Sundal et al., 2019). It has been shown that the presence of parents in hospital reduces the anxiety of both the child and the parents (Çamur & Sarıkaya Karabudak, 2021), improves recovery, and shortens the time spent in hospital (Eichner et al., 2012; Franck & O'Brien, 2019). The presence of parents has also been found to improve documentation of pain assessment and the child's pain management during procedures (Cruz et al., 2016), and there is evidence that the pain relief provided by parents is effective (Eissler et al., 2022; Inan & Inal, 2019). Based on the principles of family-centered care, parents might be expected to play a central role in pain assessment because they know their children better than nursing staff. However, few previous studies have examined children's pain assessment from a parental perspective (Ndengeyingoma et al., 2023; Uitti et al., 2018). There is some evidence that parents evaluate their children's acute pain more accurately than physicians (Brudvik et al., 2017) and nurses (Hla et al., 2014), but not all nurses involve parents when assessing pain in child patients (Zisk-Rony et al., 2015). Understanding how parents perceive their child's pain assessment and their own involvement in it is therefore essential for developing better pain assessment practices for hospitalized children.

Methods

Aims

The aim of this study was to describe parents' perceptions of their child's pain assessment in hospital care. The research questions to be addressed were:

1. What kind of pain did the children experience during hospitalization based on the parents' perceptions?
2. How were parents involved in assessing their child's pain?
3. What were the deficiencies and desires that parents perceived in their child's pain assessment?

Study design and sample

This study was a descriptive cross-sectional study based on a survey of parents whose children were hospitalized in one of the pediatric units ($n = 6$) of the University Hospital in Finland. The department including these units treats patients under the age of 16 whose examination or treatment of symptoms or illness requires special medical care. Its services include treatment of pediatric infections and internal disease, surgery and post-operative care, treatment of cancer and hematologic diseases, neurology, pediatric intensive care, and neonatal intensive and special care. All parents who met the following inclusion criteria were recruited: (a) being the child's parent or guardian; (b) having a

child hospitalized in the somatic pediatric ward; (c) speaking Finnish and (d) being willing to participate in the study.

Data collection

Data were collected between November 2018 and May 2019. The researcher handed out questionnaires ($N = 351$) to the nurses specializing in pain management on each somatic ward. The number of questionnaires per ward was determined by the number of children treated per month. The primary nurse of child handed the questionnaires to the parents for completion a day or two prior to their child's discharge. A questionnaire was also given to parents whose children had stayed in hospital for several days and whose time of discharge was not yet known. The parents were able to return completed questionnaires in sealed envelopes by placing them in a box in the ward or by handing them to their child's primary nurse. The completed questionnaires were then returned to the researcher.

The questionnaire reported in this study contained three sections. Section 1 inquired about the demographic and background factors (such as fears) of the parent or guardian and their child. Section 2 included nine questions relating to parental involvement in the child's pain assessment and the parents' satisfaction with the pain assessments performed during their child's current hospital stay. Section 3 contained two open-ended questions that asked the parents to describe a) the deficiencies that they perceived in their child's pain assessment and b) how they would have preferred their child's pain to be assessed during the current hospital stay. The data was collected as part of a research project focusing on developing an evidence-based model of pain assessment and management for pediatric hospital care. The questionnaire was based on the results of earlier studies (Cignacco et al., 2007; Yamada et al., 2008) and the opinions of an expert panel including researchers ($N = 2$) and health care providers ($N = 15$) specializing in pain management. In addition, it was pretested on a small group of parents ($N = 15$) who completed a form asking them to evaluate the questionnaire's understandability and to provide feedback on its content and response options. Some minor changes in the wording of certain items in the questionnaire were made based on these responses.

Ethical consideration

The principles of research ethics were taken into account during the research process. The Ethics Committee of the hospital granted the researchers permission to conduct the study and a research permit was applied for in accordance with the hospital's practices. The questionnaires were accompanied by a cover letter providing information on the study's purpose, the voluntary nature of participation, the anonymity of participants, and the confidentiality of their responses together with contact information for the researchers. In accordance with hospital practices, the returned questionnaires were stored in a locked cabinet and the electronic data were saved in the hospital's computer system, which is password protected. Only designated researchers have access to the survey data.

Data analysis

Quantitative data were analyzed using IBM SPSS Statistics (version 25). Descriptive statistics were used to summarize the background factors and the responses pertaining to the realization of pain assessment practices (Fisher & Marshall, 2009). For items pertaining to the parents' perception of their involvement in the child's pain assessment where the possible responses were yes, no, and don't know, responses were divided into two classes ("yes" and "no/don't know"). For items pertaining to parents' perceptions of the intensity of their child's pain or fears concerning the child's situation, where responses were given using a numeric scale ranging from 0 to 10, responses were divided into four

classes: 0 = no pain/fear, 1–3 = mild pain/fear, 4–6 = moderate pain/fear and 7–10 = severe pain/fear. Chi-squared test was used to evaluate the relationships between background factors and variables related to child's pain and parents' involvement in pain assessment (McHugh, 2012). *P*-values ≤ 0.05 were considered statistically significant.

The open-ended responses were analyzed using inductive content analysis (Bengtsson, 2016; Elo & Kyngäs, 2008; Kyngäs et al., 2019) guided by the research questions. The transcribed responses to open-ended questions were read repeatedly to obtain the sense of the whole. The meaning units of analysis were identified from the text, which were words, sentences or parts of sentences containing aspects related to the research questions. The meaning units emerging from the analysis were grouped into subcategories based on their similarities and differences and were named according to their content. Generic categories were then created by combining related subcategories.

Results

Altogether, 324 (92%) questionnaires were returned, of which 11 (3%) were excluded because of missing data. Returned questionnaires were included in the study if the parents reported that their child experienced pain during hospitalization, i.e., if they reported their child's pain intensity to be at least 1 on a scale ranging from 1 to 10 ($n = 253$). Questionnaires were also included if the parents answered at least one question relating to pain assessment without providing an assessment of their child's pain intensity ($n = 8$). Questionnaires in which parents reported their child's pain intensity to be 0, indicating no pain, were excluded ($n = 44$).

Backgrounds

A total of 261 (74%) parents or guardians aged 22 to 62 years (mean = 36.8, SD = 7.0) participated in the survey. The majority of the participants were mothers of the children being treated (82%). More than half of the parents (53%) had experienced fear during their child's hospitalization relating to the child's health or care. Of these, 14% rated their fear as mild, 30% as moderate and 56% as severe. The most common reasons for hospitalization of children were surgery (28%), infection (27%), and injury (9%). The hospitalized children were all under 15 years old (Mean = 5.3, SD = 4.5), with 30% being infants under two years of age. More than half of the children (59%) were below school age, i.e., 0–6 years old (see Table 1).

Table 1
Demographic information.

Respondent's background		Child's background	
Relationship to child, (n) %		Child's age in years, (n) %	
Mother	(209) 82	>2	(78) 30
Father	(42) 16.5	2 to <7	(76) 29.2
Other guardian	(3) 1.2	7 to <11	(64) 24.6
Parent's/guardian's age in years		≥ 11	(42) 16.1
Mean \pm SD	36.8 \pm 7.0	Mean \pm SD	5.3 \pm 4.5
Range	22–62	Range	0–14
Parent's/guardian's education, (n) %		Child gender (M/F/Not known) %	53.9/45.7/0.4
No vocational education	(6) 2.5	The reason for hospitalization, (n) %	
Vocational education	(110) 45.1	Surgical	(73) 28.0
Polytechnic degree	(73) 29.9	Infection	(71) 27.2
University degree	(55) 22.5	Injury	(23) 8.8
Parental fear (scale 0–10), (n) %		Neonatal disease/preterm	(22) 8.4
No fear (0)	(120) 46.7	Neurological disease	(17) 6.5
Mild fear (1–3)	(19) 7.4	Examinations	(15) 5.8
Moderate fear (4–6)	(41) 16.0	Cancer	(13) 5.0
Strong fear (7–10)	(77) 30.0	Pain	(9) 3.4
Mean \pm SD	5.32 \pm 4.	Other diseases/procedures	(18) 6.9
Range	0–10	Hospital stay in days	
		Mean \pm SD	4.25 \pm 11.00
		Range	0–152

Table 2

The most painful situations experienced by children during hospitalization according to their parents and the intensity of the pain felt by the children.

The most painful situation	(n) %
Needle related procedure	(100) 41.3
Post-operative care	(64) 26.4
Other procedure	(29) 12.0
Disease-related during hospitalization	(21) 8.7
On arrival at the hospital/waiting for treatment	(16) 6.6
After the effect of analgesia has diminished	(6) 2.5
Equal pain throughout hospitalization	(4) 1.7
Moving	(2) 0.8
Pain intensity, scale 1–10	
Mild pain (1–3)	(57) 22.3
Moderate pain (4–6)	(91) 35.7
Severe pain (7–10)	(107) 42.0
Mean \pm SD	5.76 \pm 2.45

Children's pain during hospitalization

A small proportion of the children (3%) were admitted to hospital primarily because of pain. Parents reported that the worst pain experienced by the children in the hospital was associated with needle-related procedures (41%), post-operative care (26%), and other procedures and examinations (12%) (Table 2). Only 9% of parents reported that their child's worst pain was caused by an illness such as an infection or high fever. A small proportion of children (2%) had equally severe pain throughout their hospitalization, with parents being unable to identify any situation causing outstandingly severe pain. Overall, 22% of parents reported that their children experienced mild pain (indicated by pain scores of 1–3), 36% reported moderate pain (pain scores of 4–6), and 42% reported severe pain (7–10). Severe pain was most common during admission to hospital/at the beginning of hospitalization (69%) and in connection with examinations and procedures (55%) (Table 3). During needle-related procedures, which were the most common cause of pain in children during hospitalization (41%), 34% of children experienced severe pain. Of the background factors, only parental fear was statistically significantly associated with the child's pain, meaning that parental fear was positively related to the severity of the child's pain ($p < 0.001$).

Involvement of parents in their child's pain assessment

Most parents reported that they had been involved in their child's pain assessment (83%) and that their expertise in assessing child's

Table 3
Pain intensity among children in different contexts.

Context	N = 240 NRS >0 f	Mild pain NRS = 1–3 %	Moderate pain NRS = 4–6 %	Severe pain NRS = 7–10 %
Needle related procedure	100	33,0	33,0	34,0
Post-operative care	64	8,1	46,8	45,1
Other procedure	29	17,2	27,6	55,2
Disease-related during hospitalization	21	9,5	47,6	42,9
On arrival/at beginning of hospitalization	16	6,3	25,0	68,7
After the effect of analgesia has diminished	6	33,3	33,3	33,4
Equal pain throughout hospitalization	4	0,0	25,0	75,0
Moving	2	0,0	50,0	50,0

pain had been considered (64%). Additionally, most parents were asked about the location of their child's pain (59%) and its duration (62%). However, parents were less likely to be asked what type of pain the child was experiencing (35%). Some parents were asked to provide a verbal assessment of the intensity of the child's pain (31%), but only a few were asked to assess their child's pain using a pain assessment scale (10%). Only 16% of parents were given guidance on the use and purpose of the scale used to assess their child's pain (Fig. 1). Overall, parents were satisfied with their child's pain assessment during hospitalization (mean satisfaction = 8.48 on a 0–10 scale, SD = 2.0). No statistically significant associations ($p > 0.05$) were found between background factors and parents' participation in their child's pain assessment.

Deficiencies in the child's pain assessment

Although parents were largely satisfied with the assessment of their child's pain during hospitalization, they also reported some shortcomings. Deficiencies in pain assessment broadly fell into two categories: failure to consider the expertise of the child and their parents, and deficiencies in staff performance when assessing pain. The formation of these categories is illustrated in Fig. 2.

Lack of consideration of child and parent' expertise

Parents felt that the expertise of the child and parents was not adequately accounted for: the children were not asked often enough about their pain, and their evaluations of the intensity of their pain were either not sought or sought too rarely. The children were also not asked questions about the type or location of their pain, nor were parents asked how sensitive the child is to pain based on their past experiences. For example, parents experienced that a medical condition requiring repeated needle pricks could affect their child's pain threshold and predispose them to needle phobia. The children's own assessments of the intensity of their pain were not trusted; pain experienced by the children was diminished and not taken seriously. Parents also felt that the children's emotions were not given adequate attention. Parents described that the hospital environment, strange procedures and medical examinations were stressful for the child and may have contributed to the pain experience; however, the child's stress was poorly addressed in pain assessment and treatment. Parents also felt that pain experienced by the child was not treated with sufficient compassion.

Additionally, parents reported shortcomings in their involvement in the child's pain assessment. Many parents felt that they were the best experts on their child because they are with their child 24/7 and know

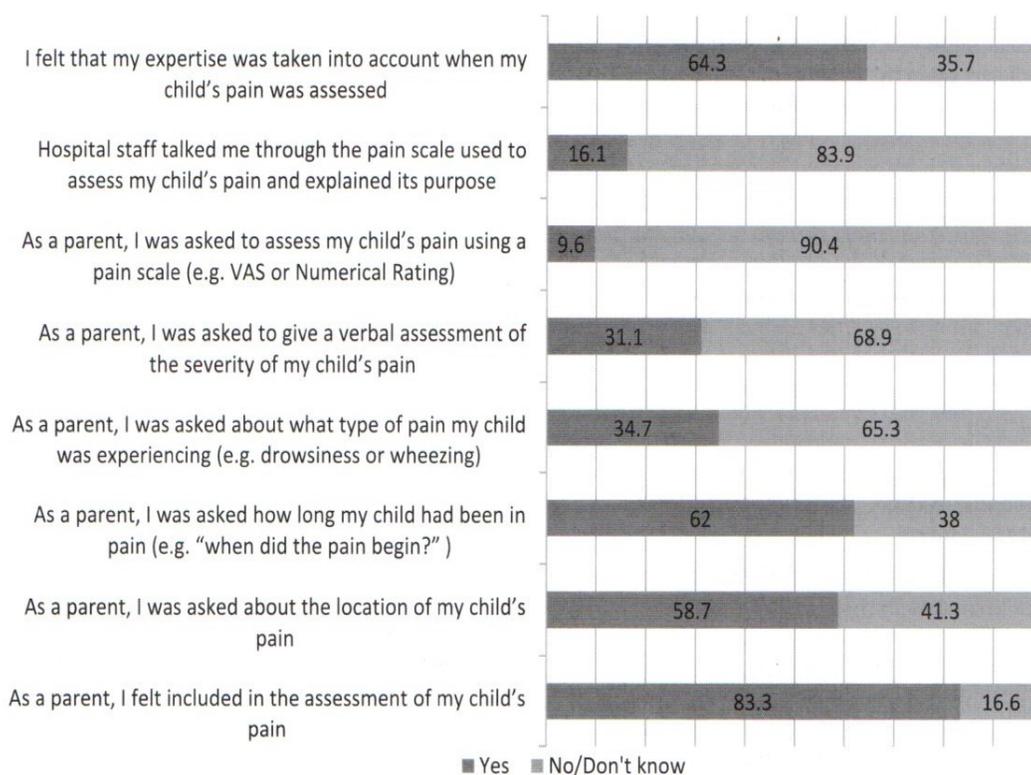


Fig. 1. Parents' views on their child's pain assessment (%).

Illustrative analysis unit	Simplified expression	Subcategory	Category
<p>"I was not always asked how intense the pain was. A child with a high pain threshold may not cry until he or she is alone with his or her parent. At that point he could already be very sore!"</p> <p>"A shy child usually won't respond immediately to a stranger or might just say something that may not be true. More specific questions should be asked."</p> <p>"... because individual differences are large, staff should ask parents at the beginning whether the child is sensitive to pain / needle fear"</p>	The intensity of the child's pain was not asked about often enough	The child was not asked enough about his pain	Lack of consideration of child and parent's expertise
	The child was not asked questions specifically about pain		
	The child was not asked about his/her sensitivity to pain		
<p>"The child's pain was not always taken seriously..."</p> <p>"...[Pain] was downplayed and we were asked to wait longer."</p> <p>"...more attention should be paid to the child's agitation"</p> <p>"there was a lack of compassion when the child was sore"</p>	The child's pain was not taken seriously	The child's own assessment of the intensity of the pain was not trusted	
	The child's pain was downplayed	The child's emotions were not taken into account	
	The child's stress related situation was poorly taken into account		
	The child in pain was not treated with sufficient compassion		
<p>"Did not listen to my experience and assessment as a parent even though I see my child 24/7"</p> <p>"During the ultrasound I would have liked to have been listened to. If I was allowed to hold my child in my arms, there would have been less pain."</p> <p>"The nursing staff should ask the parent for their opinion. Personally, I felt left out as a parent"</p>	The parent's assessment and experience of the child's pain was not listened to	Parents were not included in the pain assessment	
	The parent's views on pain management were not listened to		
	Parental expertise was ignored		
<p>"There was no discussion of pain assessment, but I am familiar with tools like VAS"</p> <p>"The child could have been shown a pain scale that would have been more suitable for assessing her pain"</p> <p>"A 1-10 scale is not suitable for all children - teddy bear cards, face pictures, or smiley pictures would be better."</p>	There was no talk of pain assessment tools	There were weaknesses in the use of the pain assessment tools	Deficiencies in staff performance when assessing pain
	The pain scale was not used in the pain assessment		
	No child-friendly pain scale was used in the pain assessment		
<p>"The staff did not always know how to interpret the child's body language correctly in relation to pain"</p> <p>"My child got really sore at times before receiving the next dose of medicine"</p> <p>"The child was not given enough time to speak about their pain - shy children won't speak up immediately."</p> <p>"There was a sense of urgency"</p>	The child's pain was not identified	Pain assessment was not sufficient	
	The child's pain was not assessed often enough.	Not enough time was spent on pain assessment	
	The child was not given enough time to report her/his pain		
	There was a sense of urgency in the pain assessment		

Fig. 2. Parents' descriptions of deficiencies in their child's pain assessment.

their child's temperament, preferences and needs. Despite this, parents' knowledge of their child's pain and assessments of its intensity were not listened to, and that their expertise in managing the child's pain was not consulted. As a result, some parents experienced they had been ignored.

Deficiencies in staff performance to assess pain

Parents considered the pain assessments performed by health care staff to be deficient. In the parents' view, the use of pain assessment scales to assess the children's pain was inappropriate. Health care staff often did not discuss the chosen pain scales with the parents or did not use a scale at all when assessing pain. In cases where a pain scale

was used, some parents felt that the chosen scale was unsuitable for assessing their child's pain, either due to the child's age or for some other reason. For example, parents felt that the numerical pain scale used to assess post-operative pain was not suitable for use with a confused child who had just woken up from surgery.

The parents considered the assessment of the child's pain to be inadequate in that the pain or the cause of the pain was often not identified. One parent, for example, wondered whether her/his child would have been spared prolonged pain if the cause of the pain had been identified and treated at an earlier stage. In addition, parents described that the child's pain was not assessed frequently enough, resulting in the child receiving too infrequently pain relief or unnecessary pain medication.

Illustrative analysis unit	Simplified expression	Subcategory	Category
<p>"In an EEG study, one might wonder whether an analgesic could be given before the electrodes are applied"</p> <p>"...I would have liked a slightly more detailed assessment of how we are doing. For example, a child could not wait in a sitting position; it was not asked...The child's pain was clearly visible, but the nursing staff did not react to it."</p> <p>"Pain should be assessed with pain scales and based on the child's reactions to situations that produce pain."</p>	Pain could have been assessed proactively	The child's pain should have been assessed and identified	Pain would be better identified by different methods
	The child's pain should have been noticed and responded to		
	The child's pain should have been assessed more reliably		
<p>"During the procedure, parents could also have been asked about the level of pain."</p> <p>"Staff could more frequently ask the child about themselves. Even a three-year-old can say where it hurts."</p> <p>"A VAS scale was used on the day of surgery, which was good. It would also have been desirable to use a pain scale on the day after surgery."</p> <p>"Through pictures. When asked, children may not be able to express themselves verbally or may not know how to."</p>	Parents could have been asked to estimate the intensity of the pain	Pain should have been assessed in many different ways	
	The pain could have been assessed by asking the child herself/himself		
	Pain could have been assessed with a pain scale		
	Pain could have been assessed using pictures		
<p>"Apparently it was interpreted as pain in the recovery room when the child was irritated. It would not have been necessary to give so much pain medication."</p> <p>"They should have listened to the child... asked if he was sensitive to pain"</p> <p>"They should have asked the child to compare the pain to previous experiences – asking if it was as sore as in the past or worse. What does the child think helps?"</p> <p>"...The child's individuality should be taken into account as well as the parent's view of what is normal for the child and what is not."</p>	The child's reactions could have been assessed more accurately	The individuality of the child would have been better taken into account when assessing pain	The child and parents could have been more closely involved in the pain assessment
	The child could have been listened to more closely		
	Information about the child's previous pain experiences should have been requested		
	Parents should be asked what is normal for their child		
<p>"Parents should be asked to discuss possible pain with their child."</p> <p>"we should be told what kind of pain the baby will feel if it feels. Does the baby feel a sore throat? Does coughing hurt? Can you even know that?"</p> <p>"that would be assessed openly by speaking and in writing with parents"</p> <p>"...but at certain times the caregiver downplayed the pain, even though the parent said the child was sore... I wish I had been believed and taken seriously."</p>	The parents should have been asked to discuss to their child	The parents would have been considered their child's experts	
	Parents should have been told of the child's pain		
	Parents should have been included in their child's pain assessment		
	Parents' assessment of the child's pain should have been used		

Fig. 3. Parents' wishes about how their child's pain should have been assessed in the hospital.

Parents felt that insufficient time was spent assessing the children's pain, and that staff were often very busy when assessing pain; as a result, the child was not given enough time to report her/his pain.

Parents' desires concerning their child's pain assessment

Several parents mentioned ways in which they felt their child's pain assessment in hospital could have been improved. Parents' wishes broadly fell into two categories: the use of different methods to identify pain more accurately, and greater involvement of parents in pain assessment. The creation of these categories is outlined in Fig. 3.

Pain would be better identified by different methods

Parents wanted their child's pain to be assessed and identified. The parents hoped that the child's pain would be assessed proactively, for example, to determine how much pain an examination or procedure

might cause. This would also allow pain to be treated proactively. In addition, parents hoped that their child's pain would be identified, that its intensity would be assessed reliably, and that it would receive an appropriate response. An appropriate response to the child's pain could include, for example, reassessing pain medication or providing a more comfortable environment for the child in pain.

Parents expected that a variety of methods would be used to assess the child's pain during hospitalization, including asking parents to assess the severity of their child's pain or asking the child himself or herself about pain. In addition, parents wanted different pain assessment scales or pictures to be used to assess the child's pain.

The child and parents could have been more closely involved in the pain assessment

Parents reported that they had hoped that both they and their child would have been more closely involved in the pain assessment.

The parents also wanted their child's individuality to be better taken into account when assessing the child's pain, felt that the child's pain responses should have been assessed more reliably, and wanted the child to be listened to more closely because it was perceived that the pain assessment procedure as implemented led to over- or under-treatment of the child's pain. Parents also wanted the child's previous experiences of pain to be taken into account when assessing pain. For example, one parent suggested that the child's current pain could have been compared with previous pain experiences in a similar situation and used that information to determine the appropriate treatment for the pain. In addition, parents felt that health care staff should have asked them about what sort of behaviors are normal and abnormal for their child.

More generally, the parents wanted to be acknowledged as experts on their own children. They desired information on their child's pain including its causes and how it feels, and would have liked the opportunity to talk to a doctor after their child had undergone a painful procedure such as surgery. Parents would also have wanted to be involved in the discussion with health professionals when the condition of the seriously ill child became painful in a new way. Parents wished they had been included in the pain assessment process by asking them to discuss the pain with their child or by being asked to assess the severity of the pain along with the nursing staff. Finally, parents felt that staff should have made greater use of parents' ability to assess their own child's pain.

Discussion

This study aimed to describe parent's perceptions of their child's pain assessment in hospital care. The results showed that children experience pain during their hospitalization, and that a significant proportion of this pain is moderate or severe in intensity. The parents reported that the most severe pain in children was associated with needle-related procedures, post-operative care, and other procedures and examinations, in accordance with previous findings (Birie et al., 2014; Walther-Larsen et al., 2017). Studies conducted in Canada (Birie et al., 2014) and Norway (Brudvik et al., 2017) found that the occurrence of such procedural pain is associated with underuse of pharmacological and non-pharmacological pain relief methods (Birie et al., 2014; Brudvik et al., 2017). Since the aim of our study was to describe parents' perceptions of their children's pain assessment, we did not record what kinds of pain relief were applied or how much was used during procedures or post-operative care. However, it is important to note that untreated procedure-related pain can have long-term effects. For example, poorly treated needle-related pain can lead to the development of needle fear, which usually occurs in childhood; the peak age of onset is between 5 and 10 years of age (Walker, 2019). Moreover, tissue-damaging procedures in premature infants have been associated with poorer neurodevelopmental outcomes at school age (Doesburg et al., 2013; Vinall et al., 2014) and neonatal surgery has been linked to increased rates of neurosensory disability in childhood (Hunt et al., 2018).

Our study revealed that parents felt they had been well involved in their child's pain assessment and that their expertise on the child had been taken into account. Some parents had been asked to provide a verbal assessment of their child's pain, but few were invited to assess their child's pain using a pain assessment scale. These findings are consistent with previous studies showing that parents were actively involved in assessing child's pain by observing the child, inquiring about possible feelings of pain and discomfort and the severity of the pain, but were not given a pain assessment scale (Lim et al., 2012). It also appears that caregivers use pain assessment scales irregularly when assessing pain in children. A Danish study (Hoffman et al., 2019) found that pain assessments were only documented in 46% of cases involving children experiencing moderate or severe pain. These assessments were most commonly done narratively (66%) or using a combination of narrative assessment and pain scores (28%); the use of an institution-

approved pain assessment scale was rare (6%). Similarly, a Norwegian study (Smeland et al., 2018) focusing on post-anesthesia care units found that only 22% of nurses used validated pain scales and that in some cases the chosen pain scale was unsuitable given the cognitive development of the children being cared for. However, the use of pain rating scales can improve the assessment of pain in children. In the Finnish study (Uitti et al., 2018), parents assessed their child's middle ear pain using a verbal rating (no pain, mild pain, moderate pain, severe pain) and two validated pain assessment scales (Faces Pain Scale-Revised (FPS-R) and Face, Legs, Activity, Cry, Consolability (FLACC) scale). The study demonstrated that parents assessed their child's pain significantly more often as moderate/severe with the FPS-R and with the FLACC scale compared with the verbal rating ($p < 0,001$). It is thus possible that without pain assessment scales, parents may underestimate their child's pain.

A large proportion of parents in our study were satisfied with their child's pain assessment, but parents also reported deficiencies in the pain evaluation. Parents felt that the nursing staff did not always trust the parents' assessment of their child's pain, and the severity of the child's pain was underestimated. Previous studies have revealed discrepancies in the assessments of pain intensity provided by caregivers, parents, and children; in general, both staff and parents reported the children's pain to be milder than the children considered it to be (Brudvik et al., 2017; Walther-Larsen et al., 2017). Conversely, an Australian study found no significant differences between the pain scores reported by children and their parents, although nurses reported lower scores than either (Hla et al., 2014). No reasons for these differences have yet been put forward. More than a third of children whose parents participated in this study were non-verbal or at a pre-verbal age, making the role of parents and caregivers in pain assessment especially important. Our findings suggest that even when a pain scale is used, parents rarely receive sufficient information to assess their child's pain in the same way as staff because they are not usually asked to evaluate their child's pain using a pain scale and few parents are given information about the scale used by staff. To improve the quality of pain assessment, it is recommended to combine the assessment of pain by the child, parents and health professionals and use pain assessment tool that is appropriate to the types of children and pain for which it has been tested (Herr et al., 2019).

The parents who participated in our study would have liked the nursing staff to work more closely with the child and parents when assessing the child's pain. Some of the parents would have liked to receive information about pain and some hoped that staff would have sought more information from the child and the parents. The principles of family-centered care state that a child receiving hospital care should be cared for by parents and caregivers acting in partnership. However, partnership necessarily shared responsibility, which requires the sharing of information, decision-making, and care (Adams & Levy, 2017; Kokorelias et al., 2019). In a family-centered pain assessment process, it may be considered essential for nursing staff to give parents information about the child's pain and the scale used for its assessment, and to give parents opportunities to participate in their child's pain assessment. Nursing staff, in turn, need information from parents about the child, the child's health, and any changes or pain perceived by the parents (Eull et al., 2023; Mikkelsen & Frederiksen, 2011).

Limitations of the study

There are some factors that limit the generalizability of the results presented herein. First, the data were collected using a questionnaire which may be subject to bias. The number of questionnaires per ward was determined by the number of children treated per month, but the time taken to hand out the questionnaires varied; in some wards, it took 4 months. We have no information on parents who chose not to participate in the survey. Another limitation is that self-reports on pain in children were not collected as this was not the focus of the

study. Thus, the actual pain experienced by children may differ from the pain assessed by parents. In addition, the study was conducted in a single hospital, so the results may not be generalizable to a wider population. On the other hand, the results are consistent with previous reports.

Practice implications

Based on the results of this study, the child's pain should be assessed regularly and frequently enough. It is important that the child and parents are involved in shared decision-making about pain assessment and treatment and have the opportunity to ask questions. Healthcare providers should pay more attention to guiding parents in the use of pain assessment scales.

Conclusions

Children in hospital experience moderate to severe pain, usually associated with procedures and post-operative treatment. Parents are involved in pain assessment, but nursing staff rarely inform them about how their child's pain will be assessed, particularly when the assessment is performed with a pain scale. Parents wanted their child's individuality to be better accounted for during hospital care and felt that their expertise should be valued and used when assessing their child's pain.

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CREDIT Statement

Anna-Kaija Palomaa: Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft, Visualization. **Mervi Hakala:** Methodology, Writing – review & editing, Visualization. **Tarja Pölkki:** Supervision, Project administration, Conceptualization, Methodology, Investigation, Data curation, Writing – review & editing.

Declaration of Competing Interest

All authors approve that they do not have any conflict of interest in this project, that could inappropriately influence bias this research.

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