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Children's individual voices are required for adequate management of fear and pain during hospital care and treatment

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Children's individual voices are required for adequate management of fear and pain during hospital care and treatment

Background: Children often report both fear and pain in conjunction with clinical care and treatment. Interventions developed in the field have still not been sufficient to prevent and relieve children's fear and pain. More knowledge, from children's own perspectives, is needed about how they deal with their experiences.

Aim: To explore child-identified strategies that children use to manage fear and pain during needle-related medical procedures in hospital.

Methods: Interviews with children, age 4–12 years, with experience of hospital care were analysed qualitatively using content analysis.

Results: Children have self-identified strategies for dealing with fear and pain during hospital care and treatment. The strategies vary depending on examination or

treatment and on how the child felt at that particular day. Children describe what they can do themselves, how adults can empower them and support from surroundings as strategies that give them a choice and a voice. Children wished to have influence, decide when and how information should be given, scream out loud or squeeze something hard, to deal with fear and pain. The results also show that children tried to be brave, gain control and think positively. Something nice to look at and opportunities to play with others also contributed.

Conclusions: Strategies vary between children and are used differently on different occasions. Healthcare professionals pose a threat to the child's needs and ability to use their strategies due to lack of knowledge of the child's chosen strategies.

Keywords: child perspective, fear, pain, strategies, young children.

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Background

Repeated hospital visits for children requiring care and treatment are often connected with experiences of fear and pain (1–4). Little is known about how children themselves manage and deal with such experiences as their care is often based on healthcare professionals and parents reports (5). The difference between the concepts of 'the child's perspective' and 'a child perspective' is a cornerstone of the continued development of childcare. The child's perspective can only be experienced by the child themselves while the child's best as seen from the eyes of the adults gives a child perspective (6). Children's

experiences may be challenging to understand, and adults often fail to interpret what children communicate in relation to the their experiences (7). Children's own perspectives and experiences will be the focus of this study.

Fear can be defined as a negative emotion or thought that occurs when you are frightened or scared by something dangerous, painful or bad that is happening or might happen (8). Fear can occur while facing unpleasant care and treatment (2,9,10) and cause emotional distress, increased heart rate, dry mouth, cold and pale face, staring and avoidance behaviour (11). Moreover, fear could be augmented as a result of being in an unfamiliar environment with unknown equipment and people (12). Evidence suggests that fear plays an important role in the experience of pain during needle procedures (13). Procedural fear can increase emotional distress, which can in turn increase pain sensation by physiologically increasing pain perception and autonomic stimulation (14). A

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child's limited understanding of certain procedures in hospital, and probable resulting fantasies, can also increase children's fears (15).

The International Association for the Study of Pain (IASP) describes pain as an unpleasant sensory and emotional state that originates from any region of the body (16). Pain depends on existing or possible tissue damage, or can be identified with this damage, and is affected by individuals past experiences. Pain in relation to medical procedures and treatments is often viewed by children as one of the worst aspects of having a long-term illness (14) particularly in connection with needle procedures (1,17).

Children younger than 7 years of age may experience a more diffuse fear and feeling of uneasiness (15). Teenagers seem to experience less pain compared to children younger than twelve (18). Although different age groups may indicate how a child is likely to react, it is important to assume that each individual child is unique and competent (19). Furthermore, children's maturity is related to their experiences rather than chronological age or development (9). Children develop their own ideas and interaction strategies in relation to health and illness in various social contexts such as family, preschool/school and hospitals (20).

There is a dearth of knowledge in the present literature on how children experiencing and managing pain and fearful experiences during hospital care want to be supported.

Aim

To explore child-identified strategies that children use to manage fear and pain during needle-related medical procedures in hospital.

Design and method

Design

A descriptive design was used, whereby interviews with children were analysed using inductive qualitative content analysis (21). Qualitative methods are appropriate for research with children, as they offer opportunities for gathering sensitive and meaningful data that enhances the child's empowerment and allows the researcher to enter the child's world of meaning and belief (19,22,23).

Children as participants

Data were collected at three paediatric healthcare units at different hospitals in Sweden over an 8-month period in 2018. The inclusion criteria were children aged 4–12 years with experience of hospital care and treatment

for at least 14 days over the previous 6 months and with ongoing outpatient contact with the hospital. Twenty-two children fulfilled the inclusion criteria and were asked to participate in the study. Six children declined participation due to their parents' concerns that the interview could evoke negative memories and it was considered ethically incorrect by the researcher to conduct an interview with three children whose condition deteriorated prior to interview. Thirteen children and parents entered the study. The participating children varied in terms of their age, diagnosis, gender and experiences of fear and pain during hospital care and treatment (Table 1). All participants spoke fluent Swedish, although eligible non-Swedish speaking participants would have been provided with an interpreter.

The children received verbal and written information adapted to children 4–12 years of age, by a nurse at each healthcare unit. All parents received verbal and written information. Permission was obtained for the researcher to contact interested parents to answer any questions and obtain their consent and the child's assent, to enter the study.

Data collection

Semi-structured interviews were performed with open-ended questions such as 'Tell me what it's like to be in

Table 1 Characteristics of participants (n = 13)

Gender	
Girls	8
Boys	5
Age (years)	
4–6	3
7–9	6
10–12	4
Diagnosis	
Different types of cancer	5
Infection	1
Autoimmune diseases	3
Inflammatory diseases	4
Times since diagnosis	
Less than 3 months	3
3 months – 12 months	3
More than 12 months	7
Number of children at each hospital	
Hospital A	5
Hospital B	3
Hospital C	5
Facilitators during the interview	
Used only polaroid photograph	2
Used only drawing	3
Used polaroid photograph and drawing	4
Used polaroid photograph and doll	1
Did not used anything	3

hospital', 'Have you ever been afraid or felt pain in the hospital?' 'Tell me what you were afraid of/or experienced pain from?', 'What helps you when you are afraid and/or feeling pain?' Follow-up questions like 'tell me more about...'. were asked to get deeper and reflective answers. All interviews were digitally recorded and transcribed verbatim. Children are known to more easily communicate their experience when using toys and images during interviews (17,23). Toys and images can lead to less unease in the research situation and reduce the power imbalance that may exist between researcher and participant (24). Therefore, some toys and craft materials were used during the interviews. In addition, a polaroid camera was used, to assist the child's interaction with the researcher. Children photographed objects or places from their care and treatment that had caused them fear and/or pain. Some children chose to talk about the photographs while taking them. Other children discussed the photographs later during the interview. The photographs were used as a facilitator for discussion only and not included as data for analysis.

All interviews took place in a secluded area at the hospital. For children attending outpatient visits, the interview was conducted either before or after the visit. Parents were present during most interviews, as the child wished, but focus was on the child and child's own experiences. Two children opted to do the interview without a parent in the room. The interviews ranged from 14 to 48 minutes.

Data analysis

A qualitative content analysis with an inductive approach according to Elo and Kyngäs (21) was performed. The transcribed interviews were initially read a number of times and reviewed repeatedly to make sense of the data as whole. All interviews read independently by the last author to contribute to the study's trustworthiness.

Meaningful text units corresponding to the study aim were highlighted in the text. These units were then condensed to smaller, more manageable units of text in the margins in an open coding (21). The codes were grouped into preliminary subcategories based on similarities and difference of content (23). A continuous movement back and forth between the codes and preliminary subcategories took place until the final subcategories were organised. Subcategories were merged into categories through interpretation and discussions with co-authors.

Ethical considerations

The regional ethical review board (blinded) approved the study (Dnr 284-18), which adheres to the Declaration of Helsinki (25). The four principles of autonomy, beneficence, justice and nonmaleficence were adhered to in

every step of the research process. Children and their parents were informed that they could withdraw participation at any time without specifying reasons, and that withdrawal would not in any way affecting the care and treatment of the child. Parents consented to participate while children themselves assented to participate, as minor children are not legally capable of entering into a contract and therefore unable to give legal consent (28).

Results

The results are presented as one main category 'Children's individual voices are required for adequate management of pain and fear', developed from categories and subcategories (Table 2).

Children's individual voices are required for adequate management of pain and fear

Children described having strategies for dealing with fear and pain during hospital care and treatment. They described what they could do themselves, how adults can empower them and support that can be gained from adults or surroundings. These strategies required the child's voice being heard and being able to choose amongst a variety of different strategies.

Table 2 An overview of subcategories, generic categories and main category

<i>Sub-category</i>	<i>Generic category</i>	<i>Main category</i>
Dare to be brave	What the child can do	Children's individual voices are required for adequate management of pain and fear
Control their thoughts		
Be in charge of their body		
Ask for the child's preferences	How children can be empowered by adults	
Information a question of timing		
Be allowed to scream out loud		
The significance of a cuddly toy		
The opportunity to meet other children	Support to be gained from the child's surroundings	
A child-friendly decòr		

What the child can do. Children described that they tried to be brave and to control their thoughts, which helped them to reduce both fear and pain. Being in charge of their body was a necessity to utilise these strategies.

Dare to be brave—Children talked about the need to have courage to speak up for themselves. Without courage, the child adapted more to what the healthcare professionals or parents thought was best for the child. This led to the children experiencing more pain. ‘It makes no difference how big I get, at the hospital I’m always little’ (six-year-old girl).

Courage was required to look at the needle stick during needle procedures and infusions because they felt that a part of their body that could be taken away from them if they did not look. When the child got scared, or if it hurt during needle procedures, they got tense which led to more pain. To be brave it was necessary to have control of themselves, both mentally and physically. It turned out that if they were in control, self-confidence followed, and then the child dared to be brave.

Control their thoughts—A silent strategy that children used was to control their thoughts. The children tried to think positive thoughts and deliberately avoided thinking about the needle procedure or other scary examinations and treatments. ‘I try to think about something else but I can’t cos it might hurt too much... I can’t really not think about it and then I think about the needle and then I’m still afraid’ (eight-year-old girl). However, this was not easy, particularly when they were afraid. ‘I hate this and am so so scared, I try really hard not to think about it... it works better if I think that it’s going to go well’ (seven-year-old boy).

Fear experienced during anaesthesia induction incorporated scary thoughts about where the medicine was going in the body, how it made the child sleep and what happens to their body while they were asleep. To reduce fear during anaesthesia, children explained their strategy of trying to fall asleep before the anaesthetic took hold. In that way, the child felt safer and fear decreased. ‘I try to do like this... now I am going to sleep, try to sleep... I don’t know if it’s me or the medicine that’s make me sleep and then I’m not afraid’ (ten-year-old girl).

Be in charge of their body—The position of the child’s body, for example laying down, during care and treatment was important to counteract and reduce fear or pain. ‘I always want to lie down even when they want to take a finger stick. They say the pain goes away quickly, but not for me. It’s better when I lie down’ (nine-year-old girl). Some children thought that sitting on a chair made the procedure less of a big thing to go through and was

better than lying down as long as they could choose themselves.

The way in which, for example, needle stick procedures should be performed varied according to the child’s mood and the type of needle stick the procedure involved. Sometimes, they wanted to look, and sometimes, the same child did not want to see because that particular day he or she was afraid. On one hand, they described being prepared as positive with reduced fear and pain. On the other hand, some children preferred not knowing when the needle stick was being made. If they knew exactly when the stick was coming, there was a risk that they would jerk their body, which could lead to more pain.

Holding hands with someone was good when they felt afraid. The reason for this was that the child could squeeze the held hand very hard and experience relief. The children were aware that healthcare professionals asked them to relax, but to squeeze hard felt so much better. ‘I stretch out my arm and hold Mommy’s hand and squeeze really, really hard. It usually always works as it doesn’t hurt so much then... you can also think about something else at the same time you are squeezing’ (nine-year-old boy). The children named how good it felt to squeeze stress balls, chairs or whatever was closest to them.

How children can be empowered by adults. Children needed to be given opportunities by adults around them to decide and have influence over their own care, and as they themselves wished. Strategies on information about what to expect, to be allowed to scream out loud and to find comfort in a cuddly toy, were described.

Ask for the child’s preferences—Influence over care decisions and sufficient facts about future care and treatment were vital for the child. ‘They tell me to look away, but I’m used to looking, I want to look, otherwise I get so scared it feels like I’ll take my hand away when I look away’ (nine-year-old girl). The children repeatedly stated that they were not always in agreement with what the adults thought was best for them. This applied to both the healthcare professionals and the parents.

There was no one definite way for how care and treatment should be administered to the child. It depended on what kind of procedure or examination the child had to go through, and the child’s mood that particular day. A sense of being seen and being important occurred when the child felt involved in decision making. ‘It’s good when it’s done the way I think it should and that they ask me what way I want it, then I’m not so afraid’ (twelve-year-old boy).

Information a question of timing—Children’s individual needs for relevant information during procedures varied.

Healthcare professionals usually informed them about what would happen, whether they wanted to know or not. Sometimes, this information came too far in advance of the procedure, which led to increased fear and anxiety. Rather, it was preferred if the healthcare professionals gave information just before it was time for the care or treatment, so the child did not have so long to think about what was going to happen. 'They came in and told me what they were going to do 2 days before, then I got really scared and got more and more afraid. Better if they don't tell too long before' (six-year-old girl). Not being given any information prior to a procedure sometimes meant a decrease in fear, but when this occurred, the children wanted to know everything afterwards instead.

If the adults present communicated with each other, it was preferred that they talked about things that interested the child and not what the children called 'over my head'. Talking over the child's head increased both fear and pain because the child felt left out and vulnerable. Sometimes dialogue with the child was good but sometimes it was better to just stay quiet and let the adults talk. 'I listen and hear what they are saying but at the same time I'm concentrating on getting through it, so I don't say anything myself' (nine-year-old boy).

Be allowed to scream out loud—Being allowed to scream helped reduce children's pain. Some children described a feeling of liberation when they screamed resulting in a calmness that made them experience less pain. 'You scream when you get afraid and they just say shh, calm down' (four-year-old girl). However, healthcare professionals and parents found it difficult to tolerate the child's screaming, according to the children, and wanted to comfort them in order to hinder them screaming. 'Maybe it's good to scream, but they don't know that, nobody asks me' (eight-year-old girl). Often, when the child screamed, the healthcare professionals stopped the examination or treatment instead of continuing with it. Children felt that healthcare professionals misinterpreted the screaming as though they were experiencing fear or pain and tried to cure this without asking them why they were screaming. 'Screaming out loud makes it better, but I must be allowed to do that, and nobody wants me to' (twelve-year-old boy).

The significance a cuddly toy—Having someone close for comfort and support was important but did not have to be a living person. Cuddly toys to hide behind were mentioned as a great support, sometimes even better than parents or other peoples. Children explained that the cuddly toy was always quiet, allowed the child to do as they needed and did not tell the child how to behave. 'Cuddles with my soft toy when I get pain, just the way I want and need them... that's the best that my soft toy is

always there and lets me do what I want to with it' (six-year-old girl). The children wanted to decide by themselves whether to use their parent or the cuddly toy to manage experiences of fear and pain. The cuddly toy was adaptable and was always there for them. Even a borrowed cuddly toy could be experienced as a better comfort than the 'uncontrollable' parent.

Support to be gained from the child's surroundings. A child-friendly décor, more friendly-looking hospital paraphernalia and possibilities to play and meet with other children were described by children as supportive in dealing with fear and pain.

The opportunity to meet other children—Children described that most of the rooms on the ward were clean, sterile and lacked things that children could play with. Free play, predominantly and preferably at the play department, helped children before, during and after performed care and treatment. If there were other children in the play department at the same time, fear decreased even more because the child thought of completely different things and felt some kind of belonging with the other children, which both distracted and calmed the child. 'It's so nice to be with other kids at the play department. You get kind of calm, thinking that they have gotten through the stuff that hurts and that you're scared of' (ten-year-old boy).

A child-friendly décor—When the children needed to undergo different examinations or treatments, one strategy for dealing with fear or pain was to have things to look at in the room. 'But I've nothing to do cos I don't know what to do and then I get scared and it hurts. Maybe they could have something on the wall to look at so I'd have something else to think about' (six-year-old girl). Child-friendly things that were hanging down from the ceiling sometimes helped them to steer their mind away from the procedure. Children explained that different things on the wall could help to reduce their experience of fear and pain. These things could be paintings, different kinds of animals, funny things to talk about and for the older children clever things like puzzles and riddles. 'Sometimes the monkeys on the ceiling help me be less afraid, cos sometimes that works and sometimes it doesn't' (four-year-old girl).

Infusions of fluid and blood were both scary and painful according to the children. The infusion pump made a scary sound that the children tried to ignore, or at least endure. Children wished for health professionals to hang something over or in front of the infusion bag, particularly if it was a blood transfusion. The same opinion applied when the children needed to undergo a needle procedure, children thought that health professionals could hang a drape between the child and the needle.

Opportunities to do arts and crafts, play games, use a digital tablet, phone or TV were all appreciated tools. The main reason for this, according to the children, was because they felt distracted and the thoughts of what created fear and pain decreased. Digital tablets, telephone and TV were just as important during examinations and treatments, as they are during the rest of their hospital stay, as fear and pain decreased when they were distracted by technology.

Discussion

This study reveals that children have several strategies for managing pain and fear during medical-related needle procedures. But it requires that adults listen to and adhere to the individual child's wishes and needs. It is important that healthcare professionals are opened minded and flexible in asking for and meeting the child's wishes, to reduce experience of fear and pain. Children are able to successfully communicate their wants and needs in a variety of ways (26). If adults misinterpret the child's will, the child's dignity may be violated leading to suffering and reduced health (27).

A silent strategy that children used was to control their thoughts. Previous research has shown that children under the age of 12 tend to use more practical strategies compared to older children in accordance to the child's cognitive development (28). However, the present study shows that children younger than 12 years also use quite advanced cognitive strategies to deal fear and pain. This may be due to the child's own will and ability as well as previous experiences from health care. It must also be noted however, that, regardless of age, not all children are capable of going into themselves and focusing on their thoughts.

Being a child in hospital requires courage. To be able to protect themselves and use strategies that could decrease fear or pain during care and treatment, children needed to be involved and empowered by adults. Although research reports the importance of including children in their own care (29,30), there seems to be a lack of communication between healthcare professionals and children of how this can be achieved. It is important to understand children's own desire to participate in healthcare situations in order to support their opportunities to participate (19). Healthcare professionals should ask for and value the child's preferences. Listening to what the child wants to say is important for the child's dignity (27). Participation, from the child's perspective, may also encourage the child to be brave and use strategies that decrease fear and pain. The present study indicates that care based on the child's terms, experiences, competence and emotional state will allow the child possibilities to take initiatives of his or her own and gain control. The child wants to be invited to tell about how

they wish procedures to be done, so they can feel secure and master the situation with their own strategies.

This study shows that screaming out loud was a preferred strategy to show their dislike when undergoing treatment or examinations. Adults tend to see the child's screaming as a defeat, which may lead to healthcare professionals and parents doing everything they can to stop the child screaming. A problem with this is that adults often fail to see that children in fact use crying as a coping strategy to vent negative emotions. They have a need to cry out, and if allowed to do so can better manage experiences of fear or pain (28). Screaming was a strategy proposed by the children themselves and healthcare professionals need to be more aware of what screaming or being allowed to scream, means to a child.

A cuddly toy helped the children decrease their fear or pain by allowing them to do exactly the things they needed to do, unlike adults who sometimes prevented children from using their self-identified strategies. The Psychologist John Bowlby believed that the child seeks the protection and comfort of their parents, in unsafe and stressful occasions (31). Parents are seen as those who know their child best (22,31) and have the child's needs and best interests in focus (32). However, this study shows that children can turn away from the safety of parents when the parents constitute an obstacle and seek other forms of comfort. To have a cuddly toy to hold and get comfort from is in line with previous research (32). Seventy years ago, the paediatrician and psychoanalyst Donald Winnicott (33) described that children have a natural need to use cuddly toys, blankets and bits of cloth. He called this the transitional object and transitional phenomena. So knowledge exists, but perhaps needs to be dusted-off, updated and spread to those working with children.

An additional strategy children raised in the present study was using the opportunity to meet other children in the play department at the hospital. Play is proven to be of high therapeutic value for ill children, contributing to both their physical and emotional well-being and to their recovery (34). Pelander and Leino-Kilpi (29) report that meeting new friends in the hospital is one of the best things about being there (29). Children who made new friends describe more positive experiences of care and treatment. Children exchange experiences with each other and give each other support, in their own way. More knowledge is needed regarding how children who socialise together in hospital can share their strategies. One possible intervention could be that two children, together with their responsible nurse, perform some type of activity together, adapted to the children's ability, interest and strength. According to the results of the present study, children in hospital can support each other but adults may overlook or under estimate this aspect of care.

Strengths and limitations

A major strength of this study is its qualitative design and interviews as data collection method of choice. Data from the child's perspective gives children a voice. Young, ill children can have a limited communicative capacity due to their age but experiences of illness and hospitalisation can mean they are more competent in expressing themselves, in relation to healthy peers (35). To help the children talk more easily during interviews, facilitators such as toys were used. The toys encouraged the child's curiosity and allowed a relationship between the child and the interviewer to develop. Parents were present during most interviews, as children wished, in order to make the children secure and able to express their experiences. However, the child's perspective was paramount during the analysis and only the child's utterances were analysed.

Throughout the study, different steps were taken to enhance trustworthiness and dependability (36). Discussions on the analysis and findings held continuously in the research group. Moreover, the manuscript was reviewed and discussed during seminars with other researchers. To strengthen confirmability (36), the analysis process was described as clear as possible and quotations from different children were used to illustrate the results. It is possible that the transferability of results is limited to children of a similar age group, 4–12 years. It is also credible that the study's results could be transferred to similar contexts and other children with a variety of diagnoses requiring hospitalisation in countries with corresponding healthcare systems.

The question could be asked whether it is possible for children to distinguish between the experience of fear and pain. However, the children in the underlying study express fear and pain as two separate experiences, which correlates with recently published research (37).

Conclusions

This study shows that children, aged 4–12 years, must be given the opportunity to influence their care in

procedures they associate with fear and pain. Children are competent in describing their needs and choosing ways of dealing with fear and pain during care and treatment in hospital. The same child may require different strategies for the same care regardless of earlier experiences of care or treatment. Thus, the child voice is of uppermost importance when planning all care and treatment. Without it, healthcare professionals and other adults risk posing a threat to the child's needs and wants. Interventions based on children's perspectives are needed in the care and treatment of children undergoing medical investigations and procedures.

Conflict of interest

None.

Author contributions

Study Design: IK, LH, AS, KK, LD; Data collection & analysis: IK, LD; Manuscript preparation: IK, LH, KK, LD, AS.

Ethical approval

The regional ethical review board of Gothenburg, Sweden, approved the study (Dnr 284-18), which adheres to the Declaration of Helsinki (24). The four principles of autonomy, beneficence, justice and nonmaleficence were adhered to in every step of the research process. Children and their parents were informed that they could withdraw participation at any time, without specifying reasons and that withdrawal would not in any way affect the care and treatment of the child. Parents consented to participate while children themselves assented to participate, as minor children are not legally capable of entering into a contract and therefore unable to give legal consent (28).

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