



## Fear and Coping in Children 5–9 years old Treated for Acute Lymphoblastic Leukemia - A Longitudinal Interview Study☆



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### ABSTRACT

**Purpose:** The aim of this study was to describe the fears of 5- to 9-year-old children related to having acute lymphoblastic leukemia (ALL) and their strategies for coping with those fears.

**Design and methods:** The study had a qualitative descriptive longitudinal design and included a total of 35 interviews with 13 children at three different times during their treatment period. Data were analyzed using a matrix-based method inspired by the work of Miles et al.

**Results:** Initially, most children reported a fear of needles, but during the treatment period, fewer children reported this fear. Children's coping strategies also changed over time, as they wanted more involvement and control during needle-related procedures. Other fears were having adhesive tapes removed, having a nasogastric tube, and taking tablets. During the treatment period, existential fears related to the seriousness of ALL and its consequences, such as having impaired physical fitness and being different from before and different from others, became more prominent and caused feelings of loneliness and alienation.

**Conclusions:** The children described various fears through their treatment period, which they coped with using cognitive, emotional, and functional strategies. Over the 2.5-year period, their strategies changed.

**Practical implications:** Because fears changed over time and varied among these different children, each child must be approached individually and attentively in every encounter.

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### Fear in children with acute lymphoblastic leukemia

Acute lymphoblastic leukemia (ALL) is the most common childhood cancer. The survival rate is approximately 80% (Johansson, 2013) to >85% with optimal risk-directed therapy (Pui et al., 2015). In the age group studied here (4–9 years), ALL is more common in boys than girls. In 2015, a total of 19 children aged 5–9 years were diagnosed with ALL in Sweden (13 boys and 6 girls), and 5 children died (National Board of Health and Welfare, 2018).

In the Nordic countries, children with ALL are diagnosed and treated according to the Nordic Society of Paediatric Hematology and Oncology (NOPHO) 2008 treatment protocol, which typically takes about 2.5 years. The treatment is initially intense and includes both intravenous and intrathecal therapy. After about a year the treatment is less intense, with fewer hospitalizations and medication more often given orally (Toft et al., 2018). Previous research has identified fear in children during the first year of treatment (Dupuis et al., 2016; Myers et al., 2014),

but because of changes in the treatment regimen over time, possible adaptation to treatment, and the natural cognitive development of the child, it is reasonable to believe that the children's fears may vary over the course of treatment. This possibility has not previously been studied. From a children's rights perspective (UNICEF, 1989), it is important to study and give voice to children's experiences of fear during their treatment for ALL.

Salmela et al. reported that >90% of children admitted to the hospital reported fear of at least one aspect of the stay including pain, treatments, and injections (Salmela, Salanterä, & Aronen, 2009). Young children, however, can have difficulty differentiating pain from fear, anxiety, anger, and sorrow as they have had fewer such experiences than adults (Blount, Piira, Cohen, & Cheng, 2006). Children who have had painful treatments express more fear than those who have not (Kerstis, Larsson, Lindberg, Sjöberg, & Söderbäck, 2010).

For most children, needle-related procedures cause pain, fear, and anxiety (Taddio & McMurtry, 2015). Although the worst fears in a hospital environment are often related to medical procedures such as injections and drawing blood, levels of fear can vary on different occasions. Children's fantasies (Karlsson, Rydstrom, Enskär, & Englund, 2014) and limited understanding of certain procedures (Salmela, Salanterä, Ruotsalainen, & Aronen, 2010) can increase their fears (Karlsson et al.,

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2014; Salmela et al., 2010). A child who is restrained during a needle-related procedure can develop a strong anticipatory anxiety about similar situations (Taddio & McMurtry, 2015). Feeling a sense of control, however, can decrease such fear (Karlsson et al., 2014).

Children with leukemia, specifically, found the initial hospitalization a negative experience; however, age, personality, and the hospital experience influenced how well children accepted their illness and changed circumstances (Han et al., 2011). Only a few studies of fear related to ALL have adopted a longitudinal design. In one study, treatment-related anxiety and pain decreased during the first year following diagnosis (Dupuis et al., 2016). Similarly, Myers et al. (2014) found increased worrying one month after treatment initiation, but at 6 and 12 months after diagnosis, these levels had returned to those of a control group. We have not found any study focused on whether coping strategies vary over time in children with ALL.

Children undergoing treatment for cancer have fears related not only to their treatment per se, but also to the thought of death and the possibility of their dying during treatment for cancer (Anderzén-Carlsson, Kihlgren, & Sorlie, 2008). In addition, these children have to adjust to greatly changed everyday lives and have been found to face social problems on their return to school after treatment (Darcy, Björk, Knutsson, Granlund, & Enskär, 2016).

Coping strategies have been described in various ways. In a study of preschool children's hospital fears Salmela et al. (2010) defined them as "the child's active attempts at cognitive, emotional and functional actions to master her/his hospital-related fears" (p. 109), which is the definition used in this study. Summarizing previous literature, Salmela et al. also divided coping into three types:

- problem-oriented coping, which can include the child seeking information from health care personnel or parents and trying to find solutions,
- emotional coping strategies, such as self-soothing, and
- function-oriented coping, exemplified by withdrawal, aggressive behavior, hyperactivity, and playing (Salmela et al., 2010).

In other literature, coping strategies have been divided into active and passive types, with active strategies considered more problem-oriented, and passive more focused on the emotions (Lazarus & Folkman, 1984). Harder, Christensson, Coyne, and Söderbäck (2011) studied 5-year-old children undergoing immunization and concluded that these young children could be active agents in that situation. Salmela et al. (2010) found that such active coping allowed children a sense of control in treatment situations, in line with findings by Ayers, Muller, Mahoney, and Seddon (2011). They found that children with cystic fibrosis most frequently used control or avoidance strategies to cope with needle-related distress.

To summarize, previous research focused on the medical fears of children with various cancer diagnoses, their fear of dying, and their existential distress. The two longitudinal studies that focused on ALL-related fear and coping from the child's perspective followed children for one year. It is important to follow the experiences (e.g., fears) of ill children over time, as their previous experiences can influence their reactions to upcoming situations, and there is a gap in our knowledge of this trajectory. It is equally important to give voice to these children's experiences to increase our understanding of their situations and fears and improve the quality of their care.

## Aim

The aim of this study was to use a longitudinal perspective in a group of 5- to 9-year-old children with ALL to describe their ALL-related fears, the strategies they use to cope with those fears, and changes in their fears and strategies over time.

## Research questions

The study aimed to answer the following research questions:

- What fears do children with ALL experience at various time points during their treatment?
- How do the children cope with their fears?

## Method

### Design

The study had a descriptive, longitudinal qualitative design (Polit & Beck, 2004). Data were collected through repeated individual interviews (Kvale, 2008), and the qualitative analysis was inspired by Miles, Huberman, and Saldaña (2014). This study is part of a larger longitudinal interview project about fears in 5- to 18-year-olds who have ALL.

### Sample and setting

Recruitment took place in collaboration with the six regional child oncology centers in Sweden during 2011–2014. One designated nurse at each center was instructed to provide verbal and written information about the study to all children aged 5 to 9 years and their parents approximately 1 month following the diagnosis of ALL. If the child agreed to be included in the study and the parent consented, the child and parent signed a consent form for the nurse to contact the researcher and share parental contact details. The researcher then contacted the parent by telephone and gave more detailed information about the study, and a date and place for the first interview was scheduled. In this study, 13 children (3 girls and 10 boys, aged 5–9 at the first interview) agreed to participate in up to three individual interviews during their treatment period. Most of the children had Swedish as their first language; 3 had other first languages but spoke Swedish fluently.

### Data collection

A total of 35 interviews were performed. All but 3 children were interviewed three times (one was interviewed once and the other two, twice). At >50% of the interviews, a parent was present and at times filled in details of the child's story or asked questions to stimulate the child's recall of certain occasions. Only one of the children was interviewed on all occasions without a parent present. The interviews were conducted in the children's homes, in the hospital, and in one case, in a café, according to the families' wishes. The interviewer was a pediatric nurse and researcher, experienced in qualitative methods and in studying fear in children with cancer, but with no practical experience of pediatric oncology nursing. The interviews lasted between 5 min and 72 min, with an average of 35 min.

Because we aimed to collect information about the children's perspectives on fear and coping strategies, qualitative interviews were considered an optimal method of data collection (Kvale, 2008; Richards & Morse, 2002). The interviews were adapted to the age and development of the child (Kortelnuoma, Hentinen, & Nikkonen, 2003). During the interviews, the children were asked to draw the situations they talked about, which enabled them to further describe their experiences of frightening situations. Drawing was, however, a voluntary task, and children could opt not to draw. The drawings were not used in the data analysis. An interview guide was used on all occasions, aimed to cover the children's experiences of fear since onset or since the previous interview, the strategies they used, and perceived supportive behaviors of parents and staff (the last will be reported elsewhere). Initially, the major focus was on the most prominent fear, but it became evident that the children had difficulty differentiating one specific prominent

experience of fear from another. The interview guide was therefore adapted to add questions that allowed for more than one experience of fear.

Data were collected from January 2011 to November 2016. The interviews were performed approximately 2 months after diagnosis, 1 year after diagnosis (when intravenous treatment was over), and 2.5 years after diagnosis (close to the end of treatment). The interviews were recorded on digital media and transcribed verbatim by a secretary. The data collection was completed prior to the start of data analysis.

### Data analysis

The data analysis was inspired by the matrix methodology described by Miles et al. (2014). In this method, matrixes are created first for individual cases and then for cross-case analysis. The general idea of this method is to visualize data, to enable conclusions that could be more difficult to reach using other, more traditional, qualitative methods. The formats of the matrixes are designed according to the aim of the study and further developed during the analysis as emerging findings are entered (Miles et al., 2014).

The researchers first read all the interviews in their entirety, while simultaneously listening to the audio-files to ensure that the transcriptions were correct. Second, all interviews were re-read, and all text related to the aim of the study was highlighted with various colored markers (one color for experiences of fear, one for coping strategies, etc.), and excerpts for each child that answered the research questions were extracted or paraphrased and inserted into an individual, study-specific matrix (Fig. 1).

In the third step, the extracted content for each child was checked against the transcripts to ensure that all relevant information had been extracted and that all extracted data were correct. Fourth, a cross-case matrix was created, in which data from the case matrixes were inserted; all answers to each question were compiled in columns according to the question answered and covering experiences reported in all three interviews. This matrix served as a basis for the answering the research questions (see Fig. 2).

The most commonly described topics were highlighted at this stage and entered into a new cross-case matrix for each reported fear, under

various headings such as *Most prominent fear: needles*. Whether or not each child had reported on this fear at each interview time was marked in this matrix and the numbers of children having experienced fear was summarized. Such cross-case matrixes were created for fears related to *needles, nasogastric tubes, removal of adhesive tape, taking medicines, and physical changes related to ALL* as a final step of analysis prior to writing up the results. The first author was responsible for the analysis in close collaboration with the second author.

The study was approved by the Regional Ethical Review Board in Uppsala (registration number 2010/195).

### Results

In all interviews, children were asked to relate the one specific situation that caused them the most or worst fear. They had difficulty choosing just one experience, and what was described as “the worst” could vary during the course of the interview. One child could address fear in more than one way, and the words used to illustrate frightening experiences also varied between the children and between different experiences. The children described the cognitive, emotional, and functional strategies they had developed during their illness. More details of the results follow the overview presented in Table 1.

#### Fear of needles

Children most often reported getting needles as their most prominent fear. They described being afraid of having blood drawn and of having injections. Two months after diagnosis, all children reported a fear of needles, and most mentioned this as their most prominent fear (Table 2). Five defined this fear as specifically related to their subcutaneous venous access. They did not like the strange feeling in their body when the needle was inserted in the access, and it hurt when the needle was removed. One year after diagnosis, the number of children rating fear of needles as the most prominent had decreased and four children reported no such fear at all. In the final interview, only two children reported fear of needles as the most prominent. As shown in Table 2, fear related to getting needles was less frequently described as most prominent in the second and third interviews. Nevertheless, at both 1 and

	2 months after diagnosis	1 year after diagnosis	2,5 year after diagnosis
<b>The most prominent fear</b>	The injection administered in the thigh is the most creepy experience	The “helicopter” [the butterfly-shaped intravenous line]	Being subjected to various needles.
<b>Fear</b>	A little scared to see the syringe, as it hurts. At the beginning of treatment was afraid of the central venous catheter (CVC) [shows it to the researcher]. Now the peripheral venous catheter is regarded as worse than the CVC.	Having a finger-prick. The “helicopter.” Having a feeding-tube inserted, and vomiting the feeding tube up. Creepy to check blood sugar oneself. Taking tablets.	Having an intravenous line inserted in the arm prior to anesthesia. It hurts when inserted.
<b>Strategies to deal with fear</b>	Apply the topical anesthetic cream (EMLA®) on the injection site at the thigh. Likes to move around at the ward.	Want the nurses to count to 3, and like to finger-prick myself. Prefer to be informed ahead of something happening, for example when going to the hospital.	Pulls mother’s or father’s hair. Strains entire body. Does not want to look when the needle is inserted, but wants to be informed prior. Hospital-play at home; including giving “needles” to friends and family.

Fig. 1. Case-specific matrix illustrating one child's most prominent and subsidiary fears and strategies in use at each of the 3 interview times.

Individual #	Most prominent fear			Subsidiary fear			Reported strategies		
	1 year	2 months	2.5 years	1 year	2 months	2.5 years	1 year	2 months	2.5 years
5		Everything is the worst. Going school with a naso-gastric tube. Having the injection in the leg. The naso-gastric tube and the fixation of it.	Mother is going back to work.	The needles penetrating the skin (drawing blood from arm or finger and test taken from the spine). Needles. [Mother: Removing the adhesive tape.]	Removing the adhesive tape, especially the fixation of the central-venous catheter	Needles/penetration of the skin. The naso-gastric tube. Feeling unsafe in the child-care after the school day. Being bullied by children in school.	Remove the adhesive tape self. Hospital play with a doll.	Close eyes. Decide to start eating to avoid the naso-gastric tube. Assist when changing dressing covering the central-venous catheter. Easier with finger-pricking if mother is pricked first.	Sits still for the flu vaccination and when being finger-pricked. Chooses which finger to prick and to look straight ahead. Searches for closeness with the attending parent
7	The penetration of the skin when drawing blood (the worst is in the arm and in the finger)	The penetration of the needle in the arm and in the subcutaneous venous access. "Never being able to run again was what I feared the most," as a consequence of the Viskristin treatment and thrombosis in the leg.		Feeling sick.		The penetration of a needle. A bit worried prior to vaccination. Intravenous treatment with sodium chloride. Taking medicines such as for cortisone, antibiotics, and gastritis prevention.	Close eyes or look in another direction. Does not think of anything, just endure it. Being used to it. Sometimes cries because of fear and pain.	Wants the staff to count 1,2,3. Wants to be prepared. Closes eyes. Does not want to see the needle. Thinks of something else. Physical training.	Closes eyes. Wants the staff to count 1,2,3. Just decides to accept the injection/drawing of blood. Be prepared.
18	Not interviewed	At first I wondered "am I going to die?" The needle. Inserting the needle into the subcutaneous venous access. The nurses hold and push hard when they touch it. It is scary to feel something foreign inside the body.	Not interviewed	Not interviewed	Being finger-pricked	Not interviewed	Not interviewed	Refuses to talk prior to finger-pricking. Physically objects by kicking and fighting. Makes the finger warm, decides to endure the finger-pricking and just go ahead with it. Counts 1,2,3 and looks away	Not interviewed

Fig. 2. Excerpt of the cross-case matrix illustrating three children's individual fears and strategies over the course of treatment.

2.5 years after diagnosis, >50% of the children still had some fear of needles. For some children, fear of needles increased when the professionals used physical constraint or spoke or behaved harshly. "They were forced to hold on to me and just because I didn't want to and was kicking and stuff ... I fought ... It felt scary ... If I was especially angry then another one came and held on to me" (18:2).

The children described various strategies for coping with their fear of getting needles. They avoided watching the puncture of the skin: "When they're going to put the needle into my subcutaneous venous access, I usually close my eyes or look away" (7:1). They also prepared themselves by counting to 3, a strategy most often mentioned one year after diagnosis. The children described wanting to participate in their care by dictating aspects such as when, where, and how the nurse should conduct needle-related procedures or by carrying out certain procedures themselves. For example, they described applying a topical anesthetic (EMLA®) to their skin prior to intravenous punctures, changing the adhesive tapes securing their venous accesses, repeating their hospital experience in their play, and pricking their own fingers: "And then I did it, I pricked my own finger" (3:2). The children said they wanted to be prepared for the insertion of needles and did not want to be fooled by the health care staff. If they felt they had been tricked, they lost trust and confidence in the person who had fooled them. It also caused them more fear prior to the next similar situation.

Table 1  
Overview of the children's most prominent reported fear and other fears expressed at each interview.

Most prominent fear	n	Subsidiary fear	n	Total n
Interview 1 (n = 11)				
Getting needles	9	Getting needles	2	11
Having a feeding tube	1	Having a feeding tube	2	3
Removal of adhesive tape	0	Removal of adhesive tape	3	3
Taking tablets	0	Taking tablets	1	1
Physical changes caused by ALL	1	Physical changes caused by ALL	1	2
Interview 2 (n = 13)				
Getting needles	7	Getting needles	2	9
Having a feeding tube	1	Having a feeding tube	2	3
Removal of adhesive tape	0	Removal of adhesive tape	3	3
Taking tablets	0	Taking tablets	2	2
Physical changes caused by ALL	1	Physical changes caused by ALL	3	4
Interview 3 (n = 11)				
Getting needles	2	Getting needles	5	7
Having a feeding tube	0	Having a feeding tube	1	1
Removal of adhesive tape	0	Removal of adhesive tape	0	0
Taking tablets	1	Taking tablets	1	2
Physical changes caused by ALL	1	Physical changes caused by ALL	6	7

Several children mentioned bringing a favorite soft toy to hospital to soothing themselves during procedures and create a feeling of security. This strategy was used at all phases of the treatment. Children sometimes also used functional coping strategies by expressing their feelings and objections to needle-related procedures by crying, screaming, and kicking: "I cried a bit when they went to put a needle into me to take some of my blood" (14:2). This strategy was most commonly described two months into treatment. The children realized that despite these strategies, the procedure would have to take place. Later during treatment, children described becoming accustomed to getting needles: "Cause I've got used to it" (15:3), which was related to reduced fear: "Yes, at first I was afraid of all the needles and stuff... but I'm not afraid anymore" (13:3).

Often the strategies were combined: "No, and I close my eyes... They count to three... I want to be prepared before the needle goes into my skin" (14:2). One child, with the help of a psychologist, made a book to use during contacts with his oncology team and other health care contacts, in which he described himself, his interests and needs, and how he wanted to be approached at the hospital. Finally, the children also described using the cognitive strategy of "thinking the right way", exemplified in Table 3. There was no universal right way of thinking; rather, it varied among the children and between interviews for each child. During the first interview, such thinking was more often related to just enduring the procedure; in later interviews, it become more sophisticated and included more strategic components.

Fear of having a feeding tube

Five children expressed fears related to having a feeding tube, two of whom rated this fear as the most prominent. This fear was mentioned at 2 months after diagnosis and after 1 year. Having the feeding tube inserted while awake caused fear, as well as having the tube in place.

Table 2  
Fear of needles reported at each interview.

Time after diagnosis (number of children interviewed)	Most prominent fear <sup>a</sup>	Subsidiary fear <sup>a</sup>	No fear <sup>a</sup>
	n	n	n
2 months (n = 11)	9	2	0
1 year (n = 13)	7	2	4
2.5 years (n = 11)	2	5	4

<sup>a</sup> Every child is represented only once at each interview time. For example, if one child reported fear related to their subcutaneous venous access as the most prominent and fear of finger pricking as less important, that is recorded in the column "most prominent fear," but not in the column "subsidiary fear."

**Table 3**

Quotations illustrative of “thinking the right way” as a strategy to cope with needle-related procedures.

Child #	2 months after diagnosis	1 year after diagnosis	2.5 years after diagnosis
7	“I don't think anything.”	“You have to try, and not look at the needle just before they're going to put it into you, because then you'll think it will hurt.”	“I just think ‘Let's get this over with’ and shut my eyes, and they put it in.”
10	“I don't think about anything. I just think it hurts.”	“I just think ‘I'll get through this now. Yup, I'll get through it just fine.’ And so I do. That's what my Dad told me.”	“Sometimes I shut my eyes for a moment and try to think right... Then I say ‘You guys can do it now. I want you to count to three, then do it.’”
13	“I lie still and think to myself ‘I'm sure not going to do this again’”	“I talk to myself a little bit... inside my head. Things like ‘It's happening now,’ and stuff like that.”	“When they prick my finger, I don't focus on it. Instead I look for something else to focus on.”
15	“They say ‘Think about something else,’... so that's what I do.”	“Thinking about something else...like, I think about candy. I adore candy!”	“I think about how I try to be okay about everything, but sometimes I just can't. Also, I have a lot of patience.”

One parent reported that the child's fear remained even after taking sedatives. Another child said that having a feeding tube was both good and bad: “It's pretty awful but also smart, when you cannot eat. But it can be awful because it can irritate your throat and nose” (21:1). Yet another child feared vomiting the tube out and having it inserted again:

It was when I had the nasogastric tube, I was afraid... I was a bit afraid, because I felt sick all the time. And then I had the tube, and sometimes I threw up and it came out, and I was always afraid of that happening.

[(3:2)]

One child decided to start eating to avoid the feeding tube, and another child started to participate in handling the tube himself. One child described evading other children's questions about the feeding tube, because such questions were hard to cope with.

#### *Fear of removing adhesive tape*

Five children described fear of removing the adhesive tapes that secured the nasogastric tube and the subcutaneous venous access, as well as other adhesive dressings: “And when they take it [the adhesive tape] off, it hurts because there's a lot of it stuck on your skin” (21:1). Another child described being afraid of the adhesive tape being removed too quickly. None of the children talked about this fear in the last interviews. During the treatment period the children had found preferred ways to deal with tape removal. Some preferred to remove it themselves, slowly, and others preferred to use any of the removal agents available for this specific purpose.

#### *Fear of taking tablets*

Fewer than half the children ( $n = 5$ ) described fear of taking tablets, but this was the most prominent fear for one child. The fear of taking tablets was most often mentioned at the second and third interview.

Despite the few children who identified fear of taking medicine as most prominent, 11 of the 13 children mentioned it as a significant problem. The problems mentioned were difficulties swallowing due to the size, shape, and taste. “I was afraid to swallow them in one piece... They were huge. And I was afraid of them getting stuck in my throat” (14:3). An aggregative factor was experiencing nausea even before starting taking the tablets. The children and their parents shared a variety of solutions. Some used a lemon-flavored pill cover. “I use Medcoat®. It makes the tablets easier to swallow; they glide down more easily, and they taste better” (13:2). The children preferred to swallow their tablets whole, as crushed tablets had a bad taste. Some children practiced before taking tablets, for example, by getting used to swallowing small sweets, and then used the same strategy with tablets; others put the tablet far back into their mouth, and some preferred to take the tablets with juice, water, or a fizzy drink. On the last occasion,

the children described getting used to taking tablets and no longer found it a source of fear. “Well, I guess it's because I have got used to it... I've done it [taken the tablets] so many times now” (16:3).

#### *Fear of the physical changes caused by ALL*

ALL affected the children's lives physically, mentally, socially, and existentially. Fears related to their changed lives were summarized under *fear related to physical changes caused by ALL*. Although this fear had an existential facet, it was often described as emanating from awareness of the illness' impact on the body. One child expressed it this way:

... actually, the doctors don't really know what happens when children get ill. They know there is something wrong in the factory [of blood cells], and this makes Mom and Dad sad. I don't want to talk [about it] anymore.

[(10:2)]

Fear related to changes in their bodies increased over the course of illness. ALL had an impact on the children's physical abilities, which in turn had an impact on the child's daily activities. One child described being more prone to falling and having less endurance during physical activities. This made it hard to climb stairs and to play outdoors with other children. “The hardest part is that you can't... you can't really go out and play... and you can fall down so easily” (3:1). The children described not being able to run as fast as their friends did, and that this could frighten them. At the last interview, looking back at his course of illness, one boy said, “I think what scared me the most was thinking I'd never be able to run again” (7:3). One child had been provided a personal fitness trainer and described the importance of being strong and able to run fast: “Cause then I can join in with my friends and keep up with them” (5:3). Another child described being unable to join in with other children because of being unable to run fast enough:

Well, I can't get to them. First, I see them and start to go over, but then a lot of people get in my way, and when I finally get there, they've run away to another place [in the schoolyard].

[(14:3)]

The children who reported these problems also described a fear of being left alone, but at least one did not blame the friends: “Well, it wasn't like they were running away from me. They were being okay” (10:3). The physical consequences of the treatment were mentioned more often in the later interviews.

Children also described what could be interpreted as social insecurity stemming from their being different both from other children and from their normal selves because of their treatment. One child described feeling uneasy about attending school with a nasogastric tube “cause everyone can see it and they all ask about it” (5:2). Similarly, one child described removing a sweater and the other children asking about the central-venous access. Some also had classmates who expressed fear

that the ALL could spread: “But sometimes... sometimes I think they are mean, they say that I might infect them” (16:3).

Alopecia was a side-effect the children described as difficult to deal with. Looking back, one child said at the third interview session, “Well, thinking about the whole time I had treatment, I guess the worst part was losing my hair” (16:3). She had liked to have her hair styled. Another child said, “It made me sad and put me in a bad mood. I told my hair to stay on my head” (21:1). For some children, the loss of hair led to fear of their friends’ reactions, “cause I was afraid they’d laugh at me or look at me funny” (21:1). Some chose to wear a hat to hide their hair loss to prevent other children asking about the baldness. One child described having worn a wig but found that it slipped off too easily.

More than two thirds of the children mentioned an existential fear of dying or of relapse. These issues were brought up most often at the third interview, at the end of treatment. Those who did not want to talk about death either said so or showed their reluctance with their body language when this topic was brought up in the interviews. The children reported being reminded of death when their classmates asked them questions about their risk of dying or risk of relapse.

One child expressed being afraid after watching a television advertisement from the Swedish Childhood Cancer Fund. In the advertisement, there were four chairs, only one of which was empty. Each of the other three chairs had a child sitting in it, meant to illustrate that three out of four children with cancer survive. The affected child, however, fixated on the fourth chair, which was empty. Because he had been born in April (the fourth month of the year), he was afraid he would be the child missing from the fourth chair—that it was a sign he would be the one to die.

Although they were not specifically asked, at the last interview some children brought up their fear of not being cured with termination of treatment. One child revealed that during his illness he had been afraid of never being cured: “I was afraid I’d never get better” (15:3). Another child had no worries about ending treatment or having a relapse, yet this statement implicitly revealed an awareness of the risk of a relapse: “I’m not really afraid about the treatment ending. I can feel in my body that the illness won’t come back” (7:3). However, she asked whether ALL could still be a threat to her. Some children described thinking privately about their fear of dying, some asked a parent about it, and some were just afraid, without specifically asking questions. One child revealed that she had been fearful at her end-of-treatment visit when she heard the doctor talking about the risk of future cardiac complications, but she did not tell the doctor or her parents about this fear.

Another existential fear was that of being left alone. At the second and third interviews, 3 children wanted their mothers nearby, both at home and in hospital. One of these was afraid at the end of treatment because the mother was returning to work after she had spent a considerable time with the child during the treatment: “I want her to stay at home... because then I feel safe” (5:3). Other children described frequently telephoning their mothers, playing in order to forget that she was not there, and persuading themselves that their mother would come soon.

## Discussion

The aim of this study was to describe, from a longitudinal perspective, the ALL-related fears and coping strategies of children aged 5 to 9 years. In a review of the literature on nursing and psychosocial research in Swedish pediatric oncology, Enskär et al. (2014) called for longitudinal studies from the perspective of the child, which the present study was aimed to achieve. Some novel knowledge gained from the longitudinal design with repeated interviews is the variety of these children’s fears, both individually over time and within the group during the course of treatment.

The children in this study reported fears related to needles and to experiences grounded in their bodies. These results are in line with

previous literature (Salmela et al., 2009; Young, 2005). Taddio et al. (2015) also found that uneasiness, pain, and fear are often associated with needle-related procedures, although this a known problem and has had considerable attention in both research and practice. In the present study, however, reports of fear of needles decreased over the treatment period. There are some possible explanations for this. The children themselves often said that they had become accustomed to getting needles, but they may also have learned to accept them as they realized that these procedures were necessary for them to regain health. Two other possible explanations are that the children found and used strategies to deal with their fears and that the treatment itself becomes less intense, with fewer needle-related procedures, during the last phase. Two recent 1-year longitudinal studies also identified that treatment-related anxiety and pain (Dupuis et al., 2016) and worrying (Myers et al., 2014) decreased over the first year after receiving a diagnosis of ALL. In a recent Chinese study on coping with acute leukemia, children aged 7 to 12 years reported that having information decreased their fears of the disease and of the treatment regimen (Han, Liu, & Xiao, 2017), so it is also important to keep children informed.

The findings indicate that the children in this study used well-known coping strategies to deal with their fears (c.f. Salmela et al., 2010), but few previous studies have followed the use of those strategies over the entire treatment period. Most of the children wanted to participate in deciding how, where, and when they would undergo treatment. The importance of having control over the situation has been previously described (e.g., Salmela et al., 2010; Söderback, Coyne, & Harder, 2011). Han et al. (2017) linked the coping styles they identified in their study to dependence on oneself (as focused on in this study), dependence on professionals, and dependence on parents or caregivers. In the present study, we did not include aspects of dependence on professionals and parents, as we regard these as aspects of support rather than coping. However, coping independently and accepting support from parents and professionals seem to overlap. For example, it is reasonable to believe that a professional or parent might suggest that the child count to or backward from 3 before an injection, which can be regarded as support, and when the child tries this strategy and has success, it may be incorporated into the child’s own repertoire of coping strategies.

The children also described using functional coping strategies. These strategies were more prominent at the beginning of the treatment period. Later, the children reported getting used to undergoing necessary treatments and realizing that there was no point in protesting. This could be because the children had become more mature and realized that they needed to undergo treatment to regain health, as evidenced by the development of the children’s ways of thinking over time. Initially, they focused more on the procedure that they feared, but at the end of treatment they had developed more strategic thinking. This is supported by Olsen and Weinberg (2017), who suggest cognitive approaches to control pediatric pain.

After the most prominent fear of needles, fear of taking tablets was most often reported. Only 5 of the 13 children explicitly reported fear of taking tablets, but the everyday problem of taking tablets was mentioned as major issue in many interviews and is thus worth reporting. The children, by trial and error, and with support and advice from nurses and parents, developed strategies to cope with this fear-inducing problem. Unwillingness to take medicines has been described before. Enskär et al. (2014), for example, identified distress related to taking tablets in literature review of Swedish psychosocial pediatric oncology research, and a Finnish study reported taking medicine as one of preschool children’s fears related to day surgery (Flinkman & Salanterä, 2004). This is a problem that needs future research in the pediatric oncology population because these children have to take tablets over an extended period to recover. Recent literature shows that mini-tablets could be an alternative administration modality for young children, even for children younger than those in this study. The acceptability and capability of 2 mm solid tablets were shown in a randomized

controlled trial to be superior to syrup in children aged 6 months to 5 years (Klingmann et al., 2013). In another study, van Riet-Nales et al. (2015) found that even infants managed to swallow 4 mm mini-tablets. These results are promising, and future research should include the development of novel dosage forms for the child oncology population. Preferably, such research should be inter-professional.

The removal of adhesive tapes and having a nasogastric tube also invoked fear in the children. These fears, however, were reported less often than those of needles and swallowing tablets. It is unknown why these fears were reported less often, but it could be related to the limited number of children in need of a nasogastric tube. Although many children still had their subcutaneous access affixed and were in need of regular dressing changes, no child mentioned removing adhesive dressings as their worst fear, and it was mentioned only during the first interview. The fear of removing adhesive tapes has previously been described from a parental perspective (Anderzén-Carlsson, Kihlgren, Svantesson, & Sorlie, 2010) and different agents are available on the market that can ease the pain of removal.

The results show that being diagnosed with ALL has an impact on the child's general well-being, which is supported by findings from previous studies (Anderzén-Carlsson et al., 2008; Enskär et al., 2014). However, the repeated interviews showed that fears transform over the treatment period, from more medical fears at the beginning toward more social and existential fears later in treatment. Darcy et al. (2016) also found that psychosocial aspects of cancer became more prominent during the later phases. These issues could be more difficult for health care professionals to ease, but the finding may indicate the need for professional support from the oncology multi-disciplinary team. This seems important, as previous research has identified depression, anxiety, negative self-image, and low quality of life in the late complete remission period of ALL (Baytan, Asut, Cirpan Kantarcioglu, Sezgin Evim, & Gunes, 2016). In the group of children under study here, only one child mentioned having met with a psychologist to deal with his existential fears.

The results reveal that young children are aware of the seriousness of having ALL, despite the relatively high survival rate. Existential fears related to death and dying were not on the interview guide, but they were brought up spontaneously by the children (and one of the parents). The current results reveal that some children had talked to their parents about their fears of death or dying, but some said they had not shared their feelings. We do not know the reason for this choice.

In terms of Eriksson's theory of suffering (Eriksson, 1994), this study shows that fears related to ALL could be interpreted as suffering. More specifically this study identified: *suffering related to care*, *suffering related to the disease*, and *suffering related to life*. Thus, it is important that all professionals are aware of and take measures to decrease each individual child's suffering. It is also important that future research focus on all these aspects in order to make the illness trajectory easier for children with ALL.

#### Strengths and limitations

One major strength of this study is its longitudinal design. The children got to know the researcher who interviewed them, and this relationship could have yielded richer data than a single-interview design. The longitudinal design also allowed us to identify some patterns in the children's fear and coping strategies during the illness trajectory, and it allowed the children to talk about their most recent memories and to reflect over the entire treatment period. The main limitation was the difficulty the children had in identifying one prominent fear. However, this gave the researchers valuable information about the complexity of the children's fears and expanded the scope of the study to explore all the aspects the children brought up.

#### Practice implications

The results contribute to our knowledge about the illness trajectory for young children suffering from ALL. It is important for professionals to be aware that fears related to ALL can change over time. Therefore, they should acquaint themselves with each individual child's fears and preferred strategies for dealing with their fears. It has previously been suggested that children undergoing needle-related procedures should be individually approached and invited to suggest what sort of support they would prefer (Karlsson et al., 2014).

#### Conclusion

The children described various fears throughout the treatment period. The fear of needles was less prominent at the end of treatment, yet >50% had some residual fear of needles at the end of treatment. Reports of social and existential fears increased during the treatment period. The results indicate that it is time to undertake more interdisciplinary research on relieving these children's fears and problems related to motor ability, which led in this study to problems keeping up with friends. Research is also needed in the very different areas of making medications more palatable and easier to swallow and addressing children's concerns about death.

The children's coping strategies included cognitive, emotional, and functional strategies. Over the 2.5-year period, these strategies changed. The most frequently mentioned strategies were those related to medical fears. This might indicate that professionals and parents are more aware of these fears and were thus able to provide more support in this area. Further research is needed focusing on psychosocial and interprofessional interventions. It is also important to study the children's preferences about support from their parents and the professionals, as such support is tightly connected to coping.

Children with ALL have several fears that change over time and add to their suffering. Although some fears diminish, and children's coping strategies tend to become more sophisticated, other more existential fears can increase. It is important that each child be listened to, their fears be taken seriously, and their coping strategies be encouraged.

#### CRedit authorship contribution statement

**Ingela Leibring:** Formal analysis, Writing - original draft, Writing - review & editing, Visualization. **Agneta Anderzén-Carlsson:** Conceptualization, Methodology, Formal analysis, Investigation, Writing - original draft, Writing - review & editing, Visualization, Supervision, Project administration.

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