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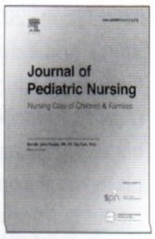

Young children's perspectives on treatment and care: A qualitative study using narrative and play-based interviewing

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ABSTRACT

Purpose: To explore young children's (age 3–6 years) own experiences and perceptions of treatment and care when living with a chronic illness.

Design and methods: The study employed a qualitative research design using a narrative and play-based interview approach. Individual face-to-face, narrative and play-based interviews were conducted with eight young children age 3–6 years with type 1 diabetes or cystic fibrosis. The play sessions took place at the home of the children and were video recorded. Interpretative phenomenological analysis was used to analyse the data and frame the study.

Results: Our analysis identified six main themes: 1. Children understood illness through their bodily experience of treatment and care, 2. Children's experience of care and treatment ranged from a feeling of powerlessness to a sense of agency, 3. Children depended on their parents to provide comfort, advocacy and protection, 4. Children's perceptions of treatment and care were inherently related to their experiences of familiarity, interpersonal relationships and trust, 5. Children with type 1 diabetes did not perceive that they played an active role during consultations, and 6. Children associated medical treatment with receiving tangible rewards or positive feedback.

Conclusion: Children expressed a need to feel safe and build agency. They experienced this through participation and interpersonal relationships with healthcare professionals.

Practice implications: We should prioritize the establishment and implementation of age-appropriate psychosocial care practices that support young children in participating, forming relationships, and building trust.

Introduction

The present study explores young children's (age 3–6 years) subjective experiences of treatment and care of one of two chronic illnesses, cystic fibrosis or type 1 diabetes. Understanding the experiences and psychosocial care needs of children who are born with or develop a chronic illness in their first years of life is vital. Early encounters with treatment and the health system may affect how they view and cope with their condition and shape the relationship with their healthcare providers (DeCosta et al., 2021a, 2021b; Hall et al., 2001). Children with cystic fibrosis are born with the condition, while an increasing number of children under 5 years of age are diagnosed with type 1 diabetes (Patterson et al., 2009).

Europe has the highest number of children and adolescents with type 1 diabetes, with an estimated total of 295,000 cases (Diabetes in Europe, 2021). The specific number of children under the age of 7 years with type 1 diabetes is not readily available. However, the observed increase in incidence rates among children is highest in the youngest age groups, suggesting a shift towards earlier onset of type 1 diabetes (Patterson et al., 2009; Patterson et al., 2019). Likewise, the precise number of children under 7 in Europe with cystic fibrosis is not readily available. In Denmark, <200 children and adolescents live with the condition (Burgel et al., 2015).

Treatment of type 1 diabetes consists of intensive insulin therapy, delivered through either multiple daily subcutaneous injections or continuous insulin infusion, via an insulin pump (American Diabetes

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Association, 2021). Treatment also includes monitoring carbohydrate intake and daily self-monitoring of blood glucose concentration up to 6–10 times a day, via a glucose metre or continuous glucose monitoring (American Diabetes Association, 2021). Insulin catheters are changed at home approximately every third day and the glucose sensor, usually placed on the upper arm, is changed every 14 days. In Denmark, children attend quarterly diabetes consultations (SDCC, 2023).

Treatment for cystic fibrosis involves dietary and enzyme supplements, inhaled and nebulized medications and chest physiotherapy (Jamieson et al., 2014). In Denmark, young children attend monthly visits to a specialized cystic fibrosis centre. The treatment aims to prevent and treat lower respiratory tract infections by targeting bacteria found in respiratory secretions. Secretion samples are obtained through laryngeal suction (Skov & Pressler, 2022).

Background

In the area of chronic illnesses in childhood, young children's (≤7 years) perspectives on treatment and care are often missing from the literature (DeCosta, Grabowski, & Skinner, 2020). A few studies have examined young children's perspectives on care and living with chronic illness, such as cancer: However, many have included older children (Alderson et al., 2006; Gibson et al., 2010) or combined young children's and their parents' perspectives (Darcy et al., 2019; Enskär et al., 2020). This makes it difficult to determine to what extent the findings are driven by young children's experiences and perceptions, or rather by those of older children or their parents. Other studies has explored young children's experiences of needle-related medical procedures (Karlsson, Englund, et al., 2016; Karlsson, Rydström, et al., 2016), hospital-related fears (Salmela et al., 2009; Salmela et al., 2011), experiences of being admitted to the hospital (Aldiss et al., 2009) and perceptions of being in a health-care situation (Stålberg et al., 2016). While findings from these studies are highly relevant, we are interested to further explore young children's experiences in the context of chronic illness. Children with chronic illnesses, such as diabetes, have considerable experience with the healthcare system and express high levels of knowledge and understanding associated with management and treatment (Alderson et al., 2006). Gaining insights into young children's perspectives on treatment and care necessitates an understanding of their developmental stage and the individual variations within and across age groups. Generally, during the preschool years, young children begin using language to articulate thoughts, emotions, and experiences. They acquire the capacity to mentally engage with people and events beyond immediate perception, enabling contemplation of both past and future occurrences. This period entails substantial cognitive, social, and emotional growth ((APA), 2023). While 6-year-olds typically demonstrate significant advancements in cognitive, social, and emotional abilities compared to 3-year-olds, each child is unique and may progress at different paces ((APA), 2023). Therefore, it is helpful to view development through the lens of providing the appropriate level of support and challenge for each individual child. Thus, when adults seek young children's participation, they need to consider not only the child's developmental age but also their specific abilities and potential for growth and learning (Vygotsky, 1978).

The knowledge gap concerning what constitutes good psychosocial or child-centred care for young children with type 1 diabetes, has previously been addressed through qualitative interviews with healthcare professionals: Findings indicate that, for young children, child-centred care involves play-based approaches (DeCosta et al., 2022) and interaction fostering interpersonal trust (DeCosta et al., 2021a, 2021b). Accordingly, in the present study we will explore vital questions of meaning, perception and understanding from the young children's own perspective. As young children's perspective on treatment and care is relevant across illnesses, and in order to explore differences and similarities to other chronic conditions, we included young children with cystic fibrosis and type 1 diabetes in the present study. Both chronic illnesses involve a high degree of daily self-management in the form of medication, diet, and technology, and they both require regular contact with the clinic (Bell et al., 2020; Kubiak et al., 2020). Further, increased life expectancy and rapid advances in technology have increased the complexity of treatment and care, leading to a substantial burden of self-management and illness monitoring in both conditions (Bell et al., 2020; Kubiak et al., 2020).

Hence, the objective of the present study is to explore young children's own experiences and perceptions of treatment and care when living with a chronic illness, using a child-centred, narrative and play-based interview approach.

Design and methods

The study is a qualitative interview study using a child-centred, narrative and play-based method for interviewing young children. Theoretically the method it is anchored in a narrative story stem approach (Kelly & Bailey, 2020), the theory of zone of proximal development (ZPD) (Vygotsky, 1978) and the related concept of scaffolding (Wood et al., 1976). The method combines visual tools, medical play and story stems, which offer young children more than one way of expressing their perceptions and views and allow the researcher to observe the children's experiences from different positions. Further, to explore children's inside perspective, the method is designed based on key constructs of child-centredness (Coyne et al., 2016). A detailed description of the narrative and play-based framework used to explore young children's perspectives can be found here (DeCosta, Skinner, Sørensen, Topperzer, & Grabowski, 2023). Standards for reporting qualitative research (SRQR) (O'Brien et al., 2014) has been followed.

Theoretical framework

The interview process was guided by Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2012). IPA entails creating a positive and responsive interaction, where the respondents feel at ease (Smith & Osborn, 2012). Accordingly, to help the children feel safe, and to communicate to them that they had something valuable to contribute, the researcher used techniques inspired by Parent-Child Interaction Therapy (Thomas & Zimmer-Gembeck, 2007). These techniques involve child-centred play, where the researcher follows and mirrors the play of the child, noting aloud what the child is doing, as well as offering specific praise for the child's efforts.

Interview questions were operationalized into medical play and story-based scenarios grounded in a narrative story stem method (Kelly & Bailey, 2020; Von Klitzing et al., 2003). The topics covered and operationalized in the play-based interview guide were based on current literature and previous research concerning young children's needs and experiences of living with a chronic illness, that is, their experiences of relationship, trust, everyday life, care and treatment (DeCosta et al., 2020; DeCosta et al., 2021a, 2021b).

The first part of the interview centred on medical play. The interviewer brought a teddy bear for the play, and children were invited to bring their own teddy. In this way, the interviewer's teddy bear could interact with and pose questions to the child and the child's teddy bear. The child's teddy bear could also answer questions on behalf of the child. The second part of the interview centred on narrative story stems, using toys and figures, which the children were asked to complete. The child could freely decide whether to choose a fictitious name for their play figure or use their own name. The play interview was semi-structured. In accordance with IPA, the interviewer's role was to facilitate and guide (Smith & Osborn, 2012), while children had the freedom to direct the interview and the play in a direction that was meaningful to them.

In addition to a narrative and play-based approach, the toolbox consisted of visual tools such as pictures of emotions, clinicians and family members (DeCosta et al., 2023).

Study setting and recruitment

Participants

Eight young children age 3–6 years, with type 1 diabetes ($n = 4$) and cystic fibrosis ($n = 4$). Two boys and 6 girls. One child age 3 years, 1 child age 4 years, 3 children age 5 years and 3 children age 6 years.

Recruitment

Children were recruited (via their caregivers) by healthcare professionals (HCPs) at three separate clinics in Denmark, covering the Capital Region and the Sealand Region. Nine families gave permission to be contacted by the researcher, who provided further information on the study. Eight children were included in the study. One child was excluded based on geographical location. In order to conduct an in-depth analysis using IPA, a small sample size of 8 children were decided on. See Table 1 for an overview of participant characteristics.

Data collection

Data collection took place between May 2021 and August 2021. Individual play-based interviews were conducted with eight young children (3–6 years) with a chronic illness. All interviews took place at the home of the children and sessions lasted between 35 and 70 min (average 50 min). Please refer to Table 2 for a translated version of the narrative and play-based semistructured interview guide. The children's parents were either present in the room quietly observing the interview or close by in an adjoining room. No questions were specifically addressed to the parents. Nonetheless, in a few rare occasions, parents engaged by attempting to prompt their child's recollection or respond to a question on behalf of their child. The main researcher (PD) conducted the interviews. The play sessions were video recorded, allowing non-verbal communication (body language, facial expression and interaction with the toys/tools) to be observed and analysed later. The data were transcribed by PD and a student assistant. This included both verbal and non-verbal communication.

Observation and pilot interviews

The main researcher (PD) passively observed several paediatric diabetes consultations at a clinic in Denmark. These observations provided knowledge and a contextual background for the interviews. Further, to adjust and refine the narrative and play-based interview guide and overall approach to the interview, two pilot interviews with young children (3 and 4 years respectively) without a chronic illness were conducted prior to data collection.

Data analysis

IPA was used to explore children's experiences of living with a chronic illness, and it framed the study from research aim to write up (Smith & Osborn, 2012). IPA is a phenomenological approach that entails detailed examination of the participant's lifeworld and personal experience, which, in the present study, constitute the child's personal perceptions or accounts of treatment and care (Smith & Osborn, 2012). In accordance with Smith and Osborn (2012), the aim of the analysis

Table 1
Overview of participant characteristics.

Child	Age (years)	Condition
Anton	4	Type 1 diabetes
Rosa	5	Type 1 diabetes
Nora	5	Type 1 diabetes
Aya	5	Type 1 diabetes
Viggo	3	Cystic fibrosis
Marie	6	Cystic fibrosis
Emily	6	Cystic fibrosis
Laura	6	Cystic fibrosis

Table 2
Semistructured, narrative and play-based interview guide (translated from Danish).

Theme	Question	Materials/toys
Relationships Family members and relationships with HCPs	Can you show me who's in your family, by placing the people in your house? Can you show me the people you meet when you go to the hospital? Can you use these smileys to tell me what you think they look like?	Picture of a house and a hospital. Cut-outs of 'cartoon' family members and staff members (HCPs). Smileys to place on the HCPs.
Child led (medical) play	Questions based on the child's lead or play	Teddy bear, the child's own stuffed toy, medical play set and dress up white coat
Knowledge / fear and coping Child's interpretation/ understanding Perception of fear and safety	Teddy has been told that he/she has diabetes (cystic fibrosis), but Teddy doesn't know what that is. Can we tell Teddy what it means to have diabetes (cystic fibrosis)? [In response to play where the child is performing a medical procedure on the teddy bear]: My Teddy doesn't like that (getting an injection, for example), [How does the child respond?] What helps Teddy if he/she is scared?	Teddy bear, the child's own stuffed toy, medical play set and dress-up doctor's coat.
Support	Who helps Teddy with her/his diabetes (cystic fibrosis)? What helps the teddy bear if he/she is sad or tired of having diabetes (cystic fibrosis)?	Teddy bear, the child's own stuffed toy, medical play set and dress-up doctor's coat.
Experience of the hospital (clinic)	Can you help build the hospital clinic? [Be curious about the things the child includes in the clinic and the reasoning behind]. A boy/girl comes to the clinic for his/her regular appointment. The family enters the consultation room. There is a doctor and a nurse sitting at the table. Can you show or tell me what happens next? Follow-up questions: What does the child do, while the parents do X? What does the parents do while the child does X?	Characters (Duplo); child, siblings, mother, father (same family constellation as the child's), nurse and doctor. Clinic room (Playmobil), desk, computer, toys and medical equipment.
(Cystic fibrosis) **Experience of treatment** Laryngeal suction And test of lung function	Then the doctor [name of HCP] says; it's time to "suck your nose", can you show or tell me what's happening next?" Then the doctor [name of HCP] says; it's time to "go in the box" (to test of lung function), can you show or tell me what is happening next?	Characters (Duplo); child, siblings, mother, father (same family constellation as the child's), nurse and doctor. Clinic room (Playmobil), desk, computer, toys and medical equipment.
(Diabetes) **Experience of (home) treatment** Change of infusion set to the insulin pump	The family is watching television. When the program ends, the mother says; now it is time to change the infusion set to the insulin pump (use the same word as the child	Characters (Duplo); child, siblings, mother, father (same family constellation as the child's). Sofa, television.

(*continued on next page*)

Table 2 (*continued*)

Theme	Question	Materials/toys
	use), can you show or tell me what happens next?	
(Cystic fibrosis) **Experience of (home) treatment** Interrupted play. (PEP mask)	[Name of child] is playing in the garden when his/her mother interrupts and say, it's time for you to put on your PEP (positive expiratory pressure) mask. The child will rather continue playing with his friend. Can you show or tell me what's happens next?	Characters (Duplo); child, friend, mother/father (same family constellation as the child's), play items.
(Diabetes) **Experience of (home) treatment** Interrupted play. High/low blood glucose	[Name of child] is playing outside in the garden when his/her father interrupts to scan the child's sensor. The child's blood glucose is low and the father wants the child to come inside to get something to eat or drink. [Name of child] would rather stay to play. Can you show or tell me what happens next?	Characters (Duplo); child, friend, mother/father (same family constellation as the child's), play items.
Kindergarten and friends Being different/ having different needs	It's lunchtime in kindergarten, it's someone's birthday and they brought a cake. Can you show or tell me what happens next?	Characters (Duplo); child, 4 friends, Childcare staff, table, chairs, food, cake.
Spontaneous story stems Cues from the child	Questions based on input from the child or parent, converted into story stems or medical play.	Relevant toys from the toolkit.

was to gain insight into the psychological and social world of young children, through the active process of interpretation of meanings. Meaning is central to IPA. With young children, the creation of meaning is observed through their bodily expressions and actions as well as their verbal accounts (Sommer et al., 2009).

IPA was chosen as a suitable method, in line with our objective to include children's insider perspective on their experiences, perceptions, and understanding of their world, i.e., exploring the child's own phenomenology (Smith & Osborn, 2012; Sommer et al., 2009). Additionally, IPA is particularly useful when exploring a novel or complex phenomenon (Smith & Osborn, 2012).

In accordance with Smith and Osborn (2012), our analysis followed three steps of analysis and interpretation: *Looking for themes in the first case, connecting the themes,* and *continuing analysis with other cases.* Our analysis involved engaging with both the transcripts and the video recordings repeatedly throughout the analysis. Concretely, we went through the first two steps (*looking for themes in the first case* and *connecting the themes*) with each child individually, creating an initial list of themes through analysis and interpretation. In this way, case descriptions of all individual interviews were written before the step of *continuing analysis with other cases* began. In this final step of the analysis, we searched for common themes across the children's accounts, looking for similarities and differences within and across themes.

All authors took part in the discussion throughout the analysis, and consensus regarding final themes was reached jointly.

Ethical considerations

The study was approved by The Institutional Ethical Review Board, University of Copenhagen, Department of Psychology (Approval no.: IP-IRB / 020221) and by the Data Protection Agency, Capital Region of Denmark (Journal no.: P-2021-338).

Children's names have been anonymised; pseudonyms are used in the article. Data was stored in a secure, restricted access file at The Capital Region of Denmark.

Informed consent

Written consent was obtained from the child's parents prior to the interview. Parents received verbal and written information on their right to withdraw from the study. Verbal consent was gained from the children at the beginning of the interview. Additionally, children were given a red stop card with a picture of a child holding up their hand in a 'stop gesture'. They were told that if they, at any time, did not wish to answer a question or continue a play activity, they could show this card. Further, the protocol included clear directions on how to react to and respect specific nonverbal cues of resistance.

Rigor and reflexivity

The underlying assumption in this study, is that active participation can be encouraged from a young age and that children benefit from being sensitively included in matters that directly concern them. We believe that while we may never fully understand the child's perspective, we can get closer. We have strived to keep such underlying assumptions in the background throughout the study. To minimize bias, our interview guide was constructed based on previous research on the psychosocial care needs of young children with a chronic illness (DeCosta et al., 2020; DeCosta et al., 2021a, 2021b; DeCosta et al., 2022). Additionally, the questions in the interview guide were operationalized based on widely accepted theoretical frameworks (DeCosta et al., 2023). Finally, the process of joint discussion and analysis of the data between the authors acted as a continuous protection against biased interpretation of the data.

Findings

A narrative and play-based approach to interviewing young children proved valuable in eliciting the participating young children's insider perspectives on living with a chronic illness and generated rich verbal and non-verbal data. We found that it provided children with an important scaffolding and framework. This allowed the children to not only participate, but also to direct and thus actively co-create data together with the researcher. Importantly, the children seemed to enjoy taking part in the research and only ever used the stop card when they needed to use the toilet or drink water.

The children were attentive, and most were eager to share their knowledge and experiences of living with a chronic illness. The children confidently and competently engaged in the interview process, often taking the lead, and diverting the play towards topics and scenarios centred on what they found meaningful. Some children were verbally highly competent and used the story stems primarily to remember and anchor their experiences, while others expressed their perceptions mainly through play and actions. Some children used the teddy bear's voice to answer questions for them, creating a playful and indirect way of communicating.

Based on the analysis and interpretations of children's intentional acts and statements, we identified five main themes in our analysis. See

Table 3
Overview over the main themes.

	Theme
1	Children's experience of care and treatment ranged from a feeling of powerlessness to a sense of agency
2	Children depended on their parents to provide comfort, advocacy and protection
3	Children's perceptions of treatment and care were inherently related to their experiences of familiarity, interpersonal relationship and trust
4	Children with type 1 diabetes did not perceive that they played an active role during consultations
5	Children associated medical treatment with receiving tangible rewards or positive feedback

Table 3 for an overview over the main themes.

Theme 1. Children's experience of care and treatment ranged from a feeling of powerlessness to a sense of agency

Children's experiences and perceptions of living with a chronic illness were closely related to the daily management tasks and bodily experience of treatment. In this way, the children understood their condition mainly through the tangible experiences of treatment and the effect on their everyday lives.

> Emily: Cystic fibrosis is sometimes about having to breathe and suck. I breathe while watching television and once I watched YouTube and there I breathed so much (Emily demonstrates how she breathes).
> […]
> Emily: Yes, sometimes I have to get my nose sucked, like that [Emily puts her index finger up her nose] and you can see it coming down the palate [Emily points to her throat]. […] you just have to use a mask where there is this air, and then when you breathe it makes a sound like [blowing sounds]. And then you get spaghetti legs, it is called.
> (Emily, age 6 years, cystic fibrosis)

Accordingly, because the children's experience of their illness was linked to their experience of treatment and care, their perceptions of these were meaningful and, thus, central to their experience of living with a chronic illness. Throughout the analysis, the connection between children's bodily experience of treatment, their feeling of agency and overall successful integration of the illness was evident.

An experience, shared by some of the children, was the perception of medical procedures as non-negotiable, as occurring without the children having any influence on the experienced outcome. This was particularly evident for Anton (age 4) and Rosa (age 5), who had recently been diagnosed with type 1 diabetes, but also for Laura (age 6) who had an experience of being restrained during medical procedures. During medical play, when the child was about to perform a procedure on the teddy bear, the interviewer moved the teddy bear away from the child pretending that it was scared. Rosa, Anton and Laura all proceeded to give the teddy bear an injection, despite the teddy bear's apparent fear and protest.

> Rosa is about to inject the teddy. The interviewer moves the teddy away as if it is scared and says; "I don't like the needle". Rosa grabs the teddy by the neck, moves her face down towards and very close to the teddy bear and says sternly:
> Rosa: You have to, Lea! [Rosa pricks her teddy Lea in the arm].
> Afterwards Rosa strokes Lea, bandages her arm and gives her a hug.
> (Rosa, age 5 years, diabetes)

Anton's medical play, in particular, continuously revolved around giving the teddy bear injections. During the narrative play, Anton asked to return to the medical play. Once more, Anton gave the teddy bear injections despite constant protests. At the end of the interview, the teddy bear had received >30 injections with the syringe. Though it might be easier for Anton to play out this experience, at one point he also managed to express it verbally. While Anton was quietly focused on opening another plaster for the teddy bear, the interviewer asked him whether there was anything good about going to the clinic?

> Anton: That you get pricked.
> Int: Does the teddy bear like it?
> Anton: Mmh.
> Int: Do you like it too?
> Anton: No (shakes his head). The teddy bear does not either.
> (Anton, age 4 years, diabetes)

Though Anton found it amusing when the interviewer pretended that Teddy was protesting, scared or attempting to run away, Anton recognized that the teddy did not like the injections, and neither did Anton. Anton expressed a feeling of powerlessness and a bodily experience of being harmed. Anton had yet to assimilate and integrate this newly experienced reality or develop a sense of agency in relation to diabetes care.

However, for now, Anton could rely on his parents to lessen his experience of distress associated with diabetes management tasks. In the narrative story stem where Anton's character needed to have his insulin catheter changed, he explained how this must occur at night.

> Anton: Only when I sleep, then I can't feel it, then it's best.
> (Anton, age 4 years, diabetes)

In contrast, for other children, treatment and management tasks had become an integrated part of their lives. During the interview, this was evident when children talked about their family, friends, pets and the games they liked to play. They also seamlessly switched between play and conversations about care and treatment as well as their everyday lives.

Some children displayed a perception of competency and agency in relation to home management or hospital treatment. Marie (age 6) did not like procedures involving blood tests and injections. She described the feeling she gets in connection with such procedures as "dangerous". However, Marie demonstrated a belief that her intentional actions enabled her to positively deal with her needle anxiety and minimize the length of time in which she had to endure feelings of anxiousness.

> Marie: Yes. No, sometimes I have, I try to, if I sit with mum or dad, and you know what, then I can sit completely still and I don't even whine, I don't say anything.
> Int: But you notice that it feels a little dangerous inside?
> Rosa: Yes. But inside my head I say: quiet game! [Rosa stiffens and sits completely still] […] because when you cry it lasts longer and stuff like that.
> (Marie, age 6 years, cystic fibrosis)

Similarly, Viggo (age 3) revealed an experience of becoming more competent in his ability to handle medical procedures involving needles. Syringes and injections were a recurrent theme throughout Viggo's medical play.

> Viggo: [Viggo has his own medical bag containing a few syringes. He proceeds to unwrap them] I will just unwrap all the syringes, so we can see what all the syringes do.
> Int: Have you tried to get an injection, Viggo?
> Viggo: Yes.
> Int: Yes. What do you do when you have to have an injection?
> Viggo: Then it is, that it's good that I don't cry.
> Int: Who helps you?
> Viggo: Mum and dad. I bring Little Monkey because she can show me how to do it, but I don't want her to come anymore, because I don't cry anymore.
> (Viggo, age 3 years, cystic fibrosis)

In this way, Viggo described a sense of agency by actively and independently choosing to let go of his teddy bear, as his confidence in his own coping abilities had increased. Crying may represent distress for Viggo, or perhaps he has internalized this understanding though his previous experiences. Either way, the ability to face treatment without crying is important to him, something that he is proud to have achieved.

Theme 2. Children depended on their parents to provide comfort, advocacy and protection

Children relied on their parents to provide comfort, advocacy and protection during clinic visits and while undergoing medical treatment. Holding hands, sitting on a parent's lap, or just being in close proximity to their parents reassured children of their safety. During the medical play, the interviewer asked Nora (age 5) what would happen if the teddy bear did not want to have an injection. Nora instinctively grabs her mermaid doll and puts it next to the teddy bear.

> Nora: Eh, the mermaid!
> Int: The mermaid. What does the mermaid do?
> Nora: Sit next to [Teddy].
> Int: What does the mermaid say to Teddy?
> Nora: That nothing will happen.
> Int: Is this the best thing, if the teddy bear is scared?
> Nora: No, it is actually not the best thing. It's holding hands.
> Int: The best thing is to hold hands. […] Who's hand would Teddy prefer to hold?
> Nora: The mother's.
> (Nora, age 5 years, diabetes)

Notably, Nora illustrated both her experience of being reassured by the words, i.e., "nothing is going to happen" and more importantly, what she found most helpful in the situation; close physical contact with a parent. It seemed as though the children's perception of safety was understood mainly thorough non-verbal communication and cues. Likewise, Viggo (age 3) intrinsically understood that his parents' presence would ensure his wellbeing during hospital visits. Their role was to keep Viggo safe.

> Int: What are the mother and father doing when Viggo [the Duplo figure] is on the hospital bed?
> Viggo: They make sure that I am ok.
> (Viggo, age 3 years, cystic fibrosis)

In contrast, Laura (age 6) had an experience of being disconnected from her mother during medical treatment, despite her mother's physical presence. At one point, Laura's character, Tobias, asked his mother where she had been, during a medical procedure in which he had been sedated.

> Laura: [Tobias asking the mother]"But where were you?"
> (Laura, age 6 years, cystic fibrosis)

Laura's experienced detachment from her mother during treatment may be closely related to Laura's experience of fear and being restrained during medical procedures. At the end of the hospital appointment, Laura's character (Tobias) seemed to let go of the fear, which had otherwise dominated the experience, and simultaneously to reconnect with the mother.

> Laura: Then he is getting this toy [the mother gives Tobias a toy ship]. "Look darling what we brought" [Voice of the mother]. "Wow, how cool is that! Thank you very much" [Voice of Tobias].
> (Laura, age 6 years, cystic fibrosis)

Theme 3. Children's perceptions of treatment and care were inherently related to their experiences of familiarity, interpersonal relationship and trust

Most children demonstrated perceiving a positive, friendly relationship with their main HCP, describing their primary HCP(s) as "happy" or "nice" when the interviewer asked them to choose a 'smiley face' to represent the HCP(s) whom they usually saw at the hospital. Some children instantly referred to HCPs by their first names; others relied on their parents to remember their names. Emily (age 6) related a distinct experience of being warmly greeted by the HCPs when attending her clinic appointments.

> Emily: I would say that sometimes she is happy [pointing to a happy smiley] and sometimes she is, so when we say hello to each other, then she looks like that [pointing to a very happy smiley].
> (Emily, age 6 years, cystic fibrosis)

Emily's perception of HCPs as caring and friendly was reflected in her overall experience of being actively included during treatment and her feeling of agency in connection with treatment and management tasks. Noticeably, Emily demonstrated perceiving trust, in that the HCPs treating her were responsive to her emotional needs. When the interviewer moved the teddy bear away from Emily, pretending it was scared, Emily reacted empathetically and explicitly asked for Teddy's consent to proceed with the procedure.

> Emily: I think we should use the tweezers.
> Int: [moves Teddy away from Emily] Oh no, I am afraid of that [in Teddy's voice]. What do we do then, Emily?
> Emily: [Emily gently stroke Teddy's head] I can, so you want [Emily is looking for something, but does not find anything]. So first, we can examine you, but then you also must [go through the procedure]. You can get this cream on [Emily gently applies cream to Teddy's ear]. Are you ready for it now [Emily asks the teddy bear]?
> (Emily, age 6 years, cystic fibrosis)

In this instance, Emily played out her expectation that the HCPs would respond empathetically to objections and displays of fear and give due consideration to the needs of the child in their care. Additionally, Emily had an experience of being included in information about medical treatment in a way that she was able to relate to.

> Int: Has Pooch [Emily's teddy bear] been in the hospital before?
> Emily: Yeah, and then it got a patch on because I was scared, but now we cannot get it off.
> Int: Well, was Pooch pricked first?
> Emily: Yes. Because then I could see that it was not very horrible. And because Pooch was a teddy bear, so he didn't cry. And then you put cream on him.
> (Emily, age 6 years, cystic fibrosis)

While Emily understood that her teddy bear could not cry, she seemed to grasp what the HCP intended when illustrating the procedure. The intention behind illustrating and explaining the procedure beforehand was to reassure her that she would not be harmed.

At the time of the interview, Rosa (age 5) had recently been diagnosed with type 1 diabetes. Despite the new diagnosis, a prevailing theme in Rosa's interview was a warm relationship with her HCP, Karen. The relationship with Karen seemed to anchor Rosa's experience of the clinic in a positive way. When asked about what happens when she goes to see Karen at the clinic, Rosa's first answer was:

> Rosa: Then Karen gives me a hug.
> (Rosa, 5 years, diabetes).

This contrasted with Anton's experience of the diagnosis, which was mostly characterized by the sudden disruption and distress of treatment, while there was no indication of Anton experiencing a meaningful relation with any HCP. In this way, a trusting relationship between the young children and HCPs was not something taken for granted. Instead, such a relationship was intentionally built over time.

Familiarity and interpersonal skills influenced Marie's (age 6) preference for and ability to trust the HCP treating her.

> Marie: I think… Um. I think Tina is best at doing it on me because I'm just not that happy when Jens does it, because he doesn't do it so often, so I get scared when he doesn't do it so often.
> (Marie, age 6 years, cystic fibrosis)

Evidently, familiarity and relationship history had a pronounced effect on Marie's experience of the same medical procedure. Marie's experience ranged from a sense of safety to feeling fear, depending on the HCP performing the task.

In our data, we noted an association between negative experiences at the hospital and the children not choosing a happy smiley face to represent the HCPs treating them. While six children chose happy smileys when describing their HCP(s), Laura (age 6) and Aya (age 5) did not. Aya and Laura were also the only children who expressed, and played out, stories of distress during their visit to the hospital. Aya did not choose a smiley face, instead she told the interviewer that the HCPs just looked "normal". Initially, Aya built the consultation room as an inpatient hospital room, where the little sister (the character representing Aya) was lying on a bed.

> Int: Then the doctor comes in, and what happens then?
> Aya: Then she had to be pricked.
> Int: Yes, was it the doctor who pricked her?
> Aya: yes.
> Int: Yes, and where did she get the prick?
> Aya: Um... On the arm. Prick! Ouch! [Makes crying sounds, in the voice of the little sister].
> (Aya, age 5 years, diabetes)

Aya was showing the interviewer her recent experience of being admitted to hospital only a few days prior to the interview. Aya played out her experience of receiving medical treatment without having previously perceived any meaningful positive interaction or any opportunity to build trust with the HCP treating her. Laura chose, in her own words, a "boring" smiley to represent the HCPs that she saw at the hospital. Throughout the narrative story play, Laura expressed her experience of fear and disempowerment during hospital appointments. Laura's character, Tobias, was crying throughout most of the procedures taking place in the clinic. Laura's fear of laryngeal suction (what the children referred to as 'being sucked') was particularly evident.

> Int: Ok. Can you show me what happens when you're being sucked? What happens?
> Laura: Then you usually have the head held like this.
> Int: Mum holds the head.
> Laura: And then someone comes and suck here, inside the nose.
> Int: Does mum sit and hold Tobias?
> Laura: Yes [Tobias is sitting on his mother].
> Int: Is it because he doesn't like it?
> Laura: Yeah, I don't like to have my nose sucked either!
> Int: No. So the mother holds him.
> Laura: [Voice of Tobias] No, no, I don't want to have my nose sucked!
> (Laura, age 6 years, cystic fibrosis)

Unlike the other children, Laura did not use the name of any HCPs when playing out what happened at the clinic. From Laura's perspective, there was no personal relationship between her and the person carrying out the procedure(s).

When Laura assumed the role of the doctor, she was eager to tell Teddy that the medical procedures "do not hurt at all", that Teddy can "just hold someone's hand", and that Teddy would get sweets or toys after the appointment. Thus, from Laura's perspective, there seemed to be a disparity between the reassurance she received from the HCPs and her own bodily experience of overpowering fear. Thus, the assurance offered to Laura was in stark contrast to her own experience of undergoing medical treatment. In this way, the inconsistency between reassurance and her own bodily experience may have contributed to Laura's feeling of distrust in the HCPs treating her.

Theme 4. Children with type 1 diabetes did not perceive that they played an active role during consultations

All four children with type 1 diabetes displayed a similar perception of HCPs as knowledgeable experts, who informed the families about the status of their diabetes based on blood glucose data.

> Int: What does Louise [pointing to the nurse character] tell you? What does she say to you?
> Nora: She tells me how it's been going.
> (Nora, 5 years, diabetes).

Anton (age 4), who was recently diagnosed with type 1 diabetes, understood that his HCP could access information about him through his diabetes devices.

> Int: What does she do at the computer?
> Anton: Uh, so when she has taken a picture of this one here [Anton points to the glucose sensor on his arm], then she can see it on there, and then she can see a picture of me.
> (Anton, 4 years, diabetes).

In this way, the children had an experience of receiving information about their health and wellbeing from the HCPs. The children did not express perceiving that the HCPs elicited their subjective perspective. Indeed, none of the children with type 1 diabetes described (or played out) an active role during the consultation.

Nora (age 6) had experienced the communication in the consultation as something that occurred between the HCPs and her parents. For Nora, this resulted in a feeling of boredom. In the following, the interviewer had asked whether there was anything Nora disliked about the diabetes consultation (Nora used the word diabetes "control").

> Nora: Having to just sit still.
> Int: Ok, it is a little hard to keep sitting on that chair [interviewer gesture at the Nora figure sitting on a chair]?
> Nora: Yes, and be bored.
> Int: And it's a bit boring?
> Nora: Yes.
> Int: Is there something you can do in there, if you're bored?
> Nora: Eh, no!
> Int: No, there isn't. So you just have to wait?
> Nora: Yes, and that 'control' is actually quite long.
> (Nora, 5 years, diabetes).

In this way, Nora essentially perceived her role in the clinic as superfluous. When asked what she liked about coming to the clinic, Nora said, "talking". This indicated that it was not the talking itself that Nora found boring. Rather, it was the passive role, or lack of inclusion in the conversation, which was the cause of Nora's disinterest.

While the children with cystic fibrosis had an experience of being more actively included during clinic visits, this may be partly due to their physical presence being required for medical tests and assessment to a greater extent than the physical presence of children with type 1 diabetes.

Theme 5. Children associated medical treatment with receiving tangible rewards or positive feedback

Receiving some kind of a tangible reward was closely related to undergoing medical treatment, and many children had an experience of receiving positive feedback and praise from their HCP(s). However, children experienced and interpreted the meaning of positive reinforcement differently, depending on the situation, context, the relationship and their previous experiences. Like the other children with type 1 diabetes, Rosa (age 5) had experienced receiving positive feedback from her HCP, Karen, based on her blood glucose data.

> Rosa places a clipboard with a graph on the consultation table and says; "And this is her blood sugar" and "Then Karen says; it's looking really good".
> (Rosa, 5 years, diabetes).

During medical play, Rosa also suggested that giving the teddy bear a reward would help it overcome its reluctance to go to the clinic. In this way, reward and positive feedback may have played a role in establishing a trusting relationship between Rosa and Karen, in the early months of living with diabetes.

Likewise, Marie's (age 6) experience of reward was coupled with a positive, playful interaction with an HCP. In the following, Marie had an experience of interacting with the HCPs outside the medical setting. It seemed like this experience was more meaningful to Marie than the act of being given an ice cream.

> Marie: And then the mother and the doctor talk a little together and then one of the doctors, maybe the one who "sucked" her nose, goes down and finds something together.
> Int: Ah, so they go and chose something together.
> Marie: Yeah, and then they go up again. There was a time when not even one minute where it, I ran all the way down to the ice cream and then I hopped on one leg all the way back up, and it hadn't even been a minute!
> (Marie, age 6, cystic fibrosis)

In contrast, for other children like Laura (age 6), the reward was perceived mainly as a bribe, or as a consolation for the distress she had been subjected to.

> Laura: I don't like having my nose sucked.
> Int: Why don't you like having your nose sucked?
> Laura: Because it hurts.
> Int: It hurts?
> Laura: Yes.
> Int: Is there nothing at all that can help you?
> Laura: That I get candy.
> Int: It helps to get candy?
> Laura: And I get toys.
> (Laura, age 6 years, cystic fibrosis)

Discussion

In line with other studies of young children with cancer (Darcy et al., 2014) and older children with diabetes (Ekra & Gjengedal, 2012), the young children's understanding of illness was closely linked to experiences of treatment and care. In this way, our results indicate that children's bodily experiences of treatment and care may directly influence and shape their experiences of illness, now and in the future. Notably, this accentuates the need for a child-centred approach to care and necessitates the child's perspective in research and in clinical practice.

Some children in the present study experienced distress in connection with physical aspects of treatment, and this was particularly evident for children who had recently been diagnosed with type 1 diabetes. Findings from our previous research suggest that having initial symptoms of distress following diagnosis is a common and "healthy" response to a distressing event in the child's life. Thus, supporting children through this experience should be a prioritized and integrated part of early diabetes care (DeCosta et al., 2020). While our results only report on a small number of young children's individual and subjective experiences, they indicate that young children's experience of a trusting relationship with an HCP can coexist with and act as a counterbalance to the initial experienced distress of diagnosis. While most children in our study had gradually developed a sense of competency and agency in relation to medical treatment, some experienced consistent fear and disempowerment. Research on older children shows that the phenomenon of medical fear is intensely experienced as a threat to the very existence of the child (Forsner et al., 2009). While appropriate pain management in young children is crucial it is not sufficient, as the experience of pain is highly subjective and comprises pain-related fear and anxiety (Franck et al., 2000). As illustrated in the present article, while treatments may objectively be the same, young children's bodily experiences of a given treatment varied significantly.

Our results are comparable to findings from a study on young children with cancer, showing that young children wish to be viewed as competent individuals who have a need for information and participation in care (Darcy et al., 2014). If information is not tailored to the young child through play and demonstration, the result will not be knowledge or participation (Karlsson, Englund, et al., 2016). Previous research has found that older children (4–10 years) with type 1 diabetes experience their position in consultations as peripheral and do not feel that they can usefully contribute (Curtis-Tyler, 2012). Similarly, the young children with type 1 diabetes in the present study did not express an experience of active participation or of their views being elicited during consultations. Based on our own experiences of interviewing young children, we argue that, given the opportunity and correct framework, young children have the competencies needed to contribute meaningfully during consultations.

Research with young children and their parents has supported the notion that HCPs play a key role in the lives of young children with chronic illness (Darcy et al., 2014; Darcy et al., 2019). Our study indicated that young children's perception of a medical procedure was directly affected by the relational trust between the child and HCP. This is in line with our previous work with HCPs, which showed that attending to young children's medical needs, while overlooking their relational needs, leads to fear and distrust (DeCosta et al., 2021a, 2021b), and research showing that hospital related fear weakens young children's willingness to trust HCPs (Salmela et al., 2011). While we do not propose a causal link, negative perceptions of treatment were mirrored in children's perceptions of the HCP's degree of friendliness (as indicated by smiley faces). Our study found that positive relations with HCPs were experienced through participatory and responsive communication, physical touch (hugs), body language (smiles), playful interaction and positive feedback.

Children in the present study linked consultations and/or treatments with receiving positive feedback and some kind of tangible reward. However, knowledge about how young children understand and perceive this practice is missing. Whether this was intentional or not, children in the present study perceived getting positive feedback when their blood glucose data were favourable, a variable these young children have no control over. Our data suggest that HCPs should use rewards in a purposeful manner that is meaningful for young children. Positive feedback, such as playful interaction, may be perceived as more genuine and less as a bribe. Further, praise for actions that are within children's control, such as active participation and engagement during consultations, may stimulate children's feelings of competence and agency. In the present study, feelings of competence and agency were central to the young children's experience of treatment and care.

Young children expressed a clear need for close proximity to and physical contact with parents during treatment. This is in line with attachment theory (Bowlby & Ainsworth, 2013) and other research indicating that parents are the fundamental source of comfort and safety during times of trauma and uncertainty (Darcy et al., 2014; Gibson et al., 2010; Stålberg et al., 2016). A recent study on young children with cancer and their parents found that parents who had participated in restraining their child felt that they had legitimized the suffering and that neither parents nor the child wanted this role (Darcy et al., 2014; Darcy et al., 2019). Another study reported that young children interpret that the adult no longer cares for them, hurts them on purpose, or is not concerned with their wishes when they are put through procedure against their will (Salmela et al., 2011). The present study indicates that, from a child's perspective, restraint may lead to a sense of disconnection and a perception of abandonment. The question of how to help children and parents reconnect and repair trust following restraint during medical procedures required further attention both in the research and clinical practice.

Recommendations for further research

More research on young children's experiences of chronic illness, treatment and care needs is necessary in the future. It would be relevant to include young children with other chronic illnesses, and children living in different geographical locations/different cultures. Longitudinal studies may further elucidate how young children's experiences and need for support may vary over time. Given the significant developmental differences between 3 and 6-year-old children, it would be interesting to replicate this study with a younger age group, specifically 3 and 4-year-olds. Such a study could provide valuable insights into the nuances of this age group's experiences and care needs. This kind of research will promote the visibility of young children's psychosocial care needs and allow their perspectives to be integrated into guidelines in the future. Findings from the present study call for projects aimed at exploring how young children, particularly those with type 1 diabetes, can be given more opportunities to participate during routine consultations. Narrative and play-based methods that operate within young children's ZPD, could be modified and tested for use in a clinical context.

Implications for policy and practice

The present findings can deepen HCPs' understanding of young children's perspectives on treatment and care, as well as of the vital role HCPs play in shaping young children's experiences, understandings and perceptions. The results suggest the need for a greater clinical focus on the young child's experiences and unique care needs as such attention will help to promote their long-term psychosocial health and wellbeing. Guidelines on young children's psychosocial care needs are necessary. Until such guidelines exist, suitable care practices that support young children's right to participation need to be established, implemented and prioritized. When offered an appropriate framework and scaffolding, even young children can provide valuable contributions by communicating their experiences and need for support. In practice, our findings suggest that child-centred care tailored to young children should revolve around establishing relational trust between the child and the healthcare provider. This can be achieved by encouraging playful participation and active engagement, ultimately fostering children's sense of competence and agency.

Strengths and limitations

A general limitation of qualitative research with a small number of participants, concerns transferability and application to practice. While IPA studies are conducted on small sample sizes, the aim is not to prematurely make more general claims about the findings (Smith & Osborn, 2012). However, such knowledge can strengthen the validity of findings from quantitative research and offers a better understanding of the underlying mechanisms.

The small sample size of eight young children with a chronic illness is simultaneously the main strength and a limitation of the present study. To explore young children's experiences in detail, and accurately capture the individual child's perspective, the sample size had to be limited. On the other hand, the small sample size may be a potential source of selection bias, especially because children were recruited from three clinics and because we did not continue data collection until we reached saturation. Moreover, the small sample size did not allow for a more detailed comparison between the two conditions, clinic of attendance, age or gender.

Our results have not been combined with actual observations of practice; they only represent the child's perception of treatment and care. For this reason, our results are not meant to stand alone. The main strength of the present study is the narrative and play-based method used. This method is grounded in theoretical and empirical knowledge about the framework needed to facilitate and scaffold young children's ability to contribute in a way that is meaningful for the child and the researchers. The method is inherently child-centred and offered young children the means to communicate their perspectives on treatment and care. Gaining this insider perspective adds valuable and central knowledge to the field that may not be obtained using more conventional interview strategies.

Conclusion

Young children's perceptions and experiences centred on the need to feel safe and have a sense of agency. This was mainly experienced through active participation and having positive interpersonal relationships with HCPs. Young children's need for active participation, and their ability to contribute to matters related to their care and treatment, should be acknowledged and encouraged both in research and in clinical practice.

CRediT authorship contribution statement

Patricia DeCosta: Conceptualization, Investigation, Formal analysis, Methodology, Project administration, Writing – original draft. **Timothy C. Skinner:** Conceptualization, Methodology, Supervision, Validation, Writing – review & editing. **Jette Led Sørensen:** Resources, Supervision, Validation, Writing – review & editing. **Martha Krogh Topperzer:** Resources, Methodology, Writing – review & editing. **Dan Grabowski:** Conceptualization, Methodology, Supervision, Validation, Writing – review & editing.

Declaration of Competing Interest

All contributing authors, declare that there is no conflict of interest regarding the publication of this article.

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