



Siblings' lived experiences of transitions between hospital and home in paediatric oncology: A qualitative study

Josefine Tang Rørbech^{a,*}, Kamilla Tofting-Olesen^a, Karin Enskär^b,
Helle Haslund-Thomsen^{c,d,e}, Claus Sixtus Jensen^{a,f}, Pia Dreyer^{g,h}

^a Department of Paediatrics and Adolescent Medicine, Unit for Research and Development in Nursing for Children and Young People, Aarhus University Hospital, Aarhus N, Denmark

^b Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden

^c Clinical Nursing Research Unit, Aalborg University Hospital, Aalborg, Denmark

^d Department of Clinical Medicine, Aalborg University, Aalborg, Denmark

^e Department of Paediatrics, Aalborg University Hospital, Aalborg, Denmark

^f Research Centre for Emergency Medicine, Aarhus University Hospital and Aarhus University, Aarhus N, Denmark

^g Department of Intensive Care, Aarhus University Hospital, Aarhus N, Denmark

^h Department of Health, Aarhus University, Aarhus, Denmark

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ABSTRACT

Purpose: Childhood cancer profoundly affects the entire family, with siblings experiencing significant changes. Transitions between paediatric oncology treatment centres and homes pose particular challenges, fragmenting family life and heightening uncertainty. This study aims to explore how siblings of children with cancer experience transitions between a paediatric oncology centre and home.

Method: A phenomenological-hermeneutic approach was employed to capture the lived experiences of eight siblings of children with cancer. Semi-structured interviews, supported by photo-elicitation methods, were conducted in the siblings' homes. The analysis was guided by Paul Ricoeur's theory of interpretation, which provided a philosophical framework for understanding the deeper meanings of siblings' narratives.

Results: Three overarching themes on hospital and home transitions emerged: Grappling to find a new family position situated in the periphery, The risk of sudden family separation left with uncertainty and Adapting to a changing siblingship shaped by the illness. These findings highlight that siblings faced considerable demands to adjust and adapt to unpredictable family separations, representing particularly vulnerable periods, amplifying feelings of uncertainty, fear, and loneliness.

Conclusion: This study provides insights into how siblings adjust to the frequent family disruptions caused by cancer treatment. While siblings strive for family closeness, they often feel distanced and placed in a peripheral role. Siblings' needs during transitions must be prioritized and addressed adequately to ensure their overall adjustment during a cancer course.

1. Introduction

Each year, approximately 400,000 children and adolescents worldwide are diagnosed with cancer (Steliarova-Foucher et al., 2017). While survival rates have successfully improved, childhood cancer remains one of the leading causes of death among children and continues to profoundly impact the entire family, including siblings (Long et al., 2018).

Siblings experience significant challenges while adapting to multiple changes within the familial ecosystem. New family roles and unexpected family disruptions with limited parental support are some challenges siblings face (Yang et al., 2016; Pariseau et al., 2020). Siblings are reported to be at risk of psychological distress (Gerhardt et al., 2015), lower academic skills (Long et al., 2018), and long-term physical health morbidities (Desai et al., 2022). Positive outcomes are also reported

* Corresponding author. Department of Paediatrics and Adolescent Medicine, Unit for Research and Development in Nursing for Children and Young People, Aarhus University Hospital, Palle Juul-Jensens Boulevard 99, 8200, Aarhus N, Denmark.

E-mail address: josefine.tang.rorbech@rm.dk (J.T. Rørbech).

@JosefineRbech (J.T. Rørbech)

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with post-traumatic growth aspects such as increased maturity, autonomy, and family closeness (Porteous et al., 2019). While the literature on siblings' psychosocial functioning remains heterogeneous, qualitative research can offer valuable insights and improve the understanding of how siblings adapt to and navigate the complexities of childhood cancer (Long et al., 2015; Carnevale, 2020).

Understanding these unique sibling experiences becomes even more crucial in the context of the rapidly evolving treatment regimens (Gore and O'Brien, 2024). The intensified treatment protocols with increasingly complex care tasks utilised in the family's home pose new life circumstances in everyday family life with cancer (Branowicki et al., 2016). Additionally, most treatment regimens are aggressive, prolonged, and multimodal, necessitating frequent hospitalisations that exacerbate family disruptions, which challenge the cohesion and resilience of the family unit (Christensen and Carlsen, 2022; Long et al., 2015). Siblings may be particularly vulnerable during intense treatment phases with frequent family disruptions, including parental absence and loss of family routines (Erker et al., 2018).

Hence, these crucial contextual aspects of childhood cancer require timely knowledge and further exploration from all family members. However, research concerning transitioning from hospital to home has so far mainly focused on parents or healthcare professionals with a primary focus on medical issues, such as symptom management, medication, tube feeding, and monitoring side effects (Roug et al., 2023; Branowicki et al., 2016; Duffy et al., 2021; Jibb et al., 2021).

Siblings are often the longest-lasting relationships people share, and sibling relationships play a central role in the lives of children and adolescents (McHale et al., 2012; Winther et al., 2015). However, studies focusing primarily on parents or incorporating siblings only as part of broader family-level analyses may neglect siblings' unique perspectives. Using parents as proxies can be problematic, as studies show significant divergence between parental and child perspectives (Knecht et al., 2015; Ali et al., 2022).

Thus, there is a gap in our understanding of how siblings experience hospital-to-home transitions in the context of families living with childhood cancer. Such understandings provide valuable knowledge to inform intervention design (Bleijenbergh et al., 2018) and healthcare professionals, providing optimal care and support with an increased focus on the entire family. Therefore, this study aimed to explore how siblings in families where one child has been diagnosed with cancer experience transitions between a paediatric oncology treatment centre and home.

2. Methods

2.1. Study design

This explorative qualitative study was part of a larger project entitled FAM-EDU-CARE, which aims to develop a family-based intervention to improve the quality of transitional care in paediatric oncology. A phenomenological-hermeneutic approach was applied to explore the phenomenon we term 'transitioning between hospital and home.' Semi-structured interviews combined with a photo-elicitation method were used to collect data. The study followed the Consolidated Criteria for Reporting Qualitative Research checklist (COREQ) (Supplementary File) (Tong et al., 2007).

2.2. Setting

This single-centre study was anchored in a paediatric oncology centre at a Danish University Hospital. This centre, which has an oncology unit, a day clinic, and an outpatient clinic, sees approximately 60 newly diagnosed children and adolescents annually.

2.3. Participants and recruitment

Recruitment was performed from 10 families already enrolled in the FAM-EDU-CARE project. Through purposive sampling, participants were included after personal contact with one of the parents. An age-appropriate project information sheet was handed out to parents for delivery to the siblings, and they were given some days to consider whether they were willing to participate. Variations concerning cancer type, time since diagnosis, age, gender, and the distance between the treatment centre and home were sought. To be included: having a brother or sister receiving active treatment for cancer, being between five and 18 years old, speaking and understanding Danish, and not having any severe concurrent illness. Participants were not eligible if the ill child was considered in the end-of-life stage. Nine siblings were eligible, with one declining participation due to lack of interest. Demographic details are shown in Table 1.

2.4. Data collection

Data was collected during Autumn 2023. Interviews were conducted in the families' home, preferably in the sibling's room, to provide the participants with a safe and confidential space. Interviews were performed by first author (n = 2) and second author (n = 6). They were interviewed without their parents' presence to limit parental influence on their response. One sibling chose to sit in the living room with the parent nearby. Both interviewers were female nurses experienced in working with children and families and conducting interviews. The interviews were recorded and transcribed verbatim by the first and second authors. The interview duration lasted an average of 32 min.

2.5. Photo elicitation interview

Photo elicitation methods are suitable when interviewing children, as they can uncover subjects that may be challenging to talk about. Furthermore, photo elicitation can enhance the recall of significant memories, helping siblings articulate their thoughts (Shaw, 2021; Mandlco et al., 2013). Hence, photos were used as a reflexive tool to elicit siblings' descriptions of their experiences, emotions, or perceptions and evoke deeper insights. The siblings were asked to take new photos or select existing ones captured during the cancer journey. The photos could include family activities, their siblings, themselves, or other visuals. They were encouraged to choose or take pictures depicting both home and hospital situations and photos that evoked joy and sadness.

The photos were supplemented with a semi-structured interview guide, which included questions about the photos and questions explicitly addressing the phenomenon of interest. The interview guide incorporated elements inspired by the SHOWED technique (Werremeyer et al., 2020), was circulated among the research team, and was slightly modified during the data collection process (see Table 2 for photo elicitation interview guide). As an opening question, siblings were asked to describe their family. Photo elicitation was offered as a method for participants, though its use remained optional, with three siblings choosing not to engage with this approach. In these cases, the interviewer asked them to recall situations related to transitional experiences, such as their first impressions of the diagnosis and experiences

Table 1
Demographic Characteristics. N = 8 siblings from 5 families range (mean).

Sibling older than the child with cancer	5
Sibling gender, male	4
Sibling age (years)	6-16 (11,8)
Time since diagnosis, mean month	6-25 (10)
Cancer diagnosis	1 solid, 1 lymphoma, 3 leukaemia
Child with cancer, age (years)	5-17 (10,5)
Distance from home to treatment centre, (km)	10-112 (62,5)

Table 2
Photo elicitation interview guide.

Questions to elicit photos	Follow-up questions
Can you tell me what is in the photo? Describe items, people, the setting	What is happening in the photo?
Is this a photo that makes you happy? Or something that makes you sad?	Why are you happy/sad about what is in the photo?
Can you tell me why you took/choose this photo?	
Do you remember how you it was for you when this photo was taken?	Did you feel something in your body? How/where did you feel that?
Can you tell me anything more about this photo?	

when the child was home from the hospital. Notes were taken to reflect the interviewer's thoughts and impressions and elaborate on significant points before and after the interview (Rogers et al., 2021).

2.6. Data analysis

To gain an in-depth understanding of the lived experiences of the participating siblings, a phenomenological-hermeneutic analysis method inspired by the French philosopher Paul Ricoeur (PR) was applied. This study draws on his philosophical work, especially concerning text interpretation and his thoughts on how humans understand and explain written discourses (Ricoeur, 1976). Dreyer and Pedersen have operationalised PR's theory of text interpretation as an analytic method useful in qualitative research (Dreyer and Pedersen, 2009). This includes three levels of dialectical analysis: a first overall interpretation, a structural analysis, and a critical interpretation and discussion. The analysis in this study was performed as follows: First, all interviews were read to get a sense of the text, creating an immediate impression of what stood out as meaningful content. The first author formulated a naïve understanding of written text. This immediate understanding was narrated in a short text. The naïve formulation was discussed with the second and last author to increase reliability. Next, the structural analysis was carried out in a three-level process using Nvivo QRS 14 (International, 2021). Across all interviews, meaning-bearing units were highlighted from the text and provided with a code by the first author. Then, all codes were closely reread, supplied with a small note, and discussed with the research team. The themes were interpreted in relation to the identified themes/subthemes, and the quotations and significant bearing units were formulated. This analytic process required a dialectic movement between the whole and the parts across the above-described analytic levels. Finally, the findings were critically interpreted and discussed using selected aspects of theories and existing research (Dreyer and Pedersen, 2009).

2.7. Ethical considerations

The study followed the declaration of Helsinki (Association, 2021). According to Danish law, this project does not require approval from the ethical committee. However, siblings who live in families with childhood cancer are potentially vulnerable, and researching children's and young people's perspectives calls for intensified ethical reflection and responsibility (Kirk, 2007). Therefore, we carefully reflected on how to design this study to be ethically sound, e.g., if interviewers sensed that the sibling was unwilling to touch upon specific details during interviews, this was not further explored regarding ethically protecting the child. Moreover, the siblings could have an appointment after the interviews with the clinical psychologist. None of the siblings used this opportunity. Parental consent and assent from the participants under 15 years old were ensured. The study was registered at the data protection authority (No. 76682).

3. Findings

Through the structural analysis of the interviews, three overarching themes on hospital and home transitions in the context of families affected by childhood cancer emerged. The themes revolve around how siblings experience navigating and adapting to a family life disrupted by childhood cancer treatment, highlighting the change of family roles, family relationships, and personal adjustments of behaviours in response to changing and uncertain circumstances in their family system. To ease the reading, we term the patient 'ill child' and participants 'siblings.' Table 3 provides the reader with a comprehensive understanding of all the findings.

3.1. Grappling to find a new family position situated on the periphery

From the moment where the child was diagnosed, siblings grappled to find their position in the family. They described a change from being siblings positioned on equal terms to having a peripheral family position where it was difficult to take part in a major event that affected not only the ill child but the entire family. Siblings described how they felt being distanced from the main focus of the family: the ill child, with the parents close by:

"My little brother is the sun, and my parents are almost a part of the sun or very close to it, like big stars. And me and my big brother are like these tiny little stars very far from the others". (Big sister, 13 years old).

Being situated in the periphery of the family was described both at the time around the diagnosis and in periods during the cancer trajectory with frequent hospitalisations. The time of diagnosis was described as confusing and dramatic. Being present while parents received a message of seriousness, siblings found it difficult to grasp the whole situation. The severity of the situation was reflected in scenarios such as "staying in kindergarten after closing hours" or "finding my father crying in the hallway in the restaurant because my brother was in an ambulance". Moreover, the siblings were not at the hospital during the first period of the cancer trajectory, which led to the siblings having an unclear understanding of the whole situation. Despite the siblings being "not really there" they sensed that something dramatic was happening, which made the siblings suspicious: "My mother keeps getting these calls ... What is going on here-ish". Being disorientated about what had happened, the siblings felt surprised and confused when the parents revealed the cancer diagnosis: "I was totally confused ... I haven't had any knowledge that it was cancer". Siblings were not only surprised by the diagnosis. The realisation of the seriousness and pervasive consequences also came as a surprise. Siblings were unable to comprehend the challenges cancer would bring, thinking that the cancer disease "would pass" or "it would soon go away on its own". However, gradually, they understood how significantly the cancer disease also would affect them:

"I didn't think it would be difficult for me, but then when it started, I wasn't really happy anymore. I couldn't think of anything else than my little sister who was at home or at the hospital being sad or feeling unwell" (Big sister, 12 years old).

While being physically separated from the family, for example, in school, their thoughts and worries centred around the ill child. Some siblings struggled to distract themselves because they were constantly occupied with worried and sad thoughts. Thus, despite being in a distanced position, cancer was at the same time very present.

Distance encompassed not only an existential dimension as the family position was also narrated in physical and practical terms. When the ill child and parents fluctuated between hospitalisations, siblings were mainly placed at home, maintaining their everyday activities and occasionally visiting the hospital. The hospital visits were almost an everyday routine for one sister, being "together at the hospital instead of home.". For others, hospital visits were narrated as "if you're allowed to

Table 3

This narrative is written based on all the research findings.

Waiting for My Family to Come Back: My Brother has Cancer
When my little brother got sick, it was very confusing. He was suddenly in the hospital for a week or something and I didn't understand what was going on. My parents were with him, so my aunt stayed in our house. When they came back home, my mom said it was cancer. Something about he has bad cells in his blood. Cancer is so annoying and takes so long time.
My brother, Mum, and Dad are almost always at the hospital, and I miss them. The house is quiet, and when I am in school, I think a lot about how my brother is doing. When they come home from the hospital, it's nice to be together but my brother can be very tired, and we can't play like before. He looks very different, and he almost doesn't look like my brother. Sometimes, my mom plays a game with me, but I can tell she is stressed and needs to stay close to him in case he gets sick and needs to go in fast.
It's hard when they suddenly leave. Once, my brother got very sick and they had to leave very quickly. I was left alone in the house because Mom couldn't call my aunt. It was so scary. I didn't know anything. I didn't know what happened to him.
I was allowed to visit him at the hospital, but it was a bit scary. There were so many people talking and doing things to my brother. But it was nice to see he was all right, and he was happy to see me. I showed him a funny picture of our cat and made him laugh.
I wish I could help him more but it's difficult. It is hard to explain but sometimes I am sort of in the way and I don't really have a place there. I know that it's about my brother now, so I take care of myself and sometimes stay with my friend. I just want the cancer to go away so we can all be together again.

come" depending on circumstances such as family routines, the condition of the sick child, and particularly the geographical distance between the treatment centre and home: "You can't just drive to the hospital when we live in this city." Being at the hospital enabled siblings to spend time with the rest of the family and gain insights into how their sister or brother was doing, which decreased their level of concern:

"It is unpleasant but also nice because then you are there, and you can see that he is okay, and the entire time there are people who can come and help him (Big brother, 14 years old).

Although siblings found it nice to be together as a family and could see for themselves that the ill child 'was all right' and in good hands, being in the hospital environment was also described as "unpleasant" and "scary." Siblings were confronted with the reality of a hospital environment that entailed distressing situations with seeing severely sick children: "In one of these hallways, a boy was laying on the floor shaking. It was a cramp or something. That, I thought. That was disturbing to witness". These 'unexpected encounters' were described as reasons they felt reluctant to visit the hospital. Siblings highlighted feeling sad when seeing small children being sick and witnessing their brother or sister undergo treatment, "having blood tests and tubes everywhere" and "being really sick." Siblings described busy hospital rooms with health care personnel "giving chemo and pills and then run off again". They did not experience the staff supporting or informing them while visiting, and the siblings expressed that information related to the illness was provided solely by their parents. They hesitated to reach out because they didn't want to claim attention while the focus was on the ill child. Thus, siblings were caught in conflicting emotions, feeling ambivalence between wanting to be present and, at the same time, needing to protect themselves without being supported by adults. Siblings applied different strategies to avoid being exposed to unpleasant confrontations. By "hiding in the bathroom" or "getting out when doctors came into the room", siblings created distance by shielding themselves or simply staying away from situations that could be too overwhelming to witness. Knowing that parental attention and care needed to be heavily focused on the sick child, siblings accepted to be positioned in the peripheral family position. However, while accepting being less important during illness, they grappled with finding a meaningful role: "It's not me that has cancer, and your parents are very close with those who have, and they really protect my little brother, so you didn't feel you had a place-ish. That they took most care of him". While families endured challenging times, the sense of family connection became important for reinforcing sibling relationships and feeling closer to the family again. The significance of simple shared moments of togetherness without illness restrictions and the value of shared experiences of family connectedness were emphasized. The siblings noted that joint trips outside the families' home were "very nice to go on together because it made me happy to be with her. Just being there.". Despite the illness, siblings were provided with moments where "the whole family were together and happy." relieving them to forget about the illness and its challenges temporarily.

3.2. The risk of sudden family separation left with uncertainty

Living in a family where the ill child and at least one parent had to undergo numerous hospitalisations resulted in frequent separations between family members. The family was described as split in half. The everyday life with established, well-known family routines was replaced with family life being "out of balance and out of sync". Disruptions due to hospitalisations made siblings live in fear of the family suddenly being separated. The pace at which the child's condition could deteriorate was highlighted as uncontrollable and "not something that starts in the day but comes within hours, and then suddenly they have to leave". Occurring very suddenly, the acute hospital admissions entailing separations were described as leaving siblings with "no chance to react". Thus, siblings lived with continuous uncertainty. The uncertainty encompassed not only the unpredictability of when their ill sibling and parents would be hospitalised but also uncertainty about the length of family separations and when they were reunited again. Described as having no clue on "how long she will be ill and when it ends" or "if it will be a week or two?" left the siblings 'on hold' where they could not plan anything within the family context. Not being able to prepare for the separation and the high frequency of the separations resulted in loss of stability in everyday life. The unpredictability related to the uncertainty of duration made siblings lower their expectations of when they would be reunited again. A little sister explained this in a resigned tone:

"You should expect that the one who is ill is very much away ... and you should not think about it and wait until your sister is coming home. Cause then you will waste your time" (Little sister, 6 years old).

'Never knowing' entailed siblings living with a constant risk of the family being separated, making them aware of how they spent their time. A sister described how time spent with the family got more critical because the situation could change: "Suddenly it just changed, you didn't want to be in your room with your phone, not knowing when they will leave again". Thus, siblings experienced being alert and more attuned towards spending family time together because this time was at a constant risk of ending suddenly. Despite siblings being in the proximity of parents, they felt the parent's attention circling around the sick child, resulting in the fear of potential deterioration could overshadow the feeling of genuine family time:

"It was very difficult. Your mother might be beside you, but she wasn't really there because still, it was like, "Oooh shit, what if he gets sick?" so they needed very much to stay in his presence." (Big sister, 13 years old).

Alongside vigilance on potential separations, the siblings also described the emotional reactions these situations elicited. Siblings felt mad, frustrated, left alone, sad, and disappointed when planned family time was unexpectedly interrupted and cancelled. Having a desire for family unity and spending time together as a family, the siblings felt disappointed and abandoned when their parents and the sick child had

to leave. An older brother described his frustrations and disappointments when the family's weekend plans were cancelled due to an unexpected hospitalisation:

"On the weekends, your parents, they could just leave. Going to the hospital ... I just thought that we should have a weekend where we were home together as a family. And then they just took off" (Big Brother, 16 years old).

Besides these feelings concerned how their expectations of planned family activities were interrupted, siblings also described having an immersive worry about the condition of the ill child. When experiencing the sudden family ruptures with the sick child rushing to the hospital, siblings narrated being left in their homes with thoughts concerning if their sibling was "really all right?". Questioning if their siblings would make it was pervasive, highlighting that "the hospitalisations were the worst part" because the siblings felt the seriousness of the situation. Still, they were not informed in further detail and were excluded from knowing what was happening. If they reached out to alleviate their worries, their questions were not typically given attention in the acute situation: "If you try to call and then your parents are in the middle of it-ish". Thinking about "what will they do?" or that something "bad will happen" created worrisome feelings. Alongside the worried thoughts and mental pressure when the ill child was hospitalised, siblings reported bodily sensations such as "my heart beats faster" and "you get this giant knot in your stomach" was narrated. Being powerless with no sense of control over the situation, the siblings expressed an abandoned feeling of being "left by yourself" with no possibility to do anything about it; "you want to do all sorts of things, but you know that you can't". To create a sense of control during these difficult times, siblings described how they forced themselves "not to think about it". Trying to distract themselves from thinking of something else while at home alone, siblings tinkered with time by watching TV series, playing video games, or seeking a connection with peers. However, siblings expressed this as "not very exciting when you have watched so many TV series as we have," pointing out how lengths and frequency of hospital stays shaped siblings' experiences of family separations.

3.3. Adapting to a changing siblingship shaped by the illness

With the frequent transitions between hospital and home, siblings also described how living together as a family changed. Siblings expressed how their siblingship was affected and became different from before the cancer diagnosis. Not being able to do things together as they used to was key in the sibling's narrations. Reflecting on and comparing life from before the diagnosis, siblings expressed a loss of activities they once enjoyed with their brother or sister: "It makes me sad because you can't do the fun things anymore". Adapting to limitations and restrictions imposed by the cancer illness became a necessity; "She couldn't really handle running and playing outside." Siblings described the need to adjust their previous interpersonal behaviour. Especially the need to be more careful when playing because of the physical vulnerability cancer treatment entailed; "I needed to be careful not to hit her or not be rough on her". The inability to play on equal terms was experienced as frustrating and "a little annoying." The mentions of this being a 'little annoying' showed siblings' mixed feelings, balancing empathy and understanding of the child's vulnerability but also frustrations about the restrictions the illness placed on normal childhood activities.

While adapting to a changed siblingship, changes in the child's physical appearance were also described. Witnessing the child losing hair, "being tired and really unwell", pale, and losing weight made the siblings describe the child as "not looking like himself anymore". The altered appearance greatly impacted the siblings as they expressed profound sadness seeing their brother or sister changing. During everyday activities, siblings could temporarily distract themselves from thinking about their brother or sister being sick. However, being confronted with the altered appearance was experienced as distressing, as it

served as a stark visual reminder of the reality of cancer: "It was when I came home and saw her, I started to think about it (the illness)". When the ill child was home between treatments, siblings described how the child's behaviour also changed. Especially in the early stages of treatment, siblings needed to navigate the changed behaviour and emotional strain:

"Oh, in the beginning, it's definitely hard. You must endure a bit more helping your sister and accepting if she doesn't want the help. Still, if you see she needs help but doesn't want it, you should leave her be". (Big sister, 12 years old)

Thus, balancing the desire to help while respecting the child's autonomy was experienced as challenging. Being attuned to "many mood swings" was described, and siblings highlighted the emotional tensions that arose due to these conflictual situations. The unpredictable emotional state with sudden changes was experienced as "very stressful". Siblings felt they needed to be more cautious in their interactions with the child, such as being mindful of choosing words and actions towards the ill child: "You couldn't talk to her without her suddenly being mad". Siblings decided to distance themselves to avoid interaction: "I just stay away. That's the easiest". While describing these changes in the siblingship, they also reflected upon how they themselves changed: "When you don't have yourself, then you can't really have others, and then you let go of something or lose it. I lost a lot of myself at that time". Trying to navigate the complex changing behaviour with emotional tensions in the family dynamics, "really wanting to help" while being rejected, made siblings stretch their limits, withdrawing and not claiming attention from family members. To get through the days, siblings expressed how having someone other than the family to lean on helped them to "just move on to forget about it." Some friends from school could support the siblings. Still, if they were not, it made the siblings reluctant to talk about their challenges with being in a family with childhood cancer because they were afraid of the reactions from classmates: "I can't really tell it to any of my friends because they will just laugh". Connecting with peers who "actually understand how you feel" was highlighted as a way of finding support and "making the days feel shorter" when classmates and friends were unfamiliar with having a brother or sister with cancer.

4. Critical interpretation and discussion

This paper explored how siblings experience transitions between hospital and home and offers an important insight into how these transitions, inherent in most paediatric oncology treatments, disrupt family life and affect siblings. Overall, these findings show that siblings are highly affected when family members fluctuate between hospital and home settings and describe the demands on siblings to adjust and adapt to unpredictable family separations. The lack of stability from disruptions and the loss of family normalcy is an unavoidable illness-related condition inescapable for the siblings. Below, we critically discuss selected findings outlined based on their prominence, focusing on distance, uncertainty, and changed sibling relationships.

'Distance' emerged as a central theme in the siblings' narrations of the hospital and home transitions. While 'distance' may often relate to a spatial concept with a geographic distance to measure, findings reveal that siblings perceive distance not only as spatial but comprising an existential level. When family members left for hospitalisation, siblings were left in their homes, creating spatial distance and aloneness. However, even in moments of family proximity, siblings described feelings of being far away from the rest of the family, for example, by using the solar system as a metaphor. Feeling distanced despite the physical closeness encompasses feelings of detachment, isolation, and loneliness. According to the theory of loneliness, existential loneliness can be present even though one might have close relationships, such as family (Bolmsjö et al., 2019). Loneliness can be intensified by a feeling of not belonging, which is described in siblings' experiences when their family role changes with siblings being relegated to a peripheral family position. To alleviate the distance, siblings sought emotional security and

family closeness, e.g., when visiting the hospital to see and know that the child was all right. However, findings also showed that siblings applied distance as a coping mechanism, which was illustrated in different strategies such as *withdrawing* from the siblingship when home or *avoiding* disturbing illness-related exposures at the hospital. These findings suggest that distance, both physical and emotional, may serve as a protective mechanism for siblings when navigating the complexities of the family system during severe illness. Findings also showed that the siblings appeared less likely to seek attention or support from parents or healthcare professionals. Reducing emotional expression to protect other family members is a well-known mechanism and illustrates the conflicting need for self-protection and protecting siblings' family members (Van Schoors et al., 2019a, 2020; Yang et al., 2016). Moreover, as siblings don't carry the caregiver role as parents do, they are less able to take control and act, reinforcing the passive and less important family role. This aligns with a recent study describing similar negative emotional reactions such as loneliness, uncertainty, and helplessness when the illness is perceived as uncontrollable (Van Schoors et al., 2019b). Today's multimodal and aggressive treatment regimens automatically draw the attention of parents to be intensively focused on the ill child. This change of parental attention was highlighted in this study and aligns with the literature explaining that siblings may retreat emotionally when they experience that their needs are secondary to those of the ill child or when they experience an imbalance in family attention and parental resources (Pariseau et al., 2020). Additionally, the findings of this study suggest that the distance between treatment centres and home, as well as the frequency and duration of hospitalisations, may contribute to heightened feelings of distress and isolation. Houtzager et al. (2004) highlighted these factors as potentially influencing siblings' overall quality of life. However, whether these contextual factors represent a significant risk to siblings' psychosocial functioning remains uncertain. The evidence on long-term psychosocial impacts differs, with some siblings reporting post-traumatic growth and increased family connectedness and others with increased risk of post-traumatic stress, poorer academic skills, and physical morbidities (Long et al., 2018). As childhood cancer trajectories are often prolonged, typically spanning years and accompanied by chronic side effects, the long-term psychosocial impacts on siblings remain complex. Future studies could focus on whether these long-term consequences exacerbate feelings of being distanced within the family, potentially leading to long-term emotional disengagement between siblings and other family members.

Uncertainty emerged as another central theme in the findings and was in many aspects related to the unpredictability of the cancer course. Uncertainty was prominent when family separations suddenly occurred, the uncertainty of time before reuniting after a hospitalisation, and when reunited in their homes. The distance between home and hospital was described as an obstacle to family connection, restricting the possibility of being with the ill child. The siblings' emphasis on the significance of small joint trips further highlights the critical role of family connection, particularly when the foundation of family life is threatened. These findings align with other studies that emphasise a need to sustain families' physical togetherness (Van Schoors et al., 2020).

Our study revealed that siblings' uncertainty was also related to a lack of knowledge about the condition of the ill child and with siblings being unable to comprehend what cancer entailed. Clearly, the first phase of cancer is filled with many 'unknowns' as children and adolescents most often are unfamiliar with childhood cancer in general (Long et al., 2015). Moreover, a childhood cancer course is, in its nature, unpredictable and highly depends on how the ill child responds to treatment. Despite these explanations for siblings' lack of knowledge, findings indicate that siblings could profit from more informational support. Obtaining knowledge may decrease their level of uncertainty, creating a better understanding and coping skills (Sievers et al., 2024; Gunter and Duke, 2018). Similar findings showing siblings' unmet needs are reported (Sievers et al., 2024; Rørbech et al., 2024; Weiner and

Woodley, 2018), reflecting a broader gap in recognizing their rights under Article 12 of the United Nations Convention on the Rights of the Child (Unicef, 2024). The exclusion of siblings from hospital visits and the withholding of information may reinforce feelings of uncertainty. Child-centred care principles and standardised support recommendations (Gerhardt et al., 2015) emphasise that involving siblings and informing them is not optional but a fundamental human right (Ford et al., 2018; Coyne et al., 2018). This is no straightforward task, with siblings being a hard-to-reach population (Franklin et al., 2018) as they either are restricted to hospital visits or, as findings from this study show, withdraw from visiting. However, this should not be an excuse for paediatric cancer institutions not taking the responsibility of facilitating support interventions for siblings. Parents can be overwhelmed practically and emotionally and thus have limited resources, knowledge, and communication skills (Pariseau et al., 2020; Kästel and Enskär, 2013). Reviews further highlight a knowledge gap in how, where, and when to support (Wawrzynski et al., 2021) or inform (Sievers et al., 2024) the siblings. This leaves this gap with unresolved questions about whether siblings are targeted with supporting interventions in the way they want and need. Interventions could be designed to reach siblings in their environment, e.g., at school or home (Mooney-Doyle et al., 2021). Additionally, using creative solutions such as play-oriented educational sessions, eHealth solutions, or connecting to peers in similar situations. Such interventions targeting siblings as an individual subgroup in the family could be beneficial. However, as this study showed, siblings mostly craved proximity and closeness with family members. Therefore, family-based interventions, including siblings in aspects of care and treatment with respect to their unique coping skills, developmental level, and needs, are warranted (Mooney-Doyle et al., 2021). Such interventions could help alleviate feelings of helplessness, foster a sense of agency, and reinforce their role as valued family members. Interventions focusing on family support provided to the family as a unit would also help promote illness-related communication (Lövgren et al., 2022). This supportive solution could stimulate family connection and ensure siblings' emotional expression sharing their cancer-related experiences, which is associated with lower levels of loneliness (Son and Kim, 2024; Van Schoors et al., 2019b).

The changed siblingship emerged as prominent in this study and was described in relation to the presence of illness in the home, as well as restrictions and the side effects of the cancer treatment, which shaped their siblingship. Despite being together, cancer still affected several aspects of family routines and siblings' interpersonal relations. The growing shift towards increasing the use of home-based cancer care and earlier discharge processes, accompanied by an increase in complex care tasks assigned to families, presents new opportunities to reduce family separations (Jibb et al., 2021; Roug et al., 2023; de Flon et al., 2021). Home care might reduce spatial distance and separation between family members (Castor et al., 2018); however, based on siblings' descriptions, new challenges arose in the family home. In this study, siblings expressed the changes in the ill child's appearance and behaviour as challenging, and siblings struggled to find their roles and space when families were together at home between treatments. This calls for sibling-focused illness-related education that could help manage expectations and reduce the unpredictability of family routines, thus fostering a greater sense of security. However, a recent review identified five nursing interventions focusing on discharge processes. All were heavily focused on educating parents before going home, leaving siblings neglected as a target group (Rørbech et al., 2024). A recent review further highlight a significant knowledge gap regarding exploring their experiences with hospital-based home care (Beisland et al., 2024). As childhood cancer treatment changes with hospital-to-home transitions becoming more common, coordination of care, including sibling support in discharge planning and follow-up care, becomes essential and warrants further research.

4.1. Limitations

This was a single-centre study conducted in an oncology setting without a structured support program for siblings during recruitment. This might limit the applicability of the findings to centres with integrated sibling support interventions. The study exclusively included siblings' perspectives, excluding other family members. While this focus may be considered a limitation when exploring family dynamics more broadly, it is also a strength. Unlike much previous research that relies on parental perspectives as proxies, this study highlights siblings' experiences as a distinct family subgroup, with data collected directly from them without parental presence during the interviews.

Despite differences in the time since diagnosis, this paper captures a partial timeframe limiting insight into siblings' experiences over time. Longitudinal studies that track siblings' experiences over time may capture the dynamic nature of transitions and the evolving impact of childhood cancer on family functioning and how a childhood cancer course may change and develop siblings' long-term bonds. Siblings' age was also diverse, spanning from 6 to 16 years. Children and adolescents are at different developmental stages, with varying verbal and abstract thinking levels (Davies et al., 2024). Thus, the findings reflect a shared experience of hospital-to-home transitions limiting the ability to capture age-specific nuances and individual variations. Power relations between the adult researchers and the siblings, whether children or adolescents, were also present, and we acknowledge that capturing a child's 'authentic' voice is challenging (Kirk, 2007; Carter and Ford, 2013). These challenges were addressed by applying photo-elicitation, which proved feasible and useful in empowering the siblings and making them decide and indicate what was important to talk about. Although some siblings chose not to use photos, we experienced a great willingness and engagement during the interview with siblings speaking freely.

4.2. Implications

This study reinforces the call for greater awareness of siblings in paediatric oncology care, recognizing their integral role in the family system and their unique psychosocial needs as a family subgroup being siblings and minors. Siblings rarely seek attention for themselves and may have several unmet needs. These must be prioritized and addressed adequately to ensure their overall adjustment during a cancer course.

Given parents' caregiver burden and responsibilities, the role of informing and supporting siblings should not fall solely on them. Instead, healthcare professionals, including nurses, should be more active in ensuring that siblings are well-informed and supported throughout the cancer journey.

Healthcare professionals should especially be attentive towards siblings when visiting the hospital and during periods with prolonged or frequent hospitalisations where siblings experience major challenges when family life is disrupted and fears of the unknown increase. Moreover, while homes become a more prevalent site for cancer care, new family routines must be incorporated, as well as providing siblings with knowledge about the restrictions and changes cancer may entail. The findings also emphasise the importance of family-based interventions that include siblings as active participants rather than passive observers, which is essential to reducing feelings of distance and strengthening family cohesion. This paper's insights will hopefully stimulate discussions among healthcare professionals not on *if* but on *how* to support them.

5. Conclusion

This paper is the first to explore how siblings experience transitions between a paediatric oncology centre and home, with findings contributing to important aspects of the emerging field of childhood cancer care. Clearly, family structures are not fixed but transform and adapt throughout the cancer trajectory. While siblings strive for family

closeness, they often feel distanced and placed in a peripheral role. Family life, including siblingship, is shaped by the illness, with its restrictions, separations, and emotional tensions.

Unplanned hospitalisations, inherent to paediatric oncology treatment, represent particularly vulnerable periods for siblings, marked by emotional insecurity and family instability, which amplify feelings of uncertainty, fear, worry, and loneliness. Importantly, the study highlights that siblings rarely seek help or articulate their needs, underscoring the critical role of healthcare professionals and caregivers in proactively offering support, especially during hospitalisations where the parental support may be limited.

CRedit authorship contribution statement

Josefine Tang Rørbech: Conceptualisation, Formal analysis; Funding acquisition; Investigation; Methodology; Project administration, Writing - original draft; and Writing - review & editing. **Kamilla Tofting-Olesen:** Investigation; Writing - review & editing. **Karin Enskär:** Supervision, Writing - review & editing. **Helle Haslund-Thomsen:** Supervision, Writing - review & editing. **Claus Sixtus Jensen:** Supervision, Writing - review & editing. **Pia Dreyer:** Supervision, Writing - review & editing.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

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