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Sheltering in chaos: parents' experiences when facing moral challenges in childhood cancer care

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ABSTRACT

Childhood cancers are life-threatening diseases that affect the whole family. During the treatment moral situations might arise. Research on how parents perceive moral challenges in childhood cancer care is sparse. The aim was to explore parents' main concern, and how they deal with their main concern, when facing moral challenges in childhood cancer care. Data collection included focus group interviews with parents. The data analysis was carried out according to a classical theory and revealed the core category "Sheltering in chaos". The strategies to handle the main concern included "To bring the child through a life-saving trajectory" by "Balancing control" and "Deliberating of suffering". The consequences included feelings of being "Torn between roles". "Familiarity" emerged as a facilitating factor to handle moral challenges. The results indicate that parents are torn between different roles, and that the care experience is improved through familiarity with the healthcare professionals. The following findings may inspire new ways of offering moral support to families in childhood cancer care.



KEYWORDS

Childhood cancer; concerns; moral; parents; qualitative research

INTRODUCTION

Childhood cancers are life-threatening diseases that affect not only the child but the whole family. Although rates of survival are high with modern therapy, childhood cancers are still serious and aggressive diseases with a mortality rate of 15%–20% in European and North American countries (Erdmann et al., 2021). Advanced medical treatment and nursing care from an early stage is crucial for the child's survival. Current treatment regimens, which can last months to years, often carry severe side effects such as pain, nausea, and infections related to neutropenia (Robison & Hudson, 2014). Treatment regimens and frequent complications require the family to adapt to frequent clinic visits and hospital stays, which burdens the family's everyday life (Kahriman et al., 2020; Van Schoors et al., 2018). Moreover, childhood cancer survivors experience late effects of a wide range and varying degrees, including both somatic and psychosocial characteristics (Erdmann et al., 2021). Erdmann et al. (2021) states that late effects also include social and socioeconomic difficulties that may impact the family.

According to Swedish legislation, parents in Sweden have a right and obligation to decide on questions related to the child's personal concerns. Parents are responsible for ensuring that

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the child's needs, such as protection and a good childhood, are met (Justitiedepartementet, 2013). Furthermore, when the child is diagnosed, parents have an important role, as they are responsible for acclimatizing to the situation and to cancer treatment (Pierce et al., 2017). Moreover, both the child (Darcy et al., 2014; Gibson et al., 2010) and the healthcare professionals (HCPs) (Ygge, 2007) see parents as the child's most important support in the hospital. In this role, parents must deal with their own fears about their child's survival (Ljungman et al., 2014). In a Canadian study, mothers often experienced overwhelming responsibilities in everyday life, when supporting the child emotionally, administering medication, and scheduling hospital visits, while continuing to manage other family tasks (Molinaro & Fletcher, 2018). Alongside this stressful situation, of having a child suffering from cancer, parents are usually also involved in the child's care and treatment at the hospital. This can lead to moral questions for parents, but also to all involved stakeholders, about what care action is best for the child. Basic questions of morality include: What should one do? What is important? How should one be or act as a person? (Rachels & Rachels, 2019). Moral challenges, derived from the basic questions of morality, are often grounded in value conflicts regarding what is morally right to do and for whose sake (Molewijk et al., 2008). When value conflicts arise, the involved stakeholders seek answers to questions about what is right or wrong, good or bad, admirable or reprehensible (Rich, 2016). In summary a moral challenge could be described as when there is uncertainty regarding how the situation should be resolved and whatever value/action is chosen, negative consequences will follow.

Difficult decisions in childhood cancer care might become even more complex, due to different perspectives among the triad of most involved stakeholders; i.e., the child, the family, and HCPs (Badarau et al., 2017; Coyne et al., 2016; Lyren & Ford, 2007). Diverse perspectives on what good care entails often arise when prognosis is uncertain and when decisions about whether or not to withdraw from curative treatment need to be made (Bartholdson et al., 2015; Weiner et al., 2022).

Research on how parents perceive moral challenges in childhood cancer care is sparse. Most studies describe only HCPs' perspectives. For example, in a recent study, HCPs reported that they found it morally difficult to know who should have the mandate to decide on care, what constitutes the limit of HCPs' responsibility, and what the right care action to take is (Weiner et al., 2022). However, some studies describe that parents feel an overwhelming responsibility regarding their child's care and experience dilemmas related to various treatment and care decisions. For example, parents have described that they have to make treatment decisions that may have life-threatening consequences for their children (Johnson et al., 2015; Pye, 2013) and be involved in giving consent for the child to participate in new and sometimes experimental treatment methods, in which the outcome is uncertain (Stevens & Pletsch, 2002). These few studies focus on the moral topics themselves, yet there is still a lack of research and knowledge about how parents *experience* these morally challenging situations in childhood cancer care.

It is important to give parents a voice to counterbalance the attention and focus on HCPs' moral challenges in the literature. Empirical knowledge about parents' experiential and unique insights into morally challenging situations may contribute to improved quality of childhood cancer care. Plausible improvements could be suggestions for how to customize support for parents dealing with morally challenging situations. For example, clinical ethics support services targeting the triad of stakeholders (children, parents and HCPs) and that fosters mutual understanding as well as attuned cooperation between parents and HCPs. In these ways, supporting parents in morally challenging situations will likely affect the quality of childhood cancer care for the better. Therefore, the purpose of this study was to explore parents' main concern and how they deal with their main concern when facing moral challenges in childhood cancer care, through grounded theory methodology.

MATERIALS AND METHODS

Design

This is a qualitative and exploratory study among parents of children who are/have been treated for childhood cancer. A classic grounded theory approach according to Glaser (1978) and Glaser and Strauss (1967) was used for the analysis. The reason for using grounded theory was that it is a structured methodology for exploring what is relevant to participants and suitable when knowledge is sparse about a phenomenon. In classic grounded theory, social patterns are explored, and the core category explains how a main concern is continually resolved (Glaser, 1978; Glaser & Strauss, 1967).

Study participants and context

In accordance with grounded theory methodology (Glaser, 1978; Glaser & Strauss, 1967), parents with experience of childhood cancer care were purposively selected, i.e. a non-probability sampling method enabling the inclusion of participants most suitable for providing information about the subject area (Polit & Beck, 2017). Parents of children with various cancer diagnoses, at different phases of their illness, and of different ages (between 0–18 years old) were invited to participate. To ensure understanding, speaking the Swedish language was an inclusion criterion. The participants were recruited from three childhood cancer centers in Sweden: Lund, Stockholm, and Umeå. The first contact was made by e-mail from the first author to consultant nurses, including information about the study. Afterward, the consultant nurses forwarded all the information about the study to purposively selected parents and asked for verbal consent for the first author to contact them. The first author then contacted all the selected parents, that had given verbal consent ($n = 22$), by phone to provide specific information and obtain written consent to participate in the study. Of these 22 parents, 20 (13 mothers and 7 fathers) agreed to participate in our study, all with children undergoing care and/or treatment at a childhood cancer center. Finally, an e-mail conversation was held to determine the date and time for the focus group interviews that were planned to be digital.

Data collection

Sociodemographic data was collected along with informed consent. Parents received a document including six questions about their gender, age range, relation to the child, as well as the age of the child/adolescent when they were diagnosed, the diagnosis of the child, and how much time had elapsed since the child received the diagnosis.

During 2021 and 2022, qualitative data collection was carried out through focus group interviews, suitable for and often used in grounded theory studies (Martin & Gynnild, 2011). Focus group interviews were used instead of individual interviews because they enable participants to share and reflect on their experiences alongside others in similar situations, which is considered to contribute so that both individual and collective experiences of the phenomenon can be explored (Barbour & Flick, 2018; Jayasekara, 2012). Individual and collective experiences were considered important when exploring the relatively undiscovered substantive area of interest. The included parents were divided into five groups and separated according to gender. Digital platforms, such as Zoom and Teams, were used for the focus group interviews. Having the camera on was voluntary, however, all participants chose to have the camera on.

The digital focus group interviews lasted for 70–90 minutes and included 3–6 participants in each group. During the digital focus group interviews, the moderator used a semi-structured interview guide, which included questions about morally challenging situations including value conflicts; for example, balancing what was important when their child underwent cancer treatment. Questions were also about diverging opinions about decisions in situations when the outcome was uncertain, for example: “Please tell us of a situation when you thought it was difficult to choose what was right to do regarding your child’s care/treatment?,” “Please tell us about a situation when you thought differently

than the other stakeholders, i.e., the child, the other parent or the HCPs?” The first and last author conducted all digital focus group interviews and took turns moderating. Field notes were taken during the digital focus group interviews by the observing author and included written notes about observations of, for example, emotional expressions. All digital focus group interviews were audio recorded and transcribed by the first author to enhance transparency and collect quotations.

Data analysis

A classic grounded theory approach, according to Glaser and Strauss (1967), was used to analyze parents' main concern and how they deal with it. In the analysis conditions, consequences and influencing variables also emerged. Grounded theory is a constant comparative method used to explore social patterns of behavior in the substantive area of interest (Glaser & Strauss, 1967), which, in this study, includes parents' experiences of morally challenging situations in Swedish childhood cancer care.

Field notes and transcribed digital focus group interviews were read through to obtain an overall picture of what was going on in the data. After each transcription, the text was thoughtfully analyzed using open line-by-line coding, keeping the following questions in mind: “What is going on?” “What is the parent's main concern?” “How do parents resolve their main concern?” and “How are patterns of behavior related?” The codes and the following analysis were written in English. Memos, i.e., notes about codes and categories, including their relationships to each other, were written down throughout the analysis. The naming of a behavioral pattern emerged when the codes were grouped into categories (Glaser, 1978). After the core category emerged, selective coding was carried out, delimiting analysis to categories related to the core. Following the process of grounded theory, the next step in the analysis was to saturate the categories by using theoretical sampling to continue exploring the categories that had already been found; for example, by interviewing parents about their experience of “balancing control.”

To complete the analysis, memos were sorted and compared to categories and raw data, which strengthened and shaped the categories through emergent theoretical coding. The process of connecting categories to each other strengthened the patterns in the data on how parents handle their main concern as well as related conditions and consequences. The analysis also revealed an influencing variable, i.e., a contingency, which is described as part of the social pattern (Glaser, 1998; Kolb, 2012). To enhance transparency, codes, and categories were repeatedly discussed between all authors. Transcribed interviews were kept in Swedish, but quotations used to illustrate, and the names of categories were translated into English.

ETHICAL CONSIDERATIONS

Information and the purpose of the study were given to participants by telephone and e-mail, consent forms were sent out for signature, and returned to the first author. Before each digital focus group interview participants were given oral and written information about the voluntariness of participation, stating that they could end their participation at any time without having to explain why. The Swedish Ethical Review Authority approved the study (2019–02651).

RESULTS

An overview of the participants' characteristics and information about the children's diagnoses is presented in Table 1. Following grounded theory methodology, in each category the general patterns of behavior, derived from our data, are first presented. Thereafter, together with quotes, the illustrations of the categories are explained by giving examples from parents' experiences.

This classic grounded theory study derives from the context of childhood cancer care when parents are experiencing moral challenges. The findings, based on the data obtained in this study, explain the main concern: “*To bring the child through a life-saving trajectory*” and how participants handle their

Table 1. Participant Characteristics.

Characteristics	Mothers		Fathers	
	n	%	n	%
<i>Parents age range</i>				
<30	-	-	-	-
30–39	2	15	1	14
40–49	8	62	4	57
50–59	2	15	2	29
>60	-	-	-	-
Not stated	1	8	-	-
<i>Relation to the child</i>				
Biological	13	100	7	100
<i>Child's age when diagnosed</i>				
<2 years	1	8	1	14
2–4 years	2	15	1	14
5–9 years	2	15	2	29
10–14 years	3	23	1	14
15–18 years	4	31	2	29
Not stated	1	8	-	-
<i>Time since the child was diagnosed</i>				
<3 months	-	-	-	-
3–11 months	5	38	2	29
1–2 years	7	54	3	43
3–5 years	-	-	1	14
>5 years/Relapse	-	-	1	14
Not stated	1	8	-	-
<i>Type of child's diagnose</i>				
Leukemia/Lymphoma	7	54	2	29
Solid tumor	5	38	2	29
Brain tumor	1	8	1	14
Not stated	-	-	2	29

N = 20 (Mothers *n* = 13, Fathers *n* = 7).

main concern by “*Sheltering in chaos*”. When sheltering in chaos: “*Balancing control*,” including “*Absorbing information*,” and “*Deliberating suffering*,” including “*Valuing the necessity of care actions*” are used as strategies. The consequences of “*Sheltering in chaos*” is the feeling of being “*Torn between roles*.” Moreover, during the analysis, an important variable affecting the ability to handle the main concern emerged; namely “*Familiarity*.”

Sheltering in chaos

“*Sheltering in chaos*” begins when life falls into pieces, resulting in chaos. Sheltering in chaos is about a perceived responsibility to guard one’s children in a chaotic situation which involves insecurity, unpredictability, and loss of control. “*Sheltering*” encompasses guarding one’s children from unpleasant experiences by deliberating on the right action to take.

In the current study, parents found themselves in a chaotic situation, with feelings of being powerless and dependent on a care organization with which they were unfamiliar.

...it was difficult ... you were completely out of your mind ... as there were so many impressions and so much that happened ... and there was chaos in the brain as well ... because my child ... oh crap my child has leukemia ... an illness which...kicks away everything in one’s world... (Father of a 13-year-old girl)

Parents were sheltering in chaos to resolve their main concern to bring the child through a life-saving trajectory. Parents viewed themselves as primarily responsible for the child’s well-being and guarding, even if they doubted what was best for the child. Parents felt responsible for making the right decisions for their child and to persevere and keep on going. In a condition of no choice and fear of the child dying, parents described how they constantly had to support and prepare the child for what would

happen throughout the trajectory. Parents also had to rely on care, even though they were uncertain about the outcome.

...But you're very much left to your own devices, because you're used to being the one who always makes decisions and looks out for the best interests of your child. And then suddenly you're the one who just goes along [with others' decisions], and it's very difficult. ... (Mother (A) of a 12-year-old boy)

To shelter in chaos, parents use various strategies, described in the following paragraphs.

Balancing control

Balancing control is about weighing various levels of control. While it is often impossible to have control of outcomes it can still be possible to control actions and behaviors. A high level of control means a high level of responsibility and a low level of dependence, while a low level of control means a low level of responsibility and a high level of dependence. When sheltering in chaos, the level of control over the child's care and treatment is balanced.

This means that parents sometimes needed to assume control over the child's care, and sometimes hand over the child's care to someone else. In our study, parents expressed how they balance the care responsibilities, and in different situations alternate between feelings of insecurity and security. Some parents expressed that they never could rest from care responsibilities due to fear that something would go wrong with the child.

...I mean the nurses didn't do it ... it probably made me not let go of control. ... so I won't give up until I know ... exactly everything and I want to keep the tabs ... (Mother of a 6-year-old girl)

Even if some parents were frustrated to hand over the responsibility and control of the child's care some parents found it liberating that the responsibility of decisions about the care and medical treatment were in the hands of the HCPs.

... Such a relief to just hand over everything ... they let me have the role of just being a mother. (Mother of an 18-year-old girl)

Moreover, handing over care could also be about handing over care to the other parent.

... I went out. ...dad had to take over. ...I couldn't see ...

(Mother (B) of a 12-year-old boy)

While the majority of parents expressed that they trusted the doctors and handed over the medical responsibility to them, as they possess the greater knowledge about childhood cancer, there were strong doubts among some parents. To balance control over the care situation, participants need to absorb the most relevant and important information for themselves and for the child.

Absorbing information

Absorbing information includes understanding and ensuring what was communicated. Absorbing can be hampered by internal factors such as fatigue, and external factors such as insufficient or overly large amounts of advanced information.

Parents in this study had difficulties knowing what was important and what they needed to act on. Difficulties of knowing was related to parents' emotional overload, lack of continuity with physicians, and an incredible flow of information, including unclear and differing information.

... I didn't really understand that, in the last phone call, then I call again and ask, and I check ... (Mother of a 6-year-old girl)

The uncertainty of not really understanding the information about illness and treatment that was given led to a search for information from other sources, such as another physician that the parents trusted.

...other [physicians] you had to interpret and pose a lot of questions to, we had one [physician] ... who was a practitioner. . .and he was very good but. . .he could talk for ten minutes. . .and then we had to go to another physician. . .to find out what it was that had actually been said. (Father of a 12-year-old boy)

Parents also needed to make sure that they had understood and not missed any information provided, which was managed by being able to read written information afterward.

Deliberating suffering

Deliberating suffering is about the choice to stand by and endure the suffering or to act in an attempt to stop it. Deliberating suffering involves feelings of helplessness, powerlessness, and emotional pain. This strategy is about deliberating both physical and psychological suffering during a life-saving trajectory.

Most often, parents endured the suffering because they knew the child needed to undergo certain painful procedures to survive. However, when procedures failed and were repeated several times, parents became insecure as to whether they should interfere. Common situations were when the child was exposed to physical restraint that involved HCPs performing procedures, including medication, nutrition, needle, or gastric tube insertion, against the child's will.

You know procedures must be done but it was horrible to watch.

(Mother (B) of a 12-year-old boy)

Parents also deliberate on how much they should endure regarding their child's psychological suffering; for example, whether they should defend the HCPs or interfere when the child's integrity and self-determination were curtailed. For example, when HCPs did not keep their promise.

... I tried to explain that it is clear that if you feel bad psychologically in connection with the treatment, it is also something that the healthcare should sort of find out in order to help. . .I tried to angle. . .but I agree with my daughter, it was a very careless choice of words to talk to my teenager in confidence and then suddenly all this is written in the journal.

(Mother to a 17-year-old girl)

When deliberating suffering, parents employ the strategy of assessing the necessity of particular care actions to which the child was exposed.

Assessing the necessity of care actions

This is about assessing whether the specific care actions performed are important and lifesaving or not, and accordingly, whether the actions should be questioned or not.

Parents in this study were uncertain about the necessity of some care actions but talked about the fear of deviating from care recommendations that could lead to the child's deteriorating health or even death. Parents found it hard to understand that painful, strenuous, and sometimes unnecessary care actions should be prioritized, such as physical therapy and needle insertions.

... it was so damn painful and at the end, they used the CVC [Central Venous Catheter] that she already had and decided that it was fine anyway. . .and then we felt like this: it is like unnecessary torture. (Father of a 4-year-old girl)

This strategy also includes balancing intervening in care procedures when parents perceived the time to be inopportune for the child. Parents questioned why more consideration was not given to the child's involvement in the care and the current well-being of the child; for example, why controls of vital parameters always had to be done at specific and less convenient times.

The above strategies emerged as facilitating "Sheltering in chaos," however a consequence of "Sheltering in chaos" is participants feeling torn between roles, as presented below.

Torn between roles

Being “torn between roles” is about overall reflection regarding the role as active or passive when facing moral challenges. Moreover, being torn between roles involves doubt as to which role should take precedence. Some roles could, to some extent, be imposed. Parents were torn between their caregiver role, which includes “nursing” and “medical responsibilities,” and their role as the sheltering parent, when involuntarily involved in treatment and care. This consequence arose both at the hospital and at home.

...it was a struggle in how much should I be a mother in this and how much a nurse in this... and if you cross any boundaries... (Mother (A) of a 12-year-old boy)

Parents in this study worried about not being able to cope with the tasks both emotionally and cognitively. In addition to the feelings of demands from healthcare, several parents also felt compelled to perform certain nursing tasks, such as dressing wounds or giving painful injections, because the child asked the parents to do it. In general, the parents felt that they were assigned different medical tasks, like one mother said:

...those wounds and wash them with like you sprayed with sodium chloride into these burrows... under the skin... to do it on your own child and being the one to perform this... is traumatic... but I steeled myself and did it for her sake, even though it was... yes, a nursing job obviously... (Mother of a 6-year-old girl)

Moreover, parents described how the “medical” responsibility of managing the medicines themselves at home, for example, caused fear of overdosing the child with potent drugs.

An influencing variable on parents’ ability to resolve their main concern “*To bring the child through the life-saving trajectory*” was familiarity.

Familiarity

Familiarity includes feeling familiar with the environment, the people in said environment, and with routines. Familiarity relates to feelings of belonging, kindness and intimacy between people and involves creating security and trust through relationships. Familiarity is influenced by continuity and predictability. In this study, familiarity was about HCPs’ responsiveness to the child and family. It also included a feeling that the whole family was welcomed and embraced in the care and given the opportunity to feel at home.

...I think what’s especially important is that you still feel like a family. And that you were...like you were in a home environment...it was important to feel that this is our space... (Mother (A) of a 12-year-old boy)

Parents in this study described that HCPs who spoke to the child in a personal way and asked about their family, school, and friends instead of just focusing on the illness and side effects, created a special sense of belonging. Several parents stated that it was important that HCPs fostered a special connection to the child.

... I thought most of the nurses were good at seeing the child... but there is a bit of a difference, you notice that they somehow connect a little more with the child and spread a sense of security in the way they act... (Father of a 17-year-old girl)

In the digital focus group interviews, parents explained that they felt togetherness and calm when the child was seen as both an individual and as an important part of the family. HCP’s warmth and sensitivity to the child, as well as the respect shown for the family’s needs in the hospital, were aspects that alleviated the degree of parental uncertainty. On the other hand, parents clarified that fewer feelings of familiarity and trust arose when there were many HCPs involved in care. Other reasons for feelings of unfamiliarity were when HCPs did not show professionalism, empathy, or interest, and when unfamiliar physicians conveyed misleading and sometimes difficult information. One example of HCPs not showing professionalism was when serious information about the child’s life-threatening illness was delivered in a thoughtless way and without having the time to evaluate reactions.

DISCUSSION

In this study, grounded theory methodology (Glaser, 1978, 1998) was used to understand parents' main concern and how they handle it when experiencing morally challenging situations in childhood cancer care. "Sheltering in chaos" emerged as a core category, as participants tried to resolve the main concern "To bring the child through a life-saving trajectory." The strategies of "Balancing control" and "Deliberating suffering" emerged, which led to the consequence of being "Torn between roles". "Familiarity" arose as an influencing variable.

The concept of "Sheltering" may be interpreted as an inactive action focusing on taking shelter from something. In an article exploring terminology within humanitarian aid, the definition of "sheltering" has recently been reviewed (George et al., 2023). The authors state that the concept's etymology has comprised a movement toward a wider definition, including, for example, reducing vulnerability and viewing care as a process. When analyzing the data, it became clear that "sheltering" in this study, means that parents are guarding their children from unnecessary suffering by deliberating on the right action to take. Furthermore, the emerging core category "Sheltering in chaos" is recognizable in previous research, where parents of children with cancer described their situation as chaotic, uncertain, and uncontrollable (Ångström-Brännström et al., 2015; Benedetti et al., 2014; Carlsson et al., 2019; Gunter & Duke, 2019). However, the results of the present study derive not only from the context of childhood cancer but also more specifically from morally challenging situations in this context.

In our study, parents used the strategies of balancing control and absorbing information. Similar to our study, other research has found (Kästel et al., 2011) that parents feel that insufficient information versus excess information, or information from "wrong" HCPs contributed to feelings of a loss of control and further increased feelings of chaos. Research also reports that parents needed and requested tailored and specific information to be able to absorb the information and handle the situation more wisely (Ljungholm et al., 2022). Moreover, in our study, parents reported the challenges of not knowing what information was relevant when they had to make a decision, which in a recent study was shown to lead to parental moral distress (Mooney-Doyle & Ulrich, 2020). It is important to consider parents' different resources and abilities to absorb and understand relevant information to prevent parental moral distress.

The results in our study indicate that the difficulty of balancing control in care is closely related to the responsibility inherited as a parent. To fulfill parental responsibility, the parents in our study tried to assume control of the chaotic situation that childhood cancer entailed, but were sometimes uncertain about how much control they should take on. Although parents are considered to be primarily responsible for the child's care (Molinaro & Fletcher, 2018), it is important to highlight that parents' burden of responsibility increases in connection with treatment-related deterioration (Tan et al., 2020).

In a study focusing on the child's perspective (Ygge & Arnetz, 2004), the results showed that children felt safe and that their perceived stress decreased when parents were involved in their care. This might be the reason why parents in our study performed various medical tasks, although they sometimes felt uncomfortable doing so. At the same time, parents often felt directed by HCPs to perform more or less advanced nursing tasks, which is congruent with results from Kästel and Enskär (2013). In situations like these, it is clear that parents have to balance the wishes from the child and the HCPs' directions, while coping with their own insecurities and fears, which can induce moral distress. This pattern of uncertainty among parents, related to the distribution of responsibility between parents and HCPs, has been discussed in other studies (Ljungholm et al., 2022; Young et al., 2002). Considering the families' different needs, it is of great importance that the families' wishes and expectations are clearly communicated between all involved stakeholders.

In a study by Hinds et al. (2009), parents were described as instinctively doing everything to guard the child by standing by the child's side and offering reassurance, affirmation, understanding, and support. This pattern of results is consistent with our findings. However, in the present study, parents

also doubted whether and how to guard the child from harm and discomfort when there seemed to be no alternative to suffering. It is most likely that parents knew that their child needed to endure unpleasant side effects and procedures in order to survive their cancer, which could be the reason why parents had doubts about whether to interfere with HCPs' care actions. The reasons for the parents' doubts seem to be driven by fear; that is, whether their actions could negatively affect the treatment's effects. Interestingly, similar concerns have been seen among HCPs, where they also doubt the necessity of certain care actions and hesitate to interfere with parents' choices in care (Weiner et al., 2022). However, the strain that suffering caused by the care entails, for both patients (Berglund et al., 2012) and for the parents in our study, risks becoming a troublesome problem that can persist over time. For example, psychological problems related to concerns about if right/wrong decisions were made. Furthermore, one can imagine the emotional stress parents experience when they feel that they are failing to shelter their child. Studies point to parents' struggle during the child's illness and treatment leading to varying levels of psychological distress (Carlsson et al., 2019; Schepers et al., 2018). Moreover, doubts concerning control and responsibility can be caused by parents' internal value conflicts about how a good parent should be and act. In a previous study in neonatal care, similar internal value conflicts in parents were described as a "moral schism" and involved different aspects of a sense of responsibility, a sense of coherence of the situation, and the level of support offered (Foe et al., 2018).

Familiarity emerged as HCPs' responsiveness to the child and family. Similar findings, such as care relationships and continuity with HCPs, influencing outcomes of care have also been described in other research (Engler et al., 2020; Fry et al., 2013; Heller & Solomon, 2005; Ljungholm et al., 2022) and are additionally described as a cornerstone for HCPs in pediatric palliative care (Schuetze et al., 2022), and it is not surprising that these aspects are also important when parents face moral challenges in the care of their children.

It is particularly important that HCPs in childhood cancer care have the competence to establish a trusting relationship with both the child and the parents, because individuals are generally fearful and suspicious of unknown people with whom they do not feel a sense of belonging (Klintman et al., 2019). Furthermore, parents have been found to experience the situation during the child's cancer treatment, as uncomfortable and unfamiliar (Skoutari et al., 2021). We reason that the caring relationship is also important, as it is essential for HCPs to be able to understand the patient's health experience and needs. We also believe that mutual trust facilitates almost everything in the care situation; above all it promotes communication and adherence to treatment and care. HCP's skills in building relationships with both the child and the family are comparable to what Fry and colleagues (Fry et al., 2013) describe as *compassionate care* and what Ekman describes as *person-centered care* (Ekman, 2022), which are central factors in providing ethically good care. Ekman argues that HCPs should have the ability to see the patient as a fellow human being and a partner and not as a passive object. Our findings regarding familiarity, and earlier research about closeness and distance in the caring relationship (Buder & Fringer, 2016) call for an awareness among HCPs of their own emotions and the need to maintain moral awareness in care relationships, which requires practice, competence, and confirmation.

From the findings in the present study, it is reasonable to assume that parents need psychosocial support, for example therapeutic conversations with a social worker or psychologist. This is consistent with previous literature demonstrating that parents need psychosocial support (Carlsson et al., 2019), which also is a standard recommendation in childhood cancer care (Kearney et al., 2015). It is especially important that HCPs and parents talk with each other after a procedure has been performed that included physical restraint or that caused suffering to the child. In addition to psychosocial support, clinical ethics support could be an additional way to support parents. Clinical ethics support entails different services for assisting stakeholders to cope and deal with moral challenges (Rasoal et al., 2017) and could be conducted through ethics rounds (Bartholdson et al., 2014; Molewijk et al., 2008) ethics consultants (Fournier et al., 2009) or ethics committees (Forde & Pedersen, 2011). For

example, inviting parents to participate in ethics rounds together with HCPs might be a way for both parents and HCPs to share their perspectives of values at stake in morally challenging situations and to feel listened to.

Study strengths and limitations

A strength of this research is the geographical spread and that it is not confined to only one institution, and that the results are represented by both mothers and fathers. However, we do not have any information on study participants' ethnicity. Being able to conduct focus group interviews via digital platforms made it possible for participants from different locations in Sweden to participate at the same time. However, there are certain limitations with digital focus group interviews, such as technical hassles and response latency i.e., delay of the sound that contributed to people sometimes speaking at the same time, which may have affected interactions between the participants. The participants in the digital focus group interviews were divided according to gender. Both positive and negative consequences of homogenous focus group interviews have been discussed in research (Nyumba et al., 2018). The reasons, for the choice of homogenous digital focus group interviews in this study, were to facilitate for the participants to share sensitive experiences related to the mother/father role.

CONCLUSIONS

When childhood cancer-related chaos occurs, it seems that the parents' basic protective and nurturing care for the child, according to our results, is somehow disrupted. It is clear that parents of children with cancer may doubt their responsibility in retrospect and wonder whether they should have interfered when their children were suffering. HCPs need to be aware that parents and children may need to talk about morally challenging situations that they and their child have experienced. This study shows the need of familiarity and continuity in care. The results also show that clear and tailored information is requested by the parents. In general, the results indicate that parents have a need for psycho-social and moral support in health care. To be able to handle moral concerns, parents might need forums in which they can reflect upon moral concerns that arise in care, and various kinds of support should be mandatory and therefore offered regularly. Future research is needed on how parents wish to participate in ethics support.

CLINICAL IMPLICATIONS

Knowledge of parents' experiences when facing morally challenging situations enables the development of targeted support to parents, for example offering adapted clinical ethics support as well as psychosocial support. When parents feel supported, their parental role will most probably be strengthened which in turn may promote their ability to handle difficult situations for their child and their family. We also believe that our results are relevant to HCPs that care for children and parents in various settings when children are seriously ill. When knowing, for example that parents deliberate suffering this can be addressed and reflected upon together with parents to reduce suffering.

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No potential conflict of interest was reported by the author(s).

DATA AVAILABILITY STATEMENT

Data are available on reasonable request.

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