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Healthcare Professionals' Perspectives on Ethical Challenges in Enrolling Children with Cancer in Research: Insights from Sweden

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Abstract

Conducting research is essential for improving treatment, survival, and quality of life in children with cancer, yet recruiting pediatric participants introduces distinct ethical dilemmas. This study aimed to explore the ethical principles and challenges healthcare professionals encounter when enrolling children with cancer in research within the Swedish healthcare context, as well as their perspectives on the role of research ethics competence in recruitment. A qualitative, exploratory approach was adopted, utilizing semi-structured interviews with key informants, including seven physicians and ten nurses. Data were analyzed using inductive qualitative content analysis. Healthcare professionals highlighted several ethical concerns during recruitment, including fostering trust and supportive relationships, providing clear and appropriate information, acknowledging the vulnerability of child participants, and balancing professional responsibilities with the interests of children and families. The development of ethical competence was emphasized, particularly regarding communication and interpersonal skills. The findings provide practical insight into the ethical considerations of recruiting children with cancer for research, emphasizing that recruitment is fundamentally relational, involving trust, relationship-building, and sensitivity to vulnerability alongside fulfilling informational needs. This study reinforces the importance of cultivating research ethics competence to ensure the protection of children's rights and welfare in pediatric research.

Keywords: Healthcare, Ethical challenges, Cancer, Sweden

Introduction

Annually, over 400,000 children worldwide are diagnosed with cancer, with "children" here referring to individuals from birth to 18 years of age. Advances in treatment have led to five-year survival rates exceeding 80% in high-income countries [1], yet childhood cancer remains a leading cause of mortality globally, with survival rates below 30% in low-income regions [1, 2]. Given the heterogeneity of this population, treatments and interventions must be specifically adapted to children's needs [3], and research remains essential to enhance treatment outcomes, survival, and quality of life [3-5].

Clinical trials play a critical role in evaluating new therapies for pediatric cancer, proceeding through successive phases: Phase I trials assess safety and side effects in patients often resistant to standard treatments, Phase II trials provide preliminary information on dosage, safety, and efficacy, and Phase III trials compare new treatments to standard care in large randomized studies [6]. Beyond clinical trials, nursing and psychosocial research is vital for supporting the long-term wellbeing of childhood cancer survivors [7, 8].

Recruiting children for research presents ethical challenges. The period following a cancer diagnosis is often characterized by family distress and medical urgency, complicating recruitment [9]. Children and parents may struggle to understand research information [9, 10], and ethical considerations must address

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vulnerability, which can involve limited capacity to consent, susceptibility to coercion or exploitation, and higher risk of harm [11].

Ethics is integral to healthcare professionals' (HCPs) training, professional competence, and healthcare legislation, as well as international ethical codes governing healthcare and research [12–16]. HCPs are morally obligated to act in the patient's best interest, upholding autonomy, integrity, and dignity, while also contributing to medical progress through research that safeguards participant welfare [16].

Enrolling children in research requires parental permission in addition to the child's assent [12, 16], with parents serving as surrogate decision-makers expected to act in the child's best interest [17]. In Sweden, children aged 15 and above can provide informed consent if they understand the implications of participation, though researchers must inform all children in an age-appropriate manner [14]. The United Nations Convention on the Rights of the Child, incorporated into Swedish law, guarantees children the right to participate in decisions affecting them [18].

Decision-making in pediatric care involves a triad of stakeholders—child, parent, and HCP—with potentially conflicting interests, creating ethical challenges [19, 20]. Research indicates that children often play a limited role in shared decision-making (SDM), with parents and HCPs making most decisions [19, 21]. Children's preferences for involvement vary, with some favoring minimal responsibility while others feel excluded when not involved [21–23]. Effective communication between patients and caregivers is essential to support children's and parents' engagement in SDM [24, 25]. The role of children in SDM for research participation is less explored than SDM for clinical care, but studies suggest that fostering trust, supporting developing autonomy, and facilitating communication with parents and HCPs are key [26, 27].

In pediatric oncology, research and care are often intertwined, yet ethical distinctions remain: care aims primarily to benefit the child, whereas research seeks to improve outcomes for future patients [28]. Children and parents may not differentiate research from treatment, sometimes assuming therapeutic intent—an issue known as the 'therapeutic misconception' [10, 28, 29]. HCPs in pediatric oncology frequently navigate dual responsibilities, balancing clinical care and research duties [13, 30]. These overlapping roles can create conflicts in values and responsibilities during recruitment [28]. Swedish research indicates that HCPs may adopt paternalistic approaches in recruitment to shield families from psychological stress, which can, however, restrict children's autonomy in research-related decisions [31].

As childhood cancer research progresses, careful attention to ethical issues becomes increasingly critical [4]. Investigating the challenges of recruiting children from the perspective of healthcare professionals (HCPs) is particularly important, as they are responsible for upholding ethical standards in research and protecting the rights of pediatric participants. Additionally, exploring these perspectives can support the development of ethical competence among HCPs [32].

In Sweden, few studies have addressed the ethical challenges involved in recruiting children with cancer, with the exception of Schröder Håkansson *et al*. (2020), who examined HCPs' perspectives on two key ethical principles—respect for autonomy and non-maleficence—alongside conflicts arising from their dual roles [17, 31]. This study adopts a wider ethical lens, incorporating ethics of care and virtue ethics. Ethics of care emphasizes relational and social dimensions, highlighting vulnerability, dependency, and interactions between key stakeholders [33, 34], which can provide insight into power dynamics, caring values, and interpersonal aspects of recruitment [35]. The concept of relational autonomy frames decision-making as a socially and emotionally influenced process, which is especially relevant in pediatric settings [36, 37]. Virtue ethics, focusing on moral character and professional values such as honesty, is closely linked to ethical competence [38, 39]. While empirical research on HCPs' views of ethical competence in pediatric research recruitment in Sweden is limited, prior reports suggest a need for additional ethical support [40–42]. This study represents empirical ethics by combining qualitative interview data with normative ethical reflection [43].

Aim

The primary objective of this study was to examine ethical values and challenges encountered by HCPs when recruiting children with cancer for research in Sweden. A secondary objective was to explore how HCPs perceive and understand ethical competence in the context of pediatric research recruitment.

Materials and Methods

Design

A qualitative descriptive approach was employed, following the Consolidated Criteria for Reporting Qualitative Research (COREQ) [44].

Recruitment and participants

Participants were purposively selected from four Swedish childhood cancer care centers, a nursing professional network, and research groups at Swedish universities. Key informants were defined as individuals with substantial expertise and engagement in the research topic [45]. The sample included seventeen HCPs—seven physicians and ten nurses—all with experience in recruiting children for medical or psychosocial research. Roles represented were principal investigators (n = 7), clinical research nurses (n = 4), care staff assisting with recruitment (n = 1), and academic researchers conducting pediatric cancer studies (n = 5). Participants included three men, thirteen women, and one non-binary individual, with most (n = 14) having over ten years of experience in childhood cancer research (range 2–30 years). The mean age was 54 years (range 39–68 years). Sampling sufficiency was guided by the concept of information power, taking into account study aims, sample specificity, theoretical framework, dialogue quality, and analytic strategy. Participants received information about the study via email and provided written consent electronically or by post.

Data collection

Semi-structured interviews were conducted by KN via Zoom in 2021, ranging from 40 to 52 minutes (average 46 minutes). The interview guide, developed by authors experienced in pediatric care, qualitative research, and research ethics, encouraged participants to share experiences, reflections, and examples related to recruitment. Interviews included prompts and follow-up questions, and pilot testing with one physician and one nurse resulted in an additional question addressing factors that facilitate informed consent; data from pilot interviews were included in the analysis. Interviews were audio-recorded and professionally transcribed verbatim. Participants provided demographic details (age, gender, role, education, clinical and research experience), though only selected information is reported to protect confidentiality.

Data analysis

A qualitative content analysis was conducted in accordance with Graneheim and Lundman (2004) [46]. This method was selected because it enables the exploration of both variations and commonalities in participants' experiences while maintaining sensitivity to the topic and its contextual nuances [46]. Given the scarcity of prior research on this subject in Sweden, an inductive approach was employed to preserve the authenticity of participants' accounts.

The analytical process began with repeated readings of the interview transcripts by KN to gain deep familiarity with the data. For the first three transcripts, KN and SFH independently identified meaning units relevant to the study aims, then compared their selections; only minor differences emerged. KN subsequently extracted and condensed meaning units from the remaining transcripts, retaining their core meaning, and assigned initial codes that stayed close to the original text. The coding and categorization were primarily led by KN in collaboration with SFH, but all four co-authors regularly discussed the evolving codes. Codes were grouped and compared based on similarities and differences, leading to the development of preliminary categories and subcategories, with emphasis placed on manifest content. The analysis was iterative, moving continually between the raw transcripts, codes, and emerging categories.

The evolving category system was repeatedly discussed among all co-authors and refined until full consensus was achieved. The first author (KN) has formal training in qualitative methods and qualitative content analysis, while SFH, ATH, and TG possess extensive experience in qualitative research and supervision of qualitative studies. NVivo 1.3 (QSR International, 2021) and Microsoft Excel were used to support data management and analysis. Illustrative examples of the analytical process are provided in **Table 1**.

Table 1. Examples from the analysis process

Meaning unit	Condensed meaning unit	Code	Subcategory	Category
It is not certain that children's perspectives align with their parents'… during discussions near the end of life with terminally ill	Children's viewpoints can diverge from parents, especially in end-of-life situations	Divergent parent-child perspectives	Conflicting views	Balancing roles and interests

children, differing opinions are even more pronounced.				
Many research studies begin at the time of diagnosis, when families are already experiencing confusion and distress. Even with ethical approval, the volume of study information can overwhelm families in crisis.	Families can feel swamped by information at diagnosis	Overwhelming study information	Information overload at diagnosis	Meeting informational needs

Results and Discussion

This section presents healthcare professionals' (HCPs) experiences and perspectives on involving children with cancer in research, focusing on ethical considerations, challenges, and their own ethical skills. Recruitment was not uniformly seen as ethically problematic; for some participants, the process was experienced as routine and manageable. Many HCPs had substantial experience in enrolling children in research and expressed confidence in handling ethical issues when they arose. However, in line with the study's focus, the results emphasize instances that the HCPs identified as ethically difficult. Analysis yielded five overarching categories: Establishing relationships and trust, Meeting informational needs, Acknowledging vulnerability, Balancing roles and interests, and Ensuring ethical competence, each containing several subcategories **(Table 2).** The following sections explore these categories in depth, illustrated with quotes, while acknowledging that the categories sometimes intersect.

Table 2. Overview of categories and subcategories

Categories	Subcategories
Establishing relationships and trust	Developing connections
	Navigating trust-related dilemmas
Meeting informational needs	Customizing information and communication
	Overload of information at the time of diagnosis
	Challenges arising from language differences
Acknowledging vulnerability	Dependence on parents
	Power imbalances and conflicting interests
	Children facing a poor prognosis
Balancing roles and interests	Upholding children's rights
	Children delegating decision-making
	Parental authority and associated responsibilities
	Conflicting opinions
Ensuring ethical competence	Understanding and applying ethical competence
	Developing skills in research ethics

Establishing relationships and trust

Many healthcare providers (HCPs) emphasized that cultivating mutual trust and strong relationships with families is essential for recruitment, though high levels of trust can complicate obtaining truly informed consent. This theme includes two subcategories: Building Relationships and The Dilemma of Trust.

Developing connections

HCPs highlighted the need to connect with families before inviting a child to join research studies. Engaging in casual conversations about everyday topics helped establish trust with both children and parents and facilitated discussions about research:

"It's crucial to form some kind of connection with the family first, otherwise these conversations aren't possible; it's about them being willing to trust you and building that trust." (Nurse 1)

They explained that these relationships allowed them to judge whether it was appropriate to approach a family about research and helped identify ethical challenges:

"When you know the family and have a relationship with them, you can see if it's actually feasible to ask them about participating in research." (Nurse 8)

However, some families were harder to engage, particularly those who had lower trust or were upset following a child's diagnosis. COVID-19 restrictions, which reduced face-to-face care contacts to limit infection risks, also made relationship building more difficult, especially for research nurses who did not have direct care responsibilities.

Navigating trust-related dilemmas

HCPs described that most parents placed high trust in healthcare providers and research, generally agreeing to participate when asked. This positive attitude was linked to broad societal awareness in Sweden about the importance of childhood cancer research. Yet, some parents, often foreign-born, were perceived as less trusting and more hesitant to enroll, which HCPs attributed to concerns about authorities, confidentiality, or fears of exploitation.

While HCPs appreciated this trust, they also recognized it as a challenge for ensuring informed consent:

"It's a dilemma that many families simply follow our guidance…they trust the healthcare system a lot…most parents do as we suggest…if you just ask for consent, you will likely receive it." (Physician 7)

HCPs were concerned that consent might not always be fully informed and often needed to encourage parents to receive sufficient information rather than agreeing immediately based on trust. One HCP described the conflict between respecting a family's wish to limit information and fulfilling the ethical requirement for informed consent:

"Many parents tell me they can't take any more information and just want to sign…they trust us to make the best decisions, but we have to ensure informed consent. At the same time, you have to respect when they say they don't want more details right now but still want to consent. You can't overwhelm them with information against their will." (Physician 4)

Meeting Informational Needs

Healthcare providers (HCPs) emphasized the importance of delivering information in a way that meets families' specific needs, enabling them to make informed decisions and understand the situation. They encountered challenges such as overwhelming families with information or facing language barriers. This theme is divided into three subcategories: Tailoring Information and Communication, Information Overload at Diagnosis, and Language-Related Challenges.

Customizing information and communication

HCPs underlined the need for adaptable communication that responds to the family's and child's level of understanding. Providing children with age-appropriate explanations was considered essential:

"We consider the whole family and make sure the children also get information. It's very important they are included because they are the ones experiencing the illness and treatment." (Nurse 3)

They highlighted that conversations should be respectful, culturally sensitive, and attentive to nonverbal signals, such as avoiding dominating the child physically or verbally. HCPs aimed for interactive, dialogue-driven communication, combining verbal explanations with written materials, while continuously checking that families understood the information.

HCPs also stressed that discussions about research must not overshadow understanding of the child's illness or treatment, and that families should clearly recognize the difference between participating in research and receiving standard care. Some HCPs noted that misunderstanding this distinction—sometimes called the 'therapeutic misconception'—could occur not only among families but also among healthcare staff:

"It's often on us if we fail to clearly distinguish research from treatment, and then families may not grasp the difference. Some children and parents may go through cancer therapy without really thinking about this distinction." (Nurse 7)

Finally, HCPs emphasized making the voluntary nature of research participation explicit:

"What matters most is that families understand participation is voluntary. They are involved in many studies, and saying no can be difficult. These patients often appreciate all that is being done for them." (Nurse 6)

Overload of information at the time of diagnosis

Recruiting families for research close to the time of diagnosis was perceived as highly challenging. HCPs expressed concern about overwhelming families who were already emotionally strained and confronted with complex decisions:

"Families are inundated with information and often emotionally shut down after the diagnosis. Everything comes at them at once—it's like an avalanche of information." (Physician 7)

Participants reflected on the tension between the importance of pediatric research and the potential strain it places on families:

"If pediatric oncology treatments could progress without studies, it would be ideal, and families wouldn't have to carry this burden…But we also have a responsibility to improve treatments, safety, and survival, which makes research necessary." (Physician 2)

HCPs described delaying or avoiding recruitment when they perceived families as too burdened to engage meaningfully, though sometimes study enrollment could not be postponed, making early recruitment ethically difficult:

"Families really need more time so they aren't so overwhelmed by their diagnosis and everything else happening around them. The hardest part is that inclusion, and sometimes even randomization, has to happen very early." (Physician 7)

They also noted that legal requirements, such as lengthy, formal study information sheets, added to the information burden and could hinder informed decision-making. Challenges increased with the number and complexity of studies, uncertainty about participation outcomes, and cases where treatment initiation depended on study enrollment. Studies such as randomized controlled trials, phase I drug trials, and genetic studies were seen as particularly demanding due to their complexity and uncertain implications.

To ease the burden, HCPs suggested strategies including stepwise recruitment, repeating information throughout the study, using broader consents covering multiple related studies, and coordinating research efforts at the organizational level to minimize family strain.

Challenges arising from language differences

HCPs emphasized their responsibility to provide clear, tailored information to ensure families' understanding. Communication challenges arose when using interpreters or interacting with non-native speakers, compounded by the lack of study materials in many languages:

"If a family comes from abroad…there's often nothing to give them, which I see as a major problem…They usually consent, but I don't think they fully grasp what they are signing up for." (Nurse 3)

"I don't understand why consent forms aren't available in different languages, especially in a multicultural country…We can't include only people who speak Swedish or English." (Nurse 2)

HCPs were concerned that non-Swedish-speaking families risked exclusion or misunderstanding in research participation. Despite these barriers, they made concerted efforts to support decision-making and ensure families received the necessary information.

Acknowledging vulnerability

The analysis identified multiple recruitment challenges linked to the vulnerability of both children and their parents. This category includes three subcategories: Parent-Dependency, Power Asymmetries and Conflicts of Interest, and Children with a Poor Prognosis.

Dependence on parents

HCPs described how a child's vulnerability and need for support after a cancer diagnosis can increase their reliance on their parents. This dependency may affect informed consent, making it harder for children to voice their own opinions or question parental decisions:

"To feel as secure as possible, they want to align with their parents… Sometimes you wonder what the child would decide if the parents weren't present." (Nurse 1)

Participants emphasized the importance of speaking with older children and adolescents separately from their parents to ensure their views are heard independently.

At the same time, parents' ability to make decisions was sometimes limited by emotional distress, including grief, desperation, or anger. One HCP noted that highly distressed parents might consent to research more readily or feel an implicit pressure to enroll:

"They are so shocked and traumatized. It's easy for them to end up in a subordinate position because they lack the strength to resist or question…so they might just consent, trying to do what they believe is best for their child." (Physician 3)

Additional factors such as psychological difficulties, intellectual disabilities, social challenges, or lower educational levels were described as further increasing vulnerability in decision-making.

Power imbalances and conflicting interests

HCPs highlighted their ethical commitment to advance treatment for children with cancer through research, while also valuing voluntariness and avoiding undue influence in recruitment. This sometimes created tension between protecting the child's interests and personal or professional interests in successful recruitment:

"If you are responsible for a study, you want to include as many participants as possible. You also think about

your reputation among colleagues…there's a lot at stake linked to our own ambitions for research success, which constantly creates dilemmas." (Physician 2)

Participants acknowledged that their knowledge of persuasive communication—for example, emphasizing past research successes that have significantly reduced childhood cancer mortality—could unintentionally increase pressure on families:

"With experience, you could persuade anyone to enroll…which puts you in a position of power. Especially with your own study, you want everyone to participate…you aim to be objective, but no one is completely impartial." (Physician 6)

HCPs also noted that the rarity of childhood cancer cases created high competition for recruitment, further complicating ethical considerations and contributing to potential conflicts of interest.

Children facing a poor prognosis

Recruitment was generally perceived as less ethically challenging when the child was relatively stable during the early stages of illness. However, HCPs expressed particular concern for children with a poor prognosis or those experiencing relapse, especially when considering participation in experimental, early-phase I trials. They described the emotional and ethical difficulties involved in approaching these families:

"These conversations are extremely hard because we first have to tell families that their child has a pontine glioma and is unlikely to survive, and then ask if they want to join a study… It's always painful to witness the parents' profound sadness, and it can be very challenging to convey information without raising false hopes." (Nurse 1)

HCPs emphasized the need for honesty and transparency regarding the limited evidence supporting treatments in early-phase trials. They also highlighted the importance of clearly presenting palliative care as a valid option, managing expectations, and respecting the child's wishes for how to spend their remaining time. According to the informants, children facing a poorer prognosis should have greater input in decision-making. Similarly, HCPs considered it inappropriate to involve children with limited survival chances in long-term follow-up studies or subject them to additional medical procedures when the likelihood of benefit is minimal.

Balancing roles and interests

HCPs described the complex task of balancing the roles and interests of children and parents in research decision-making. This category includes four subcategories: Asserting Children's Rights, Children's Delegation of Decisions, Parents' Decision Authority and Burden, and Disagreements.

Upholding children's rights

HCPs emphasized children's perspectives and rights as central to recruitment, striving to ensure children were informed and that their views were acknowledged. Even very young children were included in discussions about research, reflecting their right to information. HCPs underscored that research should respect the child's terms and holistic best interest, beyond merely matching study eligibility:

"You have to think about why this child should be included in a study. For whom is it beneficial? It's not enough to say the child fits the study; you need to consider the whole child…Not all children can take part in phase I trials, and some choose not to based on what they want from their lives." (Physician 5)

The child's role in decision-making was influenced by factors such as health status, age, maturity, personality, cognitive skills, and developmental abilities. HCPs therefore evaluated maturity on a case-by-case basis:

"You have to assess the degree of maturity of each child. It's usually less about age and more about personality…You need to understand the child's ability at that stage." (Physician 6)

Involvement also depended on the child's preferences, the type of study, and potential risks, with children having longer disease histories generally regarded as more capable of contributing to decisions.

Children delegating decision-making

HCPs noted that children often aligned with their parents' preferences during recruitment. However, in low-risk studies, such as psychosocial or psychometric research, children were typically more engaged. Due to the physical and emotional demands of cancer, many children delegated decisions to their parents:

"Many teenagers don't care; they don't read the forms. They've been removed from school, have no friends, are hospitalized…They face life-threatening diagnoses, hair loss, and potential infertility. So, studies are left to their parents. Out of panic or trust, you can't always tell." (Physician 2)

Parental authority and associated responsibilities

Parents generally made enrollment decisions on behalf of their children, especially for medical studies, often regardless of the child's age:

"In most cases, the parents simply decide, regardless of how old the child is." (Physician 2)

Parents' attitudes and behavior shaped children's opportunities to participate, with some involving their child while others dominated decisions, either to protect the child or assuming decision authority:

"Parents handle these situations very differently. Some involve the child, asking their opinion, while others decide on their own." (Physician 5)

HCPs saw it as their responsibility to balance child and parent roles, including addressing the child directly. They also recognized the emotional burden on parents, who often feared causing harm or regretting decisions, sometimes consenting primarily out of fear of negative consequences.

Conflicting opinions

HCPs reported encountering conflicts over study enrollment, either between parents or between parents and the child, particularly for early-phase I and mid-phase II trials. Disagreements often arose when parents wanted experimental treatments or to benefit future children, whereas the child wished to decline:

"At the end of life, opinions differ…Parents often feel that if participation can help someone else, it should be done. But for their child, there's only potential side effects." (Physician 6)

HCPs stressed that children should not be forced into research, prioritizing their best interests over study participation. In cases of disagreement, they generally considered it better not to enroll the child, and emphasized attending to subtle signs of a child's reluctance throughout the research process:

"We need to be attentive, because sometimes the parents want it, but the child doesn't—either due to lack of strength or having had enough." (Nurse 5)

Ensuring ethical competence

HCPs reflected on what constitutes ethical competence in the context of recruiting children for research, as well as their needs for ethical support and collegial dialogue. This theme comprises two subcategories: Perceptions of Ethical Competence and Building Competence in Research Ethics.

Understanding and applying ethical competence

Ethical competence was described as a combination of clinical skills, scientific knowledge, formal ethics education, and experience from clinical practice. Additional competencies included understanding children's cognitive development and psychological needs. Many HCPs emphasized personal qualities such as empathy, attentiveness, and communication skills:

"The most important thing is to be responsive and try to gauge how much and what type of information this family needs in this particular situation." (Physician 5)

"We often focus on informing, but I think listening is the key skill…Did the family understand my explanations? How did they receive my suggestions?" (Physician 2)

Other valued traits included calmness, honesty, sensitivity, and self-reflection. Collaboration was also seen as essential, for example having both a nurse and physician present during consent discussions to ensure no information is overlooked. Time limitations were acknowledged as a challenge to ethical recruitment, making sufficient time a critical factor.

Developing skills in research ethics

While HCPs generally felt confident and ethically capable in recruiting children with cancer for studies, they emphasized the importance of avoiding complacency. Recruitment was viewed as ethically demanding, requiring ongoing reflection, dialogue, and skill development.

HCPs described opportunities for collegial ethical discussions through both formal ethics rounds and informal conversations. While the ethical climate was seen as generally open, discussions often focused on immediate clinical care rather than research ethics. Given that medical advancements rely on clinical research, HCPs highlighted a need to strengthen competence in research ethics at both individual and organizational levels:

"Research ethics issues are not really emphasized. We need to discuss them more. Our treatment success depends on these studies…We can persuade parents to almost anything, and that's problematic." (Physician 2)

Additionally, HCPs identified a need for specialized ethical knowledge for certain study types, such as genetic research and phase I drug trials, to better navigate the unique challenges these studies present.

This study underscores the wide range of ethical challenges HCPs encounter when recruiting children with cancer for research. Participants reported ethical concerns and values connected to trust, vulnerability, power dynamics, and the negotiation of roles between parents and children in shared decision-making (SDM). Consistent with Schröder Håkansson *et al*. (2020), HCPs described conflicts between their responsibilities to provide care and obligations to conduct research [31].

Recruitment was depicted as a relational process, shaped by interdependence among the child, parents, and HCPs. Building trust and relationships with families was seen as essential for ethically sound recruitment. Such relational work is fundamental to pediatric SDM and underpins high-quality care [47, 48]. HCPs also noted instances of parental mistrust, particularly among foreign-born families, which aligns with prior studies showing that trust may vary initially due to factors like vulnerability, fear of discrimination, dependency, or language barriers [49]. Trust must often be nurtured over time and maintained through ongoing interactions characterized by honesty, empathy, and sensitivity [50, 51]. Beyond its instrumental role in facilitating SDM and care, trust is considered morally valuable in itself within ethics of care frameworks [34].

Trust-based consent emerged as a key ethical concern, reflecting the tension between meeting formal informed consent requirements and respecting parents' wishes to rely on trust rather than detailed information. Echoing O'Neill, an exclusive focus on information risks neglecting the ethical significance of trust [52]. Kongsholm and Kappel (2017) argue that trust-based consent can be ethically acceptable and compatible with autonomy, provided there are robust systems of oversight and accountability [53]. Empirical research also confirms trust as central to consent in pediatric healthcare research, strongly influencing families' decisions to participate. Yet trust can carry risks, as families may underestimate potential harms or burdens associated with research [50]. While HCPs are ethically obligated to support autonomy through the provision of information, families are not required to exercise their autonomy in any specific way; trust-based consent can itself be an expression of autonomous choice [17]. Nonetheless, parents may have ethical responsibilities to make informed decisions that safeguard their child's best interests. The complexity of trust-based consent in pediatrics highlights the need for further normative and conceptual inquiry.

HCPs in this study actively sought to support autonomy by addressing the informational needs of children and parents. Consistent with previous research, they emphasized child-centred practices, provision of high-quality information, and effective communication [25, 54, 55]. Such practices help children feel respected, safe, and empowered [24]. Aligning with findings in pediatric oncology care, participants highlighted the importance of empathy, honesty, and communicative competence [56]. Challenges included the family's emotional distress at diagnosis, as well as language and cultural barriers, which are known obstacles to effective communication [31, 57].

Power imbalances in recruitment posed significant ethical challenges. While HCPs were committed to advocating for children's rights, they sometimes acted in alignment with their professional interests as researchers, aiming for scientific outcomes and professional recognition. The participants emphasized trust, neutrality, and voluntariness as essential ethical principles in recruitment, yet expressed concern about unintentionally influencing families' decisions. Ethical tensions could arise both between parents and children, and between the dual obligations of HCPs to provide care and conduct research, potentially creating conflicts between adhering to study protocols and addressing patients' immediate care needs, consistent with findings by Larkin *et al*. (2019) [58].

Vulnerability in recruitment can be understood as either inherent or situational. Inherent vulnerability refers to universal human susceptibilities, such as those associated with childhood or illness, while situational vulnerabilities arise in specific contexts, such as during informed consent. Evaluating the intersections of children's and parents' vulnerabilities on a case-by-case basis may help identify families at particular risk [9, 59-61]. Vulnerability is not an inevitable aspect of being a child in research, and both HCPs and parents play crucial roles in mitigating it by attending to children's needs and perspectives [62].

Psychological vulnerability among children and parents following a cancer diagnosis is well documented [9, 63, 64]. HCPs may question whether parents are capable of safeguarding their child's best interests in SDM when confronted with complex study protocols [60]. Parents can experience decision-related stress and decisional regret [65], and their vulnerability may in turn contribute to children's vulnerability due to parental decision-making authority [66]. This study provides concrete

examples of how such vulnerabilities affect informed consent and assent, highlighting the emotional and cognitive dimensions of SDM under conditions of psychological and existential distress. Supporting children and parents in these circumstances may be essential for promoting autonomy [67], and strengthening parents' capacity to protect their child's best interests can reduce the child's vulnerability [66].

HCPs frequently framed their approach from a children's rights perspective, seeking to involve children in the information and decision-making process. Nonetheless, many children were not active participants and often delegated decisions to their parents. Children were generally more engaged in minor, low-risk decisions, aligning with previous research [25, 67]. These findings are consistent with prior qualitative and observational studies examining assent processes in pediatric oncology [21, 68]. A key challenge identified was balancing the roles of parents and children in SDM, particularly when disagreements arose, such as in the context of phase I trials. HCPs viewed protecting the interests of terminally ill children as paramount, guided by the principle that research must not override the child's best interests [16]. However, the interpretation of this principle is sometimes ambiguous [69], especially for early-phase trials that are unlikely to offer direct benefit to individual participants.

Traditional biomedical ethics emphasizes respect for individual autonomy, focusing on self-determination and independent decision-making [52]. However, such conceptions of autonomy are insufficient for capturing the collaborative nature of SDM involving pediatric patients, parents, and HCPs in research contexts. A relational perspective on autonomy is more applicable, recognizing that children and families are embedded in social networks and that their choices are shaped by relationships with trusted others. Relational autonomy, a core concept in ethics of care, views social connectedness not as a limitation of autonomy but as a meaningful and voluntary dimension of decision-making [36].

Our findings suggest that understanding the ethical challenges in recruiting children with cancer for research requires a broader approach than the traditional four-principle framework [17]. The relational aspects of recruitment identified in this study indicate that HCPs predominantly applied ethics-of-care reasoning. Consistent with prior qualitative work, the participants emphasized sensitivity and the protection of vulnerable individuals as central to ethical competence [70], reflecting a virtue ethics perspective [39]. This focus on moral character aligns with earlier research in which HCPs viewed ethical competence as primarily grounded in virtues [71]. Additionally, the HCPs' conceptualization of ethical competence corresponds with Eriksson *et al*.'s (2007) triad of "doing," "being," and "knowing," encompassing adherence to research ethics standards ("knowing"), cultivation of professional virtues and engagement in ongoing ethical reflection ("being"), and the ability to implement ethical decisions in practice ("doing") [38]. Participants also highlighted the need to further strengthen research ethics competence at both individual and organizational levels to ensure adherence to ethical standards in pediatric oncology research recruitment.

Strengths and limitations

The study included HCPs from four pediatric oncology centers, most of whom had extensive experience with recruitment, supporting strong sample specificity [72]. However, male HCPs were underrepresented (17.6%), and two centers were not included. Demographic details were selectively reported to preserve confidentiality, which may limit generalizability, and findings may not fully transfer to settings with different organizational structures. Comparisons between nurses' and physicians' perspectives were beyond the scope of this study.

An inductive, manifest content analysis was employed to preserve authenticity, with collaborative coding used to enhance analytic rigor [46]. Nonetheless, qualitative analysis inherently involves interpretation, and results represent probable meanings from a specific perspective [46, 73]. The interviewer (KN) has a background in psychology rather than pediatric oncology, which may have limited contextual familiarity but reduced the risk of imposing preconceptions.

Conclusion

HCPs frequently encounter ethical challenges when recruiting children with cancer for research. This study highlights recruitment as a relational process, in which trust, mistrust, and relationship building are key considerations alongside addressing families' informational needs. Psychological vulnerability and the burden of information can influence decision-making. Supporting the autonomy of children and parents in SDM may require not only providing information but also addressing psychological concerns to reduce decision-related stress. HCPs generally adopted a children's rights

perspective and aimed to facilitate children's active participation in SDM. Nevertheless, balancing the roles of HCPs, children, and parents can be difficult due to conflicting interests, power imbalances, and dependency. Recruiting children with cancer is ethically demanding and requires sensitivity, interpersonal skills, and effective communication. The findings underscore the importance of building competence in research ethics, particularly in complex areas such as genetic studies and early-phase trials. Further conceptual and normative research is warranted to explore issues including trust-based consent, relational autonomy, and situational vulnerability.

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Ethics Statement: According to Swedish legislation, a formal approval from the Swedish Ethical Review Authority was not required. The project was however presented to the Swedish Ethical Review Authority, who waived ethical approval without objections (no. 2021 − 00570). Ethical requirements, as outlined in the Declaration of Helsinki, were followed. Participants were given written study information, and were informed about voluntariness and confidentiality, and provided written informed consent. Data was treated confidentially, and kept pseudonymised. All personal identifiers have been removed in the paper to prevent identification of personnel and their workplaces.

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