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A qualitative study through the lens of compassion

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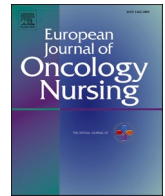
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Health professionals' presence and attributes in connecting with parents of children with cancer: A qualitative study through the lens of compassion

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ABSTRACT

Purpose: Throughout a child's cancer treatment, health professionals (HPs) constitute an important source of support for the entire family. However, the understanding of their presence and essential attributes is unclear. This study explored HPs' presence and attributes in connecting with parents and identified facilitators and barriers for connectedness.

Methods: This qualitative study was undertaken in a compassion paradigm, designed and guided by Heidegger's and Gadamer's philosophical concepts, and employed compassionate methods. Data were generated through ethnographic fieldwork (144 h), parent interviews (n = 16), and focus group interviews with parents of cancer survivors (n = 2) and HPs (n = 3). Inductive content analysis was utilised to analyse data.

Results: Many HP-parent contacts developed into close, genuine connections based on HPs' great commitment and ability to balance the act of closeness and distance. This involved HPs' sensitivity, humanity, humility, honest communication, genuine interest, and high clinical competencies; all promoting trust. Adapting and ending close relationships when approaching the end of treatment had little attention and was difficult for families, making some find ways of keeping contact on a personal level. Barriers disclosed were structural work changes, busyness, dishonest, poor, or lack of communication, and poor or lack of interpersonal chemistry.

Conclusion: Human interconnectedness is powerful in long-term professional relationships and strengthens the parents. More research and clinical attention are needed to develop the understanding and help target actions toward building, maintaining, and ending relationships. Further, cultivating being present in the moment, through mindfulness and compassion, may support HPs in maintaining a receptive mind and a caring role.

1. Introduction

Caring for a child or adolescent (hereafter collectively referred to as 'children') with cancer is an extremely demanding and emotionally exhausting task (Hopia and Heino-Tolonen, 2019). The disruption of daily, social, and family life, new roles and responsibilities, and fears of

losing their child burden the parents (Carlsson et al., 2019; Mu et al., 2015). Parents often feel lonely and isolated from others, including family members, due to geographical separation during their child's treatment (Darcy et al., 2014; Nielsen et al., 2024). Care and compassion are necessary for parents to maintain daily life and emotional functioning, and to support their ill child and other family members

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(Kearney et al., 2015; Perez-Bret et al., 2016).

Health professionals (HPs), particularly nurses, play a crucial supportive role, often becoming the ones who understand when most others do not (Nielsen et al., 2024). Their approach to parental care and support evolves throughout a child's treatment to meet changing needs and shapes how parents perceive both the care they receive and their roles as caregivers (Costa, 2023). In long-term care relationships, nurses and parents often develop close connections, making it essential to deepen our understanding of how this connectedness is managed (Brimble et al., 2019). The concept of nursing presence is central to this dynamic and refers to nurses' physical, psychological, and spiritual engagement with the families. This is characterised by being fully attentive and interconnected (Mcharo et al., 2023). Nurses' presence and compassion promote positive relationships, health outcomes, and satisfaction for both the families and themselves (Mcharo et al., 2023; Sinclair et al., 2021).

Central to this form of care – compassionate care – is emotional and relational understanding (Sinclair et al., 2021), which is grounded in the notion that suffering is inevitable and universal to human existence (Feldman and Kuyken, 2011). Suffering thus constitutes a shared human condition (Feldman and Kuyken, 2011), highlighting human interconnectedness and mutual vulnerability (Dong, 2020). As such, compassionate care is considered high-quality family care (Thienprayoon et al., 2020) and has, as a means of self-care, been linked with reduced loneliness and hopelessness in parents of children with cancer (Khosrobeigi et al., 2022). However, the understanding of HPs' presence and essential attributes in the context of long-term childhood cancer care is limited, pointed out specific to nursing (Mcharo et al., 2022). Therefore, the aim of the current study was to deepen our understanding of HPs' presence and attributes in connecting with parents during their child's treatment and to identify facilitators and barriers for connectedness.

2. Methods

2.1. Design and framework

This qualitative, descriptive study is the second in a series of studies from the Compassion in Childhood Cancer Care (CCCC) project, aiming to optimise patient trajectories. The CCCC project hypothesises that enhancing parental care and self-care abilities can improve parents' capacity to care for their ill child and family, with HPs' receptivity and presence being central to these processes. In addition to this paper, the study reports findings on family support systems (Nielsen et al., 2024) and HPs' suffering and resilience (in preparation). The study was performed in a compassion paradigm, using compassionate methods (Hansen and Trank, 2016) underpinned by Heidegger's and Gadamer's concepts of being in the world and hermeneutic circle (Lavery, 2003).

Undertaking the study in a compassion paradigm, the assumptions were that suffering is a shared human condition (Feldman and Kuyken, 2011), and 'care' concerns relieving suffering attentively and affectionately (Perez-Bret et al., 2016). Compassion thus concerns sensitivity and openness towards, cognitively understanding, and compassionately acting to relieve suffering (Gilbert, 2005; Raustøl and Tveit, 2023). Applying an open and sensitive approach to data generation and interpretation, we elucidated patterns or regularities, including tacit knowledge that might be taken for granted (Lavery, 2003). In these processes, the engaging researcher's emotions were included. These can provide valuable insight into understanding specific experiences and shaping responses to those (Hansen and Trank, 2016). Moreover, given that understanding, based on historically and culturally lived experiences, is fundamental in human existence, interpretation is appropriate for understanding human behaviour. Thus, in the encounter with participants' words, behaviours and text material, our pre-understandings were challenged. This generated new understandings in a continuous circular process of horizon fusion (Lavery, 2003). The pre-understandings of the research group responsible for this study are

based on cancer care (physician), experiences of parenting a child with cancer (two experienced mothers), and paediatric nursing and qualitative research (four nurses). Two of those nurses are also certified ambassadors of Applied Compassion Training (The Center for Compassion and Altruism Research and Education, S. U., 2023).

2.2. Participants and settings

A purposive sampling method was applied to ensure participant heterogeneity. Danish- or English-speaking parents of children under 18 years who received curative treatment were recruited in person at two Danish university hospitals. Further, parents of children who had finished a treatment protocol within the last two years (cancer survivors) were recruited from self-made parent groups. These groups were established by the parents with the aim of supporting each other throughout their children's treatment. Finally, the study included HPs with direct family contact from both hospitals. HPs were recruited face-to-face based on diverse professional and personal characteristics.

2.3. Data generation

Ethnographic and interview methods were employed to obtain a nuanced understanding of both unspoken and spoken knowledge. Prior to the study, the first author conducted a literature review and one month of natural hospital observations (Hammersley and Atkinson, 2019), which guided the development of observation and interview guides. Inspiration was also drawn from Spradley (2016) and Brinkmann and Kvale (2018). The two mothers in the research group supported this development process and tested and confirmed the content targeted parents.

To safeguard vulnerability during data generation, the first author sought to build trust with the families by demonstrating genuine interest, integrity, respect, and humility. This might promote natural and spontaneous behaviours (Bundgaard, 2010) and provide feelings of being cared for and valued (Boyd and Deluca, 2017). Further, this resonates with the author's and compassionate values (Hemberg and Wiklund Gustin, 2020; Shaw et al., 2020; Sinclair et al., 2021).

2.3.1. Short-term ethnographic fieldwork

Ethnographic fieldwork among HPs and hospitalised and outpatient visiting families at both hospitals were carried out to gain a deeper understanding of natural behaviours. The first author followed and moderately engaged with HPs during their shifts, observing and exploring, through walk-along interviews, tasks, and workflows. Further, the author passively observed families' and HPs' interactions during rounds, procedures, and other activities in the wards. Participation and observations took place on different weekdays, including weekends, during the day and evening hours. Observations were descriptive and developed from initial broad to more focused and selective (Spradley, 2016). Focus was centred on interpersonal interactions and the context surrounding those (Hammersley and Atkinson, 2019). Notes were taken to document observations, including the author's emotions, feelings, and immediate thoughts. Immediately after each observation, the notes were expanded with more details to form a narrative (Spradley, 2016).

2.3.2. Semi-structured interviews and focus group interviews

Parents of children receiving cancer treatment were recruited for interviews during the ethnographic fieldwork. Thus, they interacted with the first author and were familiar with both the CCCC project and the first author. They received written and oral information about the study's intentions and goals of improving parental care. Interviewing those parents allowed us to further explore and elaborate on observed behaviours and aimed to build trust in the first author, who conducted the interviews. The interviews were semi-structured and aimed to elucidate daily life experiences, including home, hospital, social, work,

marital, and family life. Only those aspects encompassing interactions with HPs were relevant to this study and involved experiences of both caring and uncaring behaviours (Halldorsdottir, 2008). The child's hospital room or another quiet place at the hospital provided the space for the interviews, according to the parents' preferences. Further, the couples were allowed to do joint interviews. This enabled the elicitation of both individual and shared meanings, thus exhibiting their individual story and the story they tell each other (Taylor and De Vocht, 2011). The interviews were initiated by asking the parents to tell how they experience everyday life caring for their child to gain confidence (Boyd and DeLuca, 2017), and openly inviting them to speak and thereby creating a safe space for sharing (Hansen and Thorsted, 2022).

Due to the 2019 coronavirus disease (COVID-19) pandemic restrictions, parents of cancer survivors attended online focus group interviews facilitated by the first, second, and last authors. These focused dialogues aimed to discuss everyday life aspects similar to those mentioned above. Doing so, we intended to uncover the most powerful events that might have been of personal importance or particularly significant when considering the complete picture and overall accomplishment of their child's treatment trajectory (Snelgrove and Havitz, 2010). Moreover, the first, second, and third authors undertook in-person focus group interviews with interdisciplinary groups of HPs at both hospitals. Topics relevant to these discussions were HPs' experiences of their interactions with families during treatment and how to take care of themselves and their colleagues. The latter is reported elsewhere. All interviews were audio-recorded and transcribed verbatim. The first author documented personal emotions, feelings, and immediate thoughts.

2.4. Data analysis

Graneheim and Lundman's (2004) qualitative inductive content analysis was used to analyse the data concerning HPs' and parents' perspectives, which constituted separate analyses. The first and last authors performed the analyses through multi-step dialectical processes moving between the whole and its parts. The authors have different levels of education and experience with compassion and challenged each other's pre-understandings during stepwise triangulation and discussion of inconsistencies. The first author also included her notes on sensations, feelings, and thoughts in this process. For each analysis, the material was gathered into one text and read thoroughly several times to obtain an initial impression of the whole. Next, the manifest content was divided into meaning units that were condensed by each of the two authors approaching the text closely on a low abstraction level with a low interpretation degree (Graneheim et al., 2017). Based on agreement, the meaning units were abstracted and labelled with codes and grouped into sub-categories and categories aiming to describe and enhance the understanding of the phenomena. Finally, elevating the abstraction level and interpretation degree, the latent content of the texts was interpreted. This revealed the underlying meanings cutting across categories and resulted in an overarching theme of meaning (Graneheim and Lundman, 2004; Graneheim et al., 2017). Further, we included Halldorsdottir's (2008) six-step nurse-patient relationship dynamics theory, from initiating a connection to true negotiation of care (described below). This was used as a framework to support our interpretation and presentation of the process and quality of connecting. To enhance trustworthiness, the entire research group participated in discussions on overall agreement of findings, reflections, and reach of data saturation. We considered data saturation to be reached when no new or relevant data appeared (Dworkin, 2012). We followed the COREQ checklist for reporting the study (Tong et al., 2007).

2.4.1. The nurse-patient relationship dynamics theory

The nurse-patient relationship builds upon trust and has a dialectic nature. It is illustrated as a bridge that balances the act of closeness and distance, or as a wall, which characterises detachment and negative or

lack of communication (Halldorsdottir, 2008). The theory of nurse-patient relationship dynamics to establish 'life-giving relationships' comprises six main stages.

- 1) *Reaching out: initiating connection*, where one part reaches out and the other responds. The nurse listens and asks questions.
- 2) *Removing the masks of anonymity* is about mutual acknowledgment of personhood. The nurse exhibits own personhood and self-disclosure and acknowledges the patient as a person along with the patient's life.
- 3) *Acknowledgment of connection*. Patients intuitively know when a connection has been established. The nurse responds personally to the patient and uses verbal and non-verbal expressions, such as eye-contact and body-language.
- 4) *Reaching a level of truthfulness* is characterised by the patient's feeling of safety in opening up and speaking the truth to the nurse who respects the patient.
- 5) *Reaching a level of solidarity*, the patient no longer feels alone. The nurse is on his or her side and creates a sense of equality in the relationship.
- 6) *True negotiation of care* is when the nurse understands the patient and the patient's world. The nurse can work with the patient in an equal manner without making the patient too dependent on the nurse (Halldorsdottir, 2008).

2.5. Ethical considerations

Study approval was obtained from the Data Protection Agency of the Region of Southern Denmark (21/34126). The Ethics Committee of the Region of Southern Denmark also evaluated the study (20222000-87) and provided an approval waiver. In accordance with the Helsinki Declaration, participants received written and oral information about the study and signed the study consent before participation. Those attending online interviews had the option to either sign the consent form digitally or on paper and return it by e-mail or letter.

3. Findings

3.1. Participant characteristics

A total of 144 h of fieldwork involving HPs and families at two Danish university hospitals were carried out from August to December 2021. Concurrently, 16 interviews with 22 parents of children undergoing treatment (16 families) were completed (Table 1). The average duration of interviews was 46 min (range, 17–67 min). In addition, two and three focus group interviews with parents of cancer survivors and interdisciplinary HPs, respectively, were carried out. Each of these 2-h discussions included five or six participants, involving a total of 11 parents (families) (Table 1) and 17 HPs, comprising nurses, physicians, a certified nursing assistant, and a nursery teacher (Table 2). All invited participants agreed to participate, except one HP who was absent due to maternity leave. Participant characteristics are presented in Tables 1 and 2.

3.2. Themes

The analyses resulted in six themes that reveal HPs' presence and attributes in connecting with parents and facilitators and barriers for connectedness. The themes, illustrating a step-by-step process, comprise: 1) Being plunged into and safeguarding a family who looks death in the eye, 2) Revealing the human being behind the uniform, 3) Recognising fruitful or missed connections, 4) Creating a shared third space, 5) Going the extra mile, and 6) Becoming partners in crime (Fig. 1).

Table 1
Characteristics of the included families.

Characteristics, n (%)	Receiving cancer treatment ^a	Post-cancer treatment ^b
Families	(n = 16)	(n = 11)
Relationship between the parents		
Cohabiting	14 (87.50)	9 (81.82)
Separated	1 (6.25)	2 (18.18)
Full single parent	1 (6.25)	
Home-living siblings	12 (75)	9 (81.82)
Parents	(n = 22)	(n = 11)
Females	13 (59.09)	10 (90.91)
Leave of absence from work to some degree during treatment	19 (86.36)	9 (81.82)
Full time for one parent	13 (68.42)	8 (88.89)
Mothers	11 (84.62)	7 (87.50)
Children on cancer treatment	(n = 16)	(n = 11)
Boys	10 (62.50)	5 (45.45)
Age at time of interview ^a /diagnosis ^b in years		
0-3	6 (37.50)	6 (54.55)
4-7	1 (6.25)	
8-10	2 (12.50)	3 (27.27)
11-14	3 (18.75)	2 (18.18)
15-17.9	4 (25)	
Diagnosis		
Lymphoma		
Non-Hodgkin	1 (6.25)	1 (9.09)
Hodgkin	3 (18.75)	
Neuroblastoma	2 (12.50)	
Nephroblastoma	2 (12.50)	
Brain tumor	1 (6.25)	2 (18.18)
Leukemia		
Acute Myeloid	1 (6.25)	
Acute Lymphocytic	5 (31.25)	8 (72.73)
Osteosarcoma	1 (6.25)	
Co-morbidity ^a	3 (18.75)	1 (9.09)
Time since diagnosis ^a /treatment completion ^b in months		
≤1	4 (25)	1 (9.09)
2-6	6 (37.50)	1 (9.09)
7-11	4 (25)	4 (36.36)
12-15	1 (6.25)	2 (18.18)
16-24	1 (6.25)	3 (27.27)

^a Metabolic disorder, (genetic) syndromes, and brain damage.

3.2.1. Being plunged into and safeguarding a family who looks death in the eye

Receiving the news of their child's cancer diagnosis, parents were confronted with an overwhelming fear of losing their child. They felt, for instance, that they were "looking death right in the eye" and "every parent's worst nightmare became real". These intense feelings were rooted in former experiences that cancer is a deadly disease. HPs, on the other hand, found themselves in the intimate sphere of an emotionally burdened family, which they had no knowledge of but felt obligated and motivated to grasp and help hold together. One HP explained:

"You feel plunged into a family's life, which you have no knowledge of, but have to carefully cherish. And that is what you do". (HP#8, focus group interview)

HPs focused on establishing initial connections with the families to offer safety and help them reconstruct their daily lives. In addition to rapidly initiating cancer treatment of the ill child, HPs demonstrated to dedicate time to getting to know and being present and accessible to the specific family members, to show they are there for them. They sensed the immediate atmosphere within a family when approaching them. Thus, they assessed family members' reactions toward their presence and the dynamic between family members to accommodate their individual needs and establish trust. One shared such experiences:

Table 2
Characteristics of the included health professionals.

Characteristics, n (%)	Health professionals participating in focus group interviews (n = 15)
Females	14 (93.33)
Age in years	
<30	6 (40)
30-40	3 (20)
41-50	2 (13.33)
51-60	3 (20)
>60	1 (6.67)
Professions	
Nurse	11 (73.33)
Physician	2 (13.33)
Certified nursing assistant	1 (6.67)
Nursery teacher	1 (6.67)
Work capacity	
Part-time (<37 h per week)	5 (33.33)
Full-time (37 h per week)	10 (66.66)
Years of experience in childhood cancer practice	
≤1	3 (20)
2-5	3 (20)
6-10	3 (20)
11-15	2 (13.33)
>15	4 (26.67)

"If you manage to get the child's attention, earning its trust, you will naturally earn the trust of the parents, because they realise their child feels safe in our [HPs'] hands. Conversely, if the parents' insecurity or fears are dominating, they may start expressing the things they or their child cannot manage and then the child surely cannot. Here, you definitely concentrate on accommodating the parents and establishing trust with them first, and then it comes naturally with the child". (HP#5, walk-along interview)

For the parents, it initially took some time to understand the value of HPs other than physicians due to their desperate need for a cancer cure. The fact that those HPs, e.g. the nursery teachers not involved in treatment, kept offering themselves did not align with the parents' primary focus on their child's treatment and cure. Further, some parents could not accommodate and reciprocate HPs' contact due to the shock of their child's diagnosis.

3.2.2. Revealing the human being behind the uniform

Encountering the human being behind the uniform was essential for parents to establish trust with HPs. HPs mostly found it natural and beneficial to show their vulnerability as human beings, to enable connection on a personal level. A HP explained:

"If you believe that simply presenting your uniform without revealing the person behind it will elicit their [parents'] innermost feelings, you will have to reconsider. It does not work like that. You will have to give something of yourself to have something [from parents]". (HP#3, focus group interview)

Through small talk and physical touch, HPs showed their interest in the specific family (member). They shared aspects of their lives by, e.g., telling personal stories or showing photos, often aligning with the interests of the specific family (members). Common interests and perspectives could open up conversations beyond illness, facilitating the process of getting to know one another. This was highly valued by most parents who typically, at this point of interaction, recalled the kindness of HPs rather than their names.

3.2.3. Recognising fruitful or missed connections

HPs found fruitful connections with parents challenging to describe but intuitively knew when they occurred. They generally believed that

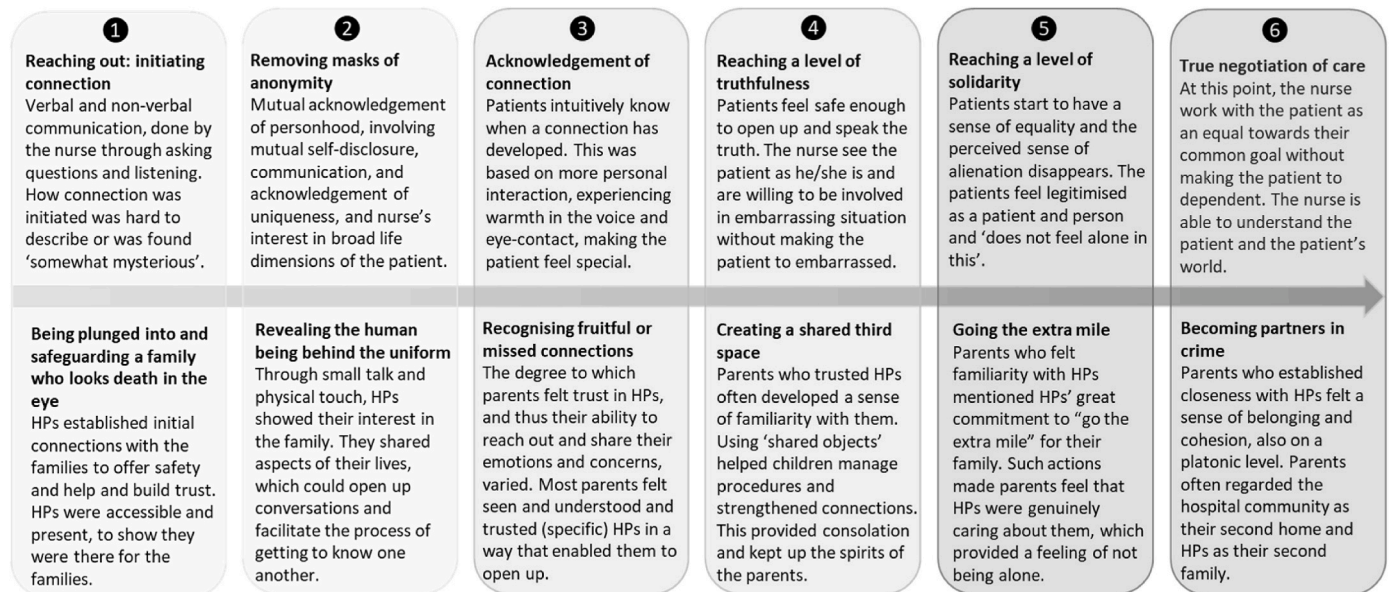


Fig. 1. – The quality and process of connecting

Above the arrow, the characteristics of connecting, according to Halldorsdottir's (2008) six-step nurse-patient relationship dynamics theory, are outlined. Below the arrow is the presentation of the characteristics of connecting as identified in this study.

every parent could reach out, whether by phone, bell cord, or in person, to at least one HP with whom they had established connection. However, they also discussed instances where parents hesitated or avoided doing so. The degree to which parents felt trust in HPs, and thus their ability to reach out and share their emotions and concerns, varied. Most parents felt seen and understood and trusted (specific) HPs in a way that enabled them to open up, like this parent:

"I was ruminating about whether we [parents] did this [genetically inherited cancer] to our child and whether we had missed some early signs and symptoms. I turned to a physician who took the time to sit with me and tell me that none of this was our fault and we did all the right things. This made me feel calmer ...) I told my child that now we fight this [cancer] together with the HPs who will help us". (Parent#6, couple interview)

Those parents recognised HPs' interest in them as a family, including their willingness to answer their many questions and validate their emotions. They often started their interview by talking about the traumatic experience of receiving the child's diagnosis. This typically represented a detailed narrative, emphasising the invaluable presence of the nurses and physicians who safeguarded the family's well-being during this traumatic event. Those HPs often had a special meaning for the parents due to having shared a pivotal moment in the life of the parents.

Other parents, on the contrary, found themselves unable to reach out to HPs for emotional support and typically felt alone in their suffering, as illustrated by this parent:

"I will never forget that day I felt so deeply sad and lonely. It was as if no one saw me or came by our room to see if we were okay. How can this happen in a hospital? I could not call [through the bell cord] them [the nurses]... I just could not (...) Instead, I wrote a message in a private group chat [on social media] with other mothers [of children with cancer]". (Parent#7, focus group interview)

Moreover, in a few cases where interpersonal chemistry was lacking, parents found HPs' communication inappropriate or insufficient and felt fundamentally misunderstood or overlooked. In these situations, HPs felt avoided or rejected by overwhelmed parents and sometimes found it challenging to navigate those parents' divergent worldviews. These

worldviews often contrasted with the healthcare system's biomedical-oriented perspective and made it challenging to find a common understanding.

3.2.4. Creating a shared third space

Parents who trusted HPs often developed a sense of familiarity with them, enhancing both the emotional and practical aspects of care. For their children, familiarity with the nurses performing unpleasant procedures was crucial for successful coping. Using "shared objects", such as a mutual love for dogs or singing a particular song, provided "a shared third space" to connect between families and nurses and helped children manage unpleasant procedures. A parent provided an example:

"It is amazing how blood samples can turn into something "funny". "Our" nurse is very forthcoming, and we all kind of play and sing to handle it [blood samples]". (Parent#12, individual interview)

This way of connecting in a shared third space provided consolation and kept up the spirits of the parents. However, maintaining such care arrangements, familiarity, and trust posed challenges due to a lack of continuity of care caused by high workloads and nursing turnover. In these circumstances, nurses tended to navigate protectively toward the families they cared for (and themselves). For example, they refrained from going into deeper conversations with parents, enabling parents to ease their hearts, if they could not give their time and full attention and follow up on them afterward. This, however, evoked the awful feeling of inadequacy for HPs. Consequently, parents showed to adjust their behaviour to minimise any inconvenience to HPs and ease HPs' burden, as demonstrated:

"Sometimes when I use the bell cord [in the hospital room], it takes ages before the nurse comes, and sometimes it is another than the one responsible for the care of us. The nurse, however, smiles and tries to help, but I can see they are very busy, and I feel with them, so I only ask for necessary practicalities". (Parent#14, individual interview)

This sometimes led to the perception that engaging personally with HPs was somewhat irrelevant. A few parents distanced themselves because repeatedly sharing their stories and connecting with new HPs made them feel vulnerable.

3.2.5. Going the extra mile

Parents who felt familiarity with HPs mentioned HPs' great commitment to "go the extra mile" for their family. This included, for example, HPs recalling and communicating significant personal details of the family or checking in on them when they were temporarily admitted to another hospital. These actions made parents feel that HPs were genuinely caring about them, which provided a feeling of not being alone, as demonstrated:

"We received a phone call from "our" nurse when we [the child] received treatment at another hospital. It meant a lot to know that she [the nurse] was still with us even though we were gone for a while". (Parent#5, focus group interview)

Such small virtues that extend beyond clinical responsibilities made parents feel seen and special. They related to HPs as fellow beings and felt a sense of closeness with them. For HPs, especially the nursing team, such close connections contributed to a sense of meaningfulness in their work.

3.2.6. Becoming partners in crime

Parents who established closeness with HPs typically felt a sense of belonging and cohesion, also on a platonic level. This often led to strong bonds that felt uplifting and energising for the parents. Those parents commonly regarded the hospital community as their second home and HPs as their second family, attributing qualities of specific HPs to those of a close friend or mother. Those HPs understood and addressed parents' unspoken needs, as exemplified:

"No matter how resourceful you are, you need a "partner in crime". That is for sure. There was especially one nurse who was like a mother to me and always knew when I needed a hug. It meant the world to me that she could see right through me like that – and it still does". (Parent#3, focus group interview)

Such close connections were characterised by mutual understanding, respect, and the ability to see each other as individuals and balance the act of closeness and distance. For parents, this meant that HPs were honest, humble, and outreach while adapting activities to the family's daily rhythm to ensure coherence, relaxation, and privacy. However, at this level of connection, dishonest communication constituted the biggest threat to maintaining connectedness. While human errors, especially in busy workflows, were understandable for parents, failing to be honest about them could break their trust in HPs, as illustrated:

"I discovered that they [HPs] had given the wrong doses [of medication to the child] without telling me. I confronted them after I had spoken to my husband. They said they would have told me (...) I felt so devastated. What about my child's health? And who can I trust after this?". (Parent#10, couple interview)

Some parents were observed monitoring HPs' actions toward their children. In these cases, or cases where implicit reconciliation of expectations was not possible, parents and HPs endeavoured to communicate more explicitly. For example, they illustrated how they used homemade door signs and circadian rhythm schemes to explicitly articulate and accommodate needs, respectively.

From HPs' perspective, parents were expected to be considerate of HPs' work schedules when making non-urgent contact to ensure optimal resource utilisation. Further, in cases where friendly chemistry developed, HPs maintained personal boundaries toward the families to ensure professionalism. For example, they rejected friend requests on social media and politely declined invitations to private family events. Finally, HPs observed that as the end of treatment approached and their prolonged, intensive contact with the families was reduced or ceased, some families had difficulty letting go. They sometimes found reasons to keep in contact, primarily due to the sense that "something" on a relational level seemed unresolved, according to a few parents. They reported their children felt anger and personal rejection from HPs with whom they had

built close connections. Also, the parents felt like becoming "outsiders" while mostly desiring to give in return to those who had been there for them.

4. Discussion

Exploring HPs' presence and attributes in connecting with parents demonstrates that professional interactions often develop into deep, meaningful connections, based on HPs' strong commitment. Applying Halldorsdottir's (2008) six-step nurse-patient relationship dynamics theory, this study demonstrates the process and different levels of connecting between HPs and parents during a child's cancer treatment. These range from missed connections in a few cases, which is illustrated as a wall where no connection is established, to fruitful connections as partners, described as a bridge (Halldorsdottir, 2008). Fruitful connections, encompassing connectedness on a deeper (platonic) level, may correspond to what Halldorsdottir (2008) characterises as 'life-giving relationships'. This is the highest quality of connection, described as a bond of energy or light (Halldorsdottir, 2008).

In our study, HPs' presence and attributes were characterised by high clinical competencies and showing availability, sensitivity, continuity, genuine interest, humanity, humility, and honesty. These were important in fostering interpersonal trust with parents (and their children), constituting facilitators for connectedness. Similarly, Hemberg and Wiklund Gustin (2020) demonstrated, in their study of nurses, that humility, honesty, humanity, and showing genuine interest mediate compassion in relationships with patients. Further, being part of a loving communion is a basis for mediating compassion in the nurse-patient relationship. This relies on mutual disclosure of personhood and vulnerability (Hemberg and Wiklund Gustin, 2020). Similarly, HPs in our study demonstrated vulnerability by including aspects of their personal life to humanise themselves and engage closely with families. Their attributes (especially nurses') sometimes resonated with what characterise those of extended family members and friends, also reported by Patterson et al. (2004). Mcharo et al. (2022) have described similar features of this form of connection; however, as a sense of belonging to the "nursing family" for parents. This relied on professional and personal attributes, similar to our and Sinclair et al.'s (2021) findings. Likewise, professional and personal attributes are recognised as the two main sides of the nurse's compassionate competence, essentially rooted in love (Halldorsdottir, 2012). As such, compassionate care has been regarded as high-quality care, and shown to be relieving and strengthening for parents in terms of mitigating loneliness (Thienprayoon et al., 2020).

When connecting closely, it is important that the patient does not become dependent on HPs in such a way that he or she cannot reach the goal of not being a patient (Halldorsdottir, 2008). However, for some parents (and their children) in this study, letting go of the close connection with HPs was difficult as the child's treatment approached the end. Aspects of relationship endings have received limited research attention within nursing. In the context of close counsellor-client relationships, endings have been shown to evoke feelings of loss among counsellors (Chambers and Pendle, 2024). Although counsellors recognise that ending relationships with clients is part of their professional role, requiring a shared responsibility in adapting to such losses and transitioning to new clients, it remains a challenging process (Chambers and Pendle, 2024). Planning the ending, including managing boundaries and expectations, is crucial, as highlighted in Tsai et al.'s (2017) study. By agreeing on the termination process and engaging in emotional closure, clients may develop adaptive behaviours for managing the difficulties of relationship endings. This involves supporting clients in gaining skills in openhearted communication (Tsai et al., 2017). The way some families continued to seek the hospital community and invited HPs to e.g. family events in our study, illustrating their need to reciprocate the care received, indicates that increased clinical and research focus on how to adjust and end close relationships from both HPs' and

the family's perspectives are warranted. This may include more systematic approaches to match expectations and needs, also on a human level, and further support HPs balance the act of closeness and distance.

Our study also identified barriers to establishing and maintaining connections. These encompass dishonest, poor, or lack of communication and poor or lack of interpersonal chemistry in a few cases. Further, barriers include structural work changes and busyness, making it difficult to maintain care arrangements and connections. For instance, lack of time to be present for the parents felt awful and made some nurses refrain from going into deeper conversations with parents. In other studies, busyness, and lack of time to establish and nurture relationships with families have been reported as distressing for nurses (Macintyre et al., 2022; Zarenti et al., 2021). In addition, lack of time (Ventovaara et al., 2021) and inadequate staffing (Pergert et al., 2019; Ventovaara et al., 2021) can lead to moral distress, especially among nurses, compared to their physician and healthcare worker colleagues (Pergert et al., 2019), and can increase their intention to leave the job (Macintyre et al., 2022). Not surprisingly, but alarming, busyness among HPs also influenced the parents' behaviours in our study. They felt sorry for the HPs and adapted their needs to be as little bother to HPs as possible. In these circumstances, both HPs and parents are "victims of busyness", according to Martinsen (2018). Martinsen (2018) argues that busyness constitutes a threat to the slowness required for being sensitively present to achieve intimacy and resonance with the surroundings. This refers to the art of sensing the room and its content, which means the atmosphere, impressions, human rhythms, and the story being told. Thus, busyness distracts HPs in a way that leads to unnoticed experiences, preventing them from dwelling on moments of life-giving phenomena, which, therefore, do not come to the patient's aid either. Consequently, the room becomes silent and senseless (Martinsen, 2018). The parent, in our study, who only addressed necessary practicalities, which can be seen as attunement to the busy nurse's behaviour (Martinsen, 2018), is a great example of this. This parent's body closed down because there was a lack of resonance with what a hospital room symbolises; a place where one is allowed to be taken care of. Thus, aspects that characterise human life were withheld for this parent, while the nurse could not sense the atmosphere of the room and human interaction, and the imagination it takes to resonate with the parent. This leads to shared stories of suffering (Martinsen, 2018), in this case among HPs and parents.

Neuroscience emphasises the importance of understanding presence more broadly than physical availability for the interpersonal interaction to be rewarding. For example, previous studies found that it takes 32–56 s to be compassionate (physical, emotional, and cognitive presence), benefitting both parties in a relationship (Trzeciak et al., 2019). This suggests that cultivating the skill of being fully present in the moment is supportive, even in demanding and busy workflows. Brun et al. (2023), Nissim et al. (2019), and Knudsen et al. (2023) all support this, demonstrating that HPs, through the practice of mindfulness and/or compassion, learned to become more present in the moment in regard to themselves and their patients (and colleagues). This practice not only improved their ability to assess and respond to their own needs, and understand and accept their own feelings, but also enhanced their ability to understand others' perspectives (Brun et al., 2023; Knudsen et al., 2023; Nissim et al., 2019). Furthermore, Cernadas Curotto and colleagues (2023) showed that compassion training can increase feelings of compassion towards individuals one may find difficult or unlikeable. Hence, a focus on compassion in investigations and clinical practice may support HPs in understanding and adapting and directing actions to create life-giving relationships in healthcare.

4.1. Strengths and limitations

The application of multiple methods resulted in rich and heterogeneous data from parents and HPs at two of the four Danish university hospitals offering childhood cancer care, strengthening the credibility of the study's findings (Graneheim et al., 2017). Further, the study also

reached the stage of data saturation according to the research group. Although all invited hospitalised and out-patient visiting parents could share their own stories and, in some cases, also the story they tell each other (Taylor and De Vocht, 2011), the data derived from interactions between HPs and parents spending the most time in the hospital may be a dominating factor. Further, our study was carried out during the COVID-19 pandemic where special restrictions were imposed, potentially having an impact on the experiences of participants. External factors such as different management and healthcare models, and cultural differences, must be taken into consideration when transferring the findings.

5. Conclusion

This study gives valuable insights into the process of building, maintaining, and the need for ending connections between HPs and families affected by childhood cancer. It describes HPs' presence and attributes, along with barriers and facilitators for connectedness. In practice, there is a huge awareness of establishing contact and trust with families, through a sensitive, caring presence. Based on HPs' compassionate attributes and great commitment, many parents and HPs connected in a way that reached the point of solidarity and being life-giving by developing into close authentic connections that strengthened both parties. However, busyness and lack of continuity were prominent barriers to connectedness and demonstrated in this study to cause suffering for both parents and HPs. Further, the lack of awareness on how to end close connections when approaching the end of treatment was personally challenging for parents (families). This indicates that human interconnectedness is powerful in long-term professional relationships. We recommend that future research focus on relationship endings between HPs and families within childhood cancer care.

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CRedit authorship contribution statement

Camilla Littau Nielsen: Writing – original draft, Validation, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Jane Clemensen:** Writing – review & editing, Validation, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization. **Claus Sixtus Jensen:** Writing – review & editing, Validation, Supervision, Resources, Data curation. **Michael Thude Callesen:** Writing – review & editing, Validation, Supervision, Funding acquisition, Data curation. **Anthony Smith:** Writing – review & editing, Validation, Methodology. **Kristina Garne Holm:** Writing – review & editing, Validation, Supervision, Project administration, Investigation, Formal analysis, Data curation.

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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