



Exploring nursing presence as experienced by parents in pediatric oncology



Solomon K. Mcharo, BSN, MSN, PhD(c)^{a,*}, Jill Bally, BSN, RN, BA(Psych), MN, PhD^b, Shelley Spurr, BSN, MBA, PhD^c, Keith Walker, D.D., Ph.D., M.Ed^d, Shelley Peacock, RN, BSc, BSN, MN, PhD^e, Lorraine Holtslander, RN, BSN, MN, PhD^f

^a University of Saskatchewan, College of Nursing, Saskatoon, SK S7N 5E5, Canada

^b University of Saskatchewan, College of Nursing, E4348 Health Sciences, Saskatoon, SK, Canada

^c University of Saskatchewan, College of Nursing, E4244 Health Sciences, Saskatoon, SK, Canada

^d University of Saskatchewan, College of Education, 3063 Education, Saskatoon, SK, Canada

^e University of Saskatchewan, College of Nursing, E4340 Health Sciences, Saskatoon, SK, Canada

^f University of Saskatchewan, College of Nursing, E4252 Health Sciences, Saskatoon, SK, Canada

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ABSTRACT

Background: Nursing presence has been viewed as a valuable way to create therapeutic relationships and has been linked to better health outcomes for patients and families. However, whether nursing presence can be described and how parents in pediatric oncology experience this phenomenon remains unanswered. Therefore, the purpose of this study was to explore how parents of children with cancer describe and experience nursing presence.

Methods: This study used Giorgi's phenomenological approach to explore nursing presence as experienced by parents of children with cancer. Ten participants from a pediatric oncology clinic in Canada were interviewed. Giorgi's approach was used to analyze these data.

Findings: Based upon participants' descriptions, a structure of nursing presence emerged which included six constituent features: An attitude of presence, a source of encouragement, clinical experience and expertise, therapeutic communication, family involvement, and a sense of home away from home. Most notably, nursing presence as experienced by parents was characterized by the 'being' and 'doing' of presence which were equally important.

Conclusion: The experiences described by parents provided rich and nuanced insights into what it meant to experience nursing presence in a pediatric oncology setting. This study provides a structure for this meaning making and expounds on its constituent features, describing what nursing presence resembles when experienced by parents of children with cancer.

Practice implications: This study informs nursing practice, policy, and education in ways that are likely to enhance care and the subsequent well-being of pediatric oncology patients and families.

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A diagnosis of cancer and management of its symptoms during cancer treatment is overwhelming for parents and their sick children. Parents often see the diagnosis as a threat to the child's life and to the family's security; posing a great challenge not only to their physical health but also to their emotional, social, and psychological well-being (MacKay & Gregory, 2011). Support of the family through family-centered care and nursing presence is essential in these times of crisis;

this is especially so during the COVID-19 pandemic where public safety demands restrict the physical presence of families for hospitalized patient (Hart et al., 2020; Mcharo et al., 2021). Family-centered care is a model of health care delivery that emphasizes collaboration between families and healthcare professionals (Thienprayoon et al., 2020). Parents play a significant role in their child's medical care and consider themselves as active members of the multi-disciplinary team, decision makers; they are experts in their children's caregiving (Kuo et al., 2012; MacKay & Gregory, 2011). Family-centered care puts the nurse in an ideal position to apply nursing presence in order to develop beneficial therapeutic relationships with parents and their loved ones (Mcharo et al., 2021).

* Corresponding author.

E-mail addresses: kasha.mcharo@usask.ca (S.K. Mcharo), jill.bally@usask.ca (J. Bally), shelley.spurr@usask.ca (S. Spurr), keith.walker@usask.ca (K. Walker), shelley.peacock@usask.ca (S. Peacock), lorraine.holtslander@usask.ca (L. Holtslander).

Nursing presence is described as a foundation for professional nursing practice, characterized by being available with the whole of oneself and open to the experience of another through a mutual interpersonal encounter (Gardner, 1992; Kostovich, 2012). Nursing literature uses presence to depict both a nurse's bodily presence, and in a metaphysical sense encompasses a nurse's full physical, psychological, and spiritual presence (Turpin, 2014). Over the years, nursing presence has been viewed as a valuable way to create therapeutic relationships that facilitate healing, and has been linked to better health outcomes for patients and family caregivers (Doona et al., 1997; Fingeld-Connett, 2006; Mohammadipour et al., 2017). For example, the intensity of feelings such as manifest in fear, powerlessness, anxiety, isolation, and distress, are diminished when parents experience nursing presence, thus improving patient satisfaction and healing (Kostovich, 2012).

Despite the investigations of presence in nursing literature, there is limited research exploring this concept amongst pediatric oncology patients. A few studies have looked at implementing nursing presence and its positive outcomes in terms of the reduction of incidence of falls and pressure ulcers (Kostovich & Clementi, 2014), together with increase in patient satisfaction with care (Penque & Kearney, 2015). Quantitative measurements of nursing presence include measuring presence from both the nurse and the patient perspectives (Hines, 1992; Kostovich, 2012). Several qualitative studies have explored the nature of presence as described by adult patients (Edvardsson et al., 2017; Mohammadipour et al., 2017), as well as nurses and family caregivers of adult patients (Osterman et al., 2010; Reis et al., 2010). To our knowledge, there are no published reports examining the nature of nursing presence as experienced by parents of children with cancer. Therefore, the purpose of this study was to explore and understand nursing presence as experienced by parents of children with cancer during cancer treatment. The specific aim of this research was to draw on the parents lived experiences to help identify how nurses might use presence to improve nursing practice in pediatric oncology. *The research question that guided the study was: How do parents of children receiving cancer treatment experience and describe nursing presence?*

Methodology and methods

A descriptive phenomenological approach as described by Giorgi (2009), was used to conduct this study. Phenomenology is the study of lived experiences (Fochtman, 2008) and is instrumental in researching phenomena related to human health and illness conditions such as loss-grieving, anxiety, hope, despair, and related human experiences of existence (Watson, 1988). Specifically, descriptive phenomenology aims to establish a rigorous and unbiased approach that aspires to arrive at an essential understanding of human consciousness and experience (Fochtman, 2008; Giorgi, 2009; Jackson et al., 2018). Our purpose in using descriptive phenomenology was to reveal the essence of nursing presence, as it is experienced physically and through consciousness (Giorgi, 2009; Watson, 1988). This method allowed the capture of invariant aspects of nursing presence, and to identify the essence of the phenomenon as described by parents in pediatric oncology.

Sampling and participants

Purposive sampling was used to select participants from a local children's hospital oncology unit. Participant selection criteria included parents of children who had been diagnosed with any cancer and who were aged birth – through 14 years (inclusive), and who were of any gender, ethnicity, and sexual orientation. Study participants were also required to have had at least one interaction with a nurse and to be fluent in English. Those who did not meet these criteria were excluded from the study. The nurse in charge of the unit was informed of the study criteria and assisted in recruiting participants by establishing first contact, then connecting the researchers to the prospective participants. A total of ten participants met the criteria and were included in the study. No participant withdrew from

the study. As suggested by Giorgi (2009), the sample size was small so that each experience could be examined in depth and to better appreciate the variation of the phenomenon. Recruitment and data collection continued until a rich and in depth understanding of participant experiences with nursing presence was obtained.

Ethical consideration

The study was approved by the Behavioural Research and Ethics Board at the University of XX (Blinded for Review) and operational approval was obtained from the related health region. The participants received information about the purpose and procedures of the study and were invited to participate through an informed and signed consent. Participants were advised that: their participation was voluntary; they could stop the interview, refuse to answer any question, or withdraw from the study at any time; their interview content was confidential; and, that research results would be published with their confidentiality maintained. All participants received an honorarium of 50 dollars after the interviews were conducted.

Data collection

Data were collected between February 2020 and April 2021. A semi-structured interview guide was developed by the authors of this study based on their knowledge in this area (Brinkmann & Kvale, 2015). A total of 12 interviews were conducted. The initial seven interviews were face-to-face and conducted at the hospital while the rest were done via Zoom (a cloud-based videoconferencing service that offers secure recording of sessions) (Zoom Video Communications Inc, 2016). The switch from face-to-face interviews to Zoom videoconferencing was done to implement physical distancing due to COVID-19 (Public Health Agency Canada, 2021). To initiate the telling of their experiences, the first question for the participant was "in as much detail as possible, please describe for me the situation in which you experienced nursing presence" (Giorgi, 2009). Follow up questions used such as "you spoke about such and such, can you please tell me more about that?" These follow up questions were intended to direct the participant to speak to the phenomenon of interest and extract aspects of the account that were presented but not fully and expressly described by the participant (Giorgi & Giorgi, 2003). A sample of the semi-structured interview questions is presented in Table 1. All interviews were audio recorded and lasted approximately 1 h. Any information that needed additional clarification was noted and, in such cases, participants were contacted again to elaborate on the descriptions of their experiences (Englander, 2012). Two out of ten participants had one additional interview to

Table 1
Interview guide.

Goal

The goal of this interview guide is to explore the care givers' in-depth knowledge and experiences of nursing presence. The topic I would want to explore in these interviews are the caregivers experience of nursing presence in the hospital as their child receives cancer treatment.

Interview Guide

The following are open-ended questions that will be used to guide the interview.

1. In as much detail as possible, please describe for me the situation in which you experienced nursing presence.
2. When you think of nursing presence what comes to mind? What does "being with" mean to you?
3. How do you understand and make sense of your experience when receiving nursing presence?
4. Is there anything else that you would like to say about nursing presence that we haven't talked about?

Prompting Questions:

Can you tell me more about...?

In what way...

What were you thinking when that happened...?

provide clarity on their previous interviews. The initial two audio recordings were transcribed by the first author and later an experienced transcriptionist was hired to transcribe the recordings.

Data analysis

Giorgi's phenomenological analysis (2009; 2012) was used to transform the raw data to reveal the *essence* of the phenomenon of nursing presence. The method was implemented using the following steps:

1. The first author worked most closely with the data and read through each interview several times to get a sense of the whole. The second and third authors provided extensive support and peer debriefing during each stage of the data analysis process. The fourth, fifth, and sixth authors contributed to the decisions regarding design and methodology, and further assisted in the last phases of the analysis, providing fresh perspectives and insights in the methodology and discussion of the findings.
2. Participants' data were divided into parts known as meaning units, where the first author would read the data and place a slash every time a transition in psychological meaning was experienced. Meaning units comprised of a sentence or paragraph.
3. Using the words spoken by the participants, the meaning units were transformed into expressions that were more revelatory of the psychological significance of what the participant said. This was a process that used free imaginative variation (Giorgi, 2009).
4. All meaning units of similar content were organized under the same category, also known as constituent feature. The respective direct and psychologically more sensitive transformations of the meaning units were then reviewed with the help of free imaginative variation and an essential structure of nursing presence was written.
5. The essential structure comprising of several constituents was used to help clarify and interpret the raw data of the research.

Rigor of the study

A reductive approach was taken, where the researchers were reflexively self aware, and presuppositions were bracketed by writing memos from data collection through to analysis in order to avoid imposing past knowledge or experience upon the phenomenon (Giorgi, 2009; Tufford & Newman, 2012). The authors maintained journals, logs, and auditable records so that the specific research process could be assessed with a critical other. Throughout the iterative data analysis process, the

method and emergent findings were discussed and critiqued by the study authors.

Findings of the study

A total of 10 participants aged 26–48 years were interviewed (see Table 2). Two participants were from rural communities, while eight came from urban centers. All participants were parents of the sick child, and the sample was comprised of fathers ($n = 2$) and mothers ($n = 8$). Three different ethnic backgrounds were represented in the study; Caucasian ($n = 7$), First Nations ($n = 2$), and African ($n = 1$). The average age of the participant's children was six years. All children were receiving treatment for cancer during the time of the interviews.

The essence of nursing presence in pediatric oncology

As indicated, the aim of descriptive phenomenology is to find a general structure of an experience that implicitly contains all of the key meanings that contribute to the determination of the structure (Giorgi et al., 2017). This aim is achieved by reviewing all the transformed meaning units during the data analysis in order to determine the essential ones that will form the basis of the structure. The interviews in this study resulted in 361 meaning units from the ten participants. Based upon all data, the following structure captured the 'being' and 'doing' of nursing presence as experienced by parents of children in pediatric oncology emerged:

Nursing presence has an intrinsic attitude characterized by a nurse's genuine concern for parents and their children in their period of distress. Through emotional and physical acts of kindness, parents feel seen as human allowing them to experience comfort and safety in their vulnerability. Nursing presence also has an extrinsic attitude experienced when nurses are skilled and competent in their care. When the patient family is involved in their child's care and information is shared in a respectable manner, parents feel appreciated and aligned with the care team. As a result, feelings of safety and belonging are experienced by parents leading to improved trust and therapeutic relationships.

As a result of the analysis, the explicit understanding and experience of nursing presence as described by parents is described in six constituent features which are captured in the essential structure: (a) an attitude of presence, (b) a source of encouragement, (c) clinical experience and expertise, (d) therapeutic communication, (e) family involvement, and (f) a home away from home.

Table 2
Description of study sample.

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Age	48 yrs	35 yrs	33 yr	37 yrs	30 yrs	26 yrs	37 yrs	31 yrs	37 yrs	40 yrs
Gender/Relationship to child	Male/ Father	Female/ Mother	Male/ Father	Female/ Mother	Female/Mother	Female/ Mother	Female/Mother	Female/ Mother	Female/ Mother	Female/ Mother
Years of education	Diploma	College	Journey person	High school	Special care aide	Grade 12	Post secondary	Graduate school	Graduate school	Bachelors
Religion	None	Orthodox	None	None	Catholic	Anglican	Catholic	None	Agnostic	Christian
Marital status	Married	Married	Married	Common Law	Married	Single	Married	Married	Married	Married
Occupation	Heavy duty mechanic	Stay home mom	Journey person	Residential cleaner	Special care aide	Financial Assistant	Recreational therapist	Nurse	Stay home mom	Nurse
Ethnicity	First nation	Caucasian	Caucasian	Caucasian	Caucasian	First nation	Caucasian	Caucasian	Caucasian	African
Rural/Urban location	urban	urban	urban	urban	urban	rural	urban	rural	urban	urban
Pediatric Patient Data										
Age	10 yrs	23 months	21 months	10 yrs	12 yrs	9 months	9 yrs	5 yrs	5 yrs	6 yrs
Gender	Male	Female	Female	Male	Male	Male	Male	Male	Female	Male
Year of diagnosis	April 2016	Aug 2019	2018	Feb 2020	Sep 2010	Feb 9th 2020	Nov 2019	2018	2018	2015
Duration of treatment	2016–2019		2018–2019	2 yrs	70 weeks	4 weeks	9 months	3 yrs	2 years	6 yrs
	Relapsed Jan 15th, 2020		21 weeks		(on & off)					

An attitude of presence

The research findings show that participants described an attitude of presence that was manifested through “seemingly insignificant” gestures. Parents experienced presence when nurses showed genuine concern and acknowledged them as ‘human beings’ rather than patients. Showing genuine concern and acknowledging patients was achieved through remembering their names and greeting them; recalling their personal stories and finding out how they were doing before procedures; being physically present in their distress without necessarily saying anything; stopping by their rooms during hospital visits even when not assigned to them; and keeping in touch after treatments. Presence was experienced when nurses would attempt to know parents or their child on a personal level, engaging them in conversations in which they were comfortable. This was described by a parent who stated (P8):

...So, if we're there because we're getting routine chemo, it's relating to him. Talking to him about his dog and, you know, remembering his brother's name and – and those little details. Because we have a Great Dane dog and – she was like two months old when he got sick, so they've been just the best of friends. So, they – oh how's Minnie? And oh, is Kev at school today? And so, he feels good going in.

Other gestures of kindness, such as grabbing a snack or a seat to make parents comfortable, portrayed presence that was pleasant and enhanced their hospital experience. Parents also felt presence when nurses went out of their way to make the hospital experience more tolerable for their sick child. One parent stated (P3):

There's one nurse that we've had a few times during the night. Super hard time with the pumps. He's got three different pumps going, right, so they're all beeping at different times. This nurse, goes and puts it into her phone to set up alarms on her cell so she comes into the room before the pumps start beeping. So, it lets him sleep longer and more calmly right because he already wakes so many times to go pee. And then with all the beeping on top makes it hard.

Parents described the kind gestures as seemingly trivial, but these had a great impact on their hospital stay. The findings also describe moments that parents did not experience nursing presence, negatively affecting their experience of care. When nurses did not portray an attitude of presence, there was a breach of trust and relationships compromised, thus affecting their nursing care. One parent (P9) stated:

We could hear them talking outside of our curtain, but no one walked in to ask if everything was OK. It took my husband going out there and saying we need help. It was so stressful and really bothered me that there was that much distress coming from behind the curtain ... and I knew they were out there, and they could hear us, and no one could just peek their head in and say, do you need help. It was so disappointing.

Findings showed that parents had an easier time describing experiences they felt a lack of presence compared to when they did. Nonetheless, it was evident that parents experienced an attitude of presence when nurses went out of their way and took some form of action, whether great or small, to enhance their hospital experience.

A source of encouragement

Parents described they experienced nursing presence when nurses were supportive and provided reassurance. Participants stated they felt presence in the humane attitude, empathy, and genuine concern when nurses not only performed their tasks but went ahead and comforted them in their distress. This support was

experienced through words of affirmation and comfort, providing suggestion for solutions when nurses observed parents' internal conflict, or spending a little extra time with parents. As one parent (P10) stated:

Like they took him back to the OR three, four times and they couldn't find the reason he was having all these complications. So, it was really good to have someone to just sit with you. She sat on the bed, and she talked to me and told me, don't worry, like, we always have this. And he'll be ok. You're taking such good care of him. And she just, yeah. She just talked to me, like, as a human being. Like, it just, yeah. It was really, really good.

When nurses were present and a source of encouragement, therapeutic relationships were formed allowing parents to be more vulnerable in sharing their fears and concerns. These relationships and intimate conversations with parents made it easier for nurses to identify their need and provide the support required.

Clinical expertise and experience

Findings showed that presence had a dimension of nursing clinical experience and expertise. For example, parents experienced presence when attended to by nurses they felt had the experience and expertise to care for their sick children. Value was placed on nursing skills such as accessing intravenous catheters and careful handling of patients during routine procedures such as X-rays, chemotherapy, or blood work. Parents felt that nurses working in the oncology clinic or oncology wards had more experience, hence, were experts in inserting intravenous catheters compared to those working in the emergency departments. Although parents had been informed that they could call on nurses from oncology to come insert their child's intravenous catheter's whenever they visited the ER, resistance was sometimes encountered causing tension and anxiety. One parent (P2) stated:

...I didn't want her to access her port because she hadn't had enough experience accessing ports and I didn't want her to miss. And she did miss. She came in, she tried to access her, she missed, so I was not pleased. And so, at that point we already knew she already had an infection – she had a fever – so I just said “Yeah, let's just take her up to the ward and they'll access her up there.” They took her up to the ward, they got it on one try and it turned out to be a line infection... yeah, they got her accessed quickly there.

Parents felt nurses with more experience in such nursing skills not only reduced the risk for infection and pain experienced by their sick children during invasive or non-invasive procedures but were able to have better interactions with them and their child during the procedures. While presence was experienced when parents had confidence in nursing skills, they also highlighted the need for nurses to pay extra attention during procedures. Furthermore, findings also showed that competence, being perceptive, and taking action when not necessarily required promoted trust between nurses and parents. Parents reported experiencing presence when interacting with nurses who were anticipative and insightful, being able to prevent trauma or solve their concerns before they occurred. Parents also expressed presence when nurses could comprehend the ‘bigger picture’ and took action to make their hospital stay comfortable. Ensuring patients' comfort was perceived as kind and empathetic thus establishing trust and emotional safety for the patients. For example, as a parent (P1) suggested:

I mean in the old hospital you had to sleep on the floor, or you got a red chair. I mean she kept getting me red chairs. I know that's stupid, but it made a huge difference to me. Yeah, that sounds silly (laughs). Yeah, every time we got admitted. Yeah, it was huge. I think she felt that – I think she was very good at empathizing and putting herself in my shoes, like, you know, your daughter just has this awful

diagnosis and the last thing you want to be doing is sleeping on a – like a one-inch mattress on the floor of a hospital, right? So just the kindness and the thoughtfulness of procuring that red chair was just so nice.

Parents had stronger relationships with nurses who were perceptive and appreciated their thoughtfulness. Nurses' consideration was sometimes experienced when they insisted parents take better care of themselves by offering them some respite. While there was no clinical expertise needed in being anticipative, nursing experience working with parents of children with cancer played a role in ensuring their hospital stay was less stressful.

Therapeutic communication

Communication emerged as a constituent feature that described nursing presence for parents. Findings showed that parents paid attention to who, what, and how the information was provided. Nursing presence was experienced when significant information was passed alone by those who were trusted by parents. Parents established trust and were more comfortable with those whom they had frequent contact. Nurses who attempted to establish rapport before sharing sensitive information were seen as more present. Describing when she received information from a student, a parent (P7) stated:

...you know, that was also, to me – I mean, I guess they have to learn too. So, it was probably a type of a teaching tool. But, you know, you hope that you hear it from them. It means more to hear it from them. Somebody that you have trusted and built somewhat of a relationship with, instead of a complete stranger. This is life altering news that you're getting. So, I think that would've been more respectful.

Parents expressed presence when information provided to them was accurate, honest, easy to understand, and timely. Although parents admitted that, at first, receiving the information was overwhelming and challenging to grasp, they were more assured when nurses were straightforward and had a plan of care. Parents felt that receiving timely and accurate information made them feel cared for, less anxious, and made it safer to care for their sick children. Parents also noted that *how* information was shared was equally as important as *what* was shared. Participants stated that nursing presence was experienced when nurses were patient in their care. This was experienced through answering parents unending questions, clarifying misinformation, using a friendly and respectful tone of voice, and carrying a pleasant attitude. Describing a nurse's interaction with her four-year-old child, one parent (P10) said:

She came in, didn't say hi, or find out how our night was. Like she just started talking, 'oh, I heard he's combative and like he gave someone a black eye. So, I'm not going to tolerate that today.' Just like that. [Laughter]. So, then I'm sitting there and she's like, 'and I'm going to come back, get all his stuff done and weigh him and do this and do this.' She was just going on and on while I sat there. So, I asked, 'are you talking to him?' She responds 'yeah'. I was like, 'why?' She says, 'well, I heard he's combative.' Then I was like, 'ok, you know what? You cannot be his nurse today.'

Participants in this study expressed a lack of presence when nurses caring for their ill child was unsympathetic in their approach, as opposed to those who showed more understanding when their child was aggravated and uncooperative. Describing presence, parents were observant in what was communicated not only through the verbal, but the non-verbal body language and attitude. An unpleasant attitude while sharing information damaged any experience of presence by creating a barrier and mistrust between the nurses and parents.

Family involvement in care

Parents experienced nursing presence when they were involved in their child's care through decision making and learning how to perform some tasks. Parents considered themselves as primary advocates for their child and felt presence when their observations, ideas, and concerns were heard and genuinely considered in decision making by nurses. Participants reported to have had a better experience when requests they felt to be reasonable, were respectfully granted. Describing her child's traumatic experience being poked and finally getting a PICC (Peripheral Inserted Central Catheter) line, one parent (P8) said:

They were in there four times a day drawing blood and he was getting transfusions and they were blowing veins and he had nothing left. The nurse, advocated for him to get a [PICC]. And he had a [PICC] in for four of five days before he got his port put in. You know, they were going to pull the [PICC] when they put the port in as well, and I said, no, because if that port doesn't work or it's not functional. So, I told the nurse please leave that [PICC] in even if it's for my mental health- you can't keep poking this kid six, seven times a day. And so, they were like, you know, whatever.

Parents not only felt presence when they were involved in nursing care at the hospital, they observed that it made the experience less traumatic for the child and less stressful for the nurse. Participants also identified patient teaching as nursing presence since they were equipped and prepared to perform their child's care in the nurse's absence:

...Probably when I'm at home, for example, all the stuff they've passed along to me and my wife. Like she has a feeding tube, her G-Tube, her port; all that, they've made sure we've understood how it works and helped to grasp it all. And so, anytime if ... let's say her G-Tube comes out, they've shown us everything if it ever comes out at home. But one of them has shown us what to do to put it back in instead of here's your kid and "goodbye" ...

Involving the family in their child's care and ensuring parents were comfortable in performing tasks through patient teaching gave parents a sense of control, allowing them to be actively involved in their child's care. Parents expressed presence when nurses involved them in decision making, provided them needed information, and equipped them with the necessary skills to look after their ill child when away from the hospital.

A home away from home

Parents described nursing presence as a sense of belonging to the 'nursing family' during their hospital visits. The term 'family' and 'home' were repeatedly used by parents describing how they felt safe and accepted by the nursing team. Frequent visits, familiarity, and empathy from nurses provided companionship for parents, thus establishing trust and developing better relationships. Describing how a nurse was like family, a parent (P1) stated:

Yeah, I think she could see that we were pretty shaken, and she just had empathy in general which is nice... She made a huge difference and a huge impact in our life, and she made this a little bit more bearable and that's – you can't take that back, right? Like this diagnosis is awful. I mean it could be worse, of course, but those first few days, I mean the shock of it, having someone who cares about you as a family, that matters...

A genuine willingness of nurses to actively cater to patients' needs made parents describe them as 'family'. Nursing presence was experienced when parents felt safe and less stressed at the hospital because nurses were proactive in their child's care. Describing why he referred to nurses as family, P2 said "It's like a husband and wife, if she threw

up, they're (husband) there to help. No questions asked, they just ... they just do it." In addition, due to the COVID pandemic, parents state they saw nurses more frequently than their families, making them a steady source of support and comfort. One parent (P9) elaborated by saying:

...especially through COVID, we see our nurses more than we see some members of our family. Like more than I've seen my parents or my brother, just because we have to keep our circles so tight. They [nurses] are a very steady presence in our lives. Yeah, they're our family...

Familiarity due to frequent hospital visits provided a steady source of support and comfort. Parents acknowledged it felt safer and easier for them and their children to relate to some nurses because they were not only familiar but pleasant and easy to relate to. Parents experienced nursing presence through warmth, trust, companionship, and safety provided to them by their 'nursing family'. A summary of the constituents and describing attributes using parents' quotations are presented in Table 3.

Analysis of participants' data provided six constituent features of the structure of nursing presence as experienced by parents is a pediatric oncology setting. These constituent features captured both an intrinsic and extrinsic dimension of nursing presence. Parents described intrinsic attributes of nursing presence that reached to their socio-emotional being, characterized by a genuine concern and care. Parents also paid attention to nursing skills, determining the extrinsic attributes that made them feel safe and involved. These attributes were intertwined to form the totality of nursing presence, leading to positive hospital experience for the parents.

Discussion

To reiterate, the purpose of this study was to use a descriptive phenomenological approach to describe the essence of nursing presence as experienced by parents of children with cancer. Findings demonstrated that nursing presence was essential in the formation of nurse-patient relationships. The essence of nursing presence was described by parents of children in oncology as highlighted by the 'being' and 'doing' of presence. In their descriptions, these dimensions tended to overlap and were equally important. This finding is consistent with Kostovich et al. (2016) who described nursing presence as multidimensional, encompassing a physical and a metaphysical presence that meets the emotional and social need of a patient. This study affirms that parents of children with cancer experienced nursing presence not only when their socio-emotional needs were met, but also the physical needs of their ill children during treatment. Parents experienced nursing presence when nurses were able to physically cater to their child's needs while being emotionally available for them.

Nursing presence was experienced when nurses were genuinely concerned, saw the child as a normal human being, and listened and remembered their stories. Parents and their child felt seen, heard, and understood when nurses showed genuine interest in them as human beings and not their illness. These results are similar to Woodgate (2006) who found that adolescents with cancer experienced nursing presence when nurses were interested in them as people; instead of treating them as if their lives evolved around cancer and its treatment. In another study, by Monterosso and Kristjanson (2008), parents found comfort in relationships where nurses demonstrated willingness to know their child as a person. Conversations held on a personal level made pediatric patients feel safer in the hospital environment and reduced their fear of the unknown that came with a cancer diagnosis (Anderzén-Carlsson et al., 2012). When a nurse has an *attitude of*

Table 3

A summary of the constituents and describing attributes using parents quotations.

Constituent	Describing Attributes using Parents Quotations
An attitude of presence	An intrinsic attitude characterized by a nurse's genuine concern for parents and their children in their period of distress. "We could hear them talking outside of our curtain, but no one walked in to ask if everything was OK. It took my husband going out there and saying we need help. It was so stressful and really bothered me that there was that much distress coming from behind the curtain ... and I knew they were out there, and they could hear us, and no one could just peek their head in and say, do you need help. It was so disappointing"
A source of encouragement	Through emotional and physical acts of kindness, parents feel seen as human allowing them to experience comfort and safety in their vulnerability. "Like they took him back to the OR three, four times and they couldn't find the reason he was having all these complications. So, it was really good to have someone to just sit with you. She sat on the bed, and she talked to me and told me, don't worry, like, we always have this. And he'll be ok. You're taking such good care of him. And she just, yeah. She just talked to me, like, as a human being. Like, it just, yeah. It was really, really good."
Clinical experience and expertise	An extrinsic attitude experienced when nurses are mature, skilled, and competent in their care. "...I didn't want her to access her port because she hadn't had enough experience accessing ports and I didn't want her to miss. And she did miss. She came in, she tried to access her, she missed, so I was not pleased. And so, at that point we already knew she already had an infection – she had a fever – so I just said 'Yeah, let's just take her up to the ward and they'll access her up there.' They took her up to the ward, they got it on one try and it turned out to be a line infection... yeah, they got her accessed quickly there."
Therapeutic communication	When information is shared in a respectable manner-paying attention to who, what, and how the information is provided "She came in, didn't say hi, or find out how our night was. Like she just started talking, 'oh, I heard he's combative and like he gave someone a black eye. So, I'm not going to tolerate that today.' Just like that. [Laughter]. So, then I'm sitting there and she's like, 'and I'm going to come back, get all his stuff done and weigh him and do this and do this.' She was just going on and on while I sat there. So, I asked, 'are you talking to him?' She responds 'yeah'. I was like, 'why?' She says, 'well, I heard he's combative.' Then I was like, 'ok, you know what? You cannot be his nurse today."
Family Involvement	When the patient family is involved in their child's care through decision making and learning how to perform some tasks "...Probably when I'm at home, for example, all the stuff they've passed along to me and my wife. Like she has a feeding tube, her G-Tube, her port; all that, they've made sure we've understood how it works and helped to grasp it all. And so, anytime if ... let's say her G-Tube comes out, they've shown us everything if it ever comes out at home. But one of them has shown us what to do to put it back in instead of here's your kid and 'goodbye' ..."
A home away from home	As a result of presence, feelings of safety and belonging are experienced by parents leading to improved trust and therapeutic relationships. "...especially through COVID, we see our nurses more than we see some members of our family. Like more than I've seen my parents or my brother, just because we have to keep our circles so tight. They [nurses] are a very steady presence in our lives. Yeah, they're our family..."

presence, they see the patient as a person and pays attention to their stories since they have meaning attached to their daily lives. Although Browning and Waite (2010) argued that it takes courage for nurses to open their hearts and listen, presence provides an opportunity for nurses to listen and understand at a deeper level in order to connect with their patients and families on a shared humanity. Nursing presence also seemed to be conveyed in small actions by nurses; these did not go unnoticed by parents. Opening the curtain to acknowledge noise from the opposite side can appear to be minor or insignificant. According to Gottman and Silver (2012) it is these seemingly insignificant gestures that provide an opportunity to establish or betray trust, which are essential means for establishing and experiencing nursing presence. Paying attention to little things and acting in the smallest ways demonstrated that nurses saw parents and their patients as more than a diagnosis, a bed number, or a task to be accomplished.

Parents experienced nursing presence when nurses were a source of encouragement and comfort in their distress. Parents felt seen and encouraged when nurses expressed sincere commitment and interest, giving hope, and helping them cope with their child's illness. These findings echo a study by Steele et al. (2013) which showed that parents needed to be encouraged that they were going to get through their difficult circumstances. Pediatric patients in Woodgate's (2006) study also experienced presence and valued nurses who were there to remind them of the importance of maintaining a positive attitude and getting on with life. Walsh (1999) described this nurse-patient interaction as 'being-with as possibility' in a shared human experience. Patient encouragement is not merely a vague hope about an unforeseeable future, but in 'being with', parents and nurses fight and strive for a possibility of what could become (Walsh, 1999). When caregivers take time to console patients, the aim of nurses in the presence is not to change or intervene, but to bear witness to the patient experiences in a non-judgemental manner and meet each other in their respective understandings of life (Mohammadipour et al., 2017).

Nursing presence was experienced when the care provided to parents was safe, desirable, and of good quality. This constituent feature of clinical expertise and experience explicitly revealed the 'doing' of presence that parents had considered significant. According to Costet Wong et al. (2015), parents mainly bring their children to the clinic to seek a diagnosis, treatment, and reassurance. Therefore, when parents experience nurses with clinical expertise and experience, they feel reassured and confident that their child is in good hands. Similar results are discussed by Mohammadipour et al. (2017) where patients described a nurse practicing presence as one who not only provided humanistic care, but one who was objective and technically competent. Most parents of children with cancer have had to endure frequent hospital visits, recurrent hospital admissions, and patient teachings, and therefore tend to be familiar with what is expected or required of them. Uncertainty, tension, and anxiety may arise when what they know to be familiar is challenged. Clinical experience and expertise allowed the nurses to engage in more meaningful exchanges in order to prevent negative consequences that may arise. According to Godkin (2001), nursing presence enabled nurses who were professionally mature to see a 'bigger picture' by going beyond the scientific data; they knew the uniqueness of the individual patient, and sensed when and how to interact with patients.

Godkin and Godkin (2004) argued that patients are unable to easily recognise whether the nurses were technically skilled or not but could effortlessly identify those nurses who had shown nursing presence. However, findings showed that parents in pediatric oncology can easily identify those nurses who they felt were less experienced and competent, as well as those who lack nursing presence. Although nurses are often trained to believe they are most effective when doing for a patient, nursing presence, being with the patient can be equally, if not more, therapeutic overall (Benner, 1984).

Parents were sensitive to not only who delivered the message, but what and how the communication occurred. Communication comprises

of what is being communicated and how the content is being communicated which includes the tone, language, and style used to deliver the message (Foronda et al., 2016). Parents sought open and honest communication delivered in a compassionate manner; preferably by someone they have established trust and rapport. Findings in this study are consistent with Steele et al. (2013) where families emphasized the importance of open and honest communication throughout the care of the ill child.

According to Furingsten et al. (2015) nursing presence may fail to materialize if honesty is missing. When parents have a clear understanding of their child's medical status their overwhelming sense of powerlessness is reduced and they gain some sense of control, allowing them to make more informed decisions on behalf of their child (Monterosso & Kristjanson, 2008). Connected with openness and honesty, nursing presence was experienced when information was delivered in a compassionate manner. When nurses use a gentle caring tone, a pleasant attitude, and practice patience with patients and their families, they demonstrate nursing presence in their relational skills. Walsh (1999) described this as a genuine being-to-being communication that takes place against a background of shared humanity, which allows us to communicate on a deep level of humanity, showing concern and understanding. Although several studies have indicated challenges involved in communication for nurses such as giving bad news, discussing end of life issues, or having conversations about sensitive issues (Sinclair et al., 2020; Steele et al., 2013) it is possible that nursing presence may provide a solution to having these difficult conversations by learning and practicing how to use presence to establish meaningful and trusting relationships that are comfortable enough to have these conversations. Further research is needed in this addressing nursing presence and having difficult conversations.

Parents of children with cancer wished to be included in the entire process of care so that they were able to support and comfort their ill child and reduce an overwhelming feeling of powerlessness. Nursing presence requires families to not only consent to but be empowered and actively involved in care decisions of their ill child. These results are similar to those of Mohammadipour et al. (2017), who found that nursing presence entails patients' involvement in care, which enables understanding and reduces anxiety and suffering.

Parents experienced nursing presence when they were helped to develop confidence and independence in their abilities to care for patients at home. Anderson (2007) stated that patients who benefit from nursing presence and received training required to realize recovery were less stressed and psychologically comfortable. Furthermore, the child's emotional trauma of being hospitalized, especially during episodes of discomfort is decreased if the parent is part of the care process (Roberts et al., 2015). With nursing presence, involving parents demonstrates that you see them as stakeholders and those who experience pain with their child. Nursing presence and patient involvement is useful to the parents and their children reducing anxiety and distress during the hospitalization.

Finally, parents likened the experience of nursing presence to a 'home', where they experienced trust, warmth, and safety with nurses as their 'family'. McGregor (2016) described a home as not only an enclosed private space, but a place where hearth, joy, protection, comfort, refuge, and belonging are experienced. In this study, parents felt loved and cared for when they visited the oncology clinic. Because of lockdown restrictions, limited freedom of movement, and social distancing due to COVID, nursing presence gave parents a sense of being in the world during their hospital visits. Seeing familiar people made them feel connected and provided a sense of belonging. Similar results are described by Woodgate (2006) where adolescents considered nurses as their second family, and experienced presence when nurses were there to: provide comfort when they were not feeling well; hold a hand when experiencing physical or mental stress; keep them from feeling less lonely; encourage them to maintain a life other than the

life that evolved around the cancer and its treatment; keep them positive; and, provide love and care when they felt moody and acted differently. Although a hospital is a busy and stressful environment, when nurses practice nursing presence, parents have a special feeling with the hospital environment where they feel safe and experience warmth and comfort due to the relationships formed and quality care received.

Strengths and limitations

This study has several strengths. A descriptive phenomenology approach was best suited for this study since it aims to provide a better understanding of anything experienced through the consciousness and determine its structure (Giorgi, 2009). Nursing presence is a human experience that appears in the consciousness (Watson, 1988) and its exploration using this method has further illuminated the phenomenon as experienced by parents of children with cancer. In addition, nurses seek an objective understanding of situations that are subjectively constituted (Giorgi, 2012). Because nursing presence is an intersubjective encounter between the nurse and the patient (Doona et al., 1997), descriptive phenomenology was the most suitable method because it extracted subjective experiences that were analyzed by an objective method of inquiry. There are some limitations to this study. All participants were recruited from one health facility. Although nursing presence is a human experience, parents from different health facilities may have provided different perspectives and strengthened the study. Furthermore, considering nursing presence is an intersubjective encounter, this study does not provide the experiences of nursing presence from the nurses' perspective.

Relevance to clinical practice and research

This study is the first to explore nursing presence as described by parents in pediatric oncology. Insights from parents in this study will inform therapeutic processes and ultimately enable the development of strategies to improve delivery of healthcare to pediatric oncology patients. Future research should explore nurses' experiences of presence in order to identify similarities or intersections with patient experiences. This will help provide a clearer picture of the phenomenon as experienced in a pediatric oncology setting. A better understanding of nursing presence would facilitate continuous improvement in knowledge, attitudes, and abilities of nurses to care for parents and their sick children. Additional qualitative research approaches, such as grounded theory, should be considered for future studies to generate a theoretical depiction of the process of nursing presence. Development of a theory will enable measurement of the ideas, making the concept more tangible and easier for practicing nurses and students to grasp and utilize. Further research could also focus on developing evidence-based approaches to guide the integration of nursing presence into pediatric oncology practice, research, and education. Nursing presence could inform new hospital policy, and practice standards to improve delivery of care to pediatric patients and their parents.

Conclusion

The experiences described by parents provides rich and nuanced insights into what it means to experience nursing presence in a pediatric oncology setting. This study provides a structure and expounds on its constituent features, describing nursing presence as experienced by parents of children with cancer. It was evident that nursing presence has both dimensions of being and doing, and both are equally significant for provision of quality nursing care. Nurses can use these findings to inform practice, policy, and education. However, further research investigating how to implement nursing presence is required to develop programs where presence can be taught and nurtured given its value in provision of quality care in pediatric oncology care setting.

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CRediT authorship contribution statement

Solomon K. Mcharo: Conceptualization, Methodology, Investigation, Formal analysis, Writing – original draft, Writing – review & editing, Funding acquisition. **Jill Bally:** Conceptualization, Methodology, Formal analysis, Writing – review & editing, Supervision, Funding acquisition. **Shelley Spurr:** Conceptualization, Methodology, Formal analysis, Writing – review & editing, Supervision, Funding acquisition. **Keith Walker:** Conceptualization, Writing – review & editing. **Shelley Peacock:** Conceptualization, Methodology, Writing – review & editing. **Lorraine Holtslander:** Conceptualization, Writing – review & editing.

Declaration of Competing Interest

None.

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