Novice Nurses' Experiences With Palliative and End-of-Life Communication CE

Verna L. Hendricks-Ferguson, PhD, RN[1],
Kathleen J. Sawin, PhD, CPNP-PC, FAAN[2],
Kitty Montgomery, PhD, RN, PCNS-BC, CPHON[3], Claretta Dupree, PhD, RN[4],
Celeste R. Phillips-Salimi, PhD, RN, CPON[5], Barb Carr, APRN, BC, PNP[6],
and Joan E. Haase, PhD, RN, FAAN[5]

Abstract

Health care providers recognize that delivery of effective communication with family members of children with life-threatening illnesses is essential to palliative and end-of-life care (PC/EOL). Parents value the presence of nurses during PC/EOL of their dying child. It is vital that nurses, regardless of their years of work experience, are competent and feel comfortable engaging family members of dying children in PC/EOL discussions. This qualitative-descriptive study used focus groups to explore the PC/EOL communication perspectives of 14 novice pediatric oncology nurses (eg, with less than 1 year of experience). Audio-taped focus group discussions were reviewed to develop the following 6 theme categories: (a) Sacred Trust to Care for the Child and Family, (b) An Elephant in the Room, (c) Struggling with Emotional Unknowns, (d) Kaleidoscope of Death: Patterns and Complexity, (e) Training Wheels for Connectedness: Critical Mentors during PC/EOL of Children, and (f) Being Present with an Open Heart: Ways to Maintain Hope and Minimize Emotional Distress. To date, this is the first study to focus on PC/EOL communication perspectives of novice pediatric oncology nurses.

Keywords

palliative care, end-of-life communication, pediatric oncology nurses

Improvement in the quality of palliative care and end-of-life (PC/EOL) care for children is identified as a research priority by federal and private health organizations (Carroll, Mollen, Aldridge, Hexem, & Feudtner, 2012). To date, the authors of this article have identified no published evidence of communication strategies or approaches recommended by health care providers when discussing PC/EOL topics (eg, curative and noncurative care goals) with pediatric patients with cancer and their families. Hence, evidence-based guidelines of communication strategies for use by health care providers when planning and conducting PC/EOL discussions about pediatric patients and family members have yet to be established (Angelini, 2011; Foster, Lafond, Reggio, & Hinds, 2010; Kain, 2011).

Still, physicians and nurses are aware that sharing clear information about PC/EOL care options with families of children with life-limiting conditions is essential to ensure that parents understand the focus and benefits of having their child receive PC versus EOL care (Foster et al., 2010). For example, parents need to receive clear information about PC/EOL care options in order for them to comprehend the purpose and benefits of receiving early PC (eg, psychosocial and symptom support during curative-focused treatments and also during EOL care) and the focus of EOL care (eg, psychosocial and symptom support after the patient is transitioned to noncurative focused care, such as during hospice home care).

[1]Saint Louis University, School of Nursing, St Louis, MO, USA
[2]University of Wisconsin-Milwaukee and Children's Hospital of Wisconsin, Milwaukee, WI, USA
[3]American Family Children's Hospital, Madison, WI, USA
[4]US Navy Retired Captain, Greensboro, NC
[5]Indiana University, School of Nursing, Indianapolis, IN, USA
[6]St Louis Children's Hospital, St Louis, MO, USA

Corresponding Author:
Verna Hendricks-Ferguson, Saint Louis University, School of Nursing, 3525 Caroline Mall, St Louis, MO 63104, USA.
Email: hendrivl@slu.edu

To date, scant literature has provided very limited information about pediatric oncology nurses' perspectives and experiences with PC/EOL care discussions with parents of children with cancer. Nurses are especially well situated during patient care for opportunities to engage in discussions about the purpose and benefits of PC/EOL with pediatric patients and their families (Angelini, 2011; Kozlowska & Doboszynska, 2012). Parents of children with cancer have reported that they were especially comforted by nurses who provided ongoing presence and support during PC/EOL care (Bradford et al., 2012). It is vital that nurses are confident to engage in discussions about PC/EOL care with parents of children with life threatening conditions. Still, little is known about nurses' perspectives and experiences to engage in these discussions, their perceived role in PC/EOL communication, and their level of confidence in communicating with dying children and their families (Beckstrand, Rawle, Callister, & Mandleco, 2010).

A few studies have focused on factors that may influence pediatric nurses' communication about PC/EOL care of children with life-threatening conditions in pediatric intensive care units (Beckstrand et al., 2010; Davies et al., 2008). However, the investigators of these studies did not focus on pediatric nurses' experiences in caring for children with cancer and related factors influencing PC/EOL discussions with family members (Beckstrand et al., 2010; Davies et al., 2008). Thus, questions exist regarding pediatric oncology nurses' PC/EOL communication experiences and specific factors (ie, years of work experience) that may affect the nurses' confidence and competence to provide PC/EOL care and engage in related discussions with pediatric patients with cancer and their family members.

With the universal care goal of providing high-quality care to children with cancer and their families during PC/EOL care and in identifying factors that may facilitate or impede PC/EOL care discussions, the communication patterns between pediatric oncology nurses, the child, family, and other health care providers should be explored. This article describes novice pediatric oncology nurses' (ie, less than 1 year of work experience) experiences and perspectives about PC/EOL communication with pediatric patients with cancer, their parents, and other health care providers. Data were obtained during focus group sessions conducted at 3 clinical sites.

Literature Review

Level of Nursing Experience and Knowledge About PC/EOL Communication

Communication with dying patients and families about PC/EOL care is commonly viewed as extremely difficult and has been described as similar to addressing "the elephant in the room" (Belcher, 2012; Quill 2000). Both adult and pediatric oncology nurses have also reported feeling uncomfortable and inadequate when talking to families about PC/EOL care (Davies et al., 2008). Unfortunately, limited or no educational preparation in PC/EOL care information has resulted in a pool of practicing nurses who are unprepared to engage in PC/EOL discussions and often primarily influenced by their own values, attitudes, and their own PC/EOL care experiences (Kassam, Skiadaresis, Habib, Alexander, & Wolfe, 2012). Investigators have reported that practicing nurses became more confident over time in discussing PC/EOL information with adult patients (Dunn, Otten, & Stephens, 2005). To date, studies of nurses caring for dying children with cancer have not focused on nurses' level of work experience in PC/EOL communication or if the extent of their PC/EOL experience influenced their ability to engage in PC/EOL discussions with children, families, and other health care providers (Beckstrand et al., 2010; Davies et al., 2008).

Effective Communication to Support Relationships During PC/EOL

Delivery of effective and caring communication by nurses is essential to establishing therapeutic alliances with families; to providing families with accurate, consistent information about the child's diagnosis and treatment; and to empowering families to make informed decisions and to confidently care for their children (Angelini, 2011). However, some parents of children with cancer have reported experiencing coldness, contradictions, laissez faire attitudes, and other avoidance behaviors displayed by health care providers during their child's PC/EOL care trajectory (Davies & Connaughty, 2002; Hendricks-Ferguson, 2007). Poor interaction between the parents and health care providers caused some parents to feel abandoned and to question the accuracy of medical information.

When communication is delivered in a clear and sensitive manner, open communication during PC/EOL care can be especially beneficial to children with cancer and their families (Kassam et al., 2012). Delivery of clear and honest communication to families can also enhance the nurses' satisfaction with the care they provide and also the parents' and child's satisfaction with the care they receive (Hinds et al., 2012). The nurse can address fears and uncertainties when children are included in the discussion of the cancer diagnosis, treatments, and prognosis (Boyd, Merkh, Rutledge, & Randall, 2011; Grainger, Hegarty, Schofield, White, & Jefford, 2010). Open communication can also foster trust between the nurse and the family and facilitate a peaceful death for the child (Foster et al., 2010).

Barriers to Communication

For the 25% of children with cancer who are at risk of dying, ineffective or poor PC/EOL care-focused communication may contribute to patients experiencing decreased quality of life (Foster et al., 2010). Commonly reported barriers to effective PC/EOL communication are the preferences of both parents and children to protect others from emotional distress (Davies et al., 2008) and parents' inability to understand their child's impending death (Kars, Grypdonck, Beishuizen, Meijer-van den Bergh, & van Delden, 2010; Kars et al., 2011). Other barriers to effective PC/EOL communication are parental concerns about finances and cultural differences among parents impeding expression of their perceptions and needs (Beckstrand et al., 2010; Dighe, Jadhav, Muckaden, & Sovani, 2008; Dunne, Sullivan, & Kernohan, 2005).

Nurses have reported a high degree of stress when caring for a dying child and when communicating with the child and parents during the child's PC/EOL care (Hughes & Fitzpatrick, 2010). In one study of nurses' experiences, struggling with multiple care challenges was a general concern of nurses who cared for terminally ill children (Davies et al., 2008). These nurses also struggled with their own grief and the fear that cancer might affect a child in their own family and also with moral distress when following physician's orders for treatments that they feared would inflict suffering without likely benefit to the dying child.

Roles of Nurses in PC/EOL Communication

Some investigators have described the important role that nurses can provide to pediatric oncology patients and their parents throughout PC/EOL care (Foster et al., 2010; Hinds et al., 2012). Specifically, during PC/EOL care, pediatric nurses were more likely to communicate with families about psychosocial, religious, and sibling issues, while physicians tend to focus on treatment-related decisions with families (Mitchell, Sakraida, Dysart-Gale, & Gadmer, 2006). Parents of children receiving PC/EOL care have described the perception that they view nurses almost like family members, with the nurse's role during the child's dying process often being viewed as more supportive than other family members and friends (Browning, 2009). In contrast, other investigators have reported that oncology nurses often viewed their role as merely supporting decisions made by the physician and family while providing care to the adult dying patient (Helft, Chamness, Terry, & Uhrich, 2011).

The results presented in this article are part of a large multisite study that included 12 focus groups of nurses with pediatric oncology experience with varying years of work experience. Because large amount of interview data were collected during the 12 focus groups for this multisite study, the investigators planned to present the results in 4 separate articles according to the enrolled nurses' years of work experience. The purpose of this article is to describe the (*a*) commonalities of perspective and experiences of novice pediatric oncology nurses (ie, those with less than 1 year of experience caring for children with cancer) and (*b*) pediatric oncology nurses' perceptions of factors that facilitate and impede PC/EOL communication with dying children, their families, and other health care providers.

Methods

Study Design

A qualitative, empirical phenomenology design based on group-as-a-whole theory was used to guide our multisite study. We conducted focus group discussions to explore pediatric oncology nurse participants' experiences and perspectives regarding communication about PC/EOL care with pediatric patients with cancer, their families, and other health care providers. During the focus groups, open-ended questions fostered rich discussion of the nurses' experiences and perspectives about PC/EOL care and related communication. Group-as-a-whole theory supports use of focus groups for phenomenology based on the idea that the behavior and experiences of individual group members are expressions of the group's collective experience (Kooken, Haase, & Russell, 2007).

Participants and Setting

Investigators of a multisite study conducted focus groups with nurses at 3 major pediatric hospitals located in the Midwest region of the United States. A total of 12 focus groups were conducted (4 groups at each of the 3 hospitals). The investigators planned focus group assignments based on the nurses' work-years of experience with caring for dying children with cancer and their current nursing role to ensure the collection of data was from homogenous groups. The investigators use of homogeneous groups was planned to (*a*) enhance the likelihood of achieving data redundancy, (*b*) minimize any differences in PC/EOL communication skills based on years of work experience, and (*c*) maintain participant confidentiality by eliminating concerns about sharing information with those who evaluate the nurses' performance.

Following are the specific member qualifications (ie, years of work experience in pediatric oncology) for each of the 4 focus groups formed at each setting. The Group 1 focus groups included staff nurses with less than 1 year of experience. The Group 2 focus groups included staff nurses with 1 to 5 years of experience. The Group 3 focus

groups included staff nurses with more than 5 years of experience, without any type of management responsibilities. The Group 4 focus groups included nurses who held current management positions. In this article, we describe the analysis of focus group interview data collected from Group 1. Eligibility criteria for the Group 1 nurses included (a) ability to speak English, (b) registered nurse currently working in a pediatric oncology setting for less than 1 year, (c) experience in caring for at least one dying child with cancer, and (d) willingness to discuss PC/EOL communication experiences with a dying child with cancer, family members, and other nurses in a focus group.

Human Subjects Protection

Prior to initiating the study at each of the 3 sites, all institutional review board (IRB) approvals were obtained. On the scheduled focus group meeting dates, eligible nurses were taken to a private room to review and sign the consent form before participating in the focus group meeting. On signing the consent form, each nurse participant completed a demographic data form. The nurse participants were assured that their participation was voluntary and that every effort would be made to protect confidentiality. At the beginning of each focus group, the focus group leader reviewed the importance of confidentiality and the ethical principles related to not disclosing any names of the focus group participants and of the content discussed during or after the focus group meeting.

Data Collection

At each data-collection site, a pediatric oncology nurse-manager assisted with identifying the names of nurses, from a generated employment database, who met the inclusion criteria. Eligible nurses received a letter via their electronic or organizational mailboxes, inviting them to participate in the study and instructing them to contact a research team member via phone or e-mail to receive information about the study. Subsequently, when contact was made with a potential nurse participant, a research team member reviewed the nurse participants' eligibility. If eligible, the research team member provided the nurse participant with information on the study purpose and planned focus group procedures. Written consent was obtained from all nurse participants immediately prior to the start of each focus group. Also, the investigators received IRB approval at each study site to provide release time for the nurse participants to attend the focus groups during scheduled work days.

The majority of the nurse participants attended the focus groups meetings during or at the end of a scheduled work day. A few nurse participants choose to attend on an unscheduled work-day. At each site, a trained moderator (the focus group leader) and a field note recorder, not affiliated with the data-collection site, conducted the focus group meeting. Each meeting lasted from 1.5 to 2 hours. The nurse participants were asked to prepare for the meeting by (a) reflecting on any past experiences with PC/EOL communication with children and their families and to identify barriers to these discussions and (b) reviewing a list of broad data-generating questions focused on PC/EOL communication experiences related to a child with cancer (see Table 1). At the start of each focus group meeting, the moderator reviewed the selected questions and the importance of maintaining confidentiality of all information shared during the focus group meeting. All focus group meetings were audiotaped. Breaks and light snacks were provided.

Data Analysis and Interpretation

The audiotaped interviews were transcribed verbatim by a professional transcriptionist. An adapted version of Colaizzi's (1978) phenomenological 8-step method was used to analyze the data (see Table 2). Implementation of the steps enhanced team members' familiarity with the nurse participants' experience as a whole.

Results

The sample included a total of 14 registered nurses with less than 1 year of work experience in pediatric oncology. All the nurse participants were Caucasian females, aged 25 to 31 years (M = 28 years); 57% were not married. The participants' nursing education preparation included nurses who had completed either an Associate of Science in Nursing (ASN) degree (n = 9) or a Bachelor of Science in Nursing (BSN) degree (n = 5). Also, none of the nurse participants reported having previously attended an educational program focused on PC/EOL care for children or to have completed the national End-of-life Nursing Education Consortium program.

Novice Pediatric Oncology Nurse Experiences

A total of 2275 significant statements were extracted and analyzed from the focus group data. The nurse participants described their perspectives of PC/EOL communication with children who have cancer, their families, and other health care providers. Table 3 outlines the identified 6 theme categories, corresponding subthemes, and representative quotes from the data. Following is a detailed description of the themes and selected subthemes. Fictitious names of the nurse participants from our focus groups were used with selected quotes to describe significant statements under each theme category.

Table 1. Data Generating Questions.

The following list of 10 questions was provided to the enrolled nurse participants prior to scheduled focus groups and was used as a guide during the focus group sessions:

1. What do you think especially helped you in communicating with children with cancer and their families about palliative and end-of-life care?
2. What literature has been available to you as an institutional resource for communicating about palliative and end-of-life care with children with cancer and their families?
3. What personnel at your institution have you used as a resource for communicating about palliative and end-of-life care with children with cancer and their families?
4. What barriers prevent you from communicating effectively about palliative and end-of-life care to children with cancer and their families?
5. What did you perceive as priority concerns for nurses in communicating to children with cancer and their families about palliative and end-of-life care?
6. What do you think especially helped you in communicating with other health care providers of children with cancer and their families about palliative and end-of-life care?
7. What literature has been available to you as an institutional resource for communicating about palliative and end-of-life care to health care providers?
8. What personnel at your institution have you used as a resource for communicating about palliative and end-of-life care to health care providers?
9. What barriers prevented you from communicating effectively about palliative and end-of-life care to health care providers?
10. What did you perceive as priority concerns for nurses in communicating with other health care providers of children with cancer and their families about palliative and end-of-life care?

Table 2. Adaptation of Colaizzi's 8-Step Process.

Step	Process Conducted
1	Two team members validated the transcript accuracy by listening to audiotapes.
2	Two team members, who were from a different site than the focus group being reviewed, repeatedly read the transcripts, identified initial significant statements, revised them into restatements, and used them to formulate meanings.
3	The entire research team reviewed the formulated meanings until a consensus was determined and meanings were finalized.
4	Pairs of team members identified tentative themes based on commonalities of the formulated meanings. A team of APNs participated in confirmation of thematic analysis.
5	Pairs of team members extracted formulated meanings and organized them into a hierarchy of themes.
6	Team members reviewed theme clusters until reaching consensus of the final categories.
7	Development of a narrative of experiences incorporated identified themes.
8	Development of narrative summarized the nurses' experiences of communicating about PC/EOL with children with cancer, their families, and HCP.

Abbreviations: APN, advanced practice nurse; PC/EOL, palliative and end-of-life care; HCP, health care provider.

Theme 1: A Sacred Trust to Care for the Child and Family

Commitment to Provide Quality PC/EOL Care. The nurse participants described a strong commitment to provide sensitive, meaningful interactions to the children and their families during PC/EOL care and after the child's death.

> To be there with family, be supportive, try to make sure the comfort needs are met, to make sure he's got enough oxygen, . . . just to be there and try to support the family as much as you possibly can, but not being in the way at the same time.

Examples of nursing care included facilitating protected and private time for parents to be with and hold their child during PC/EOL care and after their child's death. Also, the examples of nursing care included quotes illuminating the nurses' commitment to ensure consistent delivery of caring acts in support of parents during their child's life and after their child died.

Desire to Foster Meaningful Family Memories During PC/EOL Care. The nurse participants explained a desire to foster meaningful memories about the child for the families. "I didn't want to do anything that the family would be upset with, and I didn't want to do too much with her

Table 3. Summary of Themes and Focus Group Quotes.

Themes	Theme Descriptions and Subthemes	Sample Quotes
Sacred trust to care for the child and family	Meaningful commitments during and after child's PC/EOL	
	1. Commitment to provide quality PC/EOL care	". . . to be there with family, be supportive, try to make sure the comfort needs are met, to make sure he's got enough oxygen, . . . just to be there and try to support the family as much as you possibly can, but not being in the way at the same time."
	2. Desire to foster meaningful family memories during PC/EOL	"I didn't want to do anything that the family would be upset with, and I didn't want to do too much with her because I wanted the family to be able to spend time with her."
An elephant in the room	Tensions of communication about "the elephant in the room"	
	1. Role tension and uncertainty around communication related to PC/EOL	"Physicians are very involved, but also very reluctant to say, 'Are we getting to the end of what we could possibly do?' I've seen them struggle in coming to terms with that themselves."
	2. Perspectives on why the struggles occur	"How do you bring it up to parents? Do you let them approach you or do you bring things up? You can just tell they're struggling sometimes. I don't know how to approach the situation."
Struggling with the unknowns	Uneasiness with emotional responses during the child's PC/EOL	
	1. Trepidation and uneasiness with emotional responses during PC/EOL	"We were talking about it, and he said he really was not afraid of dying. The thing he was afraid of was how much he was going to miss us. That is something that I really will not forget."
	2. Bearing witness to repeated and long-term struggles for the child and family	"It's hard to know when to say something and when not to say something. That's what I find trouble with, and he was really, really sick and was here pretty much the whole time. I went down with the family when they talked about taking him off the respirator, and that was hard, too."
	3. Continued uneasiness with personal response's to the child's death	"I think it's hard to go through since you get so attached. We're so protective of our patients. And then when something happens, it is very hard to deal with. That's just hard because you're so close to them. We do have the rapport like that. Even patients who have passed away, families come back."
Kaleidoscope of death	Learning how to deal with complex communication and shifting events at time of death	
	1. Understanding that the process of end-of-life care is complex	"I just ran out to the nurse's station and I said, "He stopped breathing and what do I do?' Because I was not prepared at all for that night. But luckily the day nurse had filled out all the paper work of that person maybe a week and a half or so. And I don't know all the steps that go into, like how long they get to stay."
	2. The steepest of learning curves: Preparing family for their child's death	"I remember being really nervous when I went in the room after she actually passed away. I remember I was really shaky and I kind of had butterflies in my stomach because I was like, I don't really know what I'm doing because it was the first time it had actually happened while I was working. The nurse was actually in the room when the doctors were in there, and some of the team units from PICU were there to transfer him to PICU and intubate him. And, she said, "Wait, let's take a deep breath, mom and dad is this what you really want to do?' If she wouldn't have been in the room, I'm sure that she would have been transferred and intubated."
Training wheels in connectedness	Critical mentors during PC/EOL of children	
	1. Lessons about the processes of death and best communication practices from mentors	"My preceptor was caring for a patient, one of her primary patients who was in end stage disease and had been for several weeks at that point. I was assisting her in her care for that person maybe a week and a half or so. So, I was able to observe a really positive experience and how a very experienced nurse handled it. As a new nurse to the unit, to be faced with that right off the bat with an experienced person and feeling like I was basically in an observational role at the point, that was a tremendous asset."
	2. Learning about EOL communication is a life-long journey	"She told me that no matter what, it never gets any easier, you may handle yourself different. Your first is going to be a lot more emotional. I'm not going to tell you it gets easier, but you have more experience and you're able to see other people go through it."
Being present with an open heart	Desire to maintain hope and minimize emotional distress during and after PC/EOL by supporting each team member	
	1. Commitment to support nurses caring for child during PC/EOL	"I think it's important for us to try to be there for fellow employees whom we work with. And, his primary nurse was in the room with him. But then when it came time to clean and everything, I just went in and said, 'Here, I'll get it.' Because you know, they don't need to do it unless they want to. That's so hard. I don't know some of the patients I have as my primary. I don't know if I could go in there and do that. It would just be so hard, so I think we need to look to, not just the families. It's important that everybody who is involved in the end of life care. I know that nurse is so appreciative that she didn't have to go in there and face that, and do that."
	2. Support by the multidisciplinary team members is important	". . . and there was support from everyone, the staff. It was amazing."

Abbreviations: PC/EOL, palliative and end-of-life care; PICU, pediatric intensive care unit.

because I wanted the family to be able to spend time with her." Examples of nursing care to foster family memories included reducing parental distress by minimizing the unnatural hospital setting as much as possible (eg, concealing or minimizing intrusive medical equipment connected to a child as a way to foster natural physical contact [eg, holding] between the child and parent). Another example included creating and/or facilitating meaningful communication and memory-making experiences between parents and child.

Theme 2. An Elephant in the Room

The nurse participants explained a perceived tension inherent in PC/EOL discussions among children, families, and other health care providers, especially conversations focusing on the perceived "elephant in the room," the child's poor prognosis, and/or need for EOL care rather than a focus on curative care. The nurse participants also identified tensions related to the uncertainty of their role in talking about PC/EOL concerns with the child and their parents and understanding why some health care providers may struggle with initiating and feeling comfortable during PC/EOL care discussions.

Role Tension and Uncertainty Around Communication Related to PC/EOL Care. Role tension and uncertainty existed among physicians, patients, and family members regarding if, when, what, and how to initiate and engage in discussions about PC/EOL care. Across numerous scenarios, participants struggled greatly with having PC/EOL discussions with dying children and their families. Specifically, the nurse participants struggled: (*a*) when there was general staff knowledge of the child's worsening condition, but uncertainty about parents' and child's knowledge and acceptance of the worsening condition; (*b*) when it was clear the pediatric patient needed help to process what a physician communicated; and (*c*) when parents directly asked them for information about the child's condition and/or prognosis. When asked for information, the nurse participants described having a sense of knowing what the parents wanted to hear, but felt uncertain and/or unable to provide assurance or answer the parents' questions honestly.

Role tension was especially related to the nurse participants' perception that physicians were reluctant to accept what the nurses felt was inevitable, that is the death of the child. "Physicians are very involved, but also very reluctant to say, 'Are we getting to the end of what we could possibly do?'" The nurse participants also believed physicians are generally not skilled in having open and clear discussions with children and parents about discouraging information related to the child's prognosis, treatments, and possible death. Additionally,

subsequent to discussions with health care providers, the participants described feeling like they often were left alone to provide support when children or parents reflected on and raised questions about the information they had heard from their health care provider.

Perspectives on Why the Struggles Occur (ie, Why There is an Elephant in the Room). The nurse participants' struggles occurred about if, when, and how to communicate for a variety of reasons. For example, "How do you bring it up to parents?" "Do you let them approach you or do you bring things up? You can just tell they're struggling sometimes. I don't know how to approach the situation." The nurse participants also described the belief that physicians have difficulty accepting, and therefore difficulty communicating the inevitable. "I've seen them [physicians] struggle in coming to terms with that themselves."

The nurses participants also described reflecting on a belief that family struggles may arise from their characteristics or circumstances (eg, inability of the family to progress from avoidant-coping strategies to acceptance; inability to hear difficult information; family boundaries; and varied roles of family members, such as grandparents as primary caregivers). The nurse participants thought that the pediatric patients' struggles arose from a silent realization of their death that went unacknowledged by others and their increasing concern about creating special memories with significant others prior to their death.

Theme 3: Struggling With the Unknowns

Trepidation and Uneasiness With Emotional Responses During PC/EOL Care. The unexpected emotional responses by the pediatric patient receiving PC/EOL care and by the parents made lasting impressions on the nurse participants. For example, the nurse participants were surprised when adolescent patients receiving PC/EOL care unexpectedly shared their perspectives about death, spirituality, and when death was near for them. "We were talking about it, and he said he really was not afraid of dying. The thing he was afraid of was how much he was going to miss us. That is something that I really will not forget." The nurse participants also felt an ongoing trepidation about how to respond to such unexpected comments made by the adolescent patients.

Bearing Witness to Repeat and Long-Term Struggles of the Child and Family. The nurse participants expressed feelings of sadness when a child had prolonged, repeated struggles with side-effects of oncology treatments that required hospitalizations for PC/EOL care. The participants had a sense of unfairness that some children were required to spend extended periods of time in the hospital to receive necessary oncology care and treatments. This

translated into profound regret about the child's repeated and long-term struggles and the emotional toll this had on the child's parents.

> It's hard to know when to say something and when not to say something. That's what I find trouble with, and he was really, really sick and was here pretty much the whole time. I went down with the family when they talked about taking him off the respirator, and that was hard, too.

Continued Uneasiness With Personal Responses to the Child's Death. The nurse participants also described having the unexpected feelings of guilt and regret that continued to exist after a child's death, even though frequent monitoring of the child's condition had been done. Also, the nurse participants reflected about the time of the child's death cannot always be anticipated by experienced health care providers, and they were caught emotionally unprepared and had a sense of uneasiness related about working with children near death and during the child's dying process.

> I think it's hard to go through since you get so attached. We're so protective of our patients. And then when something happens, it is very hard to deal with. That's just hard because you're so close to them. . . . Even patients who have passed away, families come back.

When the nurse participants were present at the time of a child's death, their struggles with the intense emotions were prolonged, especially related to their first death experience.

Theme 4: A Kaleidoscope of Death: Patterns and Complexity

Understanding That the Process of End-of-Life Care is Complex. The complex and shifting pattern of events surrounding a child's death that needed to be managed is much like the changing patterns in a kaleidoscope. The shifting pattern of complex events is inherently unfamiliar, loaded with responsibility, and yet one in which, as novice nurses, participants feel they lack skills necessary to independently act. The process of death was unfamiliar; the nurse participants described PC/EOL learning needs related to (*a*) what occurs during dying process, (*b*) ways they can help the family prepare for the death, and (*c*) what to do after death.

> I just ran out to the nurse's station and I said, "He stopped breathing and what do I do?" I was not prepared at all for that night, but luckily the day nurse had filled out all the paper work of what I had to do. And, I don't know all the steps that go into, like how long they get to stay [with the child after death].

The nurse participants were highly concerned about communicating with children and families to effectively manage the child's pain during EOL care. The nurse participants also identified the need to learn to efficiently provide post-death care in a way that was respectful and takes family needs into account.

> I remember being really nervous when I went in the room after she actually passed away. I remember I was really shaky and I kind of had butterflies in my stomach because I was like, I don't really know what I'm doing, because it was the first time it had actually happened while I was working.

The Steepest of Learning Curves: Preparing Family for Their Child's Death. The nurse participants described a lack of knowledge about factors related to a child's death process. Specifically they reported having (*a*) high uncertainty about physical signs indicating that death was near, (*b*) low confidence in caring for a dying child, and (*c*) feelings of inadequacy about post-death care. The nurse participants also described experiencing high level of emotional stress when expected or unexpected deaths occurred. While the nurse participants were still learning about the dying process and effective PC/EOL communication, they usually had circumscribed responsibilities for nursing care of actively dying children and their families. Nevertheless, the memories of the nurse participants' first death experience was vivid and had lasting impact, especially related to the child's symptoms, decisions for symptom management, and their own grief and healing responses.

> The nurse was actually in the room when the doctors were in there, and some of the team units from PICU were there to transfer him to PICU and intubate him. And, she [nurse] said, 'Wait; let's take a deep breath. Mom and dad, is this, what you really want to do?' If she wouldn't have been in the room, I'm sure that he would have been transferred and intubated.

The nurse participants shared vivid memories of the difficulties in providing effective symptom management for the dying children, especially pain management. The nurse participants also described a sense of loneliness in the room after a child died, and they reflected on that there was sometimes feelings of things left undone that caused them intense sadness. The nurse participants also reported the need to learn the post-death procedures to care for the child's body after death, indicating that compassionate care of the child's body would communicate respect and caring to the family.

The nurse participants recognized the need to learn how to more effectively communicate and help parents and they acknowledged the overwhelming uncertainty of how to achieve this goal. The nurse participants shared a

sense of feeling inadequate to (*a*) prepare family members for their child's expected death, (*b*) respond to family member's questions about specifics during the time just before a child's death, (*c*) help family members give their child permission to die, (*d*) help the family come to terms with the eminent death of a child, and (*e*) provide emotional support to family members after a child's death. Also, the nurse participants reflected on impressions about the wide variations in parents' responses to their child's death experience, which only heightened their insecurity about how to communicate and intervene effectively.

Theme 5: Training Wheels for Connectedness

The nurse participants delineated the critical impact mentors had on their developing PC/EOL care-competencies. The nurse participants' reflections indicated that they perceived their mentors were like having training wheels while learning about PC/EOL care. The mentors helped the nurse participants to connect to the larger mission of holistically caring for dying children and their families at this most vulnerable time. The nurse participants also described important lessons learned from mentors and the impact these mentors had on their ongoing journey to become skillful PC/EOL caregivers. Mentors, much like training wheels, kept the nurse participants from having a wobbly start to their journey. Although the nurse participants looked forward to eventually functioning independently as a nurse without the reassuring training wheels that mentors provided, the nurse participants felt that at least for the foreseeable future, the continued close support from mentors was critical.

Learning About the Processes of Death and Best Communication Practices From Mentors. The nurse participants indicated that they were grateful to have the presence of preceptors or mentors. With this presence the nurse participants did not feel "left alone with death." Furthermore, the nurse participants talked about why it was important to observe their preceptor in providing PC/EOL care to the pediatric patient with cancer. Also, the nurse participants described being relieved to observe positive experiences with their preceptors without the responsibility of functioning independently.

My preceptor was caring for a patient, one of her primary patients who was in end stage disease and had been for several weeks at that point. I was assisting her in her care for that person maybe a week and a half or so. So, I was able to observe a really positive experience and how a very experienced nurse handled it. As a new nurse to the unit, to be faced with that right off the bat with an experienced person and feeling like I was basically in an observational role at that point was a tremendous asset.

The dominant thread for this theme was that the nurse participants did not feel prepared or ready to independently initiate or engage in PC/EOL care focused conversations patients and family members. The nurse participants shared the belief that modeling of skilled communication and care was the best way to really learn how to provide effective PC/EOL care and to conduct related discussions with families of pediatric patients with cancer. This was especially true in dealing with what the nurses called "difficult family situations," learning the use of sensitive communication strategies, and post-death care. The nurse participants conveyed an appreciation of the observing the preceptor's skill in intervening when the child's symptoms were not being managed appropriately. The nurse participants particularly learned from mentors' detailed updates on the child's condition and the family's coping responses. Having support from preceptors and other experienced pediatric oncology nurses helped to decrease the nurse participants' emotional distress and made it easier for them to (*a*) learn important PC/EOL care and communication skills, (*b*) develop effective strategies for dealing with PC/EOL care situations, (*c*) share their emotions with other staff nurses, and (*d*) recognize the importance of respite time for the primary nurse after a child's death.

Learning About EOL Communication Is a Life-Long Journey. The nurse participants reflected on advice provided by mentors that learning about PC/EOL takes a lifetime and is inherently and consistently inconsistent. "She [mentor] told me that no matter what, it never gets any easier. You may handle yourself differently; your first is going to be a lot more emotional." The nurse participants shared the belief that their mentors helped them to understand that mentors were also still learning. [Nurse's quote from mentor]: "I'm not going to tell you it gets easier, but you have more experience and you're able to see other people go through it." The nurse participants became aware that experienced pediatric oncology nurses learned daily when caring for pediatric patients with cancer and their families, especially the importance of effective communication. This acquired awareness helped the nurse participants develop an appreciation for routine communication among staff members, particularly through nursing staff updates during patient-care conferences. The nurse participants also gained clarity about the benefits of formalized PC/EOL education, including having written examples of effective and caring communication. Still in some of the data-collection settings, the nurse participants described being frustrated with the absence of PC/EOL educational opportunities.

Although most nurse participants reported strong support systems, unit leadership, and learning opportunities, these factors varied across the 3 data-collection settings,

the pediatric oncology units, and over time. Although not condoning suboptimal support, the mentors helped the nurse participants understand the inconsistent nature of learning and support from large hospital systems. The nurse participants gained an understanding about variations in the skill level of unit nursing leadership and support resources available to them. The nurse participants also shared the belief that not all experienced nurse leaders hold the necessary skills to anticipate the psychosocial needs of nursing staff or to offer emotional support needed by the nursing staff assigned to provide direct care to pediatric patients with cancer during EOL care, especially at the time of a child's death. Thus, when the support received by mentors was inconsistent, erosion was experienced in the confidence of the nurse participants and diminished connectedness to the larger unit mission.

Theme 6: Being Present With an Open Heart: Ways to Maintain Hope and Minimize Emotional Distress

The nurse participants explained how important personal, professional, and structural sources of connectedness provide hope and minimize emotional distress for the staff caring for a child and family during and after PC/EOL. Such support helped the nurse participants to foster strengths of the child and family during PC/EOL and to reflect on positive aspects of the dying process to minimize their own emotional distress after a child's death.

Commitment to Support Nurses Caring for Children During PC/EOL. The nurse participants also reflected on the importance of connectedness with other nurses related to having peer support. The nurse participants specifically articulated the value of individual and group dialogue with other pediatric oncology nurses as an avenue to discuss emotions and address questions while caring for a child during and after PC/EOL care. Also, the nurse participants described the comfort that accompanied acknowledgement from nursing peers that the death of a child they cared for had the potential to carry emotional and physical distress. Through peer interaction, a sense of trust and connectedness was fostered that resulted in generalized and situation-specific PC/EOL support to the nurse participants.

> I think it's important for us to try to be there for fellow employees whom we work with. And, his [child's] primary nurse was in the room with him. But then when it came time to clean and everything, I just went in and said, "Here, I'll get it," because you know, they don't need to do it unless they want to—that's so hard, . . . I don't know if I could go in there and do that [as a primary nurse]. It would just be so hard, so

I think we need to look to [after] not just the families. It's important that everybody who is involved in the end of life care. I know that nurse is so appreciative that she didn't have to go in there and face that, and do that [post-death care].

Support by the Multidisciplinary Team Members is Important. Multidisciplinary teams caring for children during PC/EOL care offered support to the nurse participants because of their acquired experience during years of experience caring for dying children. "And there was support from everyone, the staff. It was amazing." The nurse participants described the perspectives of social workers, physicians, chaplains, and PC teams as invaluable, providing insight to the pediatric patient with cancer and family and role modeling communication during difficult PC/EOL care situations. Additionally, the nurse participants valued the unique resources that multidisciplinary team members would individually share. Also, the nurse participants described a sense of comfort, knowing they could seek support from their peers as well as multidisciplinary members of the care team.

Discussion

We sought to understand perspectives and experiences of novice pediatric oncology nurses (ie, nurses with less than 1 year of work experience) about PC/EOL communication along with their perceptions about factors that may facilitate and impede PC/EOL discussions with pediatric oncology patients and their families during focus group meetings. The purpose of semistructured discussions using a focus group setting was to foster discussions about shared commonalities of the novice pediatric oncology nurses' experiences about PC and EOL communication with pediatric patients with cancer, their families, and other health care providers.

Six themes were derived from the novice pediatric oncology nurses' focus group discussions about their perspectives and experiences of engaging in PC/EOL discussions. In Theme 1, the experience of these nurses included the perception that they had a "Sacred Trust to Care for the Child and Family" facing death. In Theme 2, the nurses conveyed a belief that they lacked effective communication skills and experience to openly discuss what was perceived as the "Elephant in the Room" with children, families, and other health care providers. In Theme 3, the nurses further emphasized the difficulty of initiating discussions about PC/EOL care with dying children and their families because the nurses were "Struggling with the Unknowns." In Theme 4, the nurses also considered their first experiences of witnessing a child's death as a "Kaleidoscope of Death." In Theme 5, the universal importance of being mentored in PC/EOL communication during their first-death experience was like needing

"Training Wheels in Connectedness." Lastly in Theme 6, the nurses also reflected on their observations of experienced staff, who taught them about the essence of communication at this difficult time and how to "Be Present with an Open Heart."

The findings from this study are the first to report a qualitative report of PC/EOL communication perspectives and experiences that were described by pediatric oncology nurses according to their years of work experience with dying children. The 6 identified themes from our focus group data provide important PC/EOL information for nurse managers and senior nurses to consider when planning preceptor and mentorship activities for novice nurses to be more comfortable and competent to engage in PC/EOL discussions with dying children with cancer and their family members. The study findings are outlined in Table 1 related to the 6 theme categories and selected quotes which should prove to enhance the insights of nurse managers and preceptors when planning strategies to help novice nurses be more competent and comfortable to engage in discussions with children and family members during PC/EOL care of a child with cancer.

Prior to this research, no evidence was reported in the literature to support a need for and development of a pediatric oncology PC/EOL communication program for novice nurses. The 6 derived themes from the collected data provide evidence of recognized concerns and barriers related to engaging in PC/EOL communication and in providing PC/EOL care by novice pediatric oncology nurses. Our team of investigators concluded that use of a focus group setting fostered an open dialogue and provided protected time and a trusted environment for the participants to feel comfortable to share their perspectives, personal stories, and intimate disclosure of feelings and memories of observed PC/EOL communication by health care providers in the clinical setting and of the pediatric oncology patient's PC/EOL trajectory.

Still, limitations related to the interpretation of the results of this qualitative study should be considered. One limitation is related to the perception of difficult PC/EOL communication by the participating nurses in this study was only provided by female nurses. Whether the results would vary with male nurses or in other groups of female nurses requires further investigation. A second limitation is related to the concern of selection bias exists in that the enrolled nurses who chose to participate may have had different perspectives and experiences in PC/EOL care and communication than nurses from other settings and geographic locations. However, the consistency across the 3 data-collection sites provide evidence to support our findings and may suggest bias may not be a limitation. A third limitation is related to the risk that the findings represented a specific point in time in each of the 3 hospitals' trajectory to developing a PC program and the majority of participants had little education with a focus on PC/EOL care when data were collected. A fourth limitation is related to the small sample size of this study. A fifth limitation is related to the recruitment of only non-Hispanic females from hospitals in the Midwest and that the focus group interviews were conducted in only 3 states in the Midwest. Therefore, our findings are not representative of novice pediatric oncology nurses or representative of pediatric oncology nurses in other geographic locations. Also, it must be acknowledged that although our findings offer new insights into understanding a specific problem or population, the findings are not generalizable to diverse populations.

Summary/Conclusion

Pediatric oncology nurses are especially well-situated in the clinical setting to have conversations about the purpose of PC and EOL care with pediatric patients during their cancer care and also with their families. Although research has been limited regarding pediatric nurses' experiences with PC/EOL care and in engaging in PC/EOL communication during the care of dying children and their families, the findings from this study provide important information especially to practicing pediatric oncology nurses. Novice (or beginning) pediatric oncology nurses need substantial education, support, and mentorship from experienced nurse mentors to learn and acquire effective PC/EOL communication skills necessary to engage in caring and sensitive discussions with dying children and their families. Also, analyzing data collected during focus group meetings provided evidence of the advantage of using this data-collection method to gather and provide a detailed account of PC/EOL care and communication experiences and perspectives held by novice pediatric oncology nurses. Lastly, the derived themes from our study can provide an outline of priority topics to consider when clinical settings plan and provide PC/EOL communication training programs for new and novice nurses who have little or no work experience with providing nursing care to pediatric patients with cancer and in the delivery of clear and honest communication to their family members.

Declaration of Conflicting Interests

Funding

References

Angelini, D. J. (2011). Interdisciplinary and interprofessional education: What are the key issues and considerations for the future? *Journal of Perinatal & Neonatal Nursing, 25*, 175-179.

Beckstrand, R. L., Rawle, N. L., Callister, L., & Mandleco, B. L. (2010). Pediatric nurses' perceptions of obstacles and supportive behaviors in end-of-life care. *American Journal of Critical Care, 19*, 543-552.

Belcher, D. (2012). The elephant in the room project: Communication at end of life. *Nursing & Residential Care, 14*, 96-98.

Boyd, D., Merkh, K., Rutledge, D. N., & V. Randall, V. (2011). Nurses' perceptions and experiences with end-of-life communication and care. *Oncology Nursing Forum, 38*, E229-E239.

Bradford, N., Irving, H., Murray, J., Pedersen, L., Roylance, J., Crowe, L., & Herbert, A. (2012). Paediatric palliative care services in Queensland: an exploration of the barriers, gaps and plans for service development. *Neonatal, Paediatric & Child Health Nursing, 15*(1), 2-7.

Browning, A. M. (2009). Incorporating spiritual beliefs into end-of-life care. *Journal of Christian Nursing, 26*(1), 10-17.

Carroll, K. W., Mollen, C. J., Aldridge, S., Hexem, K. R., & Feudtner, C. (2012). Influences on decision making identified by parents of children receiving pediatric palliative care. *AJOB Primary Research, 3*(1), 1-7.

Colaizzi, P. (1978). *Psychological research as the phenomenological research as the phenomenologist views it.* New York, NY: Oxford University Press.

Davies, B., & Connaughty, S. (2002). Pediatric end-of-life care: Lessons learned from parents. *Journal of Nursing Administration, 32*(1), 5-6.

Davies, B., Sehring, S. A., Partridge, J. C., Cooper, B. A., Hughes, A., Philp, J. C., & Kramer, R. F. (2008). Barriers to palliative care for children: perceptions of pediatric health care providers. *Pediatrics, 121*, 282-288.

Dighe, M., Jadhav, S., Muckaden, M., & Sovani, A. (2008). Parental concerns in children requiring palliative care. *Indian Journal of Palliative Care, 14*(1), 16-22.

Dunn, K. S., Otten, C., & Stephens, E. (2005). Nursing experience and the care of dying patients. *Oncology Nursing Forum, 32*, 97-104.

Dunne, K., Sullivan, K., & Kernohan, G. (2005). Palliative care for patients with cancer: District nurses' experiences. *Journal of Advanced Nursing, 50*, 372-380.

Foster, T. L., Lafond, D. A., Reggio, C., & Hinds, P. S. (2010). Pediatric palliative care in childhood cancer nursing: From diagnosis to cure or end of life. *Seminars in Oncology Nursing, 26*, 205-221.

Grainger, M. N., Hegarty, S., Schofield, P., White, V., & Jefford, M. (2010). Discussing transition to palliative care: Evaluation of a brief communication skills training program for oncology clinicians. *Palliative & Supportive Care, 8*, 441-447.

Helft, P., Chamness, A., Terry, C., & Uhrich, M. (2011). Oncology nurses' attitudes toward prognosis-related communication: A pilot mailed survey of oncology nursing society members. *Oncology Nursing Forum, 38*, 468-474.

Hendricks-Ferguson, V. (2007). Parental perspectives of initial end-of-life communication. *International Journal of Palliative Nursing, 13*(11), 1-10.

Hinds, P. S., Oakes, L. L., Hicks, J., Powell, B., Srivastava, D. K., Baker, J. N., . . .Furman, W. L. (2012). Parent-clinician communication intervention during end-of-life decision making for children with incurable cancer. *Journal of Palliative Medicine, 15*, 916-922.

Hughes, B., & Fitzpatrick, J. J. (2010). Nurse-physician collaboration in an acute care community hospital. *Journal of Interprofessional Care, 24*, 625-632.

Kain, V. (2011). Exploring the barriers to palliative care practice in neonatal nursing: A focus group study. *Neonatal & Child Health Nursing Journal, 14*(1), 9-14.

Kars, M. C., Grypdonck, M. H., Beishuizen, A., Meijer-van den Bergh, E. M., & van Delden, J. J. (2010). Factors influencing parental readiness to let their child with cancer die. *Pediatric Blood Cancer, 54*, 1000-1008.

Kars, M. C., Grypdonck, M. H., de Korte-Verhoef, M. C., Kamps, W. A., Meijer-van den Bergh, E. M., Verkerk, M. A., & van Delden, J. J. (2011). Parental experience at the end-of-life in children with cancer: "Preservation" and "letting go" in relation to loss. *Supportive Care in Cancer, 19*, 27-35.

Kassam, A., Skiadaresis, J., Habib, S., Alexander, S., & Wolfe, J. (2012). Moving toward quality palliative cancer care: Parent and clinician perspectives on gaps between what matters and what is accessible. *Journal of Clinical Oncology, 23*, 910-915.

Kooken, C. W., Haase, J. E., & Russell, K. (2007). I've been through something: Poetic explorations of African American women's cancer survivorship. *Western Journal of Nursing Research, 29*, 896-919.

Kozlowska, L., & Doboszynska, A. (2012). Nurses' nonverbal methods of communicating with patients in the terminal phase. *International Journal of Palliative Nursing, 18*(1), 40-46.

Mitchell, A. M., Sakraida, T., Dysart-Gale, D., & Gadmer, N. M. (2006). Nurses' narratives of end-of-life care. *Journal of Hospice & Palliative Nursing, 8*, 210-221.

Quill, T. (2000). Initiating end-of-life discussions with seriously ill patients: Addressing the "elephants in the room." *Journal of the American Medical Association, 284,* 2502-2507.

Author Biographies

Verna Hendricks-Ferguson, PhD, RN, is an Associate Professor at St. Louis University School of Nursing in St. Louis, MO.

Kathy Sawin, DNS, CPNP-PC, FAAN is a professor and research chair in the nursing of children college of nursing at UW-Milwaukee and Children's Hospital of Wisconsin in Milwaukee, WI.

Kitty Montgomery, PhD, MS, RN, PCNS-BC is clincial nurse specialist at the American Family Children's Hospital in Madison, WI.

Claretta Y. Dupree, PhD, RN, U.S. Navy Retired Captain, was Assistant Professor and Pediatric Palliative Care Director of Research at the Medical College of Wisconsin at the time this research was conducted.

Celeste R. Phillips-Salimi, PhD, RN, CPON is an Assistant Professor at Indiana University School of Nursing in Indianapolis, IN.

Barb Carr, APRN, BC, PNP is an Advanced Practice Nurse at St. Louis Children's Hospital in St. Louis, MO.

Joan E. Haase, PhD, RN, FAAN is the Endowed Holmquist Professor in Pediatric Oncology Nursing at Indiana University School of Nursing and Co-Director of the IUPUI Signature Center for Research in Palliative and End-of-Life Communication and Training in Indianapolis, IN. At the time this research was conducted she was the mentor during the post-doctoral fellowship of Verna Hendricks-Ferguson.