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The Nurse's Role in Prognosis-Related Communication in Pediatric Oncology Nursing Practice

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Abstract

The experiences of pediatric oncology nurses with prognosis-related communication (PRC) remain largely unknown. The purpose of this article is to report results of focus groups wherein 15 pediatric oncology nurses from three Midwestern pediatric cancer programs provided descriptions of PRC and

how they experience PRC within their daily practice. Data from focus groups were analyzed via an interpretive descriptive approach, which resulted in three themes: (1) nurses' operational definition of PRC, (2) nurses' roles in PRC, and (3) nurses' preparation for engagement in PRC. From discussions within the focus groups, nurses recognized that PRC occurs across a continuum. Nurses distinguished that the definition of PRC expands beyond simply reporting life expectancy to describing the consequences of cancer- and treatment-related toxicities and effects. When nurses are not actively invited by their physician partners to participate in PRC, nurses will often develop workarounds to ensure that they understand what was said to patients and families. This allows them to function more effectively as supporters, advocates, and informants. Nurses described little preparation to participate in such challenging conversations. Pediatric oncology nurses need to acknowledge and embrace that they are an integral part of PRC. Interprofessional communication training is necessary to enhance the comfort and confidence of nurses engaging in PRC.

Keywords

prognosis-related communication, nurse's role, interprofessional collaboration

Over 11,000 children are diagnosed with cancer each year (Siegel, Miller, & Jemal, 2019). Subsequently, health care clinicians are responsible for sharing with pediatric patients and their families information regarding their cancer diagnoses and related prognoses. Prognosis-related communication (PRC) is not a solitary discussion. Rather it occurs before, during, and after disclosure of a new cancer diagnosis or relapse (Sisk, Kang, & Mack, 2017). PRC happens formally, such as during care conferences, and informally, when patients and families pose concerns and questions with nurses in their children's rooms. PRC often continues among children with cancer, their parents and families, and providers, addressing a myriad issues such as life expectancy, likelihood of cure, future treatment possibilities, and anticipated quality of life (Mack, Wolfe, Grier, Cleary, & Weeks, 2006). How such information is communicated to patients and families is critical. If prognostic information is improperly timed or delivered poorly and incompletely, children and parents may lose hope, struggle with decision making, and have difficulty developing therapeutic relationships with their providers (Nyborn, Olcese, Nickerson, & Mack, 2016).

Nurses caring for patients of all ages are integral members of the health care team, regularly facilitating communication among patients, families, and providers (Adams, Mannix, & Harrington, 2017; Fakhr-Movahedi, Rahnavard, Salsali, & Negarandeh, 2016). Pediatric oncology nurses are expected to provide expert education as well as psychosocial and holistic care for children and their families (Nelson & Guelcher, 2014). When nurses are not included in diagnostic and prognostic discussions between families and physicians, their ability to fulfill these expectations becomes compromised. If feelings of unpreparedness prevail, nurses become uncomfortable initiating these conversations and sometimes actively avoid them (Helft, Chamness, Terry, & Uhrich, 2011; Newman, Haglund, & Rodgers, 2019). An online survey of Association of Pediatric Hematology/Oncology Nurses (APHON) members examined pediatric oncology nurses' experiences with PRC. Results demonstrated that low levels of PRC and interprofessional collaboration were significantly associated with increased moral distress and lower nurse-perceived quality of care (Newman, Callahan, Lerret, Oswald, & Weiss,

2018). Additionally, nurses described challenges to providing optimal care when they were not included in prognostic discussions. They characterized the distress they experienced around variations in the nature and quality of diagnostic disclosure (Newman et al., 2019). Hence, while the pediatric oncology nurse's role within PRC has received little attention, nurses generally embrace having critical professional responsibilities within this realm of care (Newman, 2016).

The purpose of this article is to report nurses' descriptions of PRC and how they experience PRC within their daily practice. These results increase understanding of nurses' day-to-day engagement in PRC, which is needed to develop practices that ensure optimal nurse performance and patient and family care.

Method

Design and Parent Study

Findings presented here were obtained from a subset of data collected as part of a mixed-methods exploration of pediatric oncology nurses' perceptions and experiences with PRC. Data collection initially occurred through an online survey, which included instruments and open-ended questions examining nurses' experiences with PRC and interprofessional collaboration, moral distress, and quality of care. The survey was followed by focus groups, which aimed to generate more detailed narrative descriptions of nurses' experiences with PRC and reflect on data gleaned from the online survey. Results from analysis of quantitative survey data that measured the relationships among PRC and collaboration, moral distress and quality of care, were previously published (Newman et al., 2018). A second publication included results gleaned from open-ended survey questions and focus groups, documenting nurses' perceptions of facilitators and barriers to PRC and the impact of PRC on nursing care and patient outcomes (Newman et al., 2019). The results reported in this article provide insight into pediatric oncology nurses' day-to-day engagement in PRC in their practices. These results were derived from focus group data and have not been previously published. This study was approved by the site-specific institutional review board.

Recruitment of Sample

The original online survey was completed by APHON members from across the United States. To develop focus groups, the principal investigator (PI) went to APHON's website to obtain the names and contact information for local chapter presidents in the PI's region (100-mile radius). Two local chapters, representing members from six different institutions in the Midwest with dedicated pediatric cancer programs, were identified. The PI worked with the two local chapter presidents to distribute an e-mail to their membership inviting members to participate in focus groups with the purpose of discussing PRC, interprofessional collaboration, quality of care, and moral distress. Current membership in local and national APHON organizations and completion of the online survey were not required to participate in the focus groups. Individuals from three different institutions responded with a strong interest in participation. A focus group was conducted at each of these three institutions. Nurse participants received \$25 VISA gift cards to thank them for their time.

Data Collection

On arrival to the focus groups, nurse participants provided written informed consent and completed a demographic questionnaire. Participants were not asked if they had completed the previously

distributed online survey. Focus groups were facilitated by the PI and a research assistant, who managed the audio-recorder and took notes during the focus groups. These groups were semistructured and included open-ended questions designed to elicit nurses' experiences with PRC and associations with interprofessional collaboration, moral distress, and quality of care. Focus groups were audio-recorded, and transcribed verbatim via an online application, TranscribeMe!

Data Analysis

Transcripts were cleaned and validated by the PI, and then exported into NVivo 11 to facilitate analysis. An interpretive descriptive approach was taken to analyze the qualitative data (Thorne, 2016). Themes identified in the analysis of the qualitative survey data were used to create an initial coding template for the analysis of focus group transcripts. One researcher coded the focus group transcripts. The research team, which included specialists in pediatric oncology and general pediatric primary care, then met to review coded data. New codes and discrepancies in coding were discussed until consensus was reached. An audit trail log was maintained that included definitions of all codes, dates, and rationale for creation of new codes, and revisions to current codes. This iterative team process of coding and discussion led to the identification of three main themes.

Various methods were used to ensure rigor and limit bias. The audit trail log and process of intercoder agreement increased reproducibility, or reliability, of this study and results (Morse, 2015). An additional strategy to support the validity of results was established through members of the research team challenging each other's biases and preconceptions throughout the data analysis process (Morse, 2015). Detailed descriptions of the themes with participants' quotes allow readers to assess whether these results apply, or are transferable, to other populations of nurses.

Results

Participants' Characteristics

Eighteen nurses from three institutions in the Midwest participated in three focus groups (see Table 1). All were White, non-Hispanic females, of whom, 78% ($n = 14$) were bachelor's-prepared and 22% ($n = 4$) were master's-prepared nurses. Thirteen (73%) held primary positions as staff nurses, and three (17%) were nurse practitioners. Seven (39%) worked in the inpatient setting, while 11 (61%) worked in the outpatient setting. Over half ($n = 10$, 56%) indicated that they had received little to no training in PRC.

Table 1. Focus Group Characteristics ($N = 18$).

Characteristic	n (%)	Mean	Range
Age in years		37.4	27-67
Years of nursing experience		13.7	.5-44
Years of pediatric oncology nursing	13 (72)	10.9	.5-40
Position			
Staff nurse	3 (16)		
Nurse practitioner	1 (6)		
Nurse coordinator	1 (6)		
Clinical nurse specialist			
Training in prognosis-related communication			
None or almost none	10 (56)		

A little bit	6 (33)		
A moderate amount	1 (6)		
A great deal	1 (6)		

Themes

Three themes captured nurses' engagement in PRC within their daily practices. These included (1) nurses' operational definition of PRC, (2) nurses' roles in PRC, and (3) nurses' preparation for PRC.

Nurses' Operational Definition of PRC

Nurses distinguished that the use of the term *prognosis* did not solely speak to life expectancy; rather it can also include issues related to future quality of life and potential treatment- and disease-related complications. From the nurses' perspectives, PRC consists of a series of discussions that often occur along a continuum, namely before, during, and after the physician shares diagnostic and prognosis-related information. One participant, who predominantly worked the night shift, stated, “. . . Usually at night, it's reading notes and just trying to kind of keep everything calm and answer questions just to try to get them until morning 'til you can get them concrete answers . . .”

In focus groups, nurses discussed this concept of an expanded definition of prognosis among themselves. They identified that prognostication was required from diagnosis through the transition to survivorship, to prepare and assist patients and families to cope with ongoing or new late effects of cancer and its treatment. Nurses specifically mentioned the patients who will experience permanent disabilities and infertility. “. . . Your cancer will be cured, but you're going to have this and you're still dealing with surgeries and still multiple debridings or issues with wound healing and stuff.” One nurse commented, “. . . I think it's a very good point too—there's a lot more than just your cure.”

Nurses' Roles in PRC

Nurses perceived that it was not their responsibility to determine and inform patients and parents of diagnoses or life expectancy; rather they depicted their role as functioning as supporters, informants, and advocates. Individual job descriptions also influenced nurses' perceptions of expectations within PRC.

Supporter

Nurses identified the importance of being present when physicians provided patients and parents with new diagnostic and prognostic information. Nurses' presence during and after these conversations allowed them to help parents process and clarify the information they received. Yet nurses indicated that they frequently were not included or invited to participate in such conversations, which limited their ability to play a supportive role. Despite this, some nurses described how they would strategically place themselves in rooms to make sure that they heard what was said. For example, one nurse said,

. . . and people would get back from a scan and if they had bad news, somebody would come in to talk to them from the medical team. . . . I would just stay in the room because I felt like they needed to have a nurse in the room to process this with afterwards . . .

The close relationships pediatric oncology nurses have with patients and families enable them to provide emotional encouragement and hope. One nurse explained,

I think it's more—we need to know what the prognosis is, and then, I, myself, think that it's more being support for the family . . . be that person to support them through it, answer their questions, be someone to lean on.

Another nurse commented on the impact of her physical presence and being hopeful, “. . . I think just trying to be there if they want to talk—and showing them that even if a number is bad doesn't necessarily mean that [there is no hope]—there's still hope.”

Informant

Nurses commented on family members' expectations about what they, as nurses, know about patients' statuses and their plans of care. One nurse expressed, “. . . families . . . expect us to, as nurses who take care of them a lot, to know everything that's been going on behind the scenes like scan results . . .” However, nurses in this study articulated how challenging this was if they were not included in conversations. One nurse shared strategies she used to make sure that she was present when important conversations were undertaken. She would request parents call her whenever a member of the medical team was in the patient's room. She stated, “I always try to be in the room when any doctor is in the room, I try to be in the room, so I know everything that was said by every person.” She later added, “. . . I'm like, pretty curious and nosy and I like to know an answer when I'm asked a question from a family.” In identifying their role as informants, nurses described responding to parental questions regarding prognosis, often clarifying or providing additional insight into information provided by physicians. One nurse in this study commented, “. . . a lot is said in these conversations with them [physicians], and we're just that extra person to kind of reinforce what was said, and just help answer any other questions that they [patients and families] might have . . .”

Advocate

Nurses in this study detailed how they advocated for their patients and parents in the process of PRC. One nurse practitioner shared a situation in which the parents did not want to tell the child about his cancer diagnosis. She acknowledged that the parents knew their child best, and that she would work with them to talk to their son. Yet she relayed the importance of honesty, and replied, “Your kid does need to know, but we're going to help you with that process.” She then facilitated a meeting with psychology and Child Life to strategize how best to inform the child of what was going on. Other times, nurses as advocates found the courage to urge physicians to not lose sight of the importance of quality of life. In one focus group, several of the nurses engaged in a conversation about this issue, referencing a patient with multiply recurrent cancer:

Speaker 1:

Fight till the end.

Speaker 2:

Fight, fight, fight, fight . . .

Speaker 1:

In a good—you know, obviously on his [physician's] part . . . in a good way. But then at the same time, you know, the whole piece of the quality and everything you know, I think sometimes it gets lost sight of it a little bit.

Speaker 2:

Right, and I think that the nurse kind of goes, “Hey wait a minute . . . you really want to keep fighting, but is this really what is . . .”

Speaker 3:

. . . going to be best for that kid.

Role considerations

Nurses explained how their job titles and practice settings influenced the extent of their involvement in prognostic discussions and access to information provided to patients and families. Advanced practice nurses often disclosed prognostic information, as part of their role. This frequently occurred in collaboration with physician colleagues. Nurses who worked in the outpatient setting described partnering more closely with their physician and advanced practice nurse colleagues than nurses in the inpatient environment. Outpatient nurses reported that they were more frequently included in diagnostic and prognostic conversations, which prepared them to support patients and families and answer their questions.

Nurses’ Preparation for PRC

In this study, nurses indicated that they received little training in PRC. They shared their opinions that becoming competent in PRC cannot be facilitated by reading the literature or course participation. They believed that experience is required to feel more comfortable knowing how to respond to patients’ and parents’ questions and to not provide false hope. One nurse stated,

. . . you can teach some stuff about palliative care and end-of-life through a book . . . but I still think a lot comes from experience. And the only way you’ll get more comfortable with it is to sit in those discussions and be part of those discussions.

Nurses described how experience can also build capacity to be a more effective advocate. A nurse said,

. . . as you get more experience and you’ve seen more things, you have more experience to back up what you—if you’re going to question—or even go to see if you can . . . go above—because that kid is what is important, not if you look stupid to a doctor or whatever.

In addition to the need for experience, nurses also described a desire for more education and training to help them answer questions about prognosis, more clearly understand their role in PRC, and support patients and families in these complex discussions. A newer nurse relayed,

. . . I’ve gotten a lot of education on . . . the different diagnoses. . . I don’t think they’ve ever really had anything or tell how to approach that when a family is asking you about a prognosis issue, or like, is my kid going to make it?

Nurses indicated that they wanted more clarity around whether to provide patients and parents with concrete information, for example, specific prognostic estimates, and whether their role is to provide patients and families with that type of information. One nurse stated, “I think it’s hard . . . even as an experienced nurse.”

Discussion

These results provide further insight into pediatric oncology nurses' perceptions and experiences with PRC. Previous work has demonstrated that pediatric oncology nurses' experiences with PRC can influence their ability to provide quality care, and that their lack of engagement in PRC can be distressing (Newman et al., 2018; Newman et al., 2019). Nurses' contributions are an integral part of the PRC process. Patients and parents have articulated a need to receive more anticipatory guidance at critical junctures along the cancer trajectory, and nurses are uniquely positioned to assist them with this counsel (Feraco et al., 2018; Sisk, Mack, Ashworth, & DuBois, 2018).

Similar to the experiences of nurses within adult oncology, both tenure and advanced role preparation augment nurses' comfort and expertise with PRC (McLennon, Uhrich, Lasiter, Chamness, & Helft, 2013; Reinke, Shannon, Engelberg, Young, & Curtis, 2010). Also, when nurses are not included in critical PRC with physician partners, they may avoid these conversations in not wanting to step on toes, offer misleading information, leave a knowledge gap, or possibly increase frustration within the family unit (Newman et al., 2019).

Additional research is needed to better articulate the role of the pediatric oncology nurse in PRC. In line with traditional role expectations, nurses in this study reported functioning as supporters, informants, and advocates in the process of PRC. These results are similar to those of McLennon et al. (2013), in which nurses caring for adult patients with cancer, described advocating, facilitating, supporting, and prognosticating within the context of PRC. In this sample, nurses described workarounds to ensure that they had the critical information needed to fulfill these roles. Rarely were bedside nurses in acute settings invited by their physician partners to participate in discussions around prognosis. Thus, the role of the nurse in this process, while an active one, remains invisible, unacknowledged, and unsupported.

Interprofessional collaboration is a complex process characterized by shared objectives, decision making, responsibility, and power, directed at solving patient care problems (Petri, 2010). It is enacted when the knowledge and experience of each professional is valued and integrated into developing solutions to complex problems (D'Amour, Ferrada-Videla, San Martin Rodriguez, & Beaulieu, 2005). Communication is a critical aspect of interprofessional collaboration. Ideally, in the context of PRC, physicians would notify nurses when they are preparing to have formal conversations with patients and families about a new cancer diagnosis or relapse. Advance notice would allow the physician, nurse, and other members of the health care team (e.g., social workers, Child Life, etc.) to discuss an approach to the conversation, ensuring that interdisciplinary perspectives are shared.

Rather than waiting to be asked or invited to participate in such discussions, nurses must acknowledge that they are a vital part of this process and need to be actively engaged in diagnostic and prognostic discussions in order to support their patients, families, and physician colleagues. This work cannot be thought of as "my job" and "their job," but rather "our job." Improved collaboration has the potential to improve the communication process among the care team, patients, and families. Improved communication is essential, as high-quality communication is a critical component of care quality and patient and family satisfaction (Sanders, Curtis, & Tulsy, 2018).

While more active engagement in prognostic discussions may better prepare nurses to know what was discussed and how this information was received, pediatric oncology nurses may still lack the skills, knowledge, and capacity to fully support families throughout this process. Few nurses have received training around PRC, and repeatedly state that they do not know what to say or how to respond to some of the challenging questions posed by parents, such as “Is my child going to die?” (Boyle & Bush, 2018). Like medical school training (Kissane, 2012), nursing curricula generally provide only generic communication skills training to students prior to entering the workforce. In order to engage pediatric patients with cancer and their parents in these complex discussions, both nurses and physicians must have more formal training in serious illness communication. Ideally, such training would occur in an interprofessional environment with nurses and physicians partnering together in training. A limited number of interprofessional education (IPE) activities in pediatric oncology have been reported (Topperzger et al., 2019). One recent report by Essig et al. (2019) described an interprofessional communication skills training for nurses and physicians working with adolescents with cancer. The authors acknowledged the different agendas that doctors and nurses have regarding patient and family communication, emphasizing the importance and need for IPE. Subsequently, although participants viewed the training favorably, responses were pooled, and no comments were made regarding the interprofessional nature of the training and/or how it may have impacted the experiences of the participants.

IPE is essential as it facilitates mutual understanding and appreciation of different professional roles, promotes team development and the implementation of communication tools, and specifies ways in which to make the best use of each profession’s unique expertise and specialization (A. Fox & Reeves, 2015). While not well established in academia or professional practice, IPE programs at the preprofessional level are becoming more common, and generally include students from a variety of health professions including nursing, nutrition and dietetics, medicine, occupational therapy, and physical therapy (L. Fox et al., 2018; Ruebling et al., 2014). IPE curricula have demonstrated improved perceptions of IPE and interprofessional collaboration as well as enhanced understanding and more positive attitudes or perceptions toward other health care professionals (L. Fox et al., 2018; Ruebling et al., 2014). Whether or not this appreciation for IPE and the roles of other health care professionals will translate and persist into practice remains unknown.

A consistent method for approaching advanced communication skills training has not been identified, but simulation, which provides the opportunity to practice different communication strategies in a safe environment, appears to be an essential aspect of such training (Foronda, MacWilliams, & McArthur, 2016; Gilligan et al., 2018). Numerous reports of institutional communication skills training programs have been reported in the literature (Arnold et al., 2015; Boyle et al., 2017; Coad, Smith, Pontin, & Gibson, 2018; Weintraub, Figueiredo, Roth, & Levy, 2016). Often the programs are aimed at one discipline (e.g., medicine or nursing), although increasingly programs have become more interprofessional in nature (Erickson, Blackhall, Brashers, & Varhegyi, 2015; Grey, Constantine, Baugh, & Lindenberger, 2017). In the meantime, ad hoc workshops or trainings including VITALtalk (www.vitaltalk.org) and the End-of-Life Nursing Education Consortium (www.aacnnursing.org/ELNEC) are offered at different institutions and through various organizations throughout the country. The often-voluntary nature of these trainings as well as limited funding and time restrict the number of clinicians who have the opportunity to attend these trainings.

Yet focus group participants believed that training in the classroom, as described above, is not enough. A certain amount of experience or expertise is required to feel comfortable and confident participating in discussions around prognosis. Programs both formal and informal must be established within a unit's culture to provide peer support to one another. This seems particularly relevant for new nurses. More seasoned nurses can take the time to reflect on their own practice and what techniques they have found useful when engaging with patients, families, and physicians in PRC. Sharing of these techniques in addition to simulation experiences can serve to prepare more novice nurses for some of the challenging conversations they may be a part of, having them process through how they might respond when presented with a similar situation in the future. Administrators should consider adding language regarding communication skills to job descriptions to elevate its importance and incite a need for formal skill building.

Future research should aim to better understand, patients', parents', families', and physicians' perspectives regarding the nurse's role in PRC. With enhanced understanding and expectations around the nurse's role, partnerships between nurses and physicians can be formed to promote more collaborative discussions around prognosis. More collaborative discussions will require education of both nurses and physicians, together, on serious illness communication and collaboration principles in the professional and preprofessional arenas. Such collaborations and conversations should then be examined within the research context to determine the impact on patient, family, and clinician outcomes including quality of communication, understanding of prognosis, decision making, quality of life, therapeutic alliance, and satisfaction.

Limitations

This study captured the experiences of a small, homogenous group of female nurses whose remarks do not reflect the total experience of all pediatric oncology nurses regarding PRC including the perspective of male nurses. Although results may have limited generalizability, they do provide a detailed, candid description of nurses' day-to-day experiences with PRC. The data collected in this study did not appear to be limited by one-person dominance, lack of equal participation, insincere agreement with other speakers (conformity), or participants' withholding of relevant information (Ravitch & Carl, 2016). In each focus group, all participants actively engaged in the discussions. The nurses provided candid data about their personal experiences, which indicated their comfort in sharing in the group. Finally, while IPE appears to be an optimal way to improve interprofessional communication in PRC, the concept of IPE was not included in the design of this study or presented for discussion in focus groups.

Conclusion

PRC is a critical aspect of the illness trajectory for pediatric patients with cancer and their families. Disclosure and understanding of prognostic information assist patient and parental decision-making and have a definitive influence on coping. Unfortunately, pediatric oncology nurses feel excluded from important conversations around prognosis. This lack of inclusion limits nurses' abilities to provide supportive, emotional counseling around difficult transitions. Despite this isolation, seasoned nurses frequently develop workarounds to ensure their accessibility to prognostic information. This then enables them to function as supporters, informants, and advocates for patients and families. Experienced pediatric oncology nurses must acknowledge the discomfort of junior nurses regarding supporting and responding to patients' and parents' questions around prognosis and provide

mentorship by sharing strategies they have used to overcome their own discomfort. IPE in the provision of PRC including simulation is a requisite necessity to enhance pediatric oncology nurses' competency in this important skill.

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