

## Pediatric oncology nurses' perceptions of prognosis-related communication

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### ARTICLE INFO

#### Article history:

Received 2 August 2018

Received in revised form 25

October 2018

Accepted 5 November 2018

Available online November 15,

2018.

#### Keywords:

prognosis-related

communication

interprofessional collaboration

nurse distress

prognostication

### ABSTRACT

**Background:** Disclosure of prognosis-related information is an essential aspect of communication with pediatric patients with cancer and their families. The nurse is believed to play an important role in this process, but nurse perceptions and experiences have not been well-described.

**Purpose:** Provide an exploration of pediatric oncology nurses' experiences with prognosis-related communication (PRC).

**Method:** Mixed-methods, multiphase design. This paper highlights the qualitative portion of the study.

**Findings:** Three themes were identified: Importance of collaboration, impact of PRC, and delivery of prognostic information.

**Discussion:** Collaboration is a critical element of PRC. Nurses are often not included in the disclosure process, which limits the ability of nurses to fully function in their roles, compromising patient, family, and nurse outcomes. A paradigm shift is required to empower nurses to be more active participants. More education of physicians and nurses is necessary to consistently engage nurses in PRC and prepare nurses for critical conversations.

**Cite this article:** Newman, A.R., Haglund, K., Rodgers, CherylC (2019, January/February). Pediatric oncology nurses' perceptions of prognosis-related communication. *Nurs Outlook*, 67(1), 101–114. <https://doi.org/10.1016/j.outlook.2018.11.001>.

### Introduction

Effective communication is an essential aspect of quality health care. High quality communication optimizes the patient-clinician relationship and enhances patient care as well as the well-being of patients, families, and clinicians (Gilligan, Bohlke, & Baile, 2017). In the context of serious illness, communication that prompts sharing of goals and

values is critical to ensuring that patient care is concordant with patient and family wishes (Sanders, Curtis, & Tulskey, 2018). Further, goal-concordant care has been associated with improved quality of life, improved quality of dying, and reduced intensity of care at the end of life (Curtis et al., 2018). Quality communication can be compromised when clinicians are responsible for relaying news of a new condition, particularly one that may be life limiting.

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<https://doi.org/10.1016/j.outlook.2018.11.001>

When children, adolescents or young adults have cancer, health care providers (HCPs) have the responsibility to educate patients and parents about the diagnosis and treatment. Part of these conversations includes disclosure of prognosis. While often thought of as simply life expectancy, prognosis-related communication (PRC) also includes discussions regarding likelihood of cure and the quality of life the child is expected to have (Mack, Wolfe, Grier, Cleary, & Weeks, 2006). Conversations surrounding prognosis are critical in assisting parents with treatment-related decision making, hopefulness, and coping with their children's illnesses (Kästel, Enskär, & Björk, 2011; Mack et al., 2006; Nyborn, Olcese, Nickerson, & Mack, 2016). Disclosure of prognosis is primarily considered the responsibility of physicians, however, conversations occurring both before and after prognostic discussions often involve nurses. Parents of critically ill children and those with cancer have indicated that they look to nurses to gain understanding of prognosis and to serve as a source of support and guidance when making difficult treatment decisions (Madrigal et al., 2016; Sisk, Kang, & Mack, 2017). Nurses are clearly poised to be active participants in prognostic conversations with parents of children of cancer, yet little is known about pediatric oncology nurses' perspectives and experiences with PRC.

The exact role and responsibilities for nurses during PRC are not well delineated. Prior research suggests that nurses are generally uncomfortable responding to questions about life expectancy or disease trajectory with many preferring to play a supportive role in PRC (Helft, Chamness, Terry, & Uhrich, 2011). Nurses caring for adults with life-limiting illnesses identify fulfilling a number of different roles in the process of prognostic disclosure including that of educator, care coordinator, supporter, facilitator, and advocate (Newman, 2016), but have also indicated that lack of inclusion in prognosis-related discussions between patients and physicians can limit their ability to perform these roles successfully (Anderson et al., 2016).

While little evidence is available describing pediatric oncology nurses' experiences with PRC, several reports have documented communication difficulties (Citak, Toruner, & Gunes, 2013) and experiences with communication during palliative and end-of-life care (Hendricks-Ferguson et al., 2015; Montgomery, Sawin, & Hendricks-Ferguson, 2017). Turkish nurses indicated that their greatest communication difficulties with children and their families were responding to questions regarding negative prognoses or death (Citak et al., 2013). They found crisis periods, such as diagnosis or relapse, to be quite distressing when they felt unprepared to respond to patients' and families' questions or to support them during these challenging times. In the United States, experienced pediatric oncology nurses described feeling confident in engaging patients and families in conversations at the end of life (Montgomery et al., 2017), however, more novice nurses (less than one year of experience in pediatric

oncology) described tension and uncertainty about their role in talking about palliative and end-of-life care with patients and families (Hendricks-Ferguson et al., 2015). Thus, more research is necessary to better understand nurses' experiences with PRC.

The purpose of this mixed-methods study was to reduce this knowledge gap by conducting an in-depth exploration of pediatric oncology nurses' perceptions and experiences of PRC, the factors that impact their perceptions and experiences, and the perceived effects of PRC and physician collaboration on nurse-perceived quality of care and nurse moral distress. This paper presents the qualitative results, reporting how pediatric oncology nurses described their experiences with PRC. Enhanced understanding of PRC from the perspective of nurses will inform future intervention work aimed at optimizing patient, family, and provider communication and care.

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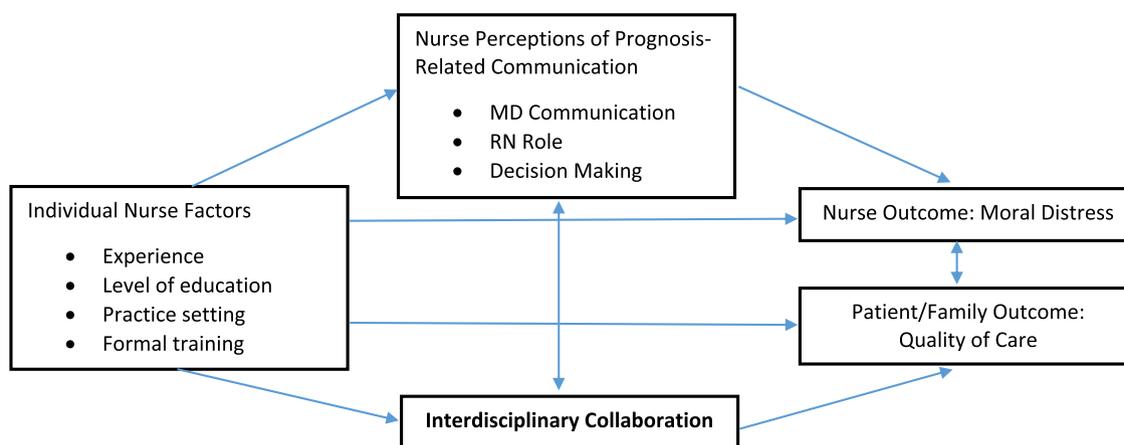
## Theoretical Framework

Merging critical elements of Donabedian's model with that of Dr. Jean Watson's Human Caring Model, the Quality Caring Model developed by Duffy and Hoskins (2003) provided the conceptual foundation for the study. The Quality Caring Model has three components: structure/causal past, process/caring relationships, and outcome/future, and aims to unveil the impact of caring nursing processes within the complex health care environment. The structure/causal past component takes into consideration the individual characteristics of nurses, and how they are associated with both processes and outcomes of care. The process component includes the interventions and practices that these nurses offer. This component includes both the independent actions of nurses as well as interdependent acts that are performed in collaboration with other members of the health care team. Outcomes are the end result of health care, and include patient, HCP, and systems outcomes. This model was aptly chosen as nurses and their role and experiences with the process of PRC were the focus of this study. The model provides insight as to how different study variables, such as nurse demographic features (structure/causal past), may be associated with process (PRC and inter-professional collaboration) and outcome variables (quality of care and nurse moral distress) (see Figure 1). As communication is relational in nature, this qualitative exploration helps provide a more in-depth understanding of relationship-centered interventions in professional encounters.

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## Methods

A mixed-method, multiphase design (Albright, Gechter, & Kempe, 2013) was used for this study. As



**Figure 1 – Proposed theoretical model of study components.**

little is known about this topic in the setting of pediatric oncology, a mixed-methods design was believed to increase the depth and breadth of understanding of the perceptions and experiences of pediatric oncology nurses. Collection of both quantitative and qualitative data occurred through an online survey format, which was followed by focus groups. Quantitative data have been previously reported (Author, 2018), therefore the focus of this paper is the presentation and discussion of qualitative data gleaned from open-ended questions on the survey and focus groups. This study was approved by a university's institutional review board.

### Participants

Survey participants were recruited from the membership roster of the Association of Pediatric Hematology/Oncology Nurses (APHON), an international association with 3,600 members. All APHON nurses received an email invitation to participate, which was distributed through the national APHON office. The principal investigator (PI) was not allowed direct access to the membership roster. The survey included an opening screen, which outlined the components of informed consent. If respondents were willing to participate, they clicked on the "I Agree" button, and then obtained access to the survey.

Pediatric oncology nurses from two different local APHON chapters in the Midwestern United States, representing 6 different institutions, were invited to participate in the focus groups. An email invitation to participate was sent out to local chapter members by

the chapter presidents. In addition, flyers were hung in respective institutions. Members were instructed to contact the PI if they were interested in participating. While participants were recruited through the local APHON chapters, membership in APHON was not a requirement to participate. Upon arrival to the focus group, nurses provided written informed consent to participate.

### Data Collection

Members of APHON were invited to complete a one-time online survey via SurveyMonkey, which included study instruments and a demographic questionnaire. Study instruments measured the different components of the theoretical model. As part of the survey, nurses were asked to complete three open-ended questions, allowing them to provide exemplars of their experiences with PRC in relationship to physician collaboration (Question 1), moral distress (Question 2), and nurse-perceived quality of care (Question 3) (see Table 1). The survey was open from April 2016 to June of 2016.

Following completion of preliminary analysis of the open-ended questions, focus groups with local chapter APHON members were held. The purpose of the focus groups was to discuss and refine preliminary themes derived from analysis of written responses to open-ended questions via member checking. Three focus groups were conducted, each comprising 5 to 6 participants. No new data were generated by the third group; thus, data saturation had been achieved. The PI led the

### Table 1 – Open-Ended Survey Questions

**Question 1.** Please reflect on your past experiences with prognosis-related communication (PRC). Please provide an example of a situation in which collaboration did or did not occur with a physician colleague, in regards to the presentation of prognostic information, and how the situation impacted you, the patient, and/or his/her parent(s). Do not include any parent, child, nurse, or physician names.

**Question 2.** Please provide an example of a situation in which you experienced inner or moral distress as a result of PRC with a patient, his/her parent(s), and/or a physician colleague.

**Question 3.** Please think about how the process of PRC impacts your ability to provide quality care to children with cancer and their families. Provide an example, whether positive or negative, of how PRC affected the care you delivered to the patient and/or the patient's parents.

focus groups with a semistructured interview guide consisting of open-ended questions to elicit nurses' experiences with PRC and their reflections on the results of the survey (see [Table 2](#)). A research assistant took field notes and managed the audiorecorder for two groups.

A number of risks to the quality of data gathered from focus groups have been identified including one-person dominance, lack of equal participation, insincere agreement with other speakers (conformity), and withholding of relevant information ([Ravitch & Carl, 2016](#)). In this study, several factors provided assurance that the data obtained were comprehensive in terms of capturing a range of opinions and depth of understanding, robust, and high quality ([Karnieli-Miller, Strier, & Pessach, 2009](#)). In each group, all participants were engaged and responded to the questions. Participants spoke uninterrupted, and the researcher used prompts to request clarification or to stimulate further elaboration from other nurses in the group, such as, "what does that mean," "what do you think," or "does that echo what your experiences have been or are they different?" The nature of the relationship between participants and researchers can also influence the quality and quantity of data obtained ([Karnieli-Miller et al., 2009](#)). Having participants who are knowledgeable about the topic of the focus group strengthens the quality of the data ([Rothwell, Anderson, & Botkin, 2016](#)). In this study, nurses provided first-hand experiences with the topic as experts, and were encouraged to share fully including content that was different from other participants or what was commonly said. Further, participants knew the PI as a respected colleague in pediatric oncology, which promoted the sense that the PI and nurse participants were equals working together to find solutions for an important problem.

**Table 2 – Focus Group Questions**

Semistructured Focus Group Questions

1. Let's start by talking about some of the experiences you have had talking with parents about their child's diagnosis and prognosis.
2. What do you think is the nurse's role in these discussions?
3. Describe the collaboration that occurs between physicians and nurses on your unit.
4. Describe the systems or processes that are in place to ensure that all members of the medical team are aware of when these conversations occur or have occurred and what the content of the conversation was.
5. What in your practice has brought you the most distress?

**Presentation of survey results and interpretation of findings**

1. How are these findings like your own experiences?
  2. How are these findings different from your own experiences?
- Any other thoughts, comments, things you feel we haven't covered or things you want to add? Things you think are important?

## Data Analysis

Responses to the open-ended questions on the online survey were exported verbatim from SurveyMonkey into NVivo 11, which was used to manage the data and facilitate the development of themes. An interpretive descriptive approach was employed to analyze the qualitative data ([Thorne, 2016](#)). Data analysis was guided by steps outlined by [Polit and Beck \(2012\)](#). Responses to each of the three questions were analyzed separately. Initially, the PI reviewed the first 10 responses to Question 1 to get a sense of them as a whole, asking "What is happening here?" and "What am I learning about this?" A preliminary coding template was developed from the first 10 responses. The preliminary coding template was shared with the two co-authors, who independently used the template to code the first 10 responses. Coded data were compared across researchers; the coding template was revised, as necessary, to achieve consensus on labels and definitions of codes. The PI and two co-authors used the revised coding template to code all of the responses to Question 1. A similar process was followed to analyze data from Questions 2 and 3. The three coders met regularly to review coded data; disagreements in the coding were discussed until consensus was reached. Data within and across codes were then compared to identify core concepts and themes that described the experiences of participants.

Transcripts of the focus groups were reviewed and cleaned by the PI. Data were then exported into NVivo 11 for analysis. The core concepts and themes derived from analysis of the open-ended survey questions were used as codes to analyze the focus group transcripts, allowing for focus group data to be combined thematically with data from the survey questions. Researchers engaged in an iterative collaborative process of coding and discussion of the entire data set to identify three themes and nine subthemes that described how pediatric oncology nurses described their experiences with PRC.

Various methods were employed to ensure rigor and limit bias. Validity refers to how well the researchers' descriptions of themes and results represent the actual phenomenon ([Morse, 2015](#)). In this study, validity was ensured through thick rich description of research results obtained from a large sample; triangulation with three data sources including quantitative survey results ([Author, 2018](#)), written short-answers, and focus group participation; and member checking. Development of a coding template with intercoder agreement, and providing a detailed account of the methods were strategies to ensure reproducibility, or reliability, of this study and results ([Morse, 2015](#)). Rich and detailed descriptions of the themes and subthemes and participants' quotes were included so readers are able to assess whether these results apply, or are transferable, to other populations. Researchers contributed both insider (pediatric oncology) and outsider (general pediatric primary care) perspectives



**Table 4 – Themes and Subthemes of Pediatric Oncology Nurses' Experiences with PRC**

| Theme<br>• Subthemes                             | Definition  | Defining Characteristics   | Illustrative Quotes   |
|--|---|--|---|
| <b>Importance of Collaboration</b>               |   |  |   |
| • Characteristics                                | Distinguishing features that promote teamwork surrounding prognostic disclosure to patients and families  | Inclusion and support of team members<br>Trust and respect among team members; different roles and unique contributions valued<br>Clear communication and documentation  | "I am thankful I work with a physician who is straight-forward and informs families from the beginning of the prognosis and realistic expectations, but also encouraging hope. He is a skilled clinician and communicator. He is also an ideal leader. He allows team members to be autonomous and come to the family with equal value and importance as he provides."  |
| • Benefits                                       | Positive outcomes that arise when nurses are part of diagnostic and prognostic conversations with patients and families   | Facilitates communication with patient and family including provision of a single message<br>Enhances care coordination and teamwork<br>Supports continuity of care  | "As I was part of the whole conversation, I was able to also include the home care RN, the hospice nurse, and ended up continuing the conversation with the mother as the next few weeks progressed. She made the decision with me to end chemotherapy, and then informed the MD. We truly worked as a team on this case, little buddy was comfortable, mother and siblings were very engaged and involved in his end of life care."  |
| • Consequences of nurse exclusion                | Results that arise when nurses are not included in formal prognostic conversations with patients and families; and when physicians do not directly share, either verbally or in written form, with the nurse what was discussed during such conversations | Limits nurse communication with patient and family<br>Limits development of trust among patient, family, and nurse<br>Limits nurse role enactment<br>Nurse frustration   | "I was caring for a patient and the MD gave the patient and family bad news regarding a prognosis. I, as the nurse, was not included in the conversation, nor did I know that the results were not good. The family asked me questions regarding the prognosis and scans and I was unaware that they had even received the news. It was challenging because I looked incompetent and uninformed/uninterested in the patient's care."  |
| <b>Impact of Prognosis-Related Communication</b> |   |  |   |
| • Benefits of adequate prognostication           | Results and/or opportunities that arise from provision of honest and/or full disclosure of prognostic information by the physician or other members of the team   | Enhances communication among patient, family, and medical team<br>Facilitates treatment-related decision making<br>Allows for inclusion of patient and family preferences and goals of care in care planning especially at end of life | "...I was assigned to a patient who was being diagnosed with metastatic Ewings sarcoma and was invited to sit in on the diagnostic and prognostic discussion with the patient and family. After hearing the difficult details, the parents excused themselves from the room and the providers moved on to other duties. With just myself and the patient in the room I was able to clarify with him his understanding of the situation and reframe some assumptions he had made incorrectly. It also gave me the opportunity to ask what was most important to him so that I could help advocate that his voice was heard." |

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**Table 4 – (Continued)**

| Theme<br>• Subthemes   | Definition   | Defining Characteristics  | Illustrative Quotes   |
|--|--|---|---|
| <ul style="list-style-type: none"> <li>• Consequences of Limited Prognostication</li> </ul>  | <p>Perceived implications of physicians or other team members failing to provide a realistic description of the patient’s prognosis or condition, failing to provide such information in a timely fashion, parents not acknowledging honest information about their child’s condition, or either physicians or parents forbidding nurses from providing patients and/or parents with accurate prognostic details</p> | <p>Patient</p> <ul style="list-style-type: none"> <li>• Unnecessary procedures and suffering</li> <li>• Limitation in focus on quality of life</li> </ul> <p>Parent</p> <ul style="list-style-type: none"> <li>• Negative emotion (anger, confusion, guilt)</li> <li>• False hope</li> <li>• Lack of preparation for patient’s death</li> </ul> <p>Nurse</p> <ul style="list-style-type: none"> <li>• Limitations in treatment-related decision making</li> <li>• Distress</li> <li>• Limitations in nurse role enactment</li> </ul> <p>Healthcare Team</p> <ul style="list-style-type: none"> <li>• Dissension among team members</li> </ul> | <p>“A family asked that their nine year old son not be told that his disease was back and he had a poor prognosis. It is stressful for me not to be honest with a patient regarding questions they have about their disease. He asked why his stomach was getting big like another patient who relapsed. He wanted to know if his cancer was back and the nurses had to lie to him because this was his mother’s wish. This caused a lot of stress and moral distress.”</p>   |
| <ul style="list-style-type: none"> <li>• Family Misunderstanding</li> </ul>  | <p>Nurse belief that patients and/or families have an inaccurate understanding of the child’s condition or prognosis, because of lack of honest, full disclosure or the presentation of conflicting or confusing information from members of the health-care team</p>  | <p>Lack of parental understanding of condition and related prognosis</p> <p>Mixed messages from healthcare team</p> <p>Lack of clarity in presentation of information</p>   | <p>“I want the child to be able to choose where they spend their final days, and they think they are going to have a normal life. Sometimes by the time they realize how sick the child is, it’s too late to get them home or to hospice, and they die in the PICU.”</p>  |
| <ul style="list-style-type: none"> <li>• Nurse Distress</li> </ul>   | <p>Emotional suffering that nurses experienced as a response to observing patients and/or families enduring physical and/or emotional distress as a result of the provision of diagnostic or prognostic information, or patient suffering that the nurse perceived as a result of parental denial of patient prognosis</p>   | <p>Brought on by:</p> <ul style="list-style-type: none"> <li>• Patient and/or family response to disclosure of diagnostic and prognostic information</li> <li>• Patient undergoing unnecessary procedures and treatments often administered by the nurse, who perceived them to cause more harm than good</li> <li>• Parental denial of prognosis</li> <li>• Hiding the truth about prognosis from the parents and/or patient</li> </ul>  | <p>“...the mother was not willing to accept that her daughter was dying from leukemia and that there wasn’t much else we could do. We continued to do invasive procedures on patient and give her chemo that really wasn’t doing much but stressing her since all she wanted to do was stay home and sit on couch and watch movies with her family. I felt so bad for her and I just wanted to let her stay home. I just wanted to cry when I would start her IVs and she’d be like I just want to go home. I tried to be as supportive to the young 9-year-old girl, but I felt at times that I was lying to her. I always gave her the best of care, but felt I was doing procedures that brought her pain for no good reason.”</p> |
| <p><b>Delivery of Prognostic Information</b></p> <ul style="list-style-type: none"> <li>• Perceptions of Good Communication</li> </ul> | <p>Nurse assessment of positive aspects of communication (verbal and non-verbal) regarding prognosis</p>   | <p>Providing honest prognostic information up front in a gentle manner</p> <p>Providing anticipatory guidance regarding end-of-life trajectory</p> <p>Engaging key members of the health-care team</p>  | <p>“Physician talked about next steps in care as not addressing cancer itself but rather symptoms and efforts to improve comfort and quality of life – avoided saying there is nothing we can do – but rather here is what we can do to help your child and</p>   |

(continued on next page)

Table 4 – (Continued)

| Theme<br>• Subthemes               | Definition  | Defining Characteristics   | Illustrative Quotes   |
|------------------------------------|---|--|---|
| • Concerns Regarding Communication | Nurse uneasiness about the manner in which prognostic information was conveyed to patient and/or family and the lack of adequate portrayal of prognosis | Soliciting and supporting patient/family preferences<br>Including a focus on quality of life when discussing therapeutic options<br>Provision of unclear, unrealistic prognostic information<br>Physician collusion when parents are unwilling to accept prognosis; provision of false hope<br>MD discomfort with prognosis-related communication<br>Lack of consideration of setting or cultural beliefs<br>Provision of only disease-directed therapies, not presenting palliative care or shifting focus to quality of life, as options | you – recognized that we couldn't cure but we could still help the child."<br><br>"I remember as an advanced practice provider, with one of our older physicians who...kind of beats around the bush, and never is a direct with the prognosis. Those conversations would make me very anxious, and nervous, and uncomfortable because it was like, 'You were so leading this family on. You're giving them false hope.' Of course, they want to do something." |

10.9 years (range 0.5–40 years) in oncology nursing. Sixteen of the nurses (89%) reported no formal training or education in PRC. Two of the three institutions had Magnet designation.

## Themes

Three themes were identified from the data (see Table 4). Each theme included two to four subthemes. The themes with subthemes are presented below with supporting quotations from respondents that exemplify the way in which the themes were voiced by the respondents.

### Theme 1: Importance of collaboration

The first theme was the "Importance of Collaboration," which reflects the significance nurses placed on teamwork surrounding prognostic discussions. Three subthemes included the characteristics of collaboration, the benefits associated with collaboration, and the consequences of nurse exclusion from PRC.

#### Characteristics of Collaboration

Nurses described a number of distinguishing features that they identified as promoting teamwork surrounding prognostic disclosure to patients and families. Essential attributes of collaboration included trust, mutual respect, and open communication. One nurse stated, "I feel free to ask questions within my team so I can clearly understand our options and help to keep families well informed." Nurses frequently highlighted the importance of having conversations among team members prior to providing patients and families with prognostic information. Nurses believed that these premeetings enabled team members to prepare for PRC with families. Specifically, nurses reported that team meetings prior to PRC (a) facilitated development of clear messages for families, (b) improved anticipation of the needs of patients and families, (c) optimized the skill sets of different team members, and (d) allowed the team to identify personalized support to assist the parents to participate in PRC. Finally, documentation of prognostic discussions and goals of care was identified as valuable to ensuring that all members of the team across the continuum of care were "on the same page."

#### Benefits of Collaboration

Nurses described positive outcomes that were achieved when their physician partners actively sought them out to collaborate in communicating diagnostic and prognostic information to patients and family members. Nurses perceived that participating in these conversations enabled them to start to develop trusting relationships with families, which enhanced communication. When nurses were certain about what had been communicated to patients and

families, they were able to continue the conversations, and provide a consistent message to families. One nurse reported, "They do not want mixed messages. As a nurse, and now an NP, I find it most useful if I understand what the MD has said and reinforce, elaborate, address questions and concerns patients and families have." Being a part of the whole conversation allowed nurses to communicate with other members of the team including community partners, such as home care and hospice providers, which they believed improved care coordination and allowed for enhanced continuity of care. Finally, active participation in prognostic discussions enabled nurses to support families in decision making and establishing goals of care.

#### *Consequences of Nurse Exclusion*

Nurses expressed the challenges that arose when they were not included in formal prognostic conversations among physicians and family members; and when physicians did not directly share, either verbally or in writing, with the nurse what was discussed during such conversations. Nurses described feeling frustrated and distressed when left out of formal conversations with family members. Nurses acknowledged the challenges of timing, for example, prognostic discussions occurring after rounds or during the day shift when the nurse works at night. They also indicated that without this information they were unable to fulfill their roles as educators, supporters, and advocates, and constantly felt as though they were playing catch up. Nurses expressed fear that they would say something to contradict what was said by physicians, and did not want to confuse families. Nurses believed they could be perceived as incompetent, uninterested, and uniformed when they were not aware of the prognostic information that had been discussed with families. Nurses feared that their lack of awareness might cause families to lose trust in them and the team.

#### **Theme 2: Impact of Prognosis-Related Communication**

The second theme, "Impact of PRC," encompassed the perceived influence that the process of PRC had upon nursing practice as well as patient and family outcomes. The impact was categorized into four sub-themes: benefits of adequate prognostication, consequences of limited prognostication, family misunderstanding, and nurse distress.

#### *Benefits of Adequate Prognostication*

Nurses valued honest, realistic disclosure of prognostic information, and believed that the provision of such information to parents and patients was beneficial in a number of different ways. They believed that adequate prognostication allowed parents to communicate more freely with their children and their children's medical teams about prognosis. This open communication facilitated decision making and care planning. Nurses related that family understanding of prognosis, particularly in the context of poor

prognosis, allowed parents to make decisions about pursuing second opinions or electing to forego additional disease-directed treatment. Parents and members of the medical team were able to talk with children about their wishes for treatment, life and death, and end-of-life care planning. Children and adolescents who had cancer had the opportunity to engage in life planning, funeral planning, or determining where they wished to die. One nurse described,

We had a 15-year-old female patient who was put on palliative chemotherapy...Her family was very open with her about her diagnosis and her options. It was a very trying year, but very amazing. We were able to celebrate every milestone and have open discussions about life and death. She was able to talk about what she wanted her funeral to be like and what she wanted to happen...And her funeral was PERFECT for her...just all the time open communication...what I wish it could be like for every patient every time...Children—even very young ones...know what's going on...and sense things even that aren't spoken.

Open communication allowed HCPs, parents, and patients to be on "the same page." One nurse reported, "Much better to provide therapeutic and relationship-based care if every team member, including patient and family, are on the same page and have open dialogues."

#### *Consequences of Limited Prognostication*

Nurses identified instances of limited prognostication that occurred when physicians or other team members did not provide parents with realistic descriptions of their children's conditions, when prognostic information was not communicated in a timely fashion, when parents received mixed messages, or when parents did not seem to acknowledge and accept poor prognostic details. Nurses indicated that limited discussions regarding prognosis often resulted in delayed palliative care consultations, which could lead to more suffering for children with cancer. Further, nurses felt that parents who did not understand their children's prognoses might not recognize that their children were facing imminent death and might miss the time that was left to share with their children in meaningful ways. Nurses raised concerns of difficulty supporting parents who had been given, what nurses perceived, to be unrealistic prognostic information. Nurses felt very uncomfortable when they believed that a child had a poor prognosis and the family had been given and appeared to believe an unrealistically optimistic prognosis. In these situations, nurses reported that they might limit or avoid communication with families in efforts to not undermine the physicians. Nurses believed that when presented with mixed-messages, parents became confused, and had difficulty making informed decisions that were in the best interests of their children.

Nurses described challenging scenarios, in which, patients' clinical conditions were rapidly deteriorating or required an escalation of care, but they perceived

that physicians did not relay the gravity of such situations to the parents. Nurses described continuing to give patients oral chemotherapy, which they perceived as futile, but thought the physicians had presented this to parents as the next step or standard of care. In one situation the nurse wrote,

A patient was very actively dying and the attending physician kept insisting that we give him his oral medication because "it's the only thing that is going to cure him." This despite the patient being unconscious and bleeding from the mouth and nose. Refusing to acknowledge to the family that the patient is actively dying and continuing to offer hope and treatment options.

The idea of false hope surfaced in a number of the nurses' comments. One nurse described, "Physicians gave what I perceived to be false hope to a patient and family and as a result the patient experienced a lot of physical and emotional pain and suffering before her eventual death."

Nurses reported experiencing considerable distress when they were instructed to not provide patients and/or parents with accurate diagnostic or prognostic details, or when caring for children whose parents were unaccepting of a poor prognosis. Nurses bore witness to suffering as they observed patients receive, what they perceived to be, futile care. One nurse wrote,

The child was literally melting before our eyes, but we kept on doing procedures and giving medications...we should have stopped interventions and let the child leave this world peacefully. Instead it was medical and a code was called on a patient that was essentially already gone.

Nurses described when parents would request that nurses not share the news of recurrence or even a diagnosis with patients,

...the family would not allow the young teenager to know her diagnosis or prognosis...knowing the patient did not realize her life was coming to an end very quickly was gut-wrenching. She was never allowed to voice anything related to the end of her own life. I hated that experience.

Nurses also reported that some parents would ask that staff not use the word "cancer" in front of their children. This along with limitations on disease-related discussions forced the nurses into compromising positions where they had to lie to children, who asked them direct questions. One nurse stated, "He wanted to know if his cancer was back and the nurses had to lie to him because this was his mother's wish."

#### *Family Misunderstanding*

At times nurses believed that parents had an inaccurate understanding of their children's conditions or

prognoses, which they thought was sometimes due to lack of honest, full disclosure, or the presentation of conflicting or confusing information from members of the health care team. Nurses provided examples where parents seemed to have misunderstandings regarding their children's conditions, "...the patient and her mother thinking her metastatic disease was a 'chronic illness, like diabetes' as they had been told." Another nurse stated,

When I saw the patient, the family kept talking about how they were going to Disney once he was better and not requiring platelets so frequently. This was not going to happen and we all knew it but he (the physician) never made the family aware.

Nurses believed that lack of accurate understanding limited decision making and realistic care planning.

#### *Nurse Distress*

Throughout their responses, but particularly in response to the question regarding moral distress, nurses described how PRC, at times, resulted in what they believed to be patient and/or parent suffering. This suffering was difficult for nurses to observe and was distressing to them. The devastation that ensued among patients and families when the team shared the news of a new cancer diagnosis or relapse was hard for nurses. One nurse described, "A teenage boy who was graduating from HS and had a scholarship to play baseball at college was given poor prognosis and he broke into tears. Although all of those discussions are difficult, that one was especially difficult." Furthermore, nurses described how parents "could not grasp the reality of this child's prognosis" and tried to "proceed as if the prognosis is better than it really is." Nurses reported that they believed that this resulted in additional procedures and tests being performed, which caused suffering for children.

#### **Theme 3: Delivery of Prognostic Information**

The third theme, "Delivery of Prognostic Information," delineated the variety of ways in which prognostic information was provided to patients and families. Because physicians are primarily responsible for conveying prognostic information, nurses focused their discussion on the manner in which they delivered prognosis-related information. The two subthemes included (a) perceptions of good communication and (b) concerns regarding communication.

#### *Perceptions of Good Communication*

Nurses listed a number of positive aspects of communication surrounding prognosis. The approach including the focus of the message as well as tone was acknowledged as essential. A more gentle tone was described as "...allowing the family to come to terms with the child's death." This tone along with language that embodied the transition of goals of care from cure to comfort and the provision of nonabandonment language were commended. One nurse described,

The patient, her family and the physician team all did a great job of asking her what she wanted the remainder of her life to look and feel like. They were honest with her prognosis and explained what next steps could look and feel like as her disease progressed. Did she want to be in the hospital? At home? At a Hospice house?

Additional steps to ensure good communication and care included collaborating with other physician colleagues and organizing a care conference with all team members.

#### *Concerns Regarding Communication*

Most nurses believed that communicating prognostic information was the responsibility of physicians, and they were at times troubled with the manner in which prognostic information was conveyed to parents. Nurses reported that on occasion physicians were not direct enough or realistic when providing parents with prognostic estimates especially when patients presented with diagnoses that portended poor prognoses. Nurses imagined that this might be due to discomfort with such sensitive conversations especially when it was time to stop disease-directed treatments. One nurse stated, "He/she could not tell the parent their child would die. I had to say the word." Another nurse described how she feared a physician's "never give up" attitude made it difficult "for patients and families to alter their treatment from curative to palliative, because they may perceive that the providers do not agree with the decision and that the family is giving up on the child." Nurses also described difficulties when physicians were not responsive to patient and/or parent cues and continued through programmed conversations without stopping to acknowledge the emotional impact of the words that were spoken. One nurse explained,

There were so many metaphors being thrown around and the physician was so programmed in delivering his 'speech' that he didn't realize the mom's eyes had welled up and glazed over after the 'he'll probably die from this soon' comment. It was a HORRIBLE discussion and left the family completely overwhelmed.

Nurses also reported concerns when physicians discussed prognosis without seemingly considering location and timing, for example, telling parents the news of a relapse while the entire multidisciplinary team was rounding in the middle of the hallway.

## **Discussion and Recommendations**

Pediatric oncology nurses' responses to open-ended questions regarding PRC with parents of children with cancer complemented and provided further depth to previously reported quantitative findings on this topic

([Author, 2018](#)), expanding our knowledge of PRC in the pediatric population. Nurses described in detail both positive and negative experiences with the process of PRC that were influenced by physician colleagues, parents, and patients.

Nurses have a great appreciation of the need for interprofessional collaboration when delivering and expanding upon prognostic information. Nurses rely upon their physician colleagues to lead such conversations, but then step-in to function in a variety of different roles, including that of advocate, facilitator, supporter, and even at times prognosticator ([McLennon, Uhrich, Lasiter, Chamness, & Helft, 2013](#)). Nurses in the current study reported that if they were not included in initial prognosis-related conversations among physicians and parents, they were unable to adequately function within their desired roles. Responses to this current survey echo an overriding theme from a previous study of nurses working with adult patients with cancer, specifically "being in the middle" (p. 430) surfaced as nurses described opportunities, barriers and actions related to PRC ([McLennon, Lasiter, et al., 2013](#)). Barriers included uncertainty, disconnect, discomfort and perceived risk that interfered with prognostic conversations. Disconnect and perceived risk occurred when physicians limited the information provided to patients, families and the nurses; or prevented nurses from discussing prognosis with patients and families. When such conversations were blocked, nurses described feelings of regret, anger, and frustration ([McLennon, Lasiter, et al., 2013](#)). In another study, adult oncology nurses relayed that the most frequent ethical dilemmas experienced within their practice surrounded truth telling including barriers and uncertainty around truth telling ([McLennon, Uhrich, et al., 2013](#)).

Such feelings were similarly described by the nurses in this study. Nurses reported distress and disconnect when they believed that parents were given skewed or inaccurate representations of children's prognoses or conditions, or when parents refused to accept or acknowledge their children's poor prognoses. Often this led to what nurses perceived to be futile treatment or interventions, which they viewed as resulting in additional suffering for the child and at times the parents. Nurses also felt that this precluded patients and families from making choices regarding the future including enrollment in palliative or hospice care, planning peaceful deaths and funerals. Limited prognostication challenged the nurse's innate sense of advocacy or the moral obligation nurses have to protect their patients' rights and interests ([Khowaja-Punjwani, Smardo, Hendricks, & Lantos, 2017](#)) and provide them with complete and trustworthy care ([McLennon, Uhrich et al., 2013](#)).

Disclosure of diagnostic and prognostic information is an emotionally challenging process. Physicians generally bear the onus of initially sharing this devastating news with patients and families. Disclosure of bad news is an arduous yet necessary task that oncologists

describe as difficult and unpleasant (Bousquet et al., 2015). Nurses must acknowledge and respect the burden that this responsibility places upon physicians. Conversely, physicians must recognize the burden that is placed upon nurses once such information has been disclosed, and patients and families begin to process the information shared with them. As the members of the health care team most intimately involved with patients and families, nurses are an integral part of these conversations (Boyle et al., 2017).

Nurses in this study described the importance of their involvement in conversations when diagnostic and prognostic information are disclosed, but simply being present is not enough. True interprofessional collaboration (IPC) is necessary with disclosure of diagnostic and prognostic information to optimize and ensure quality patient care. IPC has been depicted as a relationship between two or more health professionals, who work together to solve problems or provide services (Barr, Koppel, Reeves, Hammrick, & Freeth, 2005), or in this case, bear the burden of disclosure. IPC is characterized by shared objectives, decision-making, responsibility, and power (Petri, 2010). True IPC is enacted when the knowledge and expertise of each professional is valued and integrated into health care activities (D'Amour, Ferrada-Videla, San Martin Rodriguez, & Beaulieu, 2005). Nurses have the opportunity to more closely partner and collaborate with their physician colleagues in the process of prognostic communication, but they should not wait for an invitation. Nurses need to educate and demonstrate to their physician colleagues the value and benefit that can be achieved from collaborative partnerships in disclosure and nurses playing a more prominent role in this process.

More active engagement in the process of PRC will require a paradigm shift, in which the hierarchies long-established within medicine will be challenged. Nurses need to be more proactive in preparing for and engaging in diagnostic and prognostic conversations, accepting a more prominent role in the process. Physicians need to acknowledge and accept the complementary and leadership roles that nurses can, and should, play in enhancing the communication of prognostic information. Health care organizations need to support and help nurses take the lead in developing novel collaborative approaches to such communication and subsequently diffusing models into practice (Institute of Medicine, 2010). Such a shift will require further education and training of nurses, physicians, and other HCPs; ideally in an interprofessional setting. While the significance of education around interprofessional communication and collaboration is well-recognized (Tang, Zhou, Chan, & Liaw, 2018; World Health Organization, 2010) and considered an essential component of undergraduate nursing curricula (American Association of Colleges of Nursing, 2008), nurses report limited experience or training regarding communication, particularly serious illness communication and "breaking bad news" (Bumb, Keefe, Miller, &

Overcash, 2017). In addition, ongoing education of practicing nurses regarding communication is limited. Educators and health care administrators must critically evaluate the need for programs to enhance the communication skills of nurses, developing novel opportunities for nurses to receive additional training in communication to ensure they are prepared to engage with patients and families in a meaningful manner and also speak confidently with their physician colleagues. To that end, more funding needs to be made available on a local and national scale to ensure nurses receive adequate communication education and training, and that physicians are educated on the role of the nurse in PRC. Future research should evaluate the most effective education and training methods for enhancing communication skills and the impact that more collaborative communication may have upon patient, family, and HCP outcomes.

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## Limitations

As the open-ended questions on the survey were unable to be linked to respondent responses, a detailed description of the nurses who answered the open-ended questions was not possible nor the comparisons among groups of respondents. Further, only 12% to 14% of survey respondents answered the open-ended questions; representing only a small number of pediatric oncology nurses from the US. Notably, no nurses from outside the US participated in either the online survey or focus groups. Cultural values and norms certainly play an important role in health care communication, therefore, the results of this study may not be representative of nurses' experiences with PRC outside of the US or minority groups underrepresented in the study. Thus, generalizability is limited. Also, if responses were unclear to the research team, the anonymous nature of the survey did not allow for clarification of responses. Similar limitations are acknowledged when working with focus groups. Limitations aside, the goal of this qualitative work was to gain insight into pediatric oncology nurses' experiences with PRC. This goal was achieved, and results were consistent with reports from nurses who care for adult patients with life-limiting illnesses. The results of this study can assist in providing the framework for future work, aiming to improve the process of PRC for patients, parents, and HCPs.

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## Conclusions

Nurses perceive that they are active participants in the process of PRC, yet often feel constrained in their participation and the care they provide to patients and families as they are not always included in key

conversations around prognosis. As the HCPs most intimately involved with patients and families, nurses stand poised to play a more significant role in this process, but they must be encouraged and empowered to do so. Education at both undergraduate and professional levels must focus more time and resources in preparing nurses for challenging communication with patients, families, and other members of the health care team, ideally in an interprofessional environment. Also, physicians must be better educated on the integral role that nurses can play in this process. Critical conversations must occur among nursing and medical administrators in education and academia to support the enhanced role and leadership opportunities for the nurse in developing innovative communication models. Improved interprofessional collaboration and communication will enrich the patient and family experience and outcomes along the illness trajectory.

## Acknowledgments

Sadly, Dr. Cheryl Rodgers unexpectedly passed away as finishing touches were put on this manuscript. Dr. Rodgers was an inspiration and mentor to many. For those who knew her, our challenge is to strive to replicate her constant quest for knowledge and the translation of research into practice.

Special thanks to Dr. Lauri Linder for providing writing assistance and proof reading the article.

Special thanks to Kasey Watts, undergraduate nursing student at Marquette University, for her assistance with focus groups.

Research reported in this publication was supported by Alex's Lemonade Stand Foundation and the National Institute of Nursing Research of the National Institutes of Health under award number T32NR013456 (m-PIs: Ellington and Mooney)

## Supplementary materials

Supplementary material associated with this article can be found in the online version at [doi:10.1016/j.outlook.2018.11.001](https://doi.org/10.1016/j.outlook.2018.11.001).

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