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Broaching goals-of-care conversations in advancing pediatric cancer

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Abstract

Broaching conversations about goals of care can be difficult for clinicians. Presently, the communication strategies used by pediatric oncologists to approach goals of care conversations are not well understood. We recorded disease re-evaluation conversations between pediatric oncologists, patients, and parents, capturing 141 conversations (~2400 minutes) for 17 patients with advancing illness across the study period. We conducted content analysis to identify strategies for broaching goals-of-care conversations and found five distinct communication approaches, which were not mutually exclusive. Further research is needed to explore patient and family views on best practices for broaching discussions about goals of care.

Keywords

cancer; communication; goals of care; oncologist; pediatric

1 | INTRODUCTION

Children with advancing cancer and their families face difficult decisions related to treatment options, care location, and advance care planning.[1-3] To provide optimal person-centered care, pediatric oncologists must first understand the goals of care of the patient and family. Yet pediatric oncologists acknowledge that broaching discussions around goals of care can be challenging,[4] and the various approaches used by pediatric oncologists to introduce or open these conversations are not well understood.

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CONFLICT OF INTEREST
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The U-CHAT (Understanding Communication in Healthcare to Achieve Trust) trial was designed to better understand the communication strategies that oncologists use when sharing information about disease status with children with advancing cancer and their families across the evolving illness course.[5,6] In this subanalysis, we aimed to identify different communication approaches used to broach conversations around goals of care.

2 | METHODS

This study was reviewed and approved by the Institutional Review Board at St. Jude Children's Research Hospital (U-CHAT [Pro00006473]; approval date: July 12, 2016). Details related to the study protocol have been previously described.[5,6] We enrolled 33 patients with non-central nervous system solid tumors whose primary oncologists described their likelihood of survival as 50% or less, their parents, and their oncology clinicians. We then audio-recorded serial medical conversations between the oncologist, patient, and parent at time-points corresponding with evaluation of disease status until the patient's death or 24 months from disease progression on study, whichever occurred first.

We focused analysis on all dialogue recorded for patients who experienced disease progression during the study period. Recordings of medical dialogues were uploaded into MAXQDA, a mixed methods data analysis software system.[7] Recordings were examined for dialogue-related to goals of care, defined a priori as any discussion about what the patient or family wants, prefers, wishes, or hopes for, with respect to their illness and treatment. The "goals-of-care" code was pilot-tested by four coders to demonstrate consistency in application, then two coders independently coded all recordings, and the research team met to review any variances with third-party adjudication as needed to achieve consensus. All "goals of care" dialogues were then examined for patterns in language related to broaching the goals-of-care conversation. Patterns were synthesized and reorganized to identify themes.[8]

3 | RESULTS

Study findings related to enrollment, retention, and capture of longitudinal data have been previously described.[5,6] Within the 33 patient–parent dyads followed longitudinally, a subset of 17 patient–parent dyads treated by six participating oncologists experienced progressive disease while on study. Patient, parent, and oncologist demographics are presented in Table 1. In this cohort, 141 disease re-evaluation conversations were recorded across the illness course, comprising approximately 2400 minutes of recorded dialogue. The median number of recorded conversations per patient was seven (range one to 19). A total of 177 segments were coded as goals of care within 40 conversations (28% of recordings) involving 16 out of 17 dyads.

Analysis of goals-of-care dialogues revealed five distinct approaches used by oncologists for engaging patients and parents in conversations around goals of care. Table 2 describes each approach with supporting examples from the medical dialogues. First, oncologists summarized the history of the disease and treatments, providing context and validation that the patient/family had tried everything as segue for discussion about next steps: "[we've

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done] all the best first-line medicines, right, the best second-line medicines, the best third-line medicines, the best fourth-line medicines, experimental medicines, right?”. Second, they offered a “warning shot” that a difficult conversation lies ahead: “When do you continue or when do you stop and that’s a conversation that we, we will have to have.” Third, they asked questions that centered “what you want” language: “How much of this do you want to go through or not? So you need to tell me everything you want to do.” Fourth, oncologists solicited information using language about “what feels important” to patients or parents: “…how important it is for you and for [patient]’s dad and for her to be mostly at home?” Fifth, they framed “what if” questions to help patients/families think ahead: “What do we do if something catastrophic were to happen, right? Like if she were to stop breathing…do you go to the emergency room?” Importantly, communication strategies to broach goals-of-care discussions were not mutually exclusive; oncologists used multiple approaches in synergy to engage patients and families in these difficult conversations.

4 | DISCUSSION

In this prospective, longitudinal study of communication approaches in advancing pediatric cancer, we identified five distinct approaches used by pediatric oncologists to broach difficult conversations around goals of care with patients and families in the setting of advancing illness. These communication strategies offer options for oncologists, and particularly trainees, to consider when navigating conversations about goals of care.

Our findings build upon existing templates for structuring conversations about goals-of-care conversation in medical oncology, such as REMAP: Reframe, Expect emotion, Map out patient goals, Align with goals, and Propose a plan.[9] The REMAP framework encourages oncologists to open the discussion with a one-sentence “headliner” that the disease has worsened, similar to the summary approach thematically identified here. Subsequently, the REMAP template prompts oncologists to “map” out the patient’s goals by asking open-ended questions to help the patient align their values with their treatment decisions, which parallels the approach used by pediatric oncologists to ask questions that explore the patient’s or family’s values.

However, we also identify several other approaches for opening dialogue about goals of care in the setting of advancing pediatric cancer. The warning shot (e.g., “I’m sorry that I have bad news to share today”) has been described as a communication strategy to allow patients and families a moment to prepare for hearing difficult information related to disease progression.[10] Similarly, we identified a thematic approach in which oncologists offered a type of warning shot, not to prepare patients and families for the delivery of medical information, but rather to offer notice that a difficult conversation lies ahead. We also identified the use of “what if” dialogue used by oncologists to help patients/families think ahead. A framework for navigating “what if” conversations with children with cancer and their families has been previously described, with the goal of empowering providers to explore informational and emotional needs to inform future goals-of-care conversations.[11] To our knowledge, this is the first study to demonstrate use of this approach during real-time conversations about advancing cancer between pediatric oncologists, patients, and families.

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Prior research in medical oncology has shown that oncologists infrequently elicit patients' values or explore uncertainty when discussing goals of care.[12] Our findings suggest that these conversations do occur in the setting of advancing pediatric cancer, although future work should focus on exploring the frequency of and "missed opportunities" for goals-of-care discussions across the illness course.[13] Additionally, further research should center on and integrate the perspectives of patients and parents in the development of dedicated communication training to help oncologists broach goals-of-care discussions.

Study limitations include single-site design, potential sampling bias in the setting of an academic center that recruits patients for experimental therapies, and limited racial and ethnic diversity, which requires prioritization in future work. Additionally, the perspectives of patients and families about the value and effectiveness of these communication approaches were not assessed, and this will be important to explore in subsequent studies.

In summary, audiotaped conversations offer a window into pediatric oncologists' approaches to broaching challenging goals-of-care conversations. Further research is needed to explore patient and family views on best practices for broaching discussions about goals of care.

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Abbreviation

U-CHAT	Understanding Communication in Healthcare to Achieve Trust.

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TABLE 1

Advancing cancer cohort demographic characteristics

Variable	*n* (%)
Patient (*n* = 17)	
Gender	
Female	11 (645)
Male	6 (35)
Race	
White	15 (88)
Black	1 (5.9)
Mixed	1 (5.9)
Ethnicity	
Hispanic	0 (0)
Non-Hispanic	17 (100)
Age at diagnosis (years)	
0–2	2 (12)
3–11	6 (35)
12–18	7 (41)
19+	2 (12)
Parent (*n* = 17)	
Gender/role	
Female/mother	14 (82)
Male/father	3 (18)
Pediatric oncologist (*n* = 6)	
Gender	
Female	3 (50)
Male	3 (50)
Race	
White	6 (100)
Black	0 (0)
Ethnicity	
Hispanic	0 (0)
Non-Hispanic	6 (100)
Years in clinical practice	
1–4	2 (33)
5–9	2 (33)
10–19	0
20+	2 (33)

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TABLE 2

Strategies for broaching difficult conversations related to goals of care

Theme	Examples
Summarizing illness course	• All the best first-line medicines, right, the best second-line medicines, the best third-line medicines, the best fourth-line medicines, experimental medicines, right? So, we've done a lot, and we should be doing all of these things, right? Always with the goal to make your cancer go away… In the very, very, very beginning, when we first started, the goal was to cure, right, get rid of your cancer for ever and ever…[now] what we try to do is, we try to at least keep the cancer from growing.
Offering a warning shot	• When do you continue or when do you stop and that's a conversation that we, we will have to have. • I know before we've had some discussions about what you would want to do in the setting that things come back again?…And I think we're in the same place that we were before that we know there's disease that we know we're not going to be able to get rid of…and that doesn't mean that we shouldn't do anything at all, but I think it, I think it really gives you the option to decide what you want to do.
Asking "what do you want?"	• How much of this do you want to go through or not? So you need to tell me everything you want to do. • The next question that we need to talk about is what do you think would be the next steps? What would you like to do? Do you want to take a little break and think about it?
Eliciting "what's important to you?"	• And I don't know how important it is for you and for [patient]'s dad and for her to be mostly at home, knowing that the ultimate outcome probably is not going to be significantly affected by what we do. • I think it's so important for you to start thinking about what's important for you; because I don't know what's important for [patient]…And so, whatever we can do to do what's best for you, we will do. A hundred times over, but I'm not going to pretend I know what that is, so, what I really want you to do is come up with a list of what's important, ok? And then it helps us, it helps guide us, right?
Using "what ifs" to think ahead	• What do we do if something catastrophic were to happen, right? Like if she were to stop breathing or if she were to have a seizure you cannot control, do you go to the emergency room?