

Original Article

Tumor Talk and Child Well-Being: Perceptions of “Good” and “Bad” News Among Parents of Children With Advanced Cancer



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Abstract

Context. Little is known about how parents of children with advanced cancer classify news they receive about their child's medical condition.

Objective. To develop concepts of “good news” and “bad news” in discussions of advanced childhood cancer from parent perspectives.

Methods. Parents of children with advanced cancer cared for at three children's hospitals were asked to share details of conversations in the preceding three months that contained “good news” or “bad news” related to their child's medical condition. We used mixed methods to evaluate parent responses to both open-ended and fixed-response items.

Results. Of 104 enrolled parents, 86 (83%) completed the survey. Six (7%) parents reported discussing neither good nor bad news, 18 (21%) reported only bad news, 15 (17%) reported only good news, and 46 (54%) reported both good and bad news (one missing response). Seventy-six parents (88%) answered free-response items. Descriptions of both good and bad news discussions consisted predominantly of “tumor talk” or cancer control. Additional treatment options featured prominently, particularly in discussions of bad news (42%). Child well-being, an important good news theme, encompassed treatment tolerance, symptom reduction, and quality of life.

Conclusion. A majority of parents of children with advanced cancer report discussing both good and bad news in the preceding three months. Although news related primarily to cancer control, parents also describe good news discussions related to their child's well-being. Understanding how parents of children with advanced cancer classify and describe the news they receive may enhance efforts to promote family-centered communication. *J Pain Symptom Manage* 2017;53:833–841. © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Good news, bad news, parental perceptions, advanced childhood cancer, hope, tumor talk

Introduction

As our culture moves to increase the openness with which we address serious illness, there is increasing focus on conversations between health

care providers and patients at advanced stages of illness.^{1,2} Providers and researchers often characterize conversations with patients with advanced cancer (a prototypical serious illness) in terms of

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“breaking bad news” or “discussing transitions of care.”^{3–6} In the setting of serious illness among adults, special emphasis has been placed on providing realistic prognoses⁷ and appraising and improving communication regarding advance care planning.^{8,9} Although these efforts are vitally important, the scope of communication in serious illness extends beyond planning for end-of-life care.

As treatments for childhood cancers have improved and our understanding of cancer biology has deepened, illness trajectories for even advanced childhood cancers have become less certain.^{10–14} Although providing realistic prognoses is equally important in this setting,¹⁵ relative longevity of children with advanced cancer and frequent contact between families and clinicians may occasion communication that is not anchored solely around prognostic discussions. Furthermore, parents of children with advanced cancer may have hopes (for a long life) and expectations (death from disease in weeks to months) that appear contradictory.^{16,17} Such psychological frames shape parents’ perceptions and influence their decision making.^{18,19} Previous work suggests that parents may²⁰ or may not²¹ feel tensions between seemingly contradictory hopes and expectations, whereas pediatric health care providers frequently do.²¹ How, then, do parents of children with advanced cancer characterize conversations with their child’s medical caregivers about their child’s health? We sought to understand concepts of “good news” and “bad news” discussed by pediatric oncology care teams with families of children with advanced cancer, as described by parents.

Methods

The Pediatric Quality of Life and Evaluation of Symptoms Technology (PediQUEST) study was a pilot-randomized trial of a supportive care intervention for children with advanced cancer. The primary outcome of interest, results of which have been previously published, was use and impact of the PediQUEST software system, which was designed to collect patient-reported outcomes and to generate feedback for providers.²² Secondary objectives included understanding parents’ characterizations of conversations with their children’s medical caregivers, including their descriptions of “good news” and “bad news.” Parents were surveyed (see the following for a description of the study instrument) at the time of enrollment. To be included in the PediQUEST study, eligible patients were aged two years or more with two-or-more-week history of progressive, recurrent, or nonresponsive cancer and had received cancer care at Dana-Farber/Boston Children’s Cancer and Blood Disorders

Center, Children’s Hospital of Philadelphia, or Seattle Children’s Hospital. Each institutional review board approved the study. Consecutive families were approached between December 2004 and June 2009, and 104 children enrolled.

Study Instrument

The Survey About Caring for Children with Cancer (SCCC) is a comprehensive, self-administered survey that evaluates parents’ perceptions of the child’s illness. As previously described, it was developed from a literature review and focus groups of parents and medical providers to identify key domains.^{17,23} Pretesting was performed to assess content, wording, cognitive validity, and response burden, and items with existing validity evidence were used whenever feasible.

Participating families completed self-administered pencil-and-paper surveys which were returned via self-addressed stamped envelopes to the study team. One parent per family completed the survey, and a \$5 coffee card incentive was included with the SCCC. Parents who did not respond within two weeks received two additional reminders.

The survey domain of interest for the current analysis is “Delivery of News.” Parents were asked, “During the past three months, have you talked with your child’s caregivers about any good news related to his or her medical condition?” Fixed-response survey items then queried conversation characteristics, including persons present for the discussion, type of provider leading the discussion, conversation setting, perceived appropriateness of discussion topic and timing, perceived understanding of the discussion, and perceived degree of sensitivity of the discussant’s manner. Parents were also asked, “Would you please share some of the details of what was discussed during this conversation?” and given space to provide a free-text response. Identical items were asked for bad news, with the addition of five five-point Likert scale fixed-response items that asked to what degree parents were able to express hopes and worries during bad news discussions, to what degree these were addressed, and to what degree parents were able to make suggestions about their child’s care. Additionally, parents were asked about potential care changes that arose from these discussions (“Were changes made in your child’s care based on these discussions with your child’s care team? If yes, please specify.”), the manner in which news was conveyed (“Is there anything else you would like to add regarding how news was delivered to you and your family?”), and for relevant care context (“Is there anything else you think we should know regarding the medical care of your child during these past months?”).

Analytic Methods

We used descriptive statistics, including counts, proportions, means, and SDs, to describe the cohort of parent respondents, their children, the sites of childhood cancer care, the oncology providers who directed cancer care, and parent-reported conversation characteristics. Deaths of children of parent respondents were recorded through the end of the study data collection period (December 18, 2009). No effort was made to impute missing data. All statistical analyses were performed using Stata software version 10.1 (StataCorp, College Station, Texas).

Parent free-text responses to the questions “Would you please share some of the details of what was discussed during this conversation,” for both good news and bad news were subjected to qualitative textual analysis. Because our aim was to understand what parents characterized as “good news” and “bad news,” we maintained parent-reported categorizations. We coded free-text responses to questions about care changes, news delivery, and care context if the respondent reflected on the good news or bad news discussion in these answers. Analysis was iterative and began with open coding, followed by refinement of codes into a codebook, focused coding, and subsequent category construction.^{24,25} We then sought to understand how thematic categories related to each other. Open coding, codebook development, and focused coding was performed by one of the authors (A. M. F.) and reviewed by an additional author (V. D.) for clarity and consistency to ensure trustworthiness. Atlas.ti software version 7.5.10 (Berlin, Germany) was used for data management.

Results

Characteristics of the 86 parents who completed the SCCC (83% of enrolled parents) and their children are shown in Table 1. Most parent respondents were women, and the vast majority were white and non-Hispanic. Children were slightly more likely to be male, with a mean age of 12.1 years. Notably, all three major disease categories (hematologic malignancies, central nervous system [CNS] tumors, and non-CNS solid tumors) were represented, although a majority of children had non-CNS solid tumors. A majority of children were alive at study completion. Most children were cared for primarily by a physician pediatric oncologist, although 22% identified a nurse practitioner as their primary oncology provider. Follow-up time from completion of the SCCC to death or the end of data collection ranged from 0.8 to 58.7 months (median 11.5 months, interquartile range 6.3–22.4 months). Among children who died ($n = 37$), time from completion of the SCCC to death

Table 1
Participant and Child Characteristics at Time of Survey Completion

Characteristic	Mean (SD)	Number (%)
Parents ($n = 86$)		
Age, yrs	43.6 (7.5)	
Female sex		74 (86.0)
Ethnicity ($n = 84$)		
Hispanic		6 (7.1)
Race ($n = 82$)		
American Indian/ Alaskan Native		0 (0)
Asian		1 (1.2)
Black or African American		3 (3.7)
Native Hawaiian or Pacific Islander		0 (0)
White		76 (92.7)
Other		2 (2.4)
Children ($n = 86$)		
Age, yrs ^a	12.1 (5.8)	
Female sex		46 (53.5)
Alive at study completion ^b		49 (57)
Cancer type ($n = 86$)		
Hematologic malignancy		28 (32.6)
CNS tumor		9 (10.5)
Non-CNS solid tumor		49 (57.0)
Months since diagnosis at time of survey ($n = 84$)	26.8 (20.1)	
Health care provider (type by patient, $n = 79$)		
MD		62 (78.5)
NP		17 (21.5)
Health care site ($n = 86$)		
CHOP		21 (24.4)
DF/CH		49 (57.0)
SCH		16 (18.6)

CNS = central nervous system; CHOP = Children's Hospital of Philadelphia; DF/CH = Dana-Farber and Boston Children's Cancer and Blood Disorders Center; MD = physician oncologist; NP = nurse practitioner oncologist; SCH = Seattle Children's Hospital.

^aDetermined at study entry; for some participants, there was a delay between date of entry and date of survey completion.

^bDecember 18, 2009.

ranged from 0.8 to 42.6 months (median 7.3 months, interquartile range 4.4–13.6 months).

Conversation Characteristics and Child Outcomes

Overall, 61 parents reported discussing good news with their child's provider, and 64 parents reported discussing bad news with their child's provider. A majority of parents ($n = 46$, 53%) reported discussing both good and bad news with their child's caregivers in the preceding three months (Table 2). Children participated in most good news (42/56, 75%) and bad news (39/61, 64%) discussions. Most discussions were led by the primary oncologist (good news: 53/56, 95%; bad news: 51/62, 82%), and most occurred in the outpatient setting (good news: 38/54, 70%; bad news: 35/60, 58%). A vast majority of parents reported that both good news (45/56, 80%) and bad news (51/62, 82%) were discussed in a very sensitive manner and that the timing of the discussion was appropriate (100% for good news, five missing; 95% for bad news, two missing). Furthermore, responding parents

Table 2
Parent Perceptions of Type of News Discussed, Changes in Care, and Child Outcomes

Parent Perception of Type of News Discussed	Number (%)	Changes in Care, ^a Number (%)	Child Deceased at Study Conclusion, Number (%) ^b
Good news only	15 (17)	0 (0)	4 (27)
Bad news only	18 (21)	12 (67)	10 (56)
Good and bad news	46 (54)	34 (74)	20 (44)
No news discussed	6 (7)	N/A	2 (33)
Missing	1 (1)	N/A	1 (100)
Total	86 (100)	46 (54)	37 (43)

^aChanges in child's care that parent reported related to discussions characterized as containing good news and/or bad news. Parents who replied "no" to "During the past three months, have you talked with your child's caregivers about any good/bad news related to her medical condition" were instructed to skip this question.

^bPercentage of children deceased out of the total number for each reported news type.

reported that they clearly understood "a great deal" or "a lot" of what was being discussed in good news (50/55, 91%) and bad news (55/62, 89%) discussions. Care changes were not reported for any of the children whose parents reported discussing only good news, whereas two-thirds to three quarters of children whose parents reported discussing mixed news or only bad news were reported to have experienced changes in care (Table 2). The cumulative incidence of death was highest among children whose parents reported discussing bad news only (56%) and lowest among those who discussed good news only (27%, Table 2).

Expression of Hopes and Worries

Fig. 1 summarizes parents' reports of the extent to which they could express their hopes and worries

during discussions of bad news and how sufficiently these hopes and worries were addressed. A majority of parents were able to express their hopes and worries "a lot" or "a great deal" and most also reported that these were addressed "a lot" or "a great deal." However, approximately one-third of parents reported incomplete ability to share hopes and worries. In exploratory subgroup analyses, these parents did not differ with regard to religiosity, education, race, ethnicity, or income. Notably, nearly three quarters of parents who reported discussing bad news felt able to make suggestions about their child's care. Although there was substantial overlap in parents who expressed inability to share hopes and/or worries and those who felt unable to make suggestions about their child's care, only six parents reported

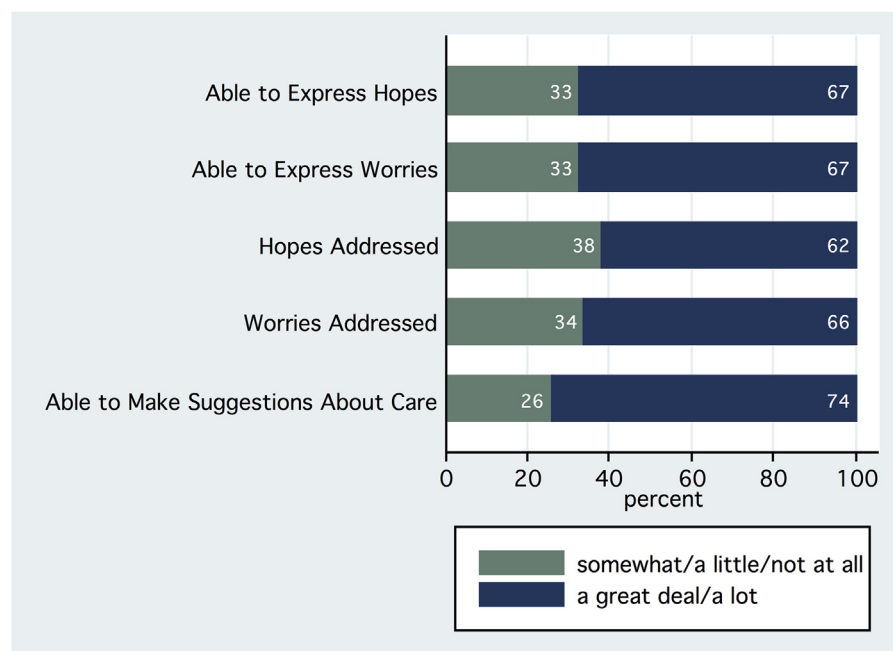


Fig. 1. Expression of and attention to hopes and worries during bad news discussions. Perceptions of ability to express hopes and worries, attention to expressed hopes and worries, and ability to make suggestions for their child's care among parents who reported bad news discussions in the preceding three months; all numbers are percentages (total $n = 61, 61, 60, 59, 62$).

“somewhat/a little/not at all” in response to all five items. Appraisal of the free-text comments by these six parents revealed that two of the six were concerned with discussing worries in front of the ill child: “I did not want to address many worries in front of my daughter at that time”; “I do not want any type of bad news delivered in front of my child.” Thus, understanding parents’ desired setting and circumstances for discussions may facilitate greater expression of hopes and worries.

Free-Response Items and Emergent Themes

Seventy-six parents (88%) answered free-response items that asked participants to share details of what was discussed during their conversations with their child’s medical caregivers. Fig. 2 summarizes the major thematic categories and their interconnectedness. A list of themes and illustrative quotes are displayed in Table 3. The organizing thematic categories for good news discussions were cancer control and child

well-being, whereas the organizing thematic categories for bad news discussions were loss/lack of cancer control and deleterious effects of treatment.

Good News. Parents described discussing good news about their child’s cancer, and specifically, control of that cancer. Parents indicated that news of cancer control often came in the form of good test results: “scan results showing shrinkage of the tumor”; “Current treatment [child] was on appeared to be working and lowering AFP [alpha-fetoprotein].” Parents wrote of reduced tumor burdens, and even tumor stability, as good news. Additional treatment options were described as the driving good in some good news discussions: “tumor dead, nodes + but Phase II trial available.” A minor theme that emerged was the primary oncology provider’s reaction as a source of good news: “I’m very happy because the MDs [doctors] were happy with how [child] is doing.” Another important good news category that emerged from

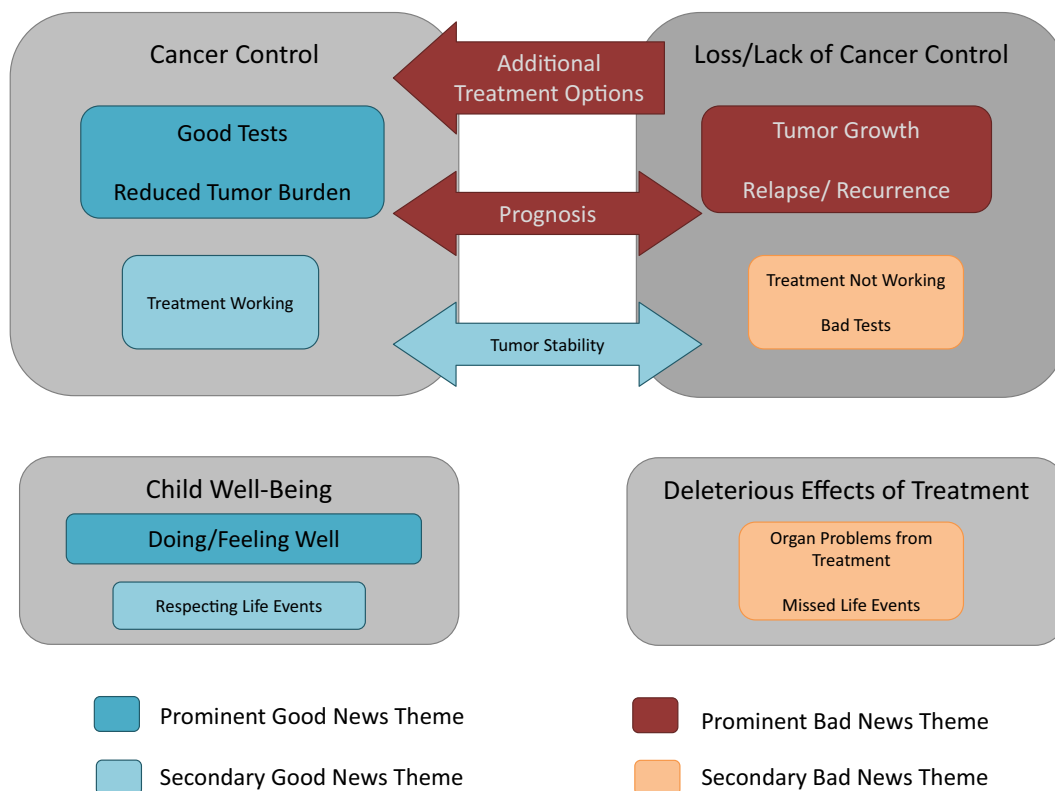


Fig. 2. Schema of thematic categories. This figure visually summarizes the good news and bad news themes parents perceived and demonstrates their relative prominence and interrelationships. Together, the top two boxes constitute “Tumor Talk,” whereas the bottom two boxes concern the greater context of the child’s overall health and life. Prominent themes were the most frequently endorsed, and each was endorsed by 15% or more of parent respondents. Prominent bad news themes are displayed in cranberry and secondary bad news themes are displayed in light orange. Prominent good news themes are displayed in teal and secondary good news themes are displayed in light blue. Cancer control and loss/lack of cancer control are perceived as dynamic, interrelated states, bridged by discussions of tumor stability, prognosis, and additional treatment options (shown as arrows). Child well-being and the deleterious effects of treatment may not be related to the state of cancer control/lack of control. (For interpretation of the references to color in this figure legend, the reader is referred to the Web version of this article.)

Table 3
Thematic Categories of Good and Bad News and Illustrative Quotes

Type of News	Category	Code	Parents Endorsing	Quotations
Good news	Cancer control	Good tests	<i>n</i> = 51 (%)	
			12 (24)	“Current treatment child was on appeared to be working and lowering AFP” “Perfect match for BMT!” “The test results showed no neuroblastoma in his bone marrow or his head—Specifically in the soft tissue around brain.”
			9 (18)	“Transplant did clear most of cancer.” “50% shrinkage of tumors on CT scan in Feb” “Secondary tumors (lung metastases) are shrinking again following 2 rounds on new regimen”
			7 (14)	“MIBG therapy would be an option for treatment. Also, stem cell harvest was a possible option”
			5 (10)	“Chemotherapy put cancer in remission!”
			3 (6)	“Last scan was stable”
			2 (4)	“That his cancer was curable and they (doctors) had a very hopeful outlook for my son.”
Bad news	Child well-being	Doing/feeling well	8 (16)	“Our son has been feeling the best yet since his diagnosis last July and we are now preparing for transplant” “Child’s great energy, disposition, appetite improvement”
			3 (6)	“We were able to make a ‘Make A Wish’ trip without worry.”
		Respecting life events ^a		
	Loss/lack of cancer control	Additional treatment options	<i>n</i> = 59 (%)	
			25 (42)	“What to do next? Chemo options, trials, tumor freezing.” “We would try decitabine (usually reserved for adults) and would see if it would help, but unlikely to be a cure.”
			17 (29)	“Another tumor. We all hoped it would not happen, but expected it.” “Secondary tumors (lung metastasis) reappeared during consolidation phase of first treatment protocol.”
			11 (19)	“Four new osteosarcoma tumors were found and removed from [child’s] right lung, 2 more than the CT scan revealed.”
			11 (19)	“That my child’s condition was nearing her death” “Statistics do not show good prognosis for ALL patients with recurrence” “At the beginning his doctors never talked much about a prognosis, only that they expected that treatment should make it go away. Now that he’s relapsed they seem ready to give up.”
			8 (14)	“We discussed the latest CT scan having shown tumor growth”
			6 (10)	“It was explained that my child’s first round of chemo did not work” “The third treatment protocol did not stop the cancer from growing.”
	Deleterious effects of treatment	Tumor stability	2 (3)	“Test results not good. Just bad news when things still have not changed.”
			5 (8)	“Possible med changes because of renal problems”; “Left kidney function only 10%”; “[Child] hospitalized for typhilitis (bowel obstruction and infection) related to chemo”
			2 (3)	“Current treatment will involve a lot of inpatient time, so our child will miss a lot of school over the next year or so.”

AFP = alpha-fetoprotein; ALL = acute lymphoblastic leukemia; BMT = bone marrow transplant; CT = computed tomography; MIBG = metaiodobenzylguanidine.

^aIn addition to parent descriptions of “good news” conversations, this code arose from parent responses to the item “Were changes made in your child’s care based on these discussions with your child’s care team? If yes, please specify.”

parents' reports was that of child well-being—even in the face of poor or uncertain cancer control. “Although all believe that [child’s] relapsed leukemia is going to be fatal, the discussions have focused on the fact that he has been doing well and holding steady in the last month.” As such, although much of the news parents interpreted as good centered on cancer control, good news was possible even in the absence of cancer control.

Bad News. Bad news of loss or lack of cancer control also often came by way of bad test results. Bad test results were reported as indicating relapse/recurrence, tumor growth, or, at times, tumor stability: “Test results not good. Just bad news when things still haven’t changed.” Bad news discussions frequently quantified the loss of cancer control: “Four new osteosarcoma tumors were found and removed from [child’s] right lung, two more than the CT scan revealed.” In the face of losing cancer control, additional treatment options were often described as ameliorating the effect of the bad news: “MRI showed progression of tumors on topotecan. We were devastated but then had a new treatment plan ready.” Notably, additional treatment options were not always cancer directed: “Dr. did a great job discussing what they could offer to minimize pain, seizures, etc.” Apart from issues of loss/lack of cancer control, prognostic implications, and additional treatment options, bad news discussion descriptions also highlighted other losses and anticipated losses, such as deleterious effects of disease or treatment on the body and on quality of life.

Although the survey item structure encouraged parents to report on “good” news and “bad” news discussions separately, parents conveyed a sense that news could be more challenging to classify: “At this point in my child’s treatment, assessing news as ‘good’ or ‘bad’ is difficult for us. I will say, however, that all news has been delivered to us in a clear, professional, and sensitive manner, both over the phone and in clinic.” One participant articulated the ambiguity of a reduction in tumor burden (“Yes, transplant did clear most but we still have small amount to clear”), indicating that the reduction signaled both good and bad news.

Discussion

In this cross-sectional, multi-institutional survey of parents of children with advanced cancer, most parents reported discussing both good and bad news over the prior three months with their child’s medical caregivers. Much of these discussions center on “tumor talk” or cancer control: discussions of test and imaging results, whether treatment is working, and whether tumors are growing or receding. This study

is based on parent assessment of which discussions entailed “good” and “bad” news. Overall, details of parents’ reports and the apparent pattern of child outcomes support the accuracy of their perceptions. Notably, none of the parents who reported discussing only good news reported changes in their child’s care related to such discussions (Table 2). Likewise, the cumulative incidence of death was higher among children of parents who described discussing only bad news. Importantly, the descriptors “good” and “bad” were imposed by the survey items and may not have been parents’ preferred terms to characterize these discussions with their child’s care team. Indeed, parents’ descriptions of “good” and “bad” news discussions suggest that their conceptions of illness are nuanced, rather than dichotomous, which is consistent with prior reports.^{16,21}

Apart from the characterization of these conversations as “good news” and “bad news” conversations, parents’ answers suggest that these discussions are conducted in a sensitive manner, are well understood, and frequently allow for expression of and attention to parents’ hopes and worries. However, it is worth noting that approximately one-third of parents reported limited ability to express hopes and worries, suggesting that for these parents and their children, shared decision making and goal-concordant care may have been more difficult to achieve. Interestingly, children were present for most good (75%) and bad (64%) news discussions, although it is unclear whether this matched parent preferences.

From parents’ characterizations of discussions, a picture emerges of fleeting triumphs and serial setbacks, as cancer grows, is whittled away, returns, is rebuffed, and so on. This dynamic, fluid picture of ground gained and lost stands somewhat in contrast to the lexicon of “breaking bad news,” which may evoke discussions that signal a discrete, unambiguous change in the illness trajectory. Instead, parents describe a nuanced and uncertain reality of living with and caring for a child with advanced cancer, wherein even the concepts of “good” and “bad” are difficult to distinguish from one another. Understanding how parents of children with advanced cancer classify, describe, and interpret discussions with their child’s medical caregivers may enhance efforts to promote family-centered communication, with implications for training and practice. In particular, the finding that approximately one-third of parents reported incomplete abilities to express hopes and worries in the context of self-described “bad news” discussions suggests that our current approaches to discussions in advanced childhood cancer may limit parents’ agency.

Importantly, what emerges from this report is how much high-stakes communication occurs outside of

advance care planning discussions. Although prognosis was a common parent-identified theme, explicit discussions of end-of-life care and decision making, such as preferred location of death²⁶ and resuscitation status, are completely absent from parents' descriptions. Because such conversations often occur more proximate to death¹⁷ (despite recognition that earlier discussions are likely more desirable), it is quite possible that such discussions occurred after parents completed this baseline survey. At least, that would be expected based on expert recommendations,^{27–29} as such conversations are highly relevant to this group of children; at the conclusion of the PediQUEST study, 43% of children of enrolled parents who completed the survey had died, and the median time to death from survey completion was 7.3 months, although time to death ranged widely.

This study has several limitations. One methodologic limitation is in the approach to sampling. Qualitative data collection and subsequent analysis can be strengthened by the use of theoretical sampling, an approach which requires that additional sampling be possible once analysis has begun and initial categories are emerging from the data.²⁵ Due to the nature of the data (survey responses completed before the current analysis), such an approach to sampling was not possible for this study. Likewise, because parents completed written free-response items without interaction with an interviewer, there was no opportunity to probe, clarify, or build on these initial parent responses. As such, the thematic categories identified in this study, and their apparent interconnections, are less richly characterized and explored than they would be in the setting of theoretical sampling and in-depth interviews. Furthermore, asking parents to recall discussions from the preceding three months might be expected to lead to preferential recollection of "bad news" discussions, so the reported prevalence of good news and bad news discussions may reflect recall bias. However, the strengths of this study are the relatively large sample of respondents, the geographic distribution of respondents, and the high response rate.

Overall, findings suggest that both good news and bad news discussions are prevalent in the setting of advanced childhood cancer, and that these discussions are most often focused on "tumor talk" as well as child well-being. Importantly, parents describe a nuanced and uncertain reality of living with and caring for a child with advanced cancer. Central to our understanding of decision making, care quality, and quality of life for children with advanced cancer are the conceptual models of illness that children, their parents, and health care providers bring to conversations. Future work should further refine these concepts, as well as their value to parents, and explore connections

between illness conceptions, communication perceptions, and decision making among parents of children with advanced cancer.

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