

How Parents of Children With Cancer Learn About Their Children's Prognosis

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abstract

OBJECTIVES: To determine which prognostic information sources parents find informative and which are associated with better parental understanding of prognosis.

METHODS: Prospective, questionnaire-based cohort study of parents and physicians of children with cancer at 2 academic pediatric hospitals. We asked parents how they learned about prognoses and evaluated relationships between information sources and prognostic understanding, defined as accuracy versus optimism. We excluded parents with pessimistic estimates and whose children had such good prognoses that optimism relative to the physician was impossible. Analytic cohort of 256 parent-physician pairs.

RESULTS: Most parents considered explicit sources (conversations with oncologists at diagnosis, day-to-day conversations with oncologists, and conversations with nurses) “very” or “extremely” informative (73%–85%). Implicit sources (parent’s sense of how child was doing or how oncologist seemed to feel child was doing) were similarly informative (84%–87%). Twenty-seven percent (70/253) of parents reported prognostic estimates matching physicians’ estimates. Parents who valued implicit information had lower prognostic accuracy (odds ratio [OR] 0.50; 95% confidence interval 0.29–0.88), especially those who relied on a “general sense of how my child’s oncologist seems to feel my child is doing” (OR 0.47; 0.22–0.99). Parents were more likely to use implicit sources if they reported receiving high-quality prognostic information (OR 3.02; 1.41–6.43), trusted the physician (OR 2.01; 1.01–3.98), and reported high-quality physician communication (OR 1.81; 1.00–3.27).

CONCLUSIONS: Reliance on implicit sources was associated with overly-optimistic prognostic estimates. Parents who endorsed strong, trusting relationships with physicians were not protected against misinformation.

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WHAT’S KNOWN ON THIS SUBJECT: Most parents value prognostic information and prefer to hear detailed information even if it is upsetting. However, it is unknown which sources parents use to learn about their children’s prognosis and which sources support prognostic accuracy as opposed to optimism.

WHAT THIS STUDY ADDS: Most parents of children with cancer relied on explicit prognostic communication, such as conversations with oncologists, and implicit communication, such as how the oncologists seemed to feel the children were doing. Using implicit information sources was associated with prognostic optimism.

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Parents of children with cancer say they want to understand their children's prognosis,¹ yet many are more optimistic about their children's chances of cure than their physicians.²⁻⁴ Although reasonable optimism can be adaptive, unrealistic expectations can inhibit informed decision-making and negatively impact children.⁵ Physicians bear some responsibility for this excessive optimism. One study found that most parents believed their children's physicians to be more optimistic about prognosis than they themselves were. Physicians, however, reported a significantly more pessimistic outlook.² Previous work has also found similar discordance between parents and oncologists regarding prognosis and goals of care for children with advanced cancer.^{3,4} Studies in adults have further demonstrated that many physicians explicitly and intentionally communicate overly optimistic prognostic estimates.⁶ Another study found that physicians seldom discussed scan results or prognosis, instead focusing on treatments.⁷ Prognostic communication is especially important because parents often seek the support of physicians and nurses in making decisions,⁸ and they often view being informed as integral to fulfilling the role of a good parent.⁹

However, explicit, factual statements are not the only means of communicating a prognosis. Physicians can convey optimism indirectly or implicitly in several ways: qualifying prognostic discussions with optimistic statements,¹⁰ avoiding discussions of prognosis unless directly asked,^{11,12} focusing conversations on the response to treatment rather than the chance of cure, or colluding in a so-called recovery plot that allows patients and physicians to avoid or delay open acknowledgment of the prognosis.¹³ Although these communication behaviors are likely

rooted in sympathy for the painful situation of patients and parents, they may prevent parents from developing realistic expectations, thus hindering their ability to make truly informed decisions.

Importantly, parents have access to multiple information sources, ranging from discussions with nurses and doctors to conversations with family and friends and their own personal awareness. Some information sources, such as the Internet, may raise concerns about veracity. Other sources, such as communication with nurses and physicians, may reassure providers that parents are receiving high-quality, accurate information. Few researchers have investigated which prognostic information sources parents find most informative or how individual sources might affect parental prognostic understanding.¹⁴ One study showed that parents who find personal intuition to be informative seem less likely to have accurate prognostic estimates, suggesting that some information sources may inhibit, rather than support, parental understanding.²

In this study, we investigated parental sources of prognostic information and examined which sources were associated with accurate parental knowledge of prognosis, as opposed to optimism. We focused on prognostic optimism by eliminating parents who were pessimistic or whose children's prognoses were so good as to preclude the possibility of optimism because our own and others' previous work have demonstrated that parental optimism is the predominant direction of discrepancy between physicians and parents.^{2,4} Given the evidence that physicians may convey optimism indirectly, we were specifically interested in understanding the role of implicit sources of prognostic information in supporting or hindering parental understanding.

METHODS

Patients

As described previously,¹⁵ we surveyed parents and physicians of children with cancer at the Dana-Farber Cancer Institute and Boston Children's Hospital (Boston, Massachusetts) and Children's Hospital of Philadelphia (Pennsylvania) between November 2008 and April 2014. One parent per family was eligible if these criteria were met: he or she was able to read English or Spanish, the child was 18 years or younger, it was 1 to 6 weeks from the cancer diagnosis at first contact, and the child's oncologist permitted the contact. We asked the parent who was primarily responsible for decision-making to participate. If parents equally shared decision-making roles, they chose which 1 participated. Parents received \$10 gift cards after completing each questionnaire. Primary oncologists were given physician surveys and \$5 gift cards.

Of 565 eligible parents, 382 (68%) completed the baseline questionnaire. Ninety-five physicians completed matched surveys for 361 parents (95%), 353 of whom completed the question on prognostic information sources. Our questionnaire did not ascertain how physicians developed prognostic understanding. We evaluated which information sources were associated with parental prognostic accuracy, which is defined as parent-physician agreement about the likelihood of cure relative to parental optimism. Using a previously described approach,² we limited our sample to 256 parent-physician pairs by sequentially excluding parents who were pessimistic relative to the physicians ($N = 22$), parents who knew they held more optimistic beliefs than the physicians (parental report that an oncologist was "much more" or "somewhat more pessimistic than I am" about

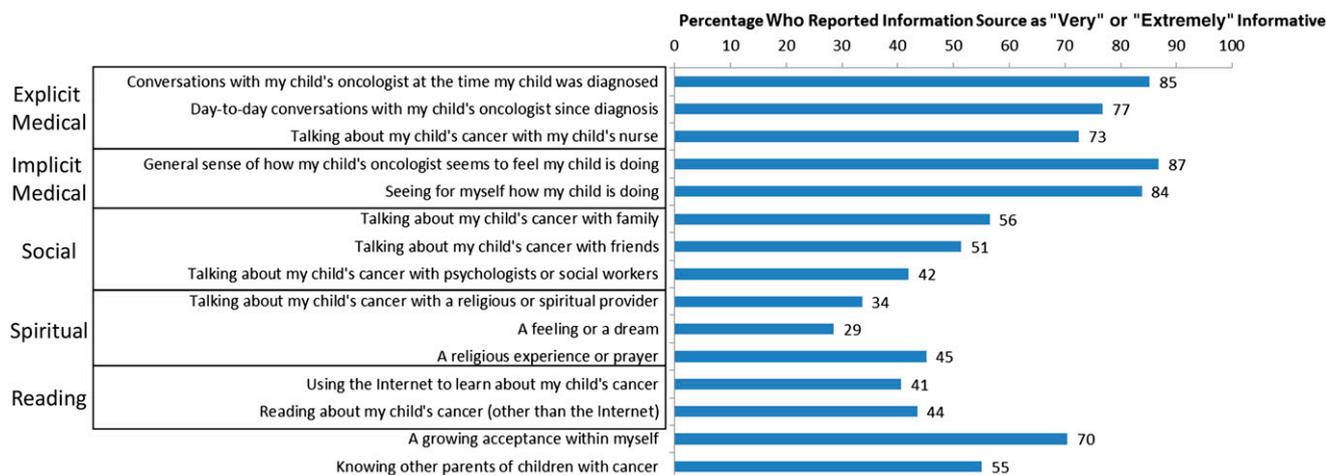


FIGURE 1 Parents' perceived value of information sources for prognostic understanding.

prognosis, $N = 14$), and parents whose children had such good prognoses that optimism relative to physicians was not possible (>90% likelihood of cure as designated by a physician, $N = 61$).

Data Collection

Survey development was previously described.¹⁵ Briefly, parent and physician questionnaires included items from previously developed surveys,^{1,2} select new items (which were subjected to pilot testing with parents for clarity and face validity before use), and items from existing validated instruments. Questionnaires were available in paper-and-pencil or electronic format and in English or Spanish.

The primary outcome was parental understanding of the likelihood of cure. Parents and physicians were each asked, "How likely do you now think it is that [your/this] child will be cured of cancer?" with response categories of "extremely likely (more than 90% chance of cure)," "very likely (75%–90%)," "moderately likely (50%–74%)," "somewhat likely (25%–49%)," "unlikely (10%–24%)," "very unlikely (<10%)," and "no chance of cure."^{2,16,17} Parental understanding of the likelihood of cure was defined as an exact agreement between parent

and physician reports. We included the following sentence in questions regarding cure to frame the concept for participants: "This information might include the likelihood that your child will be cured of cancer or the length of life that your child is expected to have."

Primary predictors of interest were parental sources of prognostic information. Parents were asked, "How informative has each of the following been in your current understanding of your child's likelihood of cure?" with response categories of "extremely," "very," "somewhat," "only a little," and "not at all." Possible information sources included explicit medical communication, with individual items addressing conversations with the oncologist at diagnosis, day-to-day conversations with the oncologist and conversations with nurses; implicit medical information, including seeing how the child is doing and a general sense of how the oncologist seems to feel the child is doing, both of which were new items for this survey; social, including conversations with psychologists or social workers, with friends, and with family; reading, including reading and the Internet; and spiritual sources, including a religious experience or prayer, a feeling or dream, and

conversations with religious or spiritual providers. The full text of the questions are provided in Fig 1. This question was developed through cognitive interviews with parents and focused on clarity, understanding of key concepts, and the cognitive process behind answers.

Questionnaires asked parents their sex, age, race, ethnicity, and highest level of education. Child age and diagnosis were determined by using medical records. Questionnaires also asked questions regarding the perceived quality of communication,^{2,18} perceived quality of prognostic information,² and trust in the physician¹⁹ by using previously developed and validated scales. Hopefulness of parents was assessed by asking, "How hopeful would you say you feel in general?" with responses of "not at all," "a little," "somewhat," "very," and "extremely." The institutional review boards of the Dana–Farber Cancer Institute and Children's Hospital of Philadelphia approved this study.

Statistical Analysis

Principal factor analysis was used to combine individual questions about sources of prognostic information into related factors. Factors with eigenvalues >1 were retained, and an oblique rotation was determined

(the SAS PROMAX procedure [SAS Institute, Inc, Cary, NC]). Factors that emerged from this analysis included a parental reliance on explicit medical communication (Cronbach's $\alpha = 0.63$), implicit medical information (Cronbach's $\alpha = 0.76$), social information (Cronbach's $\alpha = 0.87$), reading (Cronbach's $\alpha = 0.64$), and spiritual information (Cronbach's $\alpha = 0.80$). Question responses for information sources, perceived information quality, and perceived communication quality were summed and then dichotomized at the sample median for analysis. Other variables using Likert scales were dichotomized as specified in the tables and text. We used bivariable logistic regression to evaluate associations between information sources and prognostic accuracy. We evaluated associations between information sources and prognostic accuracy after adjusting for clustering by physician.

We then evaluated relationships between parent and/or child attributes and information sources by focusing on the use of implicit prognostic information sources as a variable of interest given our a priori interest in implicit communication. After evaluating bivariable relationships by using logistic regression, we used a backward-elimination technique to create a multivariable logistic regression model of factors associated with the use of implicit information (criteria for entry, $P = .10$; criteria for retention, $P = .05$). Models included physician-rated prognosis, parent race and/or ethnicity, parent education, and site regardless of significance. Similar bivariable analyses and multivariable models were developed for exploratory purposes by using the individual implicit information sources ("Seeing for myself how my child is doing" and "A general sense of how my child's oncologist seems to feel my child is doing"). Analyses were conducted by

using SAS statistical package version 9.4.

RESULTS

Participating parents were predominantly women (82%), white (79%), and well educated (Table 1). Physicians generally reported favorable prognoses for children in this cohort, with more than half of the children rated as having at least a 75% likelihood of cure at baseline. Most physician respondents were attending physicians ($N = 69$; completed 221 surveys from our sample); fellows participated if attending physicians were unavailable ($N = 26$; completed 35 surveys from our sample).

Information Sources

Parents used a range of sources for information about their children's prognoses. Explicit information sources included conversations with the oncologist at diagnosis (considered "extremely" or "very" informative by 85% of participants; 218 of 256), day-to-day conversations with the oncologist since diagnosis (77%; 195 of 254), and conversations with nurses (73%; 182 of 251). Implicit information sources included how the oncologist seems to feel the child is doing (considered "extremely" or "very" informative by 87% of participants; 218 of 251) and "seeing for myself" how the child is doing (84%; 212 of 253) (Fig 1). Smaller absolute numbers of parents considered social sources, spiritual sources, and reading and the Internet to be highly informative.

Association of Valued Information Sources With Prognostic Accuracy

Overall, 73% (183 of 253) of parents were more optimistic about prognosis than their children's physicians; 27% of parents had prognostic estimates that accurately matched their physicians' estimates.

TABLE 1 Patient and Parent Characteristics

Characteristics	N (%)
Parent age, y	
<30	27 (11)
30–39	100 (40)
40–49	97 (38)
≥50	28 (11)
Parent sex	
Female	208 (82)
Male	46 (18)
Parent race and/or ethnicity	
White	201 (79)
African American	18 (7)
Hispanic	17 (7)
Other	18 (7)
Parent education (1 missing)	
High school graduate or less	30 (12)
Some college	57 (23)
College graduate or technical school	97 (38)
Graduate or professional school	67 (27)
Parent marital status	
Married or living as married	210 (82)
Other	46 (18)
Child age at diagnosis, y	
0–2	58 (23)
3–6	56 (22)
7–12	70 (27)
13–18	72 (28)
Child sex	
Male	138 (54)
Female	117 (46)
Diagnosis	
Hematologic malignancy	137 (54)
Solid tumor	87 (34)
Brain tumor	32 (13)
Physician-rated prognosis	
Extremely likely (>90% chance of cure)	Excluded
Very likely (75%–90% chance of cure)	136 (53)
Moderately likely (50%–74% chance of cure)	67 (26)
Less than moderately likely (<50% chance of cure)	53 (21)
Site	
Boston	188 (73)
Philadelphia	68 (27)

Parents who valued implicit and spiritual sources of prognostic information were less accurate in their prognostic estimates compared with their oncologists (implicit sources odds ratio [OR] 0.50; 95% confidence interval [CI] 0.29–0.88; spiritual sources OR 0.47; 95% CI 0.26–0.85; Table 2). Valuing other sources of prognostic information was not associated with prognostic accuracy, including explicit medical

communication about prognosis (OR 0.71; 95% CI 0.40–1.27). After adjusting for physician training level (fellow versus attending), associations between information sources and accuracy remained similar (results not shown).

We next evaluated individual information sources that composed the implicit category. “Seeing for myself how my child is doing” was not associated with decreased prognostic accuracy (OR 0.93; 95% CI 0.44–1.94). However, parents who valued a “general sense of how my child’s oncologist seems to feel my child is doing” had decreased prognostic accuracy (OR 0.47; 95% CI 0.22–0.99). For exploratory purposes, we also adjusted for clustering by physician and found directionally similar ORs (Supplemental Table 4).

Factors Associated With the Use of Implicit Sources

In a multivariable model and after adjustment for prognosis, parents were more likely to value implicit prognostic information sources if they reported receiving high-quality prognostic information (OR 3.02; 95% CI 1.41–6.43), feeling hopeful in general (OR 3.45; 95% CI 1.17–10.14), trusting the physician “completely” (OR 2.01; 95% CI 1.01–3.98), and that the physician’s communication style was of high quality (OR 1.81; 95% CI 1.00–3.27) (Table 3).

We further analyzed parents who valued a “general sense of how my child’s oncologist seems to feel my child is doing.” These parents were more likely to have reported satisfaction with the extent of prognostic disclosure (OR 8.04; 95% CI 3.29–19.64) as well as trust in the physician (OR 4.13; 95% CI 1.69–10.10).

DISCUSSION

Parents of pediatric patients with cancer value many different sources

TABLE 2 Association Between Information Sources and Prognostic Accuracy of Parents

Importance of Information Source	OR Accuracy ^a	95% CI
Parent considers explicit medical information to be important to understanding of prognosis	0.71	0.40–1.27
Parent considers explicit medical information to be less important to understanding of prognosis	Ref	
Parent considers implicit medical information to be important to understanding of prognosis	0.50	0.29–0.88
Parent considers implicit medical information to be less important to understanding of prognosis	Ref	
Parent considers social sources to be important to understanding of prognosis	0.66	0.38–1.17
Parent considers social sources to be less important to understanding of prognosis	Ref	
Parent considers spiritual sources to be important to understanding of prognosis	0.47	0.26–0.85
Parent considers spiritual sources to be less important to understanding of prognosis	Ref	
Parent considers reading and/or the Internet to be important to understanding of prognosis	1.27	0.69–2.31
Parent considers reading and/or the Internet to be less important to understanding of prognosis	Ref	

Accuracy is defined as an agreement between parent and physician reports of a prognosis relative to optimism. We excluded parents who were pessimistic relative to physicians, parents who knew they were optimistic relative to physicians, and parents who were in the best prognostic category as reported by the physician such that optimism was not possible. *N* = 256.

^a ORs indicate the odds of an exact agreement between parent and physician ratings of a child’s likelihood of cure relative to a lack of an exact agreement. Because we excluded parents who were pessimistic relative to physicians, a lack of an exact agreement indicates parental optimism, which is defined as a parent rating of a child’s likelihood of cure that is higher than the physician’s rating.

TABLE 3 Factors Associated With the Use of Implicit Medical Information Sources, Multivariable Logistic Regression

Factor	OR for Use of Implicit Medical Information ^a	95% CI
Parent marital status		1.11–6.56
Married or living as married	Ref	
Other	2.70	
Parent reported high quality of prognostic information	3.02	1.41–6.43
Parent reported lower quality of prognostic information	Ref	
Parent considers self to be “extremely” or “very” hopeful	3.45	1.17–10.14
Parent considers self to be “somewhat,” “a little,” or “not at all” hopeful	Ref	
Parent trusts the physician “completely”	2.01	1.01–3.98
Parent trusts the physician “mostly,” “somewhat,” “a little,” or “not at all”	Ref	
Parent reported high-quality communication style	1.81	1.00–3.27
Parent reported lower-quality communication style	Ref	

Backward elimination was with entry criteria of *P* < .10 and retention criteria of *P* < .05. We adjusted for parent race, parent education, child prognosis, and site regardless of significance.

^a ORs indicate the odds that a parent considered implicit medical information to be important to understanding a prognosis relative to parents who considered implicit medical information less important.

of prognostic information; however, the vast majority in this study found implicit and explicit prognostic sources to be the most informative. It is expected that explicit prognostic sources are viewed as informative because data and objective facts are the native language of medicine.

However, it is somewhat surprising that parents who valued explicit prognostic information were no more accurate in prognosis compared with those who did not. This calls into question the types of facts that physicians are presenting and the manner in which they are

communicated. For example, some physicians may say that a child is “doing very well” with tolerating chemotherapy, but parents may glean prognostic information from these statements.

It was also surprising that the majority of parents valued implicit information sources, and these parents were more likely to demonstrate prognostic optimism compared with their oncologists. This association seemed to be specific to “a general sense of how my child’s oncologist seems to feel my child is doing.” We assume that pediatric oncologists intend to communicate truthfully with parents. Therefore, our results suggest that parents are also interpreting the physicians’ implicit verbal and nonverbal cues rather than solely the physicians’ explicitly factual statements. In keeping with previous studies in adults, this misinterpretation may be a result of a physician’s vague statements, nonverbal cues, or emphasis on treatment response rather than prognosis.^{6,11–13}

Alternatively, parents may conflate discussions of how their children are doing in the moment with expectations of long-term outcomes.

Perhaps most disconcerting was our finding that parents who valued implicit sources also endorsed signs of a strong and trusting relationship with their pediatric oncologists. This suggests that parents who have a strong relationship with their pediatric oncologists are more likely to value their opinions and are perhaps at greater risk of misinterpreting or overinterpreting their physicians’ optimistic signals. On the basis of our results, 1 potential model of prognostic miscommunication would entail the following: parents and pediatric oncologists develop a trusting relationship in which the physicians offer reassuring cues regarding prognosis, and parents are satisfied with the physicians’ apparent

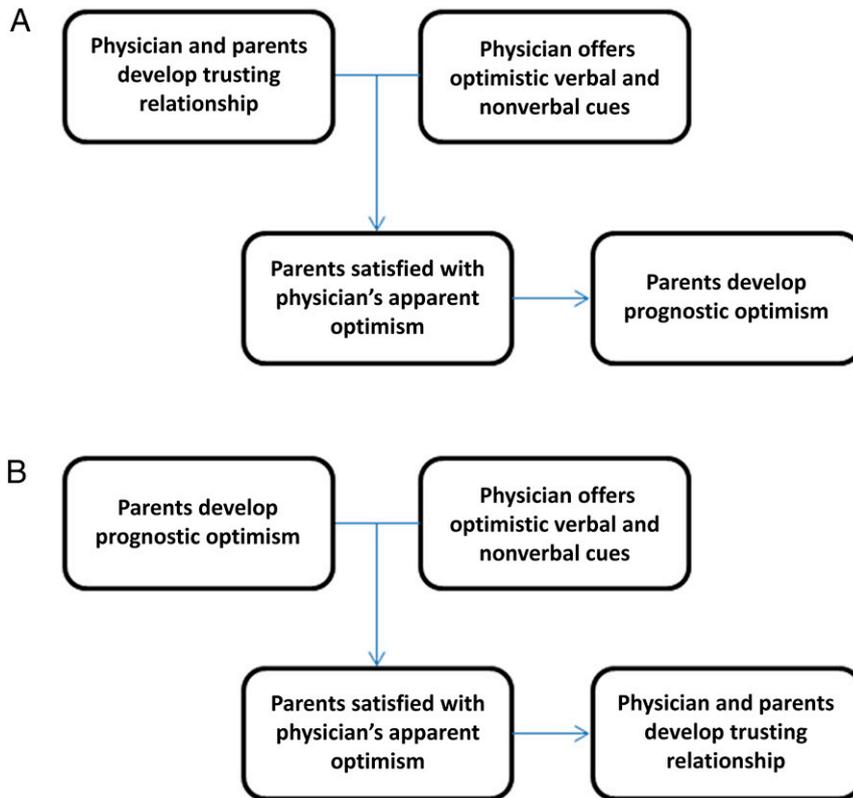


FIGURE 2

Bidirectional model of parental information sources and prognostic accuracy. A, Prognostic optimism as the outcome. B, Prognostic optimism as a causative factor.

optimism, which either reinforces or leads parents to develop prognostic optimism (Fig 2A). Such a model would help explain the previously reported disconnect between physician and parental prognostic estimations.^{2–4}

Yet, this model could go in the opposite direction (Fig 2B). It is equally possible that parents develop a higher regard for their physicians when optimistic information is conveyed. This possibility is supported by Tanco et al,²⁰ who found that patients perceived a higher level of compassion and preferred physicians who offered a more optimistic message. Similarly, Weeks et al²¹ found that adult patients with lung and colorectal cancer were more likely to have prognostic optimism if they rated communication with their physicians favorably. The authors suggested, “Physicians may be able to improve

patients’ understanding, but this may come at the cost of patients’ satisfaction with them.” Our proposed model may be bidirectional, depending on the context and the particular physician-parent relationship. Future researchers should seek to elucidate this complex interaction.

To combat prognostic misinformation, we recommend that physicians continue incorporating factual prognostic information into their disclosure conversations over time while maintaining an awareness of their use of optimistic qualifying statements. Physicians should also be aware that pessimistic statements may help to bring parents closer to the truth.¹⁰ When such statements are used, the goal is not to lay crepe but to honestly yet empathically communicate vital information. However, overly emphasizing pessimism can be perceived as

less compassionate and can lead to a sense of hitting them over the head with bad news.^{20,22} Care must be taken to find an appropriate balance of optimistic and pessimistic communication strategies. Finally, given our finding that valuing explicit prognostic information was not associated with prognostic accuracy, we recommend checking parental understanding, which can help physicians identify misconceptions. Physicians should house this exchange of information within a framework that takes into account the children's and parents' hopes, fears, and perceived duties. The onus is on the physician to take additional steps to ensure that parents are receiving the message they are intending to send.

These results should be interpreted in light of limitations in our study. First, communication in pediatric oncology is a multidisciplinary effort, and other members of the care team may have provided optimistic reassurance to parents. However, our results have shown that physician input is highly regarded by most parents, suggesting that physician interactions play an important role in parental perceptions of prognosis. Also, parents who valued implicit

information in this study described themselves as inherently hopeful. Therefore, these parents may have been predisposed to interpret physician communication in a way that reinforced optimism.

Participation bias is a potential concern in this study. Patients with brain tumors (and to a lesser extent, solid tumors) were underrepresented in this study, raising concern for lower participation among parents of children with poorer prognoses. Racial and/or ethnic minorities and less educated parents were also slightly underrepresented, and 12 patients were not included in the study because their physicians precluded contact. Additionally, this study was performed at 2 highly specialized centers. Therefore, our results may not generalize to all parents. In addition, our study included all pediatric cancers rather than focusing on advanced cancer. Although prognostic communication may be more impactful in advanced cancer, we previously found that all parents consider prognostic information to be important and relevant to decision-making regardless of prognosis.^{1,23} Lastly, without video or audio recordings

of these prognostic conversations, we cannot verify our suppositions about the content of prognostic communication.

CONCLUSIONS

The parent-physician relationship is rightly considered to be a vital component of support for families as they move through the illness experience. Our results show that parents greatly value the input of their children's oncologists. However, parents who trust their physicians will likely believe what their physicians communicate, both verbally and nonverbally. If a physician tries to comfort a parent with vague or optimistic gestures, parents may develop excessive prognostic optimism. Having a strong and trusting relationship is not enough to protect against misinformation and, in fact, may make the communication of prognostic information more challenging.

ABBREVIATIONS

CI: confidence interval
OR: odds ratio

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