

Parental Hope for Children With Advanced Cancer

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abstract

BACKGROUND: Previous work suggests that parents of children with cancer can remain hopeful despite receiving prognostic information, but we know little about what hope means to such parents, or the extent to which parents can feel hopeful even while facing the child's impending death.

METHODS: We audiotaped conversations between clinicians and parents of 32 children with relapsed or refractory cancer, and then interviewed parents about their hopes and expectations for their child.

RESULTS: Parent statements about prognosis in interviews mirrored those made by clinicians during discussions about the child's diagnosis with refractory or relapsed cancer. Clinicians used language referring to hope during these conversations but did not ask parents directly about their hopes. Parents expressed a range of hopes for their children, from hopes related to cure or treatment response, to quality of life, normalcy, and love and relationships for the child. For most parents, expectations about prognosis were not aligned with their hopes for the child; for example, many parents hoped for a cure and also reported that they did not believe cure was possible. Many parents were able to acknowledge this incongruence.

CONCLUSIONS: Parents accurately conveyed the reality of their child's serious condition in the setting of advanced cancer, and yet maintained hope. Hopes were not limited to hope for cure/treatment response. Clinicians should be encouraged to engage in direct conversations about hope with parents as a means to elicit realistic hopes that can help to focus the most meaningful plans for the child and family.

WHAT'S KNOWN ON THIS SUBJECT: Although physicians worry that communicating about prognosis or life-threatening illness can take away hope, previous work suggests that prognosis communication may even enhance hope. The nature of hopes held by parents of children with advanced cancer was not previously understood.

WHAT THIS STUDY ADDS: Parents in our study frequently recognized their child's poor prognosis, yet held many different hopes, including for cure, quality of life, and meaningful relationships. Parents who hoped for cure often recognized that this was not possible for their child.

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Hope in oncology has been historically linked to a favorable prognosis and/or cure.¹⁻³ Given this very narrow definition, the disclosure of prognostic information, particularly when felt to be grim, becomes especially challenging for the clinician^{1,4,5} and is often perceived as being in opposition to hope.^{3,6,7} Yet work in other pediatric populations suggests that hope is not necessarily incompatible with an understanding of a poor prognosis^{8,9}; instead, open and forthright dialogue around prognosis, even and especially when there is little chance of cure, preserves patient autonomy and allows for choices at the end of life that are consistent with personal values.^{6,10-13}

The physician's desire to preserve hope remains central to the ongoing provider-patient relationship.^{3,5,14} This is poignantly exemplified during discussions about prognosis between the clinician and parent of a child with relapsed or refractory cancer. We and others have previously reported that communication about prognosis can preserve, or even enhance, hope.¹⁵⁻¹⁷ However, whether and how hope can coexist with a realistic understanding of a child's poor prognosis remains incompletely understood, along with the nature of hopes held by parents with this knowledge.

To address these questions, we audiotaped conversations between parents and physicians about the child's diagnosis of relapsed or refractory cancer. We then interviewed parents about their hopes and expectations. Through these real-time conversations and interviews, we examine how a realistic understanding of the child's medical condition can coexist with hope. We delve into the nature of these hopes and suggest ways that physicians can foster hope through and beyond the prognostic dialogue.

METHODS

Study Population

The study was conducted at the Dana-Farber Cancer Institute and Boston

Children's Hospital (Boston, MA), from February 2010 to October 2013. English-speaking parents of children younger than age 18 with advanced cancer that had recurred or was refractory to first-line therapy were eligible if they had a planned meeting with the child's oncologist to discuss this diagnosis. Parents were eligible irrespective of whether the child received primary oncology care at our center or came for a second opinion. Parents of children with a first relapse of acute lymphoblastic leukemia were ineligible, given higher possibility of cure.

We first contacted the oncologist for permission to approach the parent and to ensure the parent was aware of the context of the conversation to be recorded. We aimed to approach parents after they knew the child possibly/definitely had relapsed or refractory cancer, but before a full conversation about the implications took place. Parents were invited to participate in person or by phone; written informed consent was required of all participating parents and clinicians.

One parent primarily responsible for decision-making for the child was eligible for participation in an interview conducted within 6 weeks of the audiotaped conversation.

One year after interview completion, medical records were reviewed to determine outcomes including survival.

A total of 44 (56%) of 79 eligible parents agreed to participate. Thirty-six conversations were audiotaped; the remaining conversations were not captured for logistical reasons. Thirty-two audiotaped parent interviews were subsequently performed; 3 parents could not be reached within the 6-week interview window, and 1 interview was conducted but not recorded because of equipment failure. Participating parents were not significantly different from nonparticipants or

those whose conversations could not be captured with respect to child gender, age, or diagnosis. Twenty-seven clinicians participated in the 32 discussions analyzed. All conversations included at least 1 physician; 3 nurse practitioners also participated.

Data Collection

Conversations between parents, clinicians, and children were audiotaped and transcribed in their entirety. No special constraints were placed on location, content, or participating members of discussions. Study staff members were not present for parent-clinician conversations, but came before and after to place and remove recorders. No conversations were observed directly, limiting capture of nonverbal cues. Care was taken to transcribe verbal emphasis and evidence of emotion (eg, laughter, crying).

After audiotaping and transcription of parent-clinician discussions, parents were contacted to take part in a semistructured interview. These were conducted in person or by phone per parent preference, audiotaped, and transcribed in full. Questions were open-ended, initially focused on parents' expectations for the child's future and their hopes for their child. Interviewers then probed for additional hopes: "Sometimes people have many different hopes. Are there other things you are hoping for?" Interviewers asked parents how they remained hopeful while living with their child's cancer diagnosis, and whether their hopes and expectations differed. Additional questions focused on physician communication and its impact on their hopes.

The institutional review board of the Dana-Farber Cancer Institute approved this study.

Analysis

Directed content analysis was used to analyze parent-clinician discussions and parent interviews.¹⁸⁻²¹ Before

analysis, transcripts were reviewed with audiotapes to confirm accuracy. Analysis was performed using ETHNOGRAPH software (Qualis Research, Colorado Springs, CO). Transcripts were first read through for content familiarity and to isolate broad themes. The texts were then subjected to systematic coding by using a detailed scheme based on hypotheses and questions of interest. Major categories of codes for transcribed parent-clinician discussions focused on aspects of clinician communication, including discussions about treatment and treatment-related side effects; whether the clinician recommended a particular treatment option; whether and how prognosis was addressed; and any discussion about parents' and clinicians' hopes and goals of care. Major code categories in parent interviews focused on parents' understanding of prognosis and expectations for the future, the array of hopes described by parents, whether parents described hopes and expectations as aligned or different, and parent perspectives on clinician communication. Further analysis then focused on relationships between coded elements; for example, whether parent recognition of a poor prognosis coexisted with hopes for cure, or whether hopes for cure coexisted with hopes for palliation. Relationships between content elements were displayed in matrices to facilitate understanding of interrelationships between disparate elements.

Two authors (JN and JWM) reviewed and coded all transcripts; 2 other authors (MO and TN) coded select transcripts and helped develop the coding scheme. After development of an initial coding scheme, coding was performed independently and researchers reviewed codes together, using consensus to arrive at final code assignment but also using differences of opinion as an indicator that the coding scheme required clarification.²² After expansion and clarification of codes when needed,

the coding scheme was finalized. We then continued independent coding and group review and evaluated interrater reliability on 10 consecutive transcripts.²³ All codes except 1 had interrater reliability ≥ 0.80 ; 1 code had suboptimal interrater reliability of 0.56 and was not included in the final analysis.

RESULTS

Demographics

Children of participating parents had a median age of 10.1 years (Table 1). Fourteen children (44%) presented for a second opinion, the remainder for primary oncology care. Eighty-four percent of children were present for conversations with physicians, in part (28%) or for the entire conversation (56%). One year after the audiotaped discussions, 11 children had died, whereas 10 were known to be living. Vital status was unknown for 11 children who received second opinions without further care at our center.

Parent-Clinician Discussions

In audiotaped parent-clinician conversations, most (28/32, 88%)

included at least 1 statement about the child's prognosis. More than half (17/32, 53%) offered information about likelihood of cure, including statements that the cancer was incurable ($n = 5$, 16%) or that cure was unlikely ($n = 9$, 28%). More than half of clinicians ($n = 18$, 56%) discussed prognosis in terms of treatment response, but often without stating the meaning of that response, such as whether response translated to possible cure. Finally, many clinicians (18/32, 56%) used nonspecific statements to convey worry, including "we are running out of options" or "I think we are not in a very good situation." In 8 conversations (25%), nonspecific statements were the only prognostic statements.

Discussion about treatment options and potential side effects predominated. Most clinicians presented 1 or more treatment options ($n = 30$, 94%), along with a recommendation ($n = 25$, 78%). Several clinicians ($n = 8$, 25%) suggested that parents should choose the option that fit their goals ("One thing that is really important is for you and he to be clear about what you

TABLE 1 Participating Children and Parents

Characteristic	Value
Child characteristics	
Age at enrollment, y, median (range)	10.1 (2.5–17.5)
Female gender, n (%)	11 (34)
Diagnosis n (%)	
Solid tumor	18 (56)
Brain tumor	12 (38)
Hematologic malignancy	2 (6)
Vital status 1 year after interview n (%)	
Living	10 (31)
Dead	11 (34)
Unknown (second opinion without additional follow-up)	11 (34)
Parent characteristics n (%)	
Female gender	26 (81)
White, non-Hispanic	24 (75)
Visit characteristics	
Primary or second opinion n (%)	
Primary oncology care	18 (56)
Second opinion	14 (44)
Child's presence during discussion with physician n (%)	
Present during entire discussion	18 (56)
Present during part of discussion	9 (28)
Present for none of discussion	5 (16)

guys want the most”), although no clinicians asked parents directly about their values or goals for care. Although clinicians often used language referring to their own personal hopes during conversations ($n = 18, 56\%$; “I really do hope this may be the treatment that keeps his tumor stable or shrinks it for a very, very long time”), they did not ask parents directly about their hopes. The content of these conversations did not differ significantly whether the child was receiving primary oncology care or a second opinion, and we found no notable differences in content when the child was present versus absent.

Parental Expectations

When interviewed afterward, parents often made statements about prognosis mirroring those made by clinicians. After 11 conversations in which physicians said the cancer was incurable or chances of cure were remote, 8 parents (73%) made similar statements. Five additional parents made such statements despite the absence of these statements by clinicians in the recorded conversation. Of 8 clinician conversations in which the only prognostic statements conveyed

nonspecific worry, 6 parents (75%) made nonspecific statements of concern as their only expression of prognosis. Similarly, when physician statements focused on treatment, parent statements usually did also (6/9 conversations in which treatment response was the main way of discussing prognosis, 67%). Overall, 8 parents reported that the child’s cancer was incurable (25%); 4 stated that they expected the child to die (13%); and 9 reported a remote chance of cure (28%).

Parental Hopes

Despite concerns about prognosis, parents expressed a range of hopes for their children (Table 2), with a median of 7 distinct hopes per parent (range 2–10). When first asked about their hopes, most parents focused on outcomes of cancer treatment. Almost all parents, including those who recognized that the cancer was incurable or terminal, hoped that the child would be cured (28/32, 88%). Many parents also hoped for a long life ($n = 21, 66\%$) and that the cancer would respond to treatment, resulting in tumor shrinkage or stability ($n = 15, 47\%$), life prolongation ($n = 12, 38\%$), or other aspects of treatment response,

many of which were nonspecific ($n = 25, 78\%$; “a great response” or “treatment that works”).

Parents reported broader hopes focused on the child’s well-being, especially after interviewers probed for additional hopes. These included hopes for quality of life ($n = 30, 94\%$) and minimal suffering ($n = 24, 75\%$). Most parents ($n = 28, 88\%$) hoped that their child could live a normal life: “just a long, happy, not special life, but just a regular kid.” Two-thirds of parents ($n = 21, 66\%$) reported hoping that the child would feel loved and have good relationships. Many parents also hoped for others in the family, especially siblings ($n = 9, 28\%$), and for better treatment of future children with cancer ($n = 8, 25\%$). All but 1 parent expressed both disease-directed and non-disease-directed hopes ($n = 31, 97\%$).

Hopes Versus Expectations

Nearly three-quarters of parents ($n = 23, 72\%$) acknowledged that their hopes differed from their expectations of what was likely to happen. Taken together, disparate statements during interviews were sometimes striking, ranging from focus on a miracle to planning for death; select examples are shown in Table 3.

TABLE 2 Range of Hopes Held by Parents of Children With Advanced Cancer

Hope	Parents Who Reported This Hope, n (%)	Example
Prognosis/treatment-related		
Cure	28 (88)	-I am hoping that he is going to get cured.
Treatment response: other or nonspecific statements	25 (78)	-I think just hopeful that, you know, the treatment will be effective.
A long life	21 (66)	-But my hope is that he will live to adulthood. He will grow up.
Treatment response: cancer stability or decrease	15 (47)	-To find something to slow it down and buy us some time.
Treatment response: life prolongation	12 (38)	-We hope that this hospital will help [child] live longer a little bit you know. That is the reason we came in here for.
Alternative, nontreatment-focused		
Quality of life	30 (94)	-I want her to be happy and healthy and enjoy her life and whatever she wants to do with it.
Normalcy	28 (88)	-Right now I just want her to be healthy like a normal kid. Be a human being, you know, and do all the thing[s], you know, that a kid do[es]. We want her to be healthy and act like normal children.
Minimal suffering	24 (75)	-The least pain and, you know, the least suffering through that.
Love and relationships for the child	21 (66)	-He will marry somebody that he loves. They will one way or another have children. And, um, have a happy life.
Hope for others in the family	9 (28)	-Um, he has a twin sister, so I want him to still be there for his twin sister.
Hope for future research and/or better treatment of children in the future	8 (25)	-I hope that they can find a cure for this cancer. I hope that they continue doing research.

Parents described several ways of balancing hopes with more difficult expectations. Some described cognitive dissonance: "Statistically things are not in our favor, so we just play the mental game of pushing it away." Another parent stated, "My husband and I are realistic. We know, you know, the options of what could happen but we have to for our own sanity remain hopeful." Others found humor in their hopes for what seemed impossible, even laughing as they described hopes for a cure or miraculous recovery. Some parents expressed wistfulness: "I am hoping to see him graduate from high school and get married and someday have children. I mean, that would be the ultimate." Finally, some focused on finding hope in the present moment: "We are at the, you know, the end-of-life situation" but "we just look at our day-to-day stuff so we are very hopeful every day." Another parent similarly said, "We can still enjoy a lot of daily activities that he enjoys... so that just brings about its own atmosphere of hope."

DISCUSSION

In considering hope among parents of children with advanced cancer, one might worry that parents who remain hopeful cannot possibly understand the reality of their child's situation. Our findings strongly contradicted this view. Instead, we found that parents listened carefully to clinicians' words about prognosis, often offering similar or even more explicit statements about a child's poor prognosis. Yet they remained hopeful. Many parents acknowledged this apparent contradiction directly: they were hopeful, and also recognized a difficult, different reality.

Despite parents' hopefulness, clinicians rarely engaged in conversation about hope. Instead, clinicians focused conversations on treatment and treatment-related side effects. This is understandable. If treatment is the currency of the oncologist-patient relationship,²⁴ then offering treatment may be a way of continuing to take care

of patients and affirming the relationship even as disease progresses. It is important to recognize that conversations about treatment likely met the preferences of many parents, especially those seeking second opinions. In addition, clinicians may feel that having conversations about hope is a delicate issue. Many of the clinicians were conscientious about conveying honest information, no matter how difficult. If clinicians view hope as representing false hopes for a cure, they may worry that engaging in discussions about hope can be misleading. Yet we were also struck by the richness of the content of parent interviews. The 2 sets of transcripts (clinician-parent discussions and parent interviews) were strikingly disconnected in their content. Thus, we wondered whether clinicians might be able to bring the 2 conversations together, giving time to both hope and reality.

Previous work supports the idea that parents can understand a difficult prognosis, yet remain hopeful.^{8,9,16} Previous work also suggests that the nature of hope can shift over time.⁸ Although we did not capture change over time, we did find that parents held multiple simultaneous meanings for hope, some of which were conflicting. This finding is consistent with work by Feudtner,¹ who proposes understanding a "breadth of hopes" by asking parents what they are hoping for, and then what else they are hoping for, until they have described their full range of hopes. We used a similar interview technique, and found that parents were able to report hopes for many things, some possible, some impossible. When first asked about their hopes, most parents initially discussed hopes for treatment outcomes, including cure. Thus, if one were to stop there, one might indeed feel that conversations are focused on false hopes. Yet with additional questioning, hopes arose that were possible: quality of life, limited suffering, love. Perhaps Feudtner's¹ most critical recommendation, then, is to keep asking: "and what else are you hoping for?"

One might also wonder, what is the role of such conversations? Why ask parents to detail their hopes, when so many will never be? We would suggest that conversation about hopes, even impossible ones, can be a doorway toward talking about what is possible. Back et al²⁵ have proposed that physicians can use conversation about hope to help patients prepare for the future. Possible hopes, as opposed to less likely hopes, may be used to focus plans of care for the child, and to address informational, social, or affective needs, but only if clinicians are willing to engage in these conversations.

To allow parents to fully understand the nature of the study, we sought consent during a delicate window: after learning about a child's relapse, but before participating in a full conversation about plans for care. This timing was clearly stressful, and many parents declined to participate. These conversations were also logistically challenging to capture, and in some situations we were unable to record the relevant discussion. No conversations were observed directly despite the importance of nonverbal cues.

Parents who enrolled may have been those most able to process difficult information about relapse and engage in conversations about hope. However, all of the enrolled parents were able to hold these conversations, and most distinguished hope from reality, suggesting that many parents would be able to do so in a wider population. In addition, we captured only a single conversation, while discussions likely evolved over time. For second opinion patients, however, the recorded conversation typically represented the whole parent-physician discussion at our center, and no major differences were seen between these and conversations involving primary oncology patients.

Also of note, although many children had poor prognoses and have died since study inception, some are alive still, and some potentially cured. We

TABLE 3 Concurrent Yet Often Incongruent Hopes and Expectations Held by Parents: Select Examples

Parent 1. He is expected to pass. I hope, you know, that he can be a miracle child. I just hope that he can live longer. I just want the tumor to go away. [I hope] that I can have good memories with him. Just to lead a normal, happy life. That is my goal for him, you know? And to be loved. I know what is going to happen. You know what I mean? But... yeah, I still have those hopes.	Parent 2. They are telling me that this is going to be quite complicated. So this is going to be bad. I am hoping that this is going to work but I am feeling in my heart that it is not. Well I am hoping that he is going to get cured and live a normal life. I am hoping that he is going to get better and become a police officer. [I hope that] he can live a normal life like a normal [age] year-old. I want to get him through this treatment as easy as possible. I want him to feel as comfortable as possible. I got to keep trying to look for a bright side. Saying that, you know, he is going to get better and fulfill his dreams. To be quite honest, I don't see this working out.	Parent 3. What I expect for [child] is that this won't go away. There will always be something. It's not a curable situation. I hope that it is going to be cured. I am always hoping that she survives this and I am wrong and everyone is wrong and this thing will go away. My goal is to get her to be an adult, to get her into being, um, no longer being a child. [I hope] that the disease stabilizes and she has, you know, a normal life like everyone else with the least impact on her. You hope that your child is going to be, um, healthy. [I hope my child can] make it through this stuff as whole as possible and have a normal life. The least pain and, you know, the least suffering through that.	Parent 4. I understand that his illness is terminal and that there is no cure. I already knew that, from when he was first diagnosed, that if it did come back after the first initial treatment, that there was no cure. I'm hoping for a cure while he's going through treatment, but I know that's kind of a long shot. I hope that somewhere while he's going through treatment, they do find a cure, but I know the reality of that is pretty slim. They told me when he was first on the treatment they told me that the cancer responded great and he responded great, so it's hopeful that we'll have the same results this time around. [I hope] just for as much time as possible, and to have him as healthy as possible for as long as possible. [I am hoping to] find a treatment that works. [I hope that] he can still be a normal [age] year old. [I hope] just that it gets better and stops giving him problems so that he can enjoy his life. [I hope he can] live many years happily and as healthy as possible, without having too many effects on the quality of life.	Parent 5. The reality is there is no cure for [cancer type] relapse. I know that the prognosis with a relapse is very, very difficult. I know that the relapse is a different situation. It is a lot more difficult to do but he can do it. I am just banking on that we are going to get positive results and that is all I can do because I can't think of the negative. I hope that we are getting to get rid of everything, you know, no evidence of disease and I expect that there will be no future occurrences of cancer. I am hoping that he is going to live a full life. I am hoping to see him graduate from high school and get married and someday have children. I mean that would be the ultimate. I mean I want to see him grow up. I want to see him live long enough to grow up and become an adult.	Parent 6. It is not supposed to cure him. I feel like it would be a miracle if he did go into remission. I hope that it is going to go away but in reality... I hope that he lives a long life [laughs]. My goal is that he goes into remission and that he stays there. Right now at this point we are just hoping that whatever we are doing is going to work. [I hope he can have] a normal life. That he could travel. That he could go to school. My goal is to make him happy every day.
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Each section includes statements made by a single parent during the course of an interview illustrating the range of coexisting hopes and expectations.

identified eligible children based on a probable poor prognosis, but could not predict this with certainty. This	reflects the clinical reality for many children and parents; uncertainty about the future is common, and these	parents, too, must live with the possibility of a difficult future. Children also were present in many
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conversations; their presence likely affected the tenor of discussions, particularly about difficult prognoses, even though we did not detect major differences. However, questions about hopes, goals, and values may be appropriate to every conversation, whether children are present or not, and even in the setting of clinical uncertainty.

Finally, although parents could distinguish hope and reality, not every parent was at peace with that distinction. They held hopes that

differed from reality because they wanted their children's lives to continue, and that created real struggle. Parents who openly spoke about denial as a way to live through this time exemplified that issue. Although a few parents seemed to find a way to transcend this issue, highlighted by the parent who spoke about a daily "atmosphere of hope," many did not. Thus, we should remember that a conversation about hope does not mask the pain of this situation; instead, it may unmask it. Yet parents appear to

be experiencing these struggles whether clinicians address them or not. Opening the conversation to hope may be one way for clinicians to join parents, and the children they love, through these times.

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Parental Hope for Children With Advanced Cancer

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