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Emotional Communication in Advanced Pediatric Cancer Conversations

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Abstract

Context: Cancer is a life-changing diagnosis accompanied by significant emotional distress, especially for children with advanced disease. However, the content and processes of discussing emotion in advanced pediatric cancer remain unknown.

Objectives: To describe the initiation, response, and content of emotional communication in advanced pediatric cancer.

Methods: We audio-recorded 35 outpatient consultations between oncologists and families of children whose cancer recently progressed. We coded conversations based on Verona Coding Definitions of Emotional Sequences (VR-CoDES).

Results: Ninety-one percent of conversations contained emotional cues, and 40% contained explicit emotional concerns. Parents and clinicians equally initiated cues (parents: 48%, 183/385; clinicians: 49%) and concerns (parents: 51%; clinicians: 49%). Children initiated 3% of cues and no explicit concerns. Emotional content was most commonly related to physical aspects of cancer/treatment (28% of cues/concerns, present in 80% of conversations) and prognosis (27% of cues/concerns, present in 60% of conversations). Clinicians mostly responded to emotional cues and concerns implicitly, without specifically naming the emotion (85%). Back channeling (using minimal prompts or words that encourage further disclosure, e.g. “uh-huh”) was the most common implicit response that provided space for emotional disclosure (32% of all responses). Information-advise was the most common implicit response that reduced space for further emotional disclosure (28%).

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Conclusion: Emotional communication in advanced pediatric cancer appears to be a subtle process where parents offer hints and clinicians respond with non-emotion laden statements. Also, children were seldom engaged in emotional conversations. Clinicians should aim to create an environment that allows families to express emotional distress if/when ready.

Keywords

Communication; Emotion; Physician-Patient Relationship; Supportive Care; Psychosocial Oncology

Introduction

Cancer is a life-changing diagnosis accompanied by significant emotional distress, especially for patients with advanced disease.(1) In adult oncology, most patients prefer that clinicians respond to their emotional distress with sensitive, acknowledging, and supportive statements that allow space for further disclosure.(2) Additionally, effective responses to emotional distress have been associated with decreased patient anxiety and depression(3) and higher ratings of communication quality.(4) Yet many clinicians in adult oncology miss these opportunities to engage with their patients' emotions, responding only infrequently with empathic or open language.(2, 5)

In part, this finding might be explained by difficulties clinicians have in identifying emotional cues, especially when patients express their emotions implicitly.(6) At times, for example, patients might only hint at their emotional distress through non-verbal mannerisms.(7) Even when clinicians recognize the need to address emotions, however, deficiencies persist. For example, one study found that 75% of cancer clinicians reported that they thought it was important to engage their patients about emotional distress and 50% reported that they actually had discussed emotions during a clinical encounter. However, audio-recordings showed that emotions were only discussed in 27% of these encounters.(8) Beyond these challenges, some clinicians might avoid these discussions because they feel uncomfortable with the emotional content.

In pediatric oncology, few studies have directly analyzed the communication of emotional content. This small body of literature suggests that pediatric oncologists are more likely to discuss medical information than emotions,(9–12) often deferring emotional discussions to nurses.(9) Similarly, most nurses and families considered emotional support to be a central nursing role,(13–15) and nurses were more likely to use emotional language than pediatric oncologists.(9) However, few of these studies evaluated audio-recorded conversations. Instead, they relied on the clinician's or family's recall after conversations occurred. While retrospective recall from interviews or surveys can provide useful information, data derived from these methods are subject to recall bias. Additionally, "the data derived from post hoc interviews are filtered through the lens of the listener and thereby provide an incomplete view of the communication that transpired."(16) Audio-recorded conversations offer concrete evidence of communication behaviors and interactions.

These studies have also generally focused on initial treatment rather than advanced disease. Understanding emotional communication in advanced disease is particularly important

because these conversations focus on life, death, and quality of life, often balancing hope for cure with more achievable hopes. This shifting of focus from treatment and survival to symptom management and redefining goals can lead to anxiety, anger, sadness, and frustration about the limitations of currently available treatments. Additionally, clinicians in pediatric oncology can experience emotional angst when a patient's disease progresses, which in turn can inhibit their emotional engagement with families. To engage in these discussions well necessitates an openness to the heavy emotional content, which might be challenging for some clinicians. Furthermore, it is unclear whether children are included in these emotional conversations between parents and clinicians. In keeping with the United Nations Convention on the Rights of the Child(17) and the American Academy of Pediatrics policy on the importance of children's assent and involvement in care,(18) children should be engaged in a manner that fits their unique needs.

To characterize the disclosure of and responses to negative or unpleasant emotional content in pediatric oncology, we audio-recorded 35 clinical conversations between clinicians and families of children with progressive or relapsed cancer. By analyzing the roles of each individual in these interactions and assessing the emotional content, we are able to characterize emotional disclosures and responses in pediatric oncology, highlighting areas with potential for improvement.

Methods

Participants and Recruitment

This study was conducted as part of a larger study examining clinician-parent communication regarding children with poor prognoses at the Dana-Farber Cancer Institute and Boston Children's Hospital (Boston, MA) from February 2010 to October 2013.(19, 20) 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. An interpreter is present in 1 recording because the father spoke English, but the mother did not. Parents were eligible irrespective of whether the child received primary oncology care at this center or presented for a second opinion. In the larger study, parents of children with a first relapse of acute lymphoblastic leukemia were ineligible because of higher possibility of cure. All parents provided written informed consent, and all children older than 10 years provided assent and were given an information sheet that explained the study. All parents and children were aware of probable disease relapse or progression prior to these recorded conversations.

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 or 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. A total of 44 (56%) of 79 eligible parents agreed to participate. Thirty-five conversations were audio-recorded; the remaining conversations were not captured due to timing and availability of staff.

Data Collection

Conversations between clinicians, parents, and children were audio-recorded and transcribed in their entirety. Study staff members came before and after encounters to place and remove audio-recorders; however, they were not present during the conversations. Study authors did not participate in the placement of the audio-recording equipment or in the conversations with families. Transcripts also used study ID numbers for all participants rather than names to minimize bias of coders. Care was taken to transcribe verbal emphasis and evidence of emotion (e.g., laughter, crying). The institutional review board of the Dana-Farber Cancer Institute approved this study.

Data Analysis

The coding framework for the transcripts was developed in two parts. Our primary aim was to identify parent or patient expressions of emotional distress in medical consultations using the Verona Coding Definitions of Emotional Sequences (VR-CoDES), a consensus-based, validated coding framework for identifying negative emotional cues and concerns. VR-CoDES is rooted in a “patient-centered and biopsychosocial model of healthcare consultations,” and has been studied in pediatric and adult populations.(6, 21) According to VR-CoDES, a cue is defined as a verbal or non-verbal hint that suggests an underlying unpleasant emotion but lacks clarity. A concern is defined as a clear and unambiguous expression of an unpleasant current or recent emotion that is explicitly verbalized with or without a stated issue of importance.(22) VR-CoDES was not designed to assess positive or pleasant emotional cues.

Furthermore, VR-CoDES designates all cues and concerns as elicited by either the healthcare provider or the patient. This manual defines healthcare provider-elicited cues and concerns as follows: “The expression of cues and concerns solicited, explored, or facilitated by the health provider (health provider-elicited), are an indicator of the space given to patients to explicate their concerns (they are expected to do so) without patient needing to break ‘rules’ or take initiatives.”(22) This manual further defines patient-elicited cues and concerns as follows: “The expression of patient-elicited cues and concerns is an indicator of patient’s initiative or active struggle to direct health provider’s attention to specific worries.” (22) For the purposes of this study, we modified “patient-elicited” to include “child-initiated” and “parent-initiated” cues and concerns. We changed “elicited” to “initiated” to indicate that the parent or child was actively introducing emotional content into the discussion. However, we opted to use “clinician-elicited” in order to emphasize that parents and children were responding to a prompt from the clinician.

Two authors (BAS and ABF) reviewed and coded all transcripts independently to identify emotional cues and concerns. Independent coding of the interviews and comparison of coding assured both credibility and dependability of the coding process. These two authors reconciled all differences through discussion. The authors were able to reach consensus on all codes. Once all cues and concerns had been identified, two authors (BAS and ABF) coded each transcript for the provider response to these emotional cues and concerns, using the VR-CoDES framework to identify whether a response was implicit or explicit and whether it provided space for further emotional discussion or reduced space. By definition in

the VR-CoDES framework, every emotional cue/concern has a response, even if the response is ignoring. However, in some encounters, parents disclosed multiple cues or concerns before the clinician was able to respond. For example, a mother might state an emotional cue, to which a father adds an additional cue, and then the mother follows with a concern, all before the clinician responds. In these scenarios, we only coded one clinician response to the string of cues/concerns. As such, the total number of cues/concerns does not equal the total number of responses. For more detail regarding VR-CoDES definitions, see supplemental table S1.

Next, this deductive coding was supplemented by exploratory inductive coding to determine the content of the cues and concerns. See supplemental table S2 for coding definitions. Using an iterative coding process, two authors (BAS and ABF) developed a codebook for content that was subsequently agreed upon by all authors. Using this codebook, these same two authors identified specific content areas of emotional cues and concerns through independent coding. These authors each coded all transcripts and reconciled any differences through discussion between the coders.

Results

Participant Characteristics

We analyzed 35 clinical encounters that involved 35 consenting parents for whom we also collected sociodemographic data, but some encounters also included additional parents or relatives. Additionally, these encounters included 30 children, along with 34 physicians, 6 nurses, 5 nurse practitioners, and 1 psychologist. Participating parents were predominantly white (77%) and female (83%). Participating children were predominantly male (69%) with a median age of 10.3 years. The most common diagnoses were solid tumors (54%, 19/35) or brain tumors (40%, 14/35), with only a small minority of children diagnosed with hematologic malignancy (6%, 2/35). Children were present for portions of the majority of clinical encounters (26/35 present for full clinical encounter, 4/35 present for part of clinical encounter). Of these 4 children who were only present for part of the encounter, 2 children requested to leave the room and 2 children left at the suggestion of their mothers. The median age of the 5 children who were not present was 7.3 years, ranging from 3.3 to 12.6 years, which was comparable to the median age (10.3 years) and range of ages (2.5 to 17.5 years) of children who were present. These 5 encounters without children present included a median of 3 cues/concerns per encounter, ranging from 0 to 18. The 30 encounters in which children were partially or fully present included a median of 9 cues/concerns per encounter, ranging from 0 to 40. For the majority of conversations, the clinical team was the primary oncology team for the family (60%, 21/35). For the remaining 40% (14/35), the family was meeting the clinical team to pursue a second opinion. (Table 1) Encounters with the primary oncology team contained a median of 9 cues/concerns per encounter, ranging from 0 to 40. Encounters without a prior relationship contained a median of 8.5 cues/concerns per encounter, ranging from 0 to 26.

Emotional Cues and Concerns

The vast majority of conversations contained at least 1 emotional cue (91%, 32/35), with a median of 7 cues, ranging from 0 to 36 cues per conversation. In total, we identified 385 total emotional cues in all audio-recorded conversations. In evaluating who initiated discussion of these cues, we found that parents initiated 48% of cues (183/385) and clinicians elicited 49% of cues (189/385). Only 20% of children initiated any emotional cues (6/30 children present during encounters). The median age of these children was 13.9 years (range 10.0 to 17.5 years), compared to a median age of 9.2 years (range 2.5 to 17.5 years) for children who did not initiate emotional cues. These cues initiated by children comprised 3% of all cues (13/385).

Explicit emotional concerns were less frequently expressed in these conversations, with 40% of conversations (14/35) containing no explicit concerns. Conversations contained a median of 1 concern, ranging from 0 to 10 concerns per conversation. In total, we identified 59 explicit emotional concerns in all conversations. Parents initiated and clinicians elicited about half of these concerns (51%, 30/59 for parents, and 49%, 29/59 for clinicians). Children did not initiate any explicit emotional concerns. (Table 2)

Emotional Content

These clinical encounters contained a median of 3 different types of emotional content per conversation, ranging from 0 to 6 types of content. The most common emotional content was related to physical aspects of cancer and its treatment (28% of all cues/concerns, and present in 80% of conversations). Some physical cues/concerns related to treatments or interventions: “The thought of having flipped her over and doing three or four more hours of surgery and putting her through that...” [Father] Others focused on side effects or inconveniences of the treatment. For example, “Well after the first round he had gotten very sick and I said, you know, well are you going to change the dosing and they said I don’t know. And I was like ok.” [Mother] Additionally, some parents worried about uncertainty related to experimental therapies: “He was the first patient. Um, so it was pretty scary and intense.” [Mother]

The second most common emotional content was related to prognosis (27% of cues/concerns, and present in 60% of conversations). Some of these cues/concerns mentioned the possibility of death specifically: “Does anyone survive this?” [Mother] Other cues/concerns referred to death indirectly: “Is this the worst tumor that a person can have in the brain?” [Mother]

The remaining cues/concerns were related to healthcare systems or providers (20% of cues/concerns, and present in 43% of conversations), emotional well-being (16% of cues/concerns, and present in 49% of conversations), and social issues (5% of cues/concerns, and present in 17% of conversations). The content of a small minority of cues/concerns was ambiguous (4% of cues/concerns, and present in 31% of conversations). Of these ambiguous codes, 88% (15/17) were too vague to define. For example, one father commented, “I need to go out and get some air.” In another encounter, a mother began crying and stated, “He is a good kid.” For the remaining 12% (2/17), the clinician interrupted the child or parent before

they fully described the emotional content. For example, a father stated, “I got that feeling from the beginning that we were kind of...” However, the clinician redirected the conversation before the father completed his thought, and we were unable to determine the emotional content. See Table 3 for additional examples of excerpts.

Responses to Emotion

The vast majority of emotional cues/concerns were responded to by physicians (87%, 357/409), followed by nurses (10%, 40/409) and psychologists (3%, 12/409). Most of these responses were implicit (85%, 348/409). Additionally, the majority of these responses were coded as providing space (60%, 244/409) rather than reducing space. Notably, the total number of responses to emotion (409) was not equal to the total number of cues/concerns (444) because mothers and fathers often listed a string of cues/concerns in sequence before the clinician was able to respond.

Implicit-Providing Space: Back channeling was the most common implicit response that provided space for emotional disclosure (32% of all codes, 132/409). Back channeling refers to the clinician’s use of minimal prompts or words (but not complete statements) that encourage further disclosure. This response took several related forms: “right”, “yeah”, “ok”, “mmmhmm”, and “yup.” Acknowledging was the second most common implicit response that provided space (8%, 31/409); for example, one physician told a mother, “Yeah, that wasn’t too fun at all.” [Physician speaking to mother] Implicit empathy and active invitation were seldom employed (3%, 21/409 and 1%, 4/409, respectively). (Table 4)

Implicit-Reducing Space: Information-advise was the most common implicit response that reduced space for further emotional disclosure (28%, 114/409), for example, “You know, you guys should keep on doing what you are doing and doing your research, but we have a pretty good idea of what is going around the country and, you know, give our opinion about it...” [Physician speaking to father] Clinicians seldom ignored (10%, 42/409) or shut down (1%, 4/409) emotional disclosure.

Explicit-Providing Space: Exploring content was the most common explicit response that provided space (7%, 30/409). For example, one child with a rare cancer commented, “I just don’t understand how people cannot take this cancer that seriously. I mean there is a lot of other research going on for other types of cancer and this cancer is like kind of put off to the side.” The physician responded by asking, “Have you been reading things that make you feel like [your disease has] been ignored [by the medical community] or where does that sense of...” [Physician speaking to child] The second most common explicit response that provided space was acknowledging content (4%, 18/409): “Yup. Now you just kind of suppressed the florid reaction but you just get all this vague stuff.” [Physician speaking to mother] Other explicit responses that specifically named the emotion and provided space were only utilized 1% of the time.

Explicit-Reducing Space: Switching was the only explicit response employed that reduced space for emotional disclosure. For example, one mother stated, “Like if he is having anxiety attack of something, I just can’t stand there and watch him be panicked. That

is my concern.” [Mother] The physician responded by saying, “Yeah. Let me let [other doctor] answer because the truth is she has treated all of the patients with [treatment], um, and they are kind of in their own category.” [Physician speaking to mother] Clinicians utilized this approach in 1% (5/409) of coded responses.

Discussion

Responding to a family’s emotional distress can challenge the most well-meaning clinicians, especially when emotional disclosures are subtle or vague. In our analysis of these 35 clinical conversations about advanced pediatric cancer, we identified four main findings that can inform the clinician’s approach to emotional content in clinical encounters.

First, we found that the vast majority of emotional distress was expressed through subtle cues. Parents seldom stated their emotional concern explicitly to the clinicians, and children never stated explicit concerns. Instead, families demonstrated their underlying concerns by hinting at troubling content without clearly naming a specific emotion. This was true whether the clinician elicited the emotional content or the parent or child actively initiated the discussion. Similarly, clinicians seldom explicitly named the emotion that families were expressing or hinting at. The most common responses were non-specific continuing statements (e.g. mmhmm, yeah, etc.) or informative statements. While providing information is an essential aspect of communication, this might not be the best response to emotional distress. Such an approach might lead to incorrect assumptions or bypassing of emotions, neither of which supports a healing relationship. Instead, clinicians might benefit their patients and parents by explicitly asking about the family’s emotional status, seeking to explore and normalize emotional reactions.

Back and colleagues have proposed the NURSE mnemonic to guide responses to emotional cues: **N**ame the emotion, **U**nderstand the core message, **R**espect/reassurance at the right time, **S**upport, and **E**xplore emotional content and context.(23) The NURSE approach can be especially useful when the emotional content is vague or unclear, as was often the case in the conversations we evaluated. While this approach was developed for seriously ill adult patients, these lessons likely translate to pediatrics. Pediatric patients and families might benefit if clinicians suppress the inclination to provide more information, and instead ask open-ended questions to explore emotional content. Such actions empower the parent and/or child to determine how much they want to disclose or discuss, while also further opening dialogue and avoiding misinterpretation of subtle cues. For example, a clinician might say, “It seems like this information is causing some anxiety and worry for you, which is totally normal and expected. I want you to know that our whole team is here to help your family through this tough period, and we want to help in any way that we can. How is all this stuff affecting you guys?”

Importantly, previous work has shown that parents and children often take steps to protect each other, leading at times to mutual pretense.(24) For some families, this response can be adaptive and emotional discussions should not be forced. But for other families, acknowledging and exploring emotional content can provide space for the family to work

through some of these challenging issues. By asking questions and empowering patients and parents, the clinical team can follow their lead to identify and support their needs.

Secondly, despite being present in most clinical encounters, children were seldom engaged in discussions of emotion. While it is possible that none of these children desired greater engagement of their emotions, we must recognize that many hierarchical and cultural barriers exist in these sensitive encounters. In order to allow children to engage to the extent that they want or need, clinicians should take steps to create an environment in which it is easy for children to discuss their emotional concerns. This might include providing patients with one-on-one time with their doctor or nurse, explicitly asking the child about their emotions, or paying keen attention to subtle cues that might indicate an underlying emotional concern. For some children, these subtle cues might be the only transient hints they offer to their underlying emotional state, and these openings for further exploration might only last for a short time. Furthermore, the approach taken by clinicians must adapt to the unique developmental level and emotional needs of each young patient. For example, some children may prefer not to verbalize their emotional distress, instead opting to express their emotions through artwork, music, or other media. Alternatively, some children may simply desire quiet presence rather than emotional conversations.

Third, the content of emotional distress was most commonly related to physical aspects of the cancer and its treatment, followed by worries about prognosis. While it is obvious that considering a child's death will evoke emotional distress, it might be less obvious that side effects and toxicities are similarly concerning to parents. Clinicians should be aware that some discussions of physical aspects of treatment with parents might be emotional cues disguised as technical discussions, especially if the parent raises the same concern repeatedly. As such, clinicians should consider answering some questions from parents with another question, rather than providing a technical answer. For example, imagine a parent repeats for the third time, "Wow, so he's going to need around the clock nausea medicine?" Perhaps the clinician should resist the urge to answer this question and instead ask, "Are you worried about his nausea?" This would allow the parents an opening for further emotional disclosure, but it does not force them to engage. If they respond that they are not worried, but just want to be prepared, then the clinician can provide the information they asked for, knowing that he/she has not ignored or bypassed an important emotional cue.

Notably, the conversations in our study were long and often focused on discussing extensive information about treatment options and potential toxicities. Clinicians might have felt pressured to cover all this material during one clinical visit, and parents might have been focused on information aspects themselves. However, responding to emotion is not necessarily time intensive. For example, one study found that providing empathic responses to emotional distress only prolonged visits by 21 seconds on average.⁽⁵⁾ By "leaning in" to these emotional discussions, clinicians stand to benefit patients, parents, and likely themselves. Additionally, some families might be unable to process technical information fully if they have not addressed their emotional distress. Furthermore, none of these conversations included clinicians from palliative care teams. Incorporating palliative care teams into these encounters could lend additional support to families and oncologists as they navigate these challenging discussions.

This study, however, should be interpreted in light of its limitations. First, we only examined distressing emotions, and therefore cannot describe positive emotional content of these conversations. Furthermore, individual perception is central to evaluating emotion. As such, future work should incorporate interviews or surveys to assess for satisfaction with emotional communication. Also, the Hawthorne effect could have affected emotional communication in these encounters if participants communicated differently because they knew they were being recorded. Future studies might limit this effect by longitudinally recording conversations to normalize the recording process.

We also studied only 35 families, and we recorded only one conversation per family. However, discussions about relapsed or progressive disease are inherently laden with emotions, so many of our findings likely apply to other emotionally-intense encounters. Additionally, some of these encounters were between families and clinicians who had previously developed a relationship, while other encounters were second opinions where the family was meeting the clinical team for the first time. The differences between these relationships could have affected communication about emotions. Also, only 56% of parents we approached were willing to participate, creating the potential for selection bias. Lastly, this cohort of parents was highly educated, which might affect generalizability of results. Further study of emotional communication in more diverse pediatric populations is warranted. Additionally, we restricted our analysis of emotion to parents/step-parents, patients, and clinicians in order to focus on the primary discussions that occurred in these encounters. This excluded analysis of communication from 4 grandparents, although their presence could have affected the emotional communication. Lastly, we utilized audio-recordings and were unable to assess for non-verbal emotional cues (except audible crying). This limitation might have impeded our ability to assess for children's emotional communication, since children might rely on non-verbal cues rather than explicit concerns to express their emotions.

Emotional communication in pediatric oncology appears to be a subtle process where parents offer hints to their underlying emotional concerns, and clinicians respond largely by offering vague statements or providing technical information. Children seem to be engaged infrequently in these discussions, instead appearing as observers to the clinician-parent discussions. More work is needed to determine how to best support clinicians in responding more explicitly and openly to the concerns of these children and their parents.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations:

CE clinician-elicited

PI parent/child initiated

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Key Message

This article describes the analysis of emotional discussion in 35 recorded clinical encounters relating to advanced pediatric cancer. The results indicate that emotional communication in pediatric oncology is a subtle process where parents offer hints and clinicians respond with non-emotion laden statements. Children are seldom engaged.

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Table 1.

Participant and Encounter Characteristics

Participant Characteristics	VALUE
Child characteristics	
Age at enrollment (median, range)	10.3 years (2.5–17.5 years)
Female gender, n (%)	11 (31%)
Diagnosis	
Solid tumor, n (%)	19 (54%)
Brain tumor, n (%)	14 (40%)
Hematologic malignancy, n (%)	2 (6%)
Vital status one year after recording	
Living, n (%)	12 (34%)
Dead, n (%)	12 (34%)
Unknown (second opinion without further follow-up), n (%)	11 (31%)
Parent characteristics	
Female gender	29 (83%)
White, non-Hispanic	27 (77%)
Encounter Characteristics	
Length of Conversations	
Mean (Standard Deviation)	71 minutes (29 minutes)
Range	16 to 123 minutes
Primary or second opinion	
Primary oncology care, n (%)	21 (60%)
Second opinion, n (%)	14 (40%)
Number of participants in encounter	
3	8 (23)
4	12 (34)
5+	15 (43)
Number of encounters that included participants	
Family	
Parent/Step-parent	35 (100)
Child	30 (86)
Grandparent(s)	4 (11)
Sibling	1 (3)
Clinicians	
Physician	34 (97)
Nurse	6 (17)
Nurse Practitioner	5 (14)
Psychologist	2 (6)
Interpreter	1 (3)

Table 2.

Characteristics of Cues and Concerns

Cues	Number of Codes (%)	Example
Parent-initiated Cue	183 (48)	<u>Father</u> : See I am kicking myself in the ass because [medication] was available at the time.
Child-initiated Cue	13 (3)	<u>Child</u> : Are you guys sure this is going to work?
Clinician-elicited Cue	189 (49)	<u>Physician</u> : I think, you know, it's your child and I don't know if you can ever have a comfort level with this but you have to be comfortable with your decisions and since there is not a right answer, it is hard. <u>Mother</u> : I think that is like the worst part about this, the hardest part.
Concerns	Number of Codes (%)	Example
Parent-initiated Concern	30 (51)	<u>Mother</u> : It is not even the cancer that kills them, you know, and I worry about that. I mean he was so sick and that was frightening and I think about all that stuff like is there something they can do that won't make him so sick. You know?
Child-initiated Concern	0 (0)	N/A
Clinician-elicited Concern	29 (49)	<u>Physician</u> : That's the pro and con of that. As you guys are learning, we like to pretend things are black and white. In real life and even in medicine, they aren't. From whether this is a tumor or not, to what is the best way to take it out, there is a lot of gray. So that's the first big piece, the news from yesterday, is concern that there is a little piece left... <u>Mother</u> : That's always been one of my concerns, if someone else were to look at this would they see something different, because our team has been looking at this for five years.

Table 3.

Content of Cues/Concerns

Content of Cue/Concern	Total Number of Codes (%)	Number of Encounters with Content (%)	Example
Physical	123 (28)	28 (80)	<u>Physician</u> : And is he taking any medicine? <u>Mother</u> : Nope. <u>Physician</u> : Ok. <u>*Mother</u> : Yeah. At first I was nervous because he looks green and tired but then he had that sickness.
Prognosis	118 (27)	21 (60)	<u>Physician</u> : We do this treatment plan a lot, so people will know what to do. <u>Mother</u> : Ok. <u>*Father</u> : So historically for you guys, I have to know, you haven't really had any success for relapsed [cancer], have you?
Healthcare Systems or Providers	91 (20)	15 (43)	<u>Physician</u> : I don't know. I think the MIBG gives you a good general. <u>*Father</u> : The CAT scan people are miserable, hate them... They just have no bedside manner. They are not being accommodating to him. No matter what he says, they really don't care.
Emotional Well-being	73 (16)	17 (49)	<u>Father</u> : Or are they really strict on... <u>Physician</u> : You mean... <u>Father</u> : Like reaching over the partitions. <u>*Mother</u> : Like if he is having anxiety attack of something, I just can't stand there and watch him be panicked. That is my concern.
Social	22 (5)	6 (17)	<u>Physician</u> : [Dad's name] you have alluded a couple of times about the stuff that you are going through and it would just help me to know even generally what those things are. <u>*Father</u> : Um, financially, I am...I wouldn't say destroyed but I am in the hole and, um, personal stuff that she has demonstrated now and it is really overwhelming to take it on by yourself.
Ambiguous	17 (4)	11 (31)	<u>Physician</u> : So I heard that things have been challenging? A little bit? <u>*Mother</u> : Nothing is ever straightforward, is it?

* Indicates the conversational turn coded as an emotional cue or concerns. The preceding turns are included to provide context to the cue/concern.

Table 4.

Response Characteristics

Type of response	Number of Codes (%)	Example
Implicit-Providing Space		
Back Channel	132 (32)	<u>Mother</u> : And I just felt like I was the one running all the care. <u>Physician</u> : Right.
Acknowledge	31 (8)	<u>Father</u> : Well, at this point in time, we're assuming, everything we're seeing, there's a chance of really bad stuff happening, we know that. <u>Physician</u> : Yeah, I don't mean to beat it in.
Implicit Empathy	21 (3)	<u>Father</u> : And I don't have the huge support that other people have. <u>Physician</u> : I am sorry to hear that you have all this going on. It feels like there is a lot weighing on your shoulders.
Active Invitation	4 (1)	<u>Father</u> : Plus all the other stuff that we are going through and this on top of it. <u>Physician</u> : [Father's name] you have alluded a couple of times about the stuff that you are going through and it would just help me to know even generally what those things are.
Implicit-Reducing Space		
Information-Advise	114 (28)	<u>Father</u> : That is part of the lack of understanding that we have about this that I think has raised our level of concern is while everyone doesn't seem to be doing a good job talking to each other, is this thing just exploding inside of her? <u>Physician</u> : Yeah. I really don't think that it is. We will take a quick look at her but she looks great and that marrow wasn't done very long ago.
Ignore	42 (10)	<u>Father</u> : Well if you're nervous, then I am nervous about the whole thing. <u>Physician</u> : And then I think the radiation we talked about a little bit last time.
Shutting Down	4 (1)	<u>Child</u> : [Starts crying.] No. <u>Psychologist</u> : [Child], Listen to [Doctor] because she has got to explain something. Listen.
Explicit-Providing Space		
Explore Content	30 (7)	<u>Mother</u> : I mean we talk about it time to time. I think he just tries to enjoy the days that he has. He just wants to do fun stuff and kind of use diversion as a way to kind of not think about it... <u>Physician</u> : Is he aware that he could die as well? Has he thought about that or is he more focused on his arm?
Acknowledge Content	18 (4)	<u>Mother</u> : It is just hard just not knowing how you are going to feel. That's all. It is a big day. I don't know. <u>Physician</u> : I mean the other... yeah, it is hard to predict...
Explore Affect	5 (1)	<u>Child</u> : No. I was just upset. <u>Physician</u> : You were just upset. About what?
Empathy	2 (<1)	<u>Child</u> : I don't know. I was just sad. <u>Physician</u> : You were sad? I am sorry...
Acknowledge Affect	1 (<1)	<u>Mother</u> : We were all scared to death. <u>Nurse</u> : I mean it is still...please I am not downplaying it. It is very scary.
Explicit-Reducing Space		
Switching	5 (1)	<u>Father</u> : That is part of like the past 6 months of things that are like just her behavior and stuff. <u>Physician</u> : It sounds like you both are dealing with a lot. Um, I know in the past, um, I know we have talked a little bit and you have met with [psychologist].