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THE WHY BEHIND THE QUESTIONS: QUESTION-ASKING IN PARENTS OF CHILDREN NEWLY DIAGNOSED WITH CANCER - A REPORT FROM THE CHILDREN'S ONCOLOGY GROUP

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Abstract

Purpose: For parents of children newly diagnosed with cancer, the exchange of information during initial educational processes is critical. This focused analysis was completed to describe parent question-asking during the new childhood cancer diagnosis timeframe.

Design & Methods: In previous research of new diagnosis education experiences, parents spoke extensively about asking questions. These data, captured in first level coding, were incorporated across higher level codes to describe how parents processed information after their child's cancer diagnosis. Using constant comparative analysis, we returned to our data to complete a focused analysis of our first level code, Asking Questions. Team members independently coded Asking

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In Memoriam

Cheryl Rodgers PhD RN was the Principal Investigator of the study which informed this article and was integral to our analysis and development of this paper. Dr. Rodgers died unexpectedly during the publication of this work. The authors wish to dedicate this work to her memory. Her leadership of this multi-site study was seamless and her enthusiasm for the work kept us closely knit as a team. We and the profession will miss her presence and contribution to making the care of children with cancer and their families better.

Questions data from 20 parent interviews, followed by team discussions and consensus agreement for code assignment.

Results: Parents asked questions to learn, fill an unmet need, or clarify information. Clinicians asked questions to assess parent learning.

Conclusion: Question-asking is a technique used by parents and clinicians to communicate new information, assess understanding of provided content, and/or to confirm previously provided information.

Practice Implications: Clinicians can benefit from carefully listening to patients/parents and reflecting on the type of questions asked in an effort to understand the reason behind the question. This can be used to guide further education.

Introduction

In patient education, asking questions enables the learner to identify new or verify existing information; however, there are important dynamics affecting a learner's ability and willingness to ask questions. Lower health literacy has been related to a higher likelihood that parents do not ask questions but simply rely on the physician's suggestions regarding the care of their child (Yin et al., 2012). Parents of children newly diagnosed with cancer report difficulty asking questions during informed consent discussions because of their distress (Kupst, Patenaude, Walco, & Sterling, 2003), limited knowledge or experience about the situation (Hummelinck & Pollock, 2006), or infrequent opportunities to participate in the conversation (Miller, Drotar, Burant, & Kodish, 2005).

A diagnosis of cancer in a child creates fear and anxiety for the entire family. During the early diagnosis timeframe, parents must absorb and make sense of large amounts of disease and treatment information in order to make treatment decisions and learn how to care for their child at home. Parents experience high levels of distress that affects their ability to comprehend and seek out information (Aburn & Gott, 2011; Rodgers et al., 2016; Kupst, et al., 2003). Because no evidence-based strategies to deliver information to parents of children newly diagnosed with cancer have been reported (Landier et al., 2016), the Children's Oncology Group (COG) Nursing Discipline completed a series of studies to document best practices for new diagnosis childhood cancer education as a platform upon which to launch a program of research to fill this critical evidence gap (Landier & Hockenberry, 2016). One of these studies focused on parent experiences with new diagnosis childhood cancer education (Rodgers et al., 2016).

In this COG study, parents' education experiences moved between periods of "telling" by health care providers, which occurred at diagnosis and immediately before the child's discharge from their initial hospitalization, to "teaching" that occurred after the shock of the diagnosis dissipated and parents could relate the new information to their child's current condition and treatments (Rodgers et al., 2016).

Parent learning was low during the periods of telling and high during teaching periods as evidenced by their descriptions of seeking and then using information.

Parents described the types of questions they asked and were asked by healthcare providers, which was captured in our first level coding. These question-asking descriptions were incorporated into a number of higher level codes describing how parents processed information after their child's cancer diagnosis (Rodgers et al., 2016). Given the pervasive nature of question-asking described by parents, we returned to our findings to complete a focused analysis of our first level code, Asking Questions, to better understand the role of parent question-asking after a child's diagnosis of cancer.

Methods

The study was approved by each site's IRB with Duke University serving as the coordinating center. This focused analysis was aligned with the primary study aim and planned analysis. Twenty parents whose child was diagnosed with cancer within the past year were recruited from 4 pediatric oncology treatment centers (North Carolina, South Carolina, Missouri, and Washington DC) between April 2015 and February 2016. Using interpretive descriptive methods, sampling continued until code and category saturation occurred (Sandelowski, 2000; Thorne, 2016). For this focused analysis, we explored parents' views of asking questions beyond the previously reported relationship with new diagnosis education (Rodgers et al., 2016).

To prepare the dataset for this focused analysis, the lead author (KPK) entered all data assigned to the first level code, asking questions, and memos describing our initial impressions about this code into an Excel spreadsheet. We employed constant comparative analysis to expand our initial coding. First level coding was completed using a round-robin approach. Each researcher independently examined and coded or discarded every unit of analysis from the original dataset prior to weekly conference calls for team coding discussions.

During these calls, we identified relevant characteristics of the codes and how each was distinguished from the other, which allowed for code labels and definitions to be refined as needed. Extensive memos were written to maintain an audit trail during individual analyses and group discussions. We established a coding rule that a minimum of two parents must contribute data to a code to assure adequate density of parent experiences to define each code (Kelly, Pyke-Grimm, Stewart, & Hinds, 2014). Strict adherence to these coding strategies helped to decrease bias and increase the trustworthiness and rigor of our findings (Thorne, 1998).

As we developed the asking questions dataset, we identified additional data from study transcripts that were not captured during the original coding. To assure that we analyzed all relevant data to answer the research question, we reviewed every transcript to verify that all relevant quotations were identified and coded. We examined transcripts for both explicit (parent statements that included the terms ask and asking) and latent (parent statements that referred to question-asking without using the terms ask or asking) examples of question-asking. All study team members reviewed and agreed to additions of any new quotations to the asking questions dataset. Through this iterative process all code assignments and definitions were evaluated and refined by all team members using consensus agreement.

Results

In the original study we used purposeful sampling to include mothers (n=16) and fathers (n=4) of children diagnosed with cancer in the past year (time from diagnosis: 10 weeks to 1 year). Parent ages ranged from 21-51 years. Child ages ranged <1 to 16 years and their diagnoses were closely divided between leukemia and solid tumors (Table 1).

Parents' descriptions of family members', clinicians' and their own questions (or the lack thereof) contained important contextual information to better understand their initial learning and coping after their child's diagnosis of cancer. Three major categories organized parents' views about question-asking. These included: What Affects Parent Question-asking, Parent Question-asking, and Clinician Question-asking. Within each category additional codes described parents' views of their question-asking experiences in the new diagnosis timeframe (i.e. time between child's initial admission for diagnosis and treatment and discharge to home).

What Affects Parent Question-asking describes parents' thoughts and feelings about asking questions, and question-asking behaviors of their family members, that influenced their own inquiries.

Feeling comfortable to ask questions.

Asking questions was an important way for parents to gain information about their child's cancer. Several factors allowed parents to feel at ease to ask questions. Clinician use of simple language to explain things made understanding easier. Some parents wanted time to connect with team members before they felt comfortable asking questions while other parents preferred team members to encourage their questions. Parents perceived that it was always ok to ask questions, "...even if they did tell me something, if, it was a few hours later and I completely forgot, I could always just ask" (mother of a 4-year-old with leukemia).

Not knowing enough to ask.

Parents were unable to ask their healthcare providers questions shortly after their child's cancer diagnosis because they had inadequate information to formulate an inquiry. When recalling initial discussions with physicians, one mother reported "I didn't even know what to ask" (mother of a 4-year-old with Wilms tumor).

Too overwhelmed or distraught to ask.

Parents described feeling inundated with information or being too affected by their emotions after their child's cancer to ask questions. One parent described being overwhelmed after receiving information from multiple providers making it difficult to know what questions to ask anyone. Another parent described being shocked after the cancer diagnosis and unable to think of questions, "[two doctors] ... gave us the chemo schedule and asked us if we had any questions about the drugs. Um, but still at that point you're still in a whirlwind I mean everything is still just crazy in your mind" (mother of 10-year-old with Ewing sarcoma).

Family members asking questions.

Parents described family members asking questions during their initial informational sessions with varying degrees of benefit. For some, family members asked questions that the parent had not thought of, “it would be family members asking questions because I still didn’t know what- what questions to ask” (mother of 4-year-old with Wilms tumor). Other parents perceived family members’ questions as not helpful when they caused the conversation to go in a different direction, leading to important topics potentially being overlooked “if you had more family or friends obviously they have questions...so then it can kind of get to the point where ... getting the doctors off of topic, or off track, ...that some of the very important things that they probably needed to discuss may not get brought up or mentioned” (mother of a 4-year-old with high risk leukemia). Each of the parent statements referred to adult family members asking questions. No parent referred to the child with cancer or their siblings when describing questions from family members.

Parent question-asking included the meaning of and methods used by parents to inquire about their child’s cancer.

Asking questions indicates an unmet information need.

Parents acknowledged times when learning did not occur, either because information was omitted, teaching happened too fast, or wasn’t clear enough for them to grasp the information. “I did ask a nurse about this feeding tube and I guess she just kind of like explained it real fast too” (mother of a 4-year-old with Wilms tumor). Not knowing where information could be found challenged parents. “But there have been many times ... after his diagnosis where we wondered, ‘Well I don’t know- does that come after? Is that before that?’ And there’s- there’s really nowhere to go and find that information” (mother of a 7-year-old with leukemia). It was difficult for parents to learn everything so early in their child’s diagnosis. Unmet information needs also resulted from questions asked and not answered. Parents discussed asking questions that they perceived were not answered despite multiple attempts to get them answered. This led to dissatisfaction with care, “I just don’t think it’s um...very good to keep you in the dark. And I think it’s um, if they ask you, you need to try to answer. I think you need to give ‘em the information and not try to withhold it” (mother of a 10-year-old with Ewings sarcoma).

Pondering uncertainties.

Parents also referred to the questions they asked of themselves. Sometimes these questions were worries about how they were going to cope with and manage their child’s illness. Questions were also about how they were going to fit the cancer into their own life as well as the lives of family members. “What am I supposed to do about work? How am I supposed to go to work when she can’t go to daycare? You know, who is going to take care of her? What am I supposed to do,” (mother of a 4-year-old with leukemia)?

Parents worried about potential emergencies that could arise, and keeping all the medications straight. They described being overwhelmed with the uncertainty of trying to even think about what was coming next. “We knew some facts about it but a lot of it went in

one ear and out the other cause as soon as they said, ‘Cancer’ my husband shut down and it was kind of like, what do we do now, type of thing” (mother of 3-year-old with leukemia).

Asking questions to learn.

As parents gained information they asked new questions. Parents’ comments initially related to the time of their child’s diagnosis, but they also described new questions that arose during subsequent phases of treatment. “I mean I really did- did a pretty good job of getting information. I think a lot of that has to do with me asking questions. Um I know like a lot of parents are you know sometimes afraid to ask questions but if you don’t understand something you got to ask” (father of a 15-year-old with leukemia). Parents shared how receiving new information sometimes gave them enough knowledge to ask the next question.

Asking questions to verify/clarify.

After receiving information, parents asked questions to verify and to clarify. They wanted to verify information or double check their understanding and gain additional information, “And we had to slowly learn bit by bit. We would call the doctor and say, “Okay, this is what’s going on. What do we do?” And they would be like, “No, you’re fine.” Or, “Yes we want to see you” (mother of a 3-year-old with leukemia). Parents also asked questions to gain clarity “What I missed- what I missed on one explanation I asked the question about- And got it another time, yeah” (father of 2-year-old with leukemia). Additionally, parents sought information on their own if they felt that there was other information out there, “Well I asked questions and if I didn’t like what I had to hear I would Google it” (father of 15-year-old with leukemia).

Getting questions answered by parent education materials.

Parents described using information sheets, handbooks, or the Internet to obtain information about their child’s diagnosis and/or treatment. Parents reported using these tools initially to find or confirm information, “... because a lot of times when I couldn’t exactly remember, um, how to handle a situation I could go back to that [written material]. And I would get my answer” (mother of a 10-year-old child with Ewing sarcoma). Parents also described using the educational material to obtain information in real time as things happened, “... we’ve used it [handbook] a number of times for some of the stuff that-that popped up like when ... he got sores in his mouth and what to do at that point”(father of 5-year-old child with leukemia). Parents described having information available in their educational materials when questions arose as reassuring, “It kind of helped control some of that [uncertainty]” (mother of 3-year-old child with leukemia).

Knowing who to ask.

Parents initially felt overwhelmed but over time, they learned to whom they could direct their questions. “At first it was just mostly with the doctors. I didn’t even ask nobody else questions about it” (mother of 11-year-old with osteosarcoma). Later, they stated “if we had a question for the nurse- if it was something that they immediately knew the answer they would tell us. If they didn’t know the answer they would say, ‘I’m not sure, let me ask the doctor.’ And they usually would get back with you within about ten minutes with an answer”

(father of 4-year-old with rhabdomyosarcoma). Many parents saw their nurses as being on the front line for questions. Nurses often knew the answers but were quick to get an answer from another if they did not know. This was juxtaposed with parent reports of asking the wrong doctor a question “that’s the one thing that got on my nerves though is that- they’re like, “I can’t answer that question, you have to ask a different doctor” (mother of a 2-year-old with rhabdomyosarcoma). Parents turned to nurses to help them negotiate such confusion.

Preparing to ask questions.

Parents sometimes took an active role in preparing to ask questions of the healthcare team. These actions included reviewing written educational material and searching online “And then I also went on um, like, the online which was of course to learn, um, more specifics. So I knew what kind of questions to ask them” (mother of a 2-year-old child with rhabdomyosarcoma). Parents also spoke of making lists containing their questions so that they were ready to ask when the opportunity presented itself.

Clinician question-asking included clinician behaviors that influenced parent inquiries or learning.

Asking questions to assess my understanding.

Parents described situations in which they were given information and then asked questions by clinicians to assess their understanding. For example, initial questions included ‘tell us what you know about your child’s cancer.’ Later, parents spoke of clinicians asking them to provide a return demonstration or to explain what they just heard in their own words. “Like the one nurse had asked me, Let me see what you’ve learned from your training....” (mother of a 12-year-old with rhabdomyosarcoma). One parent became frustrated by multiple clinicians asking similar questions around the time of their child’s diagnosis. The parent stated “I remember getting- I remember feeling frustrated. I just remember being like, “Why are you asking me?” And I’m sure there’s like a reason right? ... but I remember being like why are you asking like I don’t know. I know nothing. I know she has leukemia” (mother of 3-year-old with leukemia).

Clinicians available to answer questions.

The physical presence and personal characteristics of healthcare providers helped parents to ask questions. Nurses’ constant presence in the child’s room facilitated question-asking, “... they [nurses] are who we see the most, so of course if I have a question, I ask the person that I see the most, the nurse”(mother of 4-year-old child with leukemia). Parents also described clinician behaviors that were helpful, including allowing time to answer questions, demonstrating patience in answering the same questions, encouraging any type of question, and assuring parents that information will be repeated. In contrast, clinician behaviors could inhibit question-asking, “If we asked questions to the resident, then they would usually say that the information was in our folder and we should read about it. So, it kind of puts you off about asking questions to them” (mother of a 3-year-old with ALL).

Clinicians encouraging questions.

Parents described clinician efforts that encouraged question-asking as a follow-up to previously provided information. This parent reflected on a specific situation in which he knew his questions would be solicited, “The doctors always [in] during the week. They always stopped by once a day to come in, tell us what was going on with his treatment and then to find out if we had any questions” (father of a 5-year-old with leukemia). Question-asking was promoted and encouraged after the family went home from the hospital. “She gave me paperwork where I could just call and talk to certain people in the hospital that I needed to talk to if I needed-questions or if I needed to talk with her” (mother of a 10-year-old with non-Hodgkin lymphoma).

Discussion

This is the first study that details parent question-asking after their child’s cancer diagnosis. Our results indicate that there are subtle nuances to why parents ask questions after learning that their child has cancer. Not asking questions did not necessarily mean that parents had sufficiently processed and understood all of the information presented to them by their health care team. Parents who didn’t ask questions might suggest that clinicians had not provided enough information for them to formulate questions; that clinicians had delivered too much information and overwhelmed the parents; or that parents needed time to process the information and/or work through their emotions. It is important to note that no parent discussed question-asking by their children. This is likely because our interview questions focused on parents’ experiences. We did not probe about their child’s question-asking. Therefore, the impact of question-asking by the child on parent question-asking should be explored in future studies.

Question-asking has been used by communication scientists as a measure of effective clinician communication (Roter & Larson, 2002) and applied to childhood cancer informed consent research (Cousino et al., 2011; Miller, et al., 2005). Based on our findings, these measures might underestimate effective communication if the data were collected solely during the new diagnosis timeframe. Parents might simply be too overwhelmed or distressed to ask questions (Kupst, et al., 2003). Our findings also suggest that parents might be reluctant to ask physicians questions because they didn’t want to take up their time or were waiting to be invited to ask questions (Ringner, Jansson, & Graneheim, 2011). Parents also reported how impossible it is to ask questions about topics for which they have no knowledge. Early diagnosis meetings provided information that helped parents to formulate their questions (Ringner, Karlsson, & Hallgren Graneheim, 2015); however, some parents may need time to process information before formulating questions. These findings underscore the importance of examining parent communication experiences using both quantitative and qualitative methods.

Research from primarily adult cancer patients indicate that health disparities affect patient/provider communication, including question-asking (Eggly et al., 2011; Mazor et al., 2015). In our purposive sample we had a broad range of parent education levels but limited variability in race/ethnicity. Because this was a focused analysis of a first level code, we could not query our data for differences in parent race/ethnic group descriptions of their

question-asking. Given the findings from adult cancer communication, examining the impact of health disparities on parent question-asking is an important area for future research.

As a focused analysis of a first level code from our primary study, the primary limitation of this study is that we could not probe to gain additional insight into the question-asking results reported here. Our families were highly educated, which might have influenced their question-asking patterns. We were unable to ascertain experiences of question-asking in parents who spoke languages other than English, given the constraints of interviewing and translating other languages in qualitative research. Studying these populations is a priority for future research.

We focused our interviews on parent reports of their experiences only; therefore, we could not ascertain the impact of child presence during discussions and resulting impact on parent question-asking. Other researchers have described parents' preferences to have separate discussions in the new diagnosis timeframe to allow them to better attend to the discussion rather than how the discussion was affecting their child (Aburn & Gott, 2011; Young et al., 2011). The experiences of how families learn together, including asking questions, about the child's cancer diagnosis, and the impact on their self-management and coping is an important area for future research.

We cannot be assured that all of our codes and categories had informational redundancy. We recognize that some codes might be overrepresented and others underrepresented in our sample. We refrained from making interpretations based on code frequencies, but instead established an a priori coding rule that each code required a minimum of 2 parents' data. Our findings provide a compelling preliminary description of parent question-asking that can be used to inform future research.

Practice Implications

One way of incorporating question-asking into practice is for clinicians to use the teach-back method. This method is encouraged to assess parent understanding following an educational session (Kornburger, Gibson, Sadowski, Maletta, & Klingbeil, 2013). When using teach-back, or questionasking in general, clinicians should maintain vigilance in evaluating the family's response to the question and a family's attitude towards responding to questions. Overuse of question-asking by staff may be perceived as burdensome by some families as was noted in our findings. Appropriate use of the teach-back method, however, has been positively associated with the uptake of provided education which can in turn improve patient outcomes (Ha Dinh, Bonner, Clark, Ramsbotham, & Hines, 2016).

This study underscores the need for clinicians to utilize question-asking in a purposeful manner in order to assist parents with the educational process related to learning about their child's diagnosis and care. In addition, the study highlights the need for health care providers to reflect on the type of questions that parents are asking and what this might represent.

Conclusion

This study demonstrates how question-asking was used by parents, family members, and their healthcare providers during new diagnosis childhood cancer communication. Parents described their question-asking as a method to help initially learn new material, as well as to validate understanding of prior information. They also described times when they didn't or couldn't ask questions such as when they didn't know enough or were overwhelmed with information or by their emotions. Clinicians commonly use the phrase, "Do you have any questions?" to assess parents' understanding of their teaching. Given our findings, it might be better to ask, "Is there anything that you are still worried or wondering about?" Likewise, clinicians must not assume that when parents are not asking questions, they do not have any questions or conversely, if they are asking many questions, that they do not understand. In these instances, is possible that parents may be too overwhelmed to ask any questions, or that they simply may be verifying or clarifying information previously conveyed.

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Highlights

- Question asking is frequently used during the initial educational process.
- Clinician actions can influence parent question asking.
- Parents and clinicians ask questions for different reasons.

Table 1.

Parent Demographics

ID#	Relation to Patient	Parent Age (years)	Parent Race/Ethnicity	Parent highest education completed	Age of child (Years)	Child Diagnosis
1	mother	38	Caucasian	High school	16	Leukemia
2	mother	36	Caucasian	College	3	Leukemia
3	mother	33	African American	Graduate school	4	Leukemia
4	mother	42	Caucasian	College	10	Ewings sarcoma
5	mother	29	Asian	College	3	Leukemia
6	father	28	Caucasian/Hispanic	Some college	4	Rhabdomyosarcoma
7	mother	21	African American	Some college	<1	Leukemia
8	mother	36	African American	Some college	16	Leukemia
9	mother	44	African American	Some high school	10	Non-Hodgkin Lymphoma
10	father	32	Caucasian	Some graduate school	5	Leukemia
11	mother	24	Hispanic or Latino	Some college	4	Leukemia
12	mother	26	Caucasian	Some college	4	Wilm's Tumor
13	mother	21	Caucasian	High school	2.5	Rhabdomyosarcoma
14	mother	37	Hispanic or Latino	Some graduate school	17	Osteosarcoma
15	mother	36	African American/Caucasian	Some college	11	Osteosarcoma
16	mother	32	Caucasian	College	3	Leukemia
17	father	28	Caucasian	College	2	Leukemia
18	father	37	Caucasian	Some high school	15	Leukemia
19	mother	51	African American	Graduate school	12	Rhabdomyosarcoma
20	mother	43	African American	Graduate school	7	Leukemia

Table 2.

Code list with definitions and exemplar quotes

Code/category name	Code definition	Exemplar quotes
What affects parent question-asking	Thoughts and feelings that influence parent inquiries.	
FEELING COMFORTABLE TO ASK QUESTIONS	Parents are at ease to make inquiries because of their inherent nature or clinician behaviors.	"And everyone here explains things on a normal person's level not-with a bunch of terms you don't understand." (father of a 2-year-old with leukemia)
NOT KNOWING ENOUGH TO ASK	Parents are unable to generate questions because they have insufficient information at the time.	"...I still didn't know what- what questions to ask. I didn't know- yeah I just- I didn't know what questions to ask." (mother of a 4-year-old child with Wilms tumor)
TOO OVERWHELMED OR DISTRAUGHT TO ASK	Parents describe situations that make it difficult to pose their queries because they are besieged by emotions and information.	"But, on the other hand, there's probably things that I probably needed to ask, but because, you know, I'm distraught I didn't think to ask..." (mother of a 4-year-old child with leukemia)
FAMILY MEMBERS ASKING QUESTIONS	Relatives query parents and/or staff to obtain information.	"they explained to us the best way- you know I asked questions, my mom asked questions as well" (mother of a 4-year-old with leukemia)
Parent question-asking	The ways and reasons that parents inquire about their child's cancer.	
ASKING QUESTIONS INDICATES AN UNMET INFORMATION NEED	Family recognizes that learning has not occurred and that additional information is needed to fill a knowledge gap.	"I think it you know someone else too mentioned like um, another mom was like, 'Oh yeah like if they throw up they say like- like you know- it's their bodily fluids it's got chemo- you should be really careful about that type of stuff.' I'm like- I'm like the mom who like will like hold their child the whole time, and just let her throw up on me." (mother of a 3-year-old with leukemia)
PONDERING UNCERTAINTIES	Parents' internal questions that reflect their worries about the child's new cancer diagnosis, their ability to provide care for their child at home and to handle other family issues.	"...you have the shock of everything like, 'What do I do with my life and work?'" "They wondered how am I going to explain this to my child?" (father of a 5-year-old with leukemia)
ASKING QUESTIONS TO LEARN	Inquires made to seek out new information or to inquire about how to apply information in caring for their child.	"But we did ask a lot of questions to everyone because we wanted to learn about everything. We had never been in the hospital before, so we needed to know about the hospital, and the different kinds of doctors, and the different kinds of nurses, and what resources were available." (mother of an 8-year-old with leukemia)
ASKING QUESTIONS TO VERIFY/CLARIFY	Inquires made to double check or elucidate additional information related to prior education so that understanding is refined.	"What I missed- what I missed on one explanation I asked the question about- And got it another time, yeah" (father of a 2-year-old with leukemia)
GETTING QUESTIONS ANSWERED BY PARENT EDUCATION MATERIALS	Parents use written and online cancer information as knowledge sources or to back up knowledge received from interactions with the clinical team.	"And it [WebMD] helped my asking the questions that I needed to ask ... WebMD like answered most of 'em." (mother of 2-year-old with rhabdomyosarcoma)
KNOWING WHO TO ASK	With experience parents recognize which clinicians will reliably get their questions answered.	"We felt comfortable enough that the nurses were not just take blood, take blood pressure, they were oncology nurses and they could answer those questions that we needed answers to." (mother of a 3-year-old with leukemia)

Code/category name	Code definition	Exemplar quotes
PREPARING TO ASK QUESTIONS	Parents describe how they get ready for interactions with the clinical team so that they can pose their queries.	“You talking about reading about it or? I think for me reading about it and then- because once I read about it I was able to ask questions.” (mother of 16-year-old with leukemia)
Clinician question-asking	Clinician behaviors that influence parent inquiries or learning	
ASKING QUESTIONS TO ASSESS MY UNDERSTANDING	Staff members evaluate parents' comprehension of previous education and/or determine current learning need.	“But some of ‘em has asked you know, ‘Have you learned how to flush? Have you learned to draw you know- do a blood return and all of that?’ ... and so they would you know ask me, ‘You know you want to come over here and I’ll show you? Or you can do it yourself and I’ll watch you and instruct you’ ...” (mother of a 12-year-old with rhabdomyosarcoma)
CLINICIANS AVAILABLE TO ANSWER QUESTIONS	Physical presence of nurses and receptive disposition of doctors and nurses empowered parents to make inquiries.	“...at that point they [nurses] were our people ... we spent hour upon hour with the nurses and they answered our questions...” (mother of 3-year-old child with leukemia)
CLINICIANS ENCOURAGING QUESTIONS	Staff follow up with parents to inquire about previously provided education.	“Um, the nurses they really-every time they would come in, if they were going to- you know they didn’t just come in and start hooking bags of fluids up and giving it to him and them leaving. They would come in and say, ‘Okay this is what I’m doing. This is what this is. This is why he’s getting it, how long it’s gonna take.’ And they (nurses after providing information) would always ask you know, ‘Do you have any questions?’” (father of a 4-year-old with Rhabdomyosarcoma)