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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 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

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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 spread sheet. 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 to 51 years. Child ages ranged <1-17 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) (Table 2).

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.