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Processing Information after a Child's Cancer Diagnosis – How Parents Learn: A Report from the Children's Oncology Group

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Abstract

Parents of a child newly diagnosed with cancer must receive an extensive amount of information before their child's initial hospital discharge; however, little is known about best practices for providing this education. An interpretive descriptive study design was used to describe actual and preferred educational content, timing, and methods among parents of children newly diagnosed with cancer prior to their child's first hospital discharge. Twenty parents of children diagnosed with various malignancies participated in individual interviews 2 to 12 months after their child's diagnosis. Data were analyzed using constant comparative analysis. Education delivery occurred in a telling manner at diagnosis transitioning to a reciprocal process of teaching during the inpatient stay, then primarily back to telling immediately before discharge. Parents expressed a variety of preferred learning styles but noted that their preferences were rarely assessed by healthcare providers. Multiple factors influenced parents' ability to process educational information received during their child's initial hospitalization. Findings suggest that nursing practices should include assessing for influencing factors, providing anticipatory guidance, and incorporating parents' preferred learning style into the educational plan.

Keywords

education; parents; pediatric oncology; new diagnosis

The diagnosis of cancer in a child and its subsequent treatment is extremely stressful for parents (Rabineau, Mabe, & Vega, 2008). Parents report that the initial stages of diagnosis and treatment are the most overwhelming time because of uncertainty (Jackson et al., 2007; McGrath, 2002). Additional stressors include difficulties managing their emotional reaction to the diagnosis, seeking to identify a cause for their child's cancer, being able to explain the diagnosis to their child, and reorganizing family roles and routines to accommodate the treatment regimen (Tackett et al., 2016; Rabineau, Mabe, & Vega, 2008). Parental reactions to the cancer diagnosis often make learning about their child's treatment and care difficult (Aburn & Gott, 2014). Parents must typically learn about their child's diagnosis, treatment plan, and necessary home management during the child's initial hospitalization. These hospital stays are often of short duration, so providing education efficiently and effectively is critical.

Informing parents about their child's diagnosis and treatment plan helps to relieve uncertainty. This information can also enhance parental coping, improve their ability to make informed decisions, and assist with the transition to home (Kelly & Porock, 2005). Parents are more likely to experience peace of mind when their child's oncologist provides high quality information regarding the disease (Mack et al., 2009); however, some parents feel overwhelmed with the amount of information and exhausted by the initial teaching (Aburn & Gott, 2014; Jackson et al., 2007; Flury, Caflisch, Ullmann-Bremi, & Spichiger, 2011). Stress can negatively affect cognitive abilities and memory. In one study, researchers found that 17% of parents of children newly diagnosed with cancer did not remember any information from the initial meeting and wanted the content repeated until they were able to comprehend the material (Eden, Black, MacKinlay, & Emery, 1994).

Receiving information about a child's cancer diagnosis can be both beneficial and stressful to parents. There is limited information available about best methods to deliver education within this stressful context. Written information, verbal discussions, simple videos, and websites are all potential resources that can be used to educate parents of children newly diagnosed with cancer (Aburn & Gott, 2014; Matutina, 2010; Lewis, Gundwardena, & Saadawi, 2005; Eden et al., 1994); however, there is no definitive information regarding parental preferences among these various resources. For example, parents of newly diagnosed oncology patients reported a parent education website as beneficial; however, less than half of parents accessed the specific website during the first six weeks following their child's diagnosis because they were too overwhelmed and tired (Svavarsdottir & Sigurdardottir, 2006; Ewing et al., 2009).

Nurses have a core responsibility to provide education to patients and parents; however, there is a paucity of evidence to inform best practices for performing this important task (Landier, Leonard, & Ruccione, 2013). Because optimal educational practices can improve the quality of life for patients and parents (Slone, Self, Friedman, & Heiman, 2014), further research is needed to identify best educational practices for parents of children with a new oncology diagnosis. Learning from parents directly will contribute to the identification of best educational practices for parents of children with a new oncology diagnosis.

This study explored the educational experiences of parents after their child's diagnosis of cancer, and described actual and desired parent educational experiences from the time of their child's initial oncology diagnosis until the first hospital discharge. Specific aims of this study were to describe the content (topics), timing, and methods of information delivery that parents of children newly diagnosed with cancer received and preferred to receive, prior to their child's first hospital discharge.

Methods

Design

We used an interpretive descriptive design to identify parents' actual and preferred experiences of receiving information when their child was initially diagnosed with cancer. Interpretive descriptive design uses a naturalistic method of inquiry without pre-selection of specific variables or a priori commitment to a particular theoretical viewpoint (Sandelowski, 2000). It uses an inductive approach to identify information from participants that provides a basis to identify common patterns and themes of the experience (Thorne, Kirkham, & MacDonald-Emes, 1997).

Setting

Parents were recruited from the pediatric oncology services at Duke Children's Hospital & Health Center in Durham, NC; Children's Mercy Hospital & Clinics in Kansas City, MO; Children's National Health System in Washington D.C.; and Palmetto Health Children's Hospital in Columbia, SC. These sites have expertise in childhood cancer care and are actively involved in Children's Oncology Group (COG) clinical trials. Combined, the four centers diagnose approximately 450 children and adolescents with cancer, ages 0 to 17 years, each year.

Sample

Study participants were identified using purposive sampling. Inclusion criteria consisted of a mother, father, or legal guardian who provided care to a child (ages 0–17 years) diagnosed with any type of cancer at least two but no more than twelve months prior to study participation. This timeframe was selected to ensure that participants had adequate time to process their child's diagnosis and treatment plan, while still having recent recall of the diagnosis experience. Participants were required to speak English and be willing to discuss their experiences with the research team. Due to variations in new patient education, parents were excluded from the study if their child was diagnosed with a non-malignant disease, received the cancer diagnosis while hospitalized on a non-oncology unit (i.e., surgical ward), experienced disease relapse, had not yet been discharged from the hospital since the diagnosis, or received a bone marrow transplant. Parents or legal guardians of deceased children were not approached due to potential distress associated with the reflection necessary for the interview. Patients were recruited between April 2015 and February 2016. Due to a predominance of mothers of patients with a leukemia diagnosis recruited initially, the investigators purposefully sampled fathers and parents of patients with solid tumors during the last three months of the study. Sampling continued until theoretical redundancy

occurred, specifically when no new information was obtained and information did not change the conclusions that had already been reached (Sandelowski, 1995).

Procedures

Recruitment began after obtaining approval by the Institutional Review Board at Duke University and the affiliated institutions. Parents signed a consent form after the study information was discussed and all questions were answered. Interviews occurred at a place and time comfortable and convenient to parents.

All authors performed interviews at their affiliated institutions. Interviews were audio-recorded and followed a semi-structured interview guide that focused on experiences of the education that parents received and preferred to receive after their child's cancer diagnosis. The interview guide was developed by the investigators based on existing research and clinical expertise and was reviewed by a patient advocate affiliated with the Children's Oncology Group. The interview guide contained questions regarding how parents learned about their child's diagnosis, education that occurred during the hospitalization, preparation for discharge, and preferred methods for education. Parents were encouraged to elaborate on these topics and any others they deemed important. Following the interview, parents were asked to complete a demographic form and were given the opportunity to ask questions. Field notes were audio-recorded or recorded electronically by the investigators immediately following each interview. During one of the interviews, the audio recorder malfunctioned and the interview was not recorded. Immediately following this interview, the researcher wrote detailed notes regarding this parent's statements in order to capture the information shared. These notes were coded and incorporated into the analysis but no quotes were used.

Analysis

Interviews were transcribed verbatim by a trained research transcriptionist. The first author listened to each tape while reading the transcriptions to verify accuracy and remove any identifying demographics. Field notes were inserted at the end of the document.

Constant comparative analysis, consisting of three stages: open, axial, and selective coding was used to analyze the data (Dantas, Leite, de Lima, & Stipp, 2009; Corbin & Strauss, 2015). The codebook was initially developed from text descriptions of events associated with the educational process. One author independently completed the initial coding for each interview. After this, a second author reviewed the codes and suggested alternate codes as indicated. Changes were made to codes as a deeper understanding of the educational process occurred through data immersion. All code labels were named from the parents' viewpoint, consistent with the study's focus.

Coding, definitions, and category development were reviewed by all investigators during biweekly conference calls. Any discrepancies were resolved via consensus agreement. After this, the researchers moved to axial coding to categorize codes based on similarities and relationships. New category names were derived from the data to represent emerging themes (Foley & Timonen, 2015; Corbin & Strauss, 2015). Finally, a central selective category was identified to describe the overall theme under which all other categories and codes were

integrated regarding parental descriptions of their educational experience (Foley & Timonen, 2015; Corbin & Strauss, 2015).

Rigor was maintained through prolonged engagement (credibility), verification with parents of newly developed findings in subsequent interviews (dependability), and an audit trail that chronologically indexed the study's procedures and analysis decisions (confirmability) (Speziale & Carpenter, 2010).

Results

Twenty parents participated in the study; their characteristics are reported in Table 1. Details about parental role and child diagnosis are reported in Table 2. All parents spoke English, although it was not the primary language for one parent.

For this study, the term "healthcare providers (HCPs)" refers to a variety of clinicians, including physicians, advanced practice nurses, physician assistants, nurses, social workers, child life specialists, dieticians, and/or pharmacists. During the initial hospitalization, parents received information from HCPs through two processes, coded as *telling* and *teaching* (Figure 1). Upon initiation of education, parents began processing information. "Processing" in this study refers to the parents' management of information that led to learning how to care for their child with a new cancer diagnosis (Table 3). Evidence of learning was demonstrated by parents *seeking* and *using information* (Figure 1). The ability of parents to process information was highly individualized and influenced by conditions such as *responding to the diagnosis*, *receiving reassuring provider communication*, *pacing of information*, *receiving consistent information*, *figuring out life*, and *worrying about discharge* (Table 3). Positive aspects of these influencing factors assisted parents with processing the information, while negative aspects hindered their processing ability.

Telling at Diagnosis

At the time of diagnosis, parents received an extensive amount of information about their child's diagnosis and treatment plan. Table 4 lists actual and desired content that parents reported at the time of diagnosis. The physician team communicated information to the parents at a fast pace, often because of the urgent need to obtain informed consent and begin treatment. Communication at this time was predominantly one-way with physicians *telling* parents information. *Telling* was described by one parent as, "And she [physician] came in with the whole- with like this whole plan and this whole overview. She just gave like the whole overview spiel..." (parent 5). Parents began to process information as it was delivered but parental knowledge level was usually minimal at the time (Figure 1). Some parents described shutting down immediately upon hearing the word "cancer," and not remembering anything else (parents 2 and 3); however, one parent found all of the information helpful during the diagnostic discussion (parent 13). Regardless of the rate of processing, most parents perceived primarily being *told* information during this time, with little reciprocity.

Teaching During the Hospital Stay

Following the diagnostic period, children frequently remained hospitalized to initiate treatment and receive supportive care. During this initial inpatient stay, obtaining

information transitioned from *telling*, dominated by HCPs delivering information, to *teaching*, a reciprocal information exchange between HCPs and parents (Figure 1). One parent described the reciprocal process of *teaching*, “I read through it and then you know... someone knowledgeable about the subject talks to me about [it]...” (parent 18). Actual and desired content delivered during the hospital stay is listed in Table 4. Parents found several different teaching methods useful in this time of information exchange (Table 3). During the hospital stay, parents expressed an ever-increasing knowledge level, “... once things actually start happening, you move away from the initial rush and get into the treatment, that’s when it starts to all come together” (parent 10).

Parents reported a variety of preferred and actual approaches by HCPs to help them learn (Table 5). Almost all parents had a particular learning style; however, most parents did not recall being asked by any HCP what that style was. Although most parents reported approaches that were helpful, one parent described particular frustration with multiple HCPs repeatedly asking her what she knew about the cancer diagnosis at a time when she had very little information (parent 16). Another parent reported not being informed about neutropenic precautions and suddenly finding a “neutropenic precautions” sign on their hospital room door (parent 2). In both of these instances, parents indicated that a short explanation would have eased their stress and frustration.

Return to *Telling* at Discharge

Immediately prior to discharge, parents’ statements suggest that HCPs returned to *telling* them information, rather than continuing with the more interactive exchange of information that had been occurring during the hospital stay (Figure 1). Parents perceived information was conveyed to them prior to discharge with little regard as to how they were processing it. One parent described, “But I just remember feeling like, this all moves so quick ... like we had no time to let it soak in and then we’re already going home” (parent 16). The rate of processing information at discharge was highly individualized depending on the parent’s previous medical experience and the duration of their child’s hospitalization. One parent whose child had been in the hospital for several weeks was ready to listen and able to understand the discharge information (parent 12); however, another parent who had only been there one week stated that she “...sort of blanked out on that [discharge information] ...” (parent 15). Eleven parents reported that their discharge education was adequate; however, all parents reported feeling “scared” and/or “nervous” about caring for their child at home. Major concerns included medication schedules, and care of the central venous access device (parent 7). Parents expressed a preference for concise discharge information, such as a magnet or one sheet of paper listing signs that they needed to watch for at home (parent 2). Table 4 lists the actual and desired content delivered at discharge.

Seeking Information

As parents began to process information, many responded by seeking additional information. *Seeking information* was beginning evidence of parent learning – as they learned new information about their child’s cancer and its treatment, they sought out more information. The majority of parents reported asking questions to seek or clarify information; however, parents required some knowledge base before they were able to ask

questions. One parent described, "... so as I learn more, I ask more questions" (parent 8). Furthermore, most parents eventually recognized that different HCPs provided different types of information and parents learned from whom to seek different types of information. The majority of parents identified nurses as key informants, with one parent stating, "... 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. And they don't get upset; they answer the same question over and over" (parent 3). Parents reported that nurses educated in an informal and formal manner throughout the day, and that this helped them to process the information. One parent described, "... 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" (parent 2).

It is equally important to note that a few parents purposefully avoided information. One parent described, "...I just choose not to read certain things because I don't want to see things that's going to make me upset" (parent 3). When a parent reported avoiding information, their partner often times had different preferences for information and wanted detailed information. For example, parent 3 who didn't want much information stated, "... he's [child's father] the type that wants to know ... he'll probably go online and, like look it up".

Using Information

Although parents were not specifically queried about events after the hospital discharge, many parents shared stories about processing information after leaving the hospital. At this point parents began to use information to care for their child, another indicator of learning (Figure 1 and Table 3). Parents described their ability to make sense of the information as events occurred at home; for example one parent described her actions when her daughter was in pain, "Like I decide to call and I start looking in the [educational] book" (parent 14). Parents recognized their need for ongoing education after their initial hospital discharge. They called HCPs for additional information once they were home, asked questions of home care nurses, requested additional information from cancer organizations, and reviewed written material that they had previously received once they were home. When parents were specifically asked about the time frame within which they felt they understood the cancer information they received, parents reported a span of three to ten weeks after diagnosis.

Although eleven parents reported that their discharge teaching was adequate, this did not translate directly into feelings of preparedness. Only four parents felt prepared and comfortable to care for their child after discharge. Six parents reported feeling unprepared after discharge and described concerns about caring for their child's central line, giving medications, complying with neutropenic precautions, and being adequately prepared for their child's hair loss. One parent described being unprepared with the medications, "...my first like panic attack when we got home... I realized the names on the calendar did not match the names on the bottle" (parent 16). However, three parents reported feeling unprepared at discharge but when they got home, they realized they were comfortable providing care. One parent stated, "I didn't think I was ready before I left, but I guess I was. It wasn't as hard as it seemed" (parent 7)

Influencing Learning

Several factors affected parents' ability to process information (Table 3). Factors included both positive aspects that promoted parents' ability to process information and negative aspects that impeded processing.

Responding to the diagnosis—Parents reported intense feelings of shock, sadness, and stress when hearing the cancer diagnosis. One parent described, "I was so stressed and oh, gosh it was just an overwhelming feeling" (parent 9). These reactions interfered with parents' ability to process the information delivered to them. One parent stated, "...it's like the lady [physician] was saying it ... but I couldn't hear it" (parent 15).

Receiving reassuring provider communication—Parents valued HCPs who displayed care and support during their interactions. Behaviors that were perceived this way included being empathetic, gentle, and calm when delivering information; being attentive to questions; repeating information; and "...sitting down and giving me the time of day" (parent 12). One parent reported, "And I remember one of the nurses he said, 'You know you're already doing a really good job...' I thought like- that really helped my confidence" (parent 16). Another parent described nurses spending time with the patient and mother, which provided an opportunity to have an open conversation that made the mother feel comfortable (parent 5).

Pacing of information—The ability to process information was affected by parental perception of how much and how quickly information was delivered. At diagnosis, parents reported receiving a large amount of information at a fast pace, which made processing difficult, "...there's just a ton of information coming at you at once" (parent 20) and "... I felt like at the time that it was just too much" (parent 6). Parents reported that the pacing of information delivery slowed down during the inpatient stay, which enabled them to process information more proficiently. One parent described, "... as that week slowed down, some of it just- it starts sinking in more" (parent 16). However, parents reported difficulty processing information immediately before discharge when the pacing of information delivery increased again. One parent described feeling overwhelmed and confused when receiving a large amount of information at the end of her child's hospitalization (parent 1).

Receiving consistent information—Providing information consistently was important to parents. Consistency included both a preference for the same provider giving information and uniformity in information provided. Parents appreciated receiving information from one HCP and having the same HCPs involved in their child's care, "It's been really nice to have somebody [oncologist] with him since day one" (parent 5). Frustration arose from unfamiliar HCPs, "Cause then you start to get comfortable with a familiar face and that's you know you're like, Okay well where's that doctor that I was talking to yesterday?" (parent 6). In addition, parents were frustrated and confused when they received mixed messages. For example, one parent described confusion related to the mixed messages about administering acetaminophen because some HCPs told her not to give it because it would mask a fever, but others told her that it was okay to give because fever was a side effect of some of the

medications (parent 1). Parents felt it was also important for HCPs to be familiar with written content, so that the written information was the same as the verbal information.

Figuring out life—Following the diagnosis, many parents described feelings of uncertainty about what the diagnosis meant for their family. One parent stated, “...I was so lost- we never had this type of situation in our family, ever” (parent 9). Some parents needed to figure out their life after the diagnosis and make necessary adjustments. One parent reported, “...things that most concerned me ... like I have a job, okay, what am I supposed to do about work?” (parent 3). These concerns required parents’ attention prior to their ability to process the information about their child’s disease.

Worrying about going home—Feelings of uncertainty arose again immediately before discharge when parents became apprehensive about caring for their child at home. These parents’ experiences illustrated this uncertainty, “Cause I didn’t know what to expect” (parent 11) and “Cause there’s no way you can remember everything” (parent 10). Parents expressed concerns about being solely responsible for caring for their child after discharge, and one parent noted what was at stake, “... we can’t mess it up” (parent 5).

Discussion

This study aimed to explore the content, timing, and methods of education experienced by parents of children newly diagnosed with cancer during the initial hospitalization. A prevailing finding of this study is the distinct need for individualization of education (content, timing, and methods) among parents, including individual parents within a couple. Tailoring the educational methods and amount of desired information according to the preferences of each parent is critical to enable parents to optimally process the information. Nurses are at the patient’s bedside far more frequently than any other HCP, which provides opportunities to become familiar with the each parent’s preferred learning style and unique characteristics. Incorporating the unique needs and preferred teaching methods into the plan of care may improve parents’ ability to process the information. The quality of education, in particular the delivery of discharge teaching, has been associated with parent readiness for discharge and coping afterward, which in turn predicts post-hospital health service utilization (e.g. emergency room visits, unscheduled clinic visits, calls to hospital/provider, and unplanned readmission) (Weiss et al., 2008).

When a child is diagnosed with cancer, the initial hospitalization provides an opportunity for nurses to advocate for parents. Nurses play a significant role in educating and supporting parents of children newly diagnosed with cancer (Aburn & Gott, 2014; Kelly & Porock, 2005). Parents in our study identified nurses as HCPs from whom they can learn. Nurses’ frequent presence at the bedside provides opportunities to reinforce and clarify information, describe events as they are occurring, and involve the parent in actively caring for their child. Many parents report not knowing what questions to ask after the diagnostic discussion; however, nurses can support parents by sharing information and discussing questions that other parents commonly ask, while providing ongoing care. Providing anticipatory guidance to parents through explanations of what to expect during treatment, upon discharge, and during follow up visits can enhance the educational process.

Understanding factors that influence learning is essential in order for HCPs to support parents as they respond to the diagnosis and figure out life before receiving detailed information regarding their child's treatment and care. Critical attention to pacing of education allows parents to process information before the delivery of additional information. For example, Eder and colleagues (2007) recommended an initial meeting to discuss the cancer diagnosis then allowing time for parents to cope with their emotions before discussing details of the treatment. Nurses are ideally situated to assess for signs that parents are overwhelmed and advocate adjusting the pacing of information. When nurses identify that parents are no longer able to process information, they can stop an educational session and reschedule for a later time when parents are better able to focus and engage in the informational exchange. In addition, nurses can assure parents that learning is a process that will continue throughout the hospitalization and after discharge, and that information will be repeated as needed. Education does not end at hospital discharge, and it is important for nurses to inform parents about its ongoing nature.

Limitations of this study include a sample that included only parents of children diagnosed with cancer on an inpatient oncology unit. Some children with cancer are diagnosed as outpatients or on a non-oncology unit in the hospital. Educational experiences and needs of those parents may differ and should be explored in future studies. In addition, the majority of the children of the parents (n=15) in this sample were hospitalized two weeks or longer. Many children with cancer are discharged within a few days of their diagnosis and their educational experiences may differ. Although the focus of this study was on the initial hospitalization following diagnosis, many parents noted that the timeframe when they truly understood what was being taught extended far beyond their child's initial hospitalization. These findings suggest that education should be an ongoing process throughout the course of treatment, in order to meet the needs of parents across the treatment trajectory. Future studies are needed to evaluate parents' processing of information and continued learning needs beyond the initial hospitalization.

Conclusion

In this study, parents described the process through which they gained information related to their child's new cancer diagnosis through HCPs *telling* and *teaching* and parents *seeking* and *using* information. Their insights emphasize the need for HCPs to be aware of how they provide education, particularly in regard to the *pacing* and *consistency* of information. All parents have preferred methods of learning. Our findings suggest that these preferences should be identified early in the hospitalization in order to incorporate them into the educational plan. In addition, parents in this study indicated that they want HCPs to be sensitive to their ability to process information, and that HCPs should pace learning appropriately. Parents may also benefit from anticipatory guidance related to the discharge process. Assessing influencing factors and parental concerns related to discharge will assist HCPs in identifying areas in which parents need additional reassurance or education. As one parent noted, "everything is at stake."

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References

- Aburn G, Gott M. Education given to parents of children newly diagnosed with acute lymphoblastic leukemia: A narrative review. *Journal of Pediatric Oncology Nursing*. 2011; 28(5):300–305. [PubMed: 21946195]
- Aburn G, Gott M. Education given to parents of children newly diagnosed with acute lymphoblastic leukemia: The parents' perspective. *Pediatric Nursing*. 2014; 40(5):243–256. [PubMed: 25929116]
- Corbin, J., Strauss, A. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 4th. Los Angeles, CA: Sage; 2015.
- Dantas C, Leite J, de Lima S, Stipp M. Grounded theory – conceptual and operational aspects: A method possible to be applied in nursing research. *Revista Latino-Americana de Enfermagem*. 2009; 17(4):573–579. [PubMed: 19820867]
- Eden OB, Black I, MacKinlay GA, Emery AE. Communication with parents of children with cancer. *Palliative Medicine*. 1994; 8:105–114. [PubMed: 8081551]
- Eder ML, Yamokoski AD, Wittmann PW, Kodish ED. Improving informed consent: Suggestions from parents of children with leukemia. *Pediatrics*. 2007; 119(4):e849–e859. [PubMed: 17403829]

- Ewing LJ, Long K, Rotondi A, Howe C, Bill L, Marsland AL. Brief report: A pilot study of a web-based resource for families of children with cancer. *Journal of Pediatric Psychology*. 2009; 34(5): 523–529. [PubMed: 18784185]
- Foley G, Timonen V. Using grounded theory method to capture and analyze health care experiences. *Health Services Research*. 2015; 50(4):1195–1210. [PubMed: 25523315]
- Flury M, Caflisch U, Ullmann-Bremi A, Spichiger E. Experiences of parents caring for their child after a cancer diagnosis. *Journal of Pediatric Oncology Nursing*. 2011; 28(3):143–153. [PubMed: 21490277]
- Jackson AC, Stewart H, O-Toole M, Tokatlian N, Enderby K, Miller J, Ashley D. Pediatric brain tumor patients: Their parent's perceptions of the hospital experience. *Journal of Pediatric Oncology Nursing*. 2007; 24:95–105. [PubMed: 17332423]
- Kelly KP, Porock D. A survey of pediatric oncology nurses' perceptions of parent educational needs. *Journal of Pediatric Oncology Nursing*. 2005; 22:58–66. [PubMed: 15574727]
- Landier W, Leonard M, Ruccione KS. Children's Oncology Group's 2013 blueprint for research: Nursing discipline. *Pediatric Blood & Cancer*. 2013; 60(6):1031–1036. [PubMed: 23255369]
- Lewis D, Gundwardena S, Saadawi GE. Caring connections: Developing an Internet resource for family caregivers of children with cancer. *CIN: Computers, Informatics, Nursing*. 2005; 23(5): 265–274.
- Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Peace of mind and sense of purpose as core existential issues among parents of children with cancer. *Archives of Pediatric & Adolescent Medicine*. 2009; 163(6):519–524.
- Matutina R. Educating families of children newly diagnosed with cancer. *Cancer Nursing Practice*. 2010; 9(1):28–30.
- McGrath P. Beginning treatment for childhood acute lymphoblastic leukemia: Insights from the parents' perspective. *Oncology Nursing Forum*. 2002; 29(6):988–996. [PubMed: 12096296]
- Rabineau KM, Mabe PA, Vega RA. Parenting stress in pediatric oncology populations. *Journal of Pediatric Hematology/Oncology*. 2008; 30(5):358–365. [PubMed: 18458569]
- Sandelowski M. Whatever happened to qualitative description? *Research in Nursing & Health*. 2000; 23:334–340. [PubMed: 10940958]
- Sandelowski M. Sample size in qualitative research. *Research in Nursing & Health*. 1995; 18:179–183. [PubMed: 7899572]
- Slone JS, Self E, Friedman D, Heiman H. Disparities in pediatric oncology patient education and linguistic resources: Results of a national survey of pediatric oncologists. *Pediatric Blood & Cancer*. 2014; 61(2):333–336. [PubMed: 24167088]
- Speziale, H., Carpenter, D. *Qualitative Research in Nursing, Advancing the Humanistic Imperative*. 5th. Philadelphia, PA: Lippincott, Williams & Wilkins; 2010.
- Svavarsdottir EK, Sigurdardottir AO. Developing a family-level intervention for families of children with cancer. *Oncology Nursing Forum*. 2006; 33(5):983–990. [PubMed: 16955126]
- Tackett AP, Cushing CC, Suorsa KI, Mullins AJ, Gamwell KL, Mayes S, Mullins LL. Illness uncertainty, global psychological distress, and posttraumatic stress in pediatric cancer: A preliminary examination using a path analysis approach. *Journal of Pediatric Psychology*. 2016; 41(3):309–318. [PubMed: 26423322]
- Thorne S, Kirkham SR, MacDonald-Emes J. Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*. 1997; 20:169–177. [PubMed: 9100747]
- Weiss M, Johnson NL, Malin S, Jerofke T, Lang C, Sherburne E. Readiness for discharge in parents of hospitalized children. *Journal of Pediatric Nursing*. 2008; 23(4):282–295. [PubMed: 18638672]

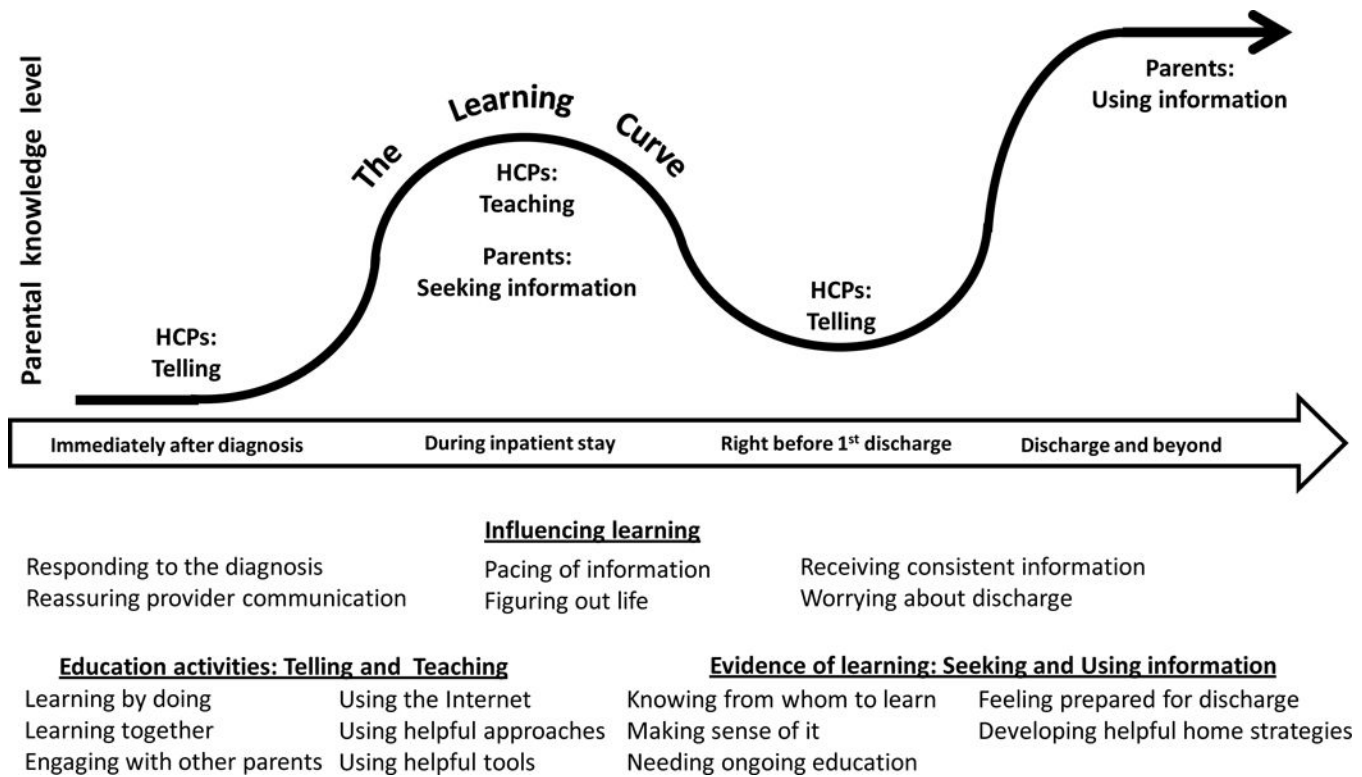


Figure 1.
Parental processing of information after a child’s cancer diagnosis

Table 1

Parent Characteristics

Characteristics	N (%)
Gender	
Female	16 (80)
Male	4 (20)
Age	
21–29	7 (35)
30–39	9 (45)
40–49	3 (15)
> 50	1 (5)
Race	
Caucasian	10 (50)
African American	6 (30)
Asian	1 (5)
Other	3 (15)
Education	
Some high school	2 (10)
High school graduate	2 (10)
Some college	6 (30)
College graduate/graduate school	10 (50)
Marital Status	
Single, never married	6 (30)
Single, divorced	2 (10)
Single, parents cohabitating	1 (5)
Married	11 (55)
Patient Characteristics	
Age	
< 3 years	3 (15)
3–6 years	9 (45)
7–12 years	5 (25)
13–18 years	3 (15)
Diagnosis	
Leukemia	12 (60)
Lymphoma	1 (5)
Solid Tumor	7 (35)
Initial Hospital Length of Stay	
< 2 weeks	5 (25)

Characteristics	N (%)
2-4Weeks	8 (40)
> 4weeks	7 (35)

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Table 2

Parent Listing

Parent ID Number	Parent Role	Child's Age	Child's Diagnosis
1	mother	16 years	APML
2	mother	3 years	ALL
3	mother	4 years	ALL
4	mother	10 years	Ewing sarcoma
5	mother	3 years	ALL
6	father	4 years	Rhabdomyosarcoma
7	mother	10 months	Infant ALL
8	mother	16 years	AML
9	mother	10 years	Non Hodgkin Lymphoma
10	father	5 years	ALL
11	mother	4 years	ALL
12	mother	4 years	Wilms Tumor
13	mother	2.5 years	Rhabdomyosarcoma
14	mother	17 years	Osteosarcoma
15	mother	11 years	Osteosarcoma
16	mother	3 years	ALL
17	father	2 years	ALL
18	father	15 years	ALL
19	mother	12 years	Rhabdomyosarcoma
20	mother	7 years	ALL

Abbreviations: APML=acute promyelocytic leukemia; ALL=acute lymphoblastic leukemia; AML=acute myeloid leukemia

Table 3

Selective, Axial, and Associated Codes

Processing information after my child's cancer diagnosis (Selective code): Parents manage information from the new diagnosis discussion and inpatient teaching in ways that lead to learning to apply new skills to the care of their child with cancer after discharge		
Telling (Axial code): Health care providers' one-way education processes that are used to deliver large quantities of information at diagnosis and initial discharge		
Teaching (Axial code): Interactive education processes characterized by a reciprocal information exchange between health care providers and parents		
<i>Associated code name</i>	<i>Code definition</i>	<i>Exemplar Parent Statements</i>
Learning by doing	Parents are actively engaged in their new diagnosis cancer education	"... I learned and it's because I learned again hands on. You know and I- I- thrive on hands on you experiences. So yeah" (parent 19)
Learning together	Parents acquire new diagnosis cancer information in structured classes with other parents	"...in that class it's like the one time you get a bunch of other parents in the room. So if they had like questions about things yourself hadn't thought of, you had those extra brains around..." (parent 10)
Engaging with other parents	Parents find meeting and interacting with other parents of children variably helpful.	"...it was a lifeline for us to reach out and find other people who- maybe not the same cancer but that were walking a similar journey so that they kind of understood." (parent 2) "...they were dealing with their own personal issues" (parent 6)
Using the Internet	Parents feelings about the helpfulness of computer-based resources as a source of new diagnosis cancer education.	And give us websites to go to with accurate information. You know we are going to look, we all have laptops or smart phones and we are going to use them. So give us a list of good links to go to. (parent 1)
Using helpful approaches	Parents found or perceived various strategies beneficial during the new diagnosis cancer education process	"I actually had a nurse tell me a couple of days in, 'You may want to take notes.' Yeah, so after that I started carrying my notebook and started writing everything down." (parent 4)
Using helpful tools	Parents' preferred and actual educational tools that they identified as helpful during the educational process	A notebook for copies of blood counts, the calendar, and paper to write questions (parent 13)
Seeking information (Axial code): Parents pursue knowledge important to them as they assimilate their child's cancer diagnosis and associated home care into their lives		
Using information (Axial code): Parents are able to apply new diagnosis cancer education to the process of caring for their child		
<i>Associated code name</i>	<i>Code definition</i>	<i>Exemplar Parent Statements</i>
Making sense of it	Parents begin to process information as events occur after discharge	"I felt that- it was a little bit harder [flushing lines at home] ... but I had the paper and so it was step-by step and so I think you do it a couple times, you kind of get used to it." (parent 8)
Needing ongoing education	Parents require additional information after going home the first time	"The one thing I would say is um, there's a lot of assumptions going around when we come in now, that we know everything." (parent 10)
Knowing from whom to learn	Parents recognize that different providers meet their varying new diagnosis cancer education needs	"I mean they [nurses] were the ones who really I felt like- were like our anchor you know? And kind of guided us- like gave us the lowdown you know what I mean?" (parent 16)
Feeling prepared for discharge	Parents perceive different levels of adequacy regarding understanding information to successfully implement tasks associated with the care of their child after going home the first time	"So I mean it's- we kind of left in confusion and then I just sorted it out after I got home." (parent 4) "Yeah because when I got home it was easy. It was easy to make the chart... and all I had to do was leave the chart and everything went down perfectly." (parent 15)
Developing helpful home strategies	Parents identify tactics that they find useful to care for their child at home after discharge.	"I started writing everything down, yeah of ah- I wrote a schedule out. And then I started writing down everything ah, time-wise what I gave her. Until

<i>Processing information after my child's cancer diagnosis (Selective code): Parents manage information from the new diagnosis discussion and inpatient teaching in ways that lead to learning to apply new skills to the care of their child with cancer after discharge</i>		
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<i>Teaching (Axial code): Interactive education processes characterized by a reciprocal information exchange between health care providers and parents</i>		
<i>Associated code name</i>	<i>Code definition</i>	<i>Exemplar Parent Statements</i>
		it became routine and then I didn't have to do it." (parent 4)
<i>Influencing learning (Axial code): Responses to the cancer diagnosis, and to health care provider approaches to education, that affect parents' ability to process information</i>		
<i>Associated code name</i>	<i>Definition</i>	<i>Exemplar Parent Statements</i>
Responding to the diagnosis	Parent emotions and reactions to the news of their child's cancer	"I'd say the only thing is just trying to retain everything with the fog that you're in from being hit with it." (parent 4)
Receiving reassuring provider communication	Parents feel comfort and support from clinicians by the ways they interact with them	"... and I think he is a really good example of a doctor who I think understood um the- the emotional moment that was happening with our family and what that- what this change was meaning for our family. ... I felt like he was very empathetic which was good. But he was very factual you know but open and nice." (parent 16)
Figuring out life	Parents must adjust their family activities, including work and children's activities, after the child's diagnosis	"That was my hardest experience just having to juggle the logistics with you know who can I shuffle car pool off with you know for my daughter. And you know who's gonna pick up this meal or who's gonna let the cleaners in. You know just like the little logistics that you don't think crowds you until it crowds you." (parent 5)
Worrying about discharge	Parents feel uncertainty and apprehension as they prepare to take their child with cancer home for the first time	"Like that whirlwind still hadn't worn off and they're like, Okay, now you take her home. And I just remember that scared me the most" (parent 16)
Pacing of information	Parents' sensitivity to the timing of new diagnosis cancer education and their ability to take it in and retain it	"Cause I know that first meeting was three hours and ... I'm sure that they told us three hours worth of information. I don't remember three hours worth of information." (parent 2)
Receiving consistent information	Parents express a need for uniform educational content, including a preference for having the same clinicians provide the education	"I would have fifty different doctors telling me things and every doctor's got a different opinion. So I kind felt like sometimes I got fifty different opinions, you know?" (parent 6)

Table 4

Actual and Desired Content throughout the Hospitalization

DIAGNOSIS	
<i>Actual</i>	<i>Desired*</i>
Disease Prognosis Treatment (immediate and overview of phases of treatment) Clinical trials and randomization Side effects of treatment Blood counts Transfusions Calculating absolute neutrophil count (ANC) Neutropenia Defining fever and what to do Central venous access device How to talk to patient's siblings	Stories of children surviving cancer Duration of treatment
INITIAL HOSPITALIZATION STAY	
<i>Actual</i>	<i>Desired*</i>
Fevers – what is it, when to call, what to expect Medications and side effects of the medications Mood swings and diet for child on steroids Symptoms to watch for Blood cells Transfusions Hand washing Hygiene and oral care Filgrastim injection How to take temperature Care of central venous access device Signs of central venous access device infection Not to give over the counter medications Infertility Roadmap for treatment When patient should wear mask Nutrition Preparing the home for discharge Information for siblings Activity restrictions after discharge Hospital routines Reassurance that parents did not cause the cancer Overview of full treatment Reliable websites	Length of hospitalization and possible discharge date Likelihood for hospital readmissions Why patient is receiving a transfusion Timeframe for neutropenia Implications of neutropenia once discharged (i.e., need to stay home, need to avoid restaurants, when is it okay to go to school) Ways to encourage child to eat and drink Chemotherapy precautions for family members Activity restrictions (i.e., swimming) Duration of treatment and need for long-term follow up Support groups through social media and physical meetings
DISCHARGE	
<i>Actual</i>	<i>Desired*</i>
Emergency phone numbers Fever Need to go to local hospital if fever develops and call treating hospital Medications – schedule, dosing, purpose, side effects How to administer injections Do not administer over the counter medications Signs and symptoms to call immediately Neutropenic precautions Thrombocytopenic precautions and signs of bleeding that parents should call about Care of central venous access device Hygiene Hand washing Oral care and diet if mucositis develops Nutrition and diet precautions Preparing home Minimize sun exposure Reassurance to call with any questions after discharge Expect unplanned admissions and have emergency bag packed and ready Frequency of clinic visits Information for siblings	How to give young child oral medications What to do if child vomits after oral medication Specific warning signs to call immediately Clinic routine Needle size for port access Precautions for siblings Precautions for visitors at home Diet precautions (i.e., what does it mean to wash fruits and vegetables really well?) Support groups through social media and local meetings

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* Desired content is in addition to, and not exclusive of, actual content

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Table 5

Healthcare Provider Approaches that Help Parents Learn

Teaching Strategies	Exemplar Parent Statements
Discussing	"...when they came in they explained everything" (parent 13)
Written information and discussion	"...the doctors took the time to give me the paper and then sit down and you know, talk to me about it, not just give it to me, here read this over" (parent 18)
Written information	"...getting like that notebook" (parent 16)
Emphasizing important information	"...they told me the most important parts to read" (parent 13)
Describing current events	"So they did a good job I think, about explaining and teaching us about kind of the things that they were doing" (parent 16)
Repeating information	"...she went over it a lot of times" (parent 15)
Providing an opportunity for questions	"Them staying around long enough for me to ask them questions...even if you asked it to them three different ways they tried to give you an answer for it" (parent 6)
Providing consistent information	"Everyone was kind of saying the same thing" (parent 17)
Using layman's terms	"...everyone here explains things on a normal person's level" (parent 17)
Structured teaching	"... we also had the poster and the board regarding like the steps that we were taking..." (parent 11)
Practice	"...they set up to give me, like with the needle and something to stick, and they really go over the teaching of it..." (parent 3)
Learning parent cues	"...I'd be worried about something, and I guess they could tell..." (parent 3)
Displaying compassion while teaching	"... they also kind of piggy backed from like the medical advice and the medical aspects of it, but then they also gave the you know, the- the loving and the support and you know the therapy kind of deal too" (parent 5)
Providing anticipatory guidance	"And they were very good at you know telling us ... this is the things you need to look out for, this would be something that I would be worried about, this would be something that I wouldn't be so worried about..." (parent 6)