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Parental expectations of support from healthcare providers during pediatric life-threatening illness: A secondary, qualitative analysis

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Abstract

Purposes—To explain parental expectations of support from healthcare providers for their parenting roles and goals during a child's life-threatening illness (LTI).

Design and Methods—Qualitative interpretive study guided by the Family Adjustment and Adaptation Response Model. Thematic analyses were conducted with data from 31 semi-structured interviews of parents of children with LTI using systematic strategies to ensure rigor including audit trails and prolonged engagement.

Results—We identified three themes and one meta-theme or overall theme: (1) "Help us survive this," (2) "Let's fight together: please fight with me, not against me, to care for my family," and (3) "Guide me through the darkness: I am suffering." Overall, the parents conveyed that they expect mutuality with the health care providers and system in order to keep *Fighting together for my family survival*.

Conclusions—In the daily work of caring for their families, parents of children with LTI consider survival on multiple levels. They consider the life, illness, and potential death of one child while considering the on-going survival and sustenance of family relationships. Practice Implications: Parents are distressed and grapple with conflicted feelings about managing competing needs of various family members. Relationships with health care providers can influence parents' management of the situation and be a source of support as their parenting role changes over the illness trajectory, time, and in response to adversity.

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Keywords

parenting; palliative care; qualitative; secondary analysis

Parenting a child with a life-threatening illness (LTI), one that carries a substantial chance of mortality in childhood, is transformational for the parents and the entire family unit (Association for Children with Life-Threatening or Terminal Conditions and their Families and The Royal College of Paediatrics and Child Health (ACT/RCPCH), 2004). Parents face challenges of typical parenting tasks and communication (removed for blind review), while also facing a profound meaning-making process and enter into a “battleground” for the life of their child (Whiting, 2012). The parents’ new roles and responsibilities subsequently change the way they interact with and relate to others members of the family (removed for blind review). Facing and coping with the challenges of redefining parental roles can have serious consequences for the parents and other family members (Muscara, McCarthy, Woolf, Hearps, Burke, and Anderson, 2015). Uncertainty related to the prognosis and the lived experience of sadness and guilt create emotional distress (Burke et al., 2014; Dighe, Jadhav, Muckaden, & Sovani, 2008) that increase psychological risk for parents. This risk, in turn, can have profound effects on other family members and the family unit (Bally et al., 2014; Muscara et al., 2015).

Parents of children with LTI make sense of their roles through personal, social, and cultural influences, previous or current illness experiences, and their experience of parenting over the entire illness trajectory (Hall & Hill, 1996). In particular, the provision of meaningful social support (relatives, friends and the health care system) can shape how parents view the illness experience and, subsequently, the outcomes for the patient and family over the illness trajectory.

While hospitals endeavor to be less threatening for parents exercising their role in caring for their children, such efforts must overcome barriers created by complex medical treatments and vestiges of traditional ideas about parents and family members as guests or visitors (Baird, Davies, Hinds, Baggott, & Rehm, 2015). Collaboration between parents and healthcare providers can enable the parents to meet the demands of caregiving, fulfill their parental and family goals, and strengthen their capabilities. As healthcare providers provide security, continuity of care, and safe haven (Kearney & Byrne, 2014), parents’ sense of confidence can become stronger, enabling them to redefine their parental role and reprioritize their goals as parents (Heller & Solomon, 2005; Nuss, 2014). Therefore, a need exists for coherence between care provided by the healthcare team and parents’ goal of caring for their children, from diagnosis through bereavement. Recent research, however, revealed that parents of children with serious illnesses wanted healthcare providers to be concerned about their emotional health, but they did not perceive that such concern existed (Aschenbrenner, Winters, & Belknap, 2012).

Multifaceted, systematic psychosocial assessments of youth and their families throughout the treatment continuum create a caring context for parents (Kazak et al., 2015) and assist in identifying adaptive and problematic reactions (Muscara et al., 2015). Such assessments are the building blocks of genuine relationships that are highly valued by parents. Delivery of competent care and symptom management to the ill child and recognition of parental expertise are also important components of the parent-provider relationship (Melin-Johansson, Axelsson, Jonsson Grundberg, & Hallqvist, 2014). The quality of such relationships and interactions are important sources of support for parents during the illness course and for improving long-term grief (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Heller & Solomon, 2005; Van der Geest et al., 2014)

To fill a gap in the literature regarding parents' perceptions of the challenges they face in fulfilling their parenting roles within the healthcare system, we sought to answer the following question, "How do parents describe their expectations of healthcare providers for support of their parenting roles and goals during their child's life-threatening illness (LTI)? The results of this study will enhance understanding of family adaptation in childhood LTI and the demands placed on parents in contemporary hospital environments, as well as their perceived capabilities.

Methods

Framework

The Family Adjustment and Adaptation Response Model informs this secondary analysis (Patterson, 2002), integrating the clinical family resilience perspective with family stress theory. We chose this model because of the emphasis placed on family capacity and potential for growth, as well as the view of family adaptation as dynamic over the course of a child's illness experience, contextual, and rooted in the meaning the family ascribes to the LTI.

Various traditions have investigated parenting and parenthood, including psychoanalytic tradition, feministic perspective, developmental psychology, and attachment theory perspective (Mayseless, 2006). Patterson's model informs the definitions used in this study (Figure 1) in that we consider normative aspects of parenting demands, capabilities, or sources of meaning for parents of a child with LTI. In addition, this model displays the dynamism of family adaptation over time and over the trajectory of both healing and deterioration in the child's condition.

Study Design

The primary study was qualitative descriptive since the phenomenon of parenting and intrafamilial relationships in pediatric life-threatening and life-limiting illness is an under-explored phenomenon (removed for blind review). Our approach to this secondary, interpretive process was to answer a research question with an aim and focus that transcends that of the original research (Heaton, 2008; Thorne,1994). We conducted this secondary analysis to understand how parents decribe and explain their expectations of the healthcare providers and the healthcare system to support their achievement of parenting goals in peditric LTI. We sought to extend beyond description of how parenting is supported by clinicians to an interpretive analysis necessary to uncover patterns of human behavior or subjective experience (Thorne, 2008). This interpretive analysis allowed us to understand the meaning parents ascribed to support offered by healthcare providers and system as they lived out their daily role of parenting both ill and healthy children. This systematic approach provides strategies to look beyond the words of these parents who are in an extremely difficult situation, one in which their children were most likely getting closer to the ends of their lives, to capture their overall context and meaning. (Thorne, 2008).

Setting, Sampling, and Recruitment

The first author recruited parents and collected data for the primary study from February 2013-November 2013 at a large, tertiary, mid-Atlantic children's hospital. She recruited parents of children with LTI who were not expected to recover or survive childhood. The children received treatment of the LTI or associated exacerbation in the intensive care units, oncology unit, stem cell transplant unit, or from the palliative care team. In order to attain variation in our sample, the first author recruited across shifts, weekdays/weekends, and units so that parents who may not be at the bedside during the workweek could participate and to attain variation in parent gender, socio-economic status, severity and type of illness in the ill child, and age of ill child. In the primary mixed-methods study, 36 mothers and fathers enrolled and 31 completed the qualitative interview. In terms of the five who did not complete the study, one parent completed the quantitative survey only (which is not included in this analysis), one parent withdrew because she felt overwhelmed by her child's hospitalization and illness care needs, and three parents had children who died after they enrolled and prior to data collection.

Data Collection

The first author interviewed each participating parent separately in a location chosen by the parent and conducted most interviews in the ill child's hospital room or in a conference room on the same unit. For several parents (4), telephone interviews were the primary mode of data collection. Parents requested telephone interviews to accommodate their employment schedules or if their child had been discharged from the hospital prior to data collection. The first-author used a semi-structured interview guide for all interviews, which contained questions to elucidate the phenomenon of parenting in childhood LTI, such as "What is most important to you in being (ill child)'s parent? How about for your other children? What would have been helpful for your healthcare providers to do that did not happen? What other kinds of support would have helped you?" What was difficult about this hospitalization?" Interviews were digitally recorded and transcribed verbatim. The first author checked the transcripts for completeness and imported to *Atlas.ti* (v.7) qualitative analysis software.

We used pseudonyms to protect participant identity and removed all identifying information from the analysis. The hospital and associated university IRB approved the study and participating parents provided informed consent.

Analysis

We used the principles of thematic content analysis and followed a standard procedure for conducting qualitative analysis (Braun & Clarke, 2006; Corbin & Strauss, 2014; Vaismoradi, Turunen, & Bondas, 2013). We reviewed transcripts in their entirety followed by coding of phrases, sentences, and paragraphs. We applied a start-list of codes, based on the semi-structured interview guide to the data, as well as new codes that emerged from the data. We further refined the codes and gathered them into a codebook, which guided subsequent application. For example, early codes included, “what is stressful for us;” “family: what helps or hinders;” and, “resources: harder.” We then grouped these refined codes into categories, which were more abstract. For example, we grouped the above codes into categories of, “needing information” and “having social work support.” This process led to the establishment of the broader themes from the data and was a continuation of the bottom-up process. The themes described relationships among categories that elucidate key elements of parental expectations of the healthcare providers and systems so that they could meet their demands and enhance their capabilities when a child is ill. For example, the categories described above are the foundation for the subthemes of instrumental support to survive the situation and keep their family intact in the first theme, “Help me survive this.” Table 1 displays an example of how codes and categories connect with themes. Our study team created the themes to capture our interpretations of the data. Participating parents’ words are included in the pertinent quotes.

There were minimal missing data since all parents answered questions about the support they desired from their child’s healthcare team and changes they would like to see in the healthcare setting. All authors had access to de-identified, transcribed data relevant to the secondary analysis research question and a de-identified description of each participant (e.g. number of children in the family, length/severity of illness in the ill child, the family’s illness story). Additionally, the primary study team (removed for blinded review) were members of the secondary analysis team along with (removed for blinded review) so that questions could be answered and issues about the data and participants could be clarified. To maintain qualitative rigor, we maintained an audit trail, engaged with the data for a prolonged period, created a thick description of parenting and parenting needs, and reviewed the data and analysis with qualitative experts and across multiple researchers who are experts in pediatric palliative care. During the primary study, the first author also maintained a fieldwork journal, and used maximum variation sampling to ensure a sample diverse in gender, social class, race, child’s diagnosis and severity of illness (Guba, 1981).

Results

Data from in-depth qualitative interviews with 31 parents of 28 children are included in this analysis, including 25 mothers and 6 fathers. We described the sample in findings from the primary study (removed for blind review). Table two displays the characteristics of the sample of parents and children with LTI. Most of the parents had been caring for their children since birth due to prematurity, congenital heart disease, or genetic disorders. Three of the 28 children had cancer and received a diagnosis during middle childhood or adolescence; the parents of children with cancer experienced the transition from having a previously healthy child to having a child with a LTI. All parents described the child with LTI as having multiple chronic illnesses or effects from the LTI. Most of the parents in this sample had been caring for their child for at least one year and fourteen stopped working entirely in order to provide this care. Eleven parents made end-of-life decisions during the child’s hospitalization in which the interviews took place, such as enrolling in a Phase I clinical trial, limiting life-sustaining therapies, or enacting/withdrawing a do-not-resuscitate order. While parents made some of these decisions to provide life-sustaining measures during this particular hospitalization, their presence demonstrates the severity of the child’s illness state and their fragile clinical status during the interview period. Considering the children in the family, more than half of the index children with LTI were younger than five years old and most families had one or two other children in addition to the child with the LTI. More than half of the parents lived at least one hour away from the hospital to which their ill child received care. Four parents lived outside the tristate area, with one family from another nation.

Themes

We identified three themes from the qualitative data that represent how parents describe their expectations of healthcare providers and system to support their achievement of parenting goals in peditric LTI. The first theme "Help us survive this," expresses the elemental support parents believed they needed to manage and preserve their family on a daily basis in order to continue to live and exist as a family despite the LTI. The second theme, "Let's fight together: please fight with me and not against me to care for my family," includes recognition of the intense work involved in caring for the ill child and a request to prioritize preserving the family. Theme three, "Guide me through the darkness; I am suffering," again asks for recognition of their suffering in terms of negative emotions and for support with their problem solving. The meta-theme, *Fighting together for my family survival*, summarizes the mutuality parents expect of healthcare providers and healthcare system providing care in the context of LTI.

Theme 1: Help us survive this—The supportive measures described by parents both built on their capabilities as parents and decreased the complex demands of LTI by alleviating illness-related demands and reducing the demands of the child's life-threatening condition. Such demands include completing basic tasks or managing the chaos generated from an acute decompensation or hospitalization. As one mother described, limited resources to meet demands caused distress:

> "*I pray for the baby in her situation now, but we pray for our situation, too, because we need gas, food. They [the people at the hospital] gave us money and said, 'that's for you and your family for food and gas." I cried to them and said thank you because you are with us" (Elissa).*

Parents reported that supportive measures to increase their capabilities were vital for managing and engaging in the day-to-day demands of parenting. Supportive measures allowed them to create order and regain a sense of control so they could do what they believe is necessary for their children. Within this overarching theme, two subthemes describe the specific support needed to survive the situation: instrumental needs (or basic survival needs) and family preservation needs.

Instrumental needs: Instrumental needs (or basic survival needs) are those demands that are part of day-to-day living, such as food, vouchers, money, job security and flexible work arrangements, chores/home maintenance, and transportation. For example, families may encounter cumulative financial demands that put them at increased risk for stress and that can overwhelm their financial capabilities. One mother describes the impact succinctly, yet poignantly, "Money would take care of a lot of the things I cry about." As seen in Tyler's quote, the day-to-day cost of having a child in the hospital overwhelmed the savings he accumulated in anticipation of his child’s surgery:

> *I was working. I had money and everything saved up for this. But the first week in the hospital, I didn’t know nothing about food vouchers. I didn’t know about the $3 discount parking, so I am paying $12, $21 for parking every day, so I spent a lot. Everything that I had saved, I spent it all that first week here (in the hospital). Then the second week I start meeting the social workers, they’re like hey, “I got a voucher!” You come now? (Tyler).*

Parents described lapses in communication between the hospital staff and families posed a challenge to getting instrumental needs met. As one mother describes, such lapses in communication may lead families to perceive that the healthcare providers do not understand their plight or are not concerned:

> *They don’t really offer help until you ask for it. They don’t come out and just give you a handbook and say, ‘here’s what we have to offer.’ My daughter hates the food here. I didn’t know I could get vouchers for her until two years later…a mother told me. There’s some kind of miscommunication like, they don’t tell you things. I don’t know if it’s cause they don’t want you to use it or don’t want you to know about it (Valerie).*

Family preservation needs: Family preservation needs are in response to demands parents perceived regarding the survival of their family relationships, including balancing the competing demands of all their children, a desire to remain connected to their healthy children during the ill child’s health crisis, and a desire to enhance the relationships between all the siblings. Parents expressed this need across several family relationships: support for relationships with sibling, ill child, and other family members that helps them keep the family together and promotes connection among its members.

Parents also expressed a sense of desperation to preserve their relationships with the ill child’s siblings so that those children could thrive despite the complex illness situation. Parents described resources, in the form of guidance from healthcare providers or family-friendly hospital policies that would help them maintain relationships with all of their children and provide an avenue for parents to carry out parenting tasks for these children. Parents sought alignment or unity between what they perceive they need to do to help these relationships survive and what they are realistically able to do. The weight of caring for a family when it is in two different places, along with the perception of a high-stakes situation, can be distressing. As Caroline and Georgia point out, hospital-based resources that build on parents’ capability to parent and be physically present to a child were highly desired.

> *I need my son to be involved in a sibling room to play…It would balance his needs and he wouldn’t feel like he was being bounced because I could keep him here all day. He would be here with me and it would give him a chance to go play and come back. He could participate in the care, like he’s a valuable part of the family. I wish people would give me the tools to allow him to be this kid. He wants to be involved so much and he’s a great motivator for her (child with LTI) (Caroline).*

> *If a hospital offered some type of daycare for kids…we could just have Bridget here somewhere during the day…since my husband is here but is still working remotely and I have to tend to Max all day because you never know when the doctors are coming around and I can't have her in the room all day. So if there was a daycare or school at a hospital that siblings could go to, I think Bridget could be here and we could be her parents at night (Georgia).*

In summary, parents desired supportive measures by healthcare providers and the healthcare system that built on family capabilities to control or manage the competing demands of the situation. Parents were deeply concerned about the needs within the family and preserving connection. Underlying this desire for preservation, however, parents expressed fear of their family falling apart and losing connection, as well as a sense of desperation to prevent this from happening. The demands of carrying this out were so intense or different from what the family had previously encountered that demands threatened to overwhelm capabilities. Parents sought support and resources to increase their capabilities and provide a sense of control that they believed could help them focus on maintaining connection and emotional security and enhance their feeling of safety and ability to parent and care for the children. Parents sought support and resources to bolster their capability of maintaining family relationships and diminish the demands, such as resources for siblings, supports for parents' partnered relationship. These sources of support were perceived to be a way to maintain control of some elements of an uncontrollable situation. Sources of support desired by parents in this instance included hospital based resources for siblings so that they could simultaneously parent the ill and healthy children, as well as support during lengthy hospitalization for the parental relationship or partnered relationship

Theme 2: Let's fight together: please fight with me and not against me to care for my family—In this theme, parents expressed a desire for healthcare providers to work with them (and not against them) to care of the child who is ill. Parents wanted healthcare providers to take care of their child the same way they do; they wanted healthcare providers to provide competent care that goes beyond the task to providing care with love and recognizing the uniqueness of the child and family. As April, the mother of a young child who was dependent on technology, notes:

> *They get so robotic, believing everybody is the same…until boom, they meet me and it's like, why is she asking for things to be different. My thing is everyone's different. Don't put me in no box. This is my daughter. I want the best for her. She is loved.*

This theme illuminates the movement from competent care to individualized, family care because it demonstrates a desire for care provided by the healthcare team to be rooted in mutuality, engaged with the child and family, and aligned with child and family goals. For example, several parents described suboptimal experiences with their child's home healthcare nurses because the care, while competent and task-oriented, did not incorporate parental goals for engaging in care (i.e. teaching parent how to do the care) or did not recognize family goals for the child's care (i.e. maintaining normality and promoting growth and development). For example, one mother of a young child with ventilator-dependency described how she interviewed home health nurses herself, even though the home health agency deemed them competent. She believed a nurse caring for her daughter must “not only be good at what she [or he] does, but also love my child, get on the floor and read to her.” Such care contributes to parents’ sense of being able to manage an unmanageable situation. Health care providers are trusted with the care that parents have directed at home during a child’s hospitalization so that parents can concentrate on collaborating, engaging, and activating to meet family demands. Parents want mutuality and collaboration with the healthcare team and to be a conduit of inspiration, yet they perceive their vulnerability and want protection and support.

When health care providers worked with parents on issues the parents perceived were important, they felt acknowledged and supported in work that they thought was essential. In addition, caregiving tasks became central to the way they defined being a parent for the child with LTI in that they were caring for, protecting their child, and communicating love to the child. When healthcare providers did this well, as Georgia describes, parents feel included, empowered, and part of a team.

> *That’s the one thing that is very different at [large mid-Atlantic children’s hospital] versus the hospital we came from. Here, I feel like it’s a team effort. The doctors, NPs, everybody really listens to us. (Georgia).*

Conversely, as Will demonstrates, when this does not go well, parents can feel alienated and unsupported.

> *When you have people who are supposed to fight for you or say that they will, and they don’t; they love to say what their job is, tell how great they are and how much easier it will make this for you and then you can’t get a hold of them, they don’t return voicemails or emails; give you the run-around (Will).*

This support was also desired considering the siblings of the ill child. Parents decribed wanting support for and recognition of the work needed to parent multiple children. As one mother points out, it was difficult in the acute care setting to do what she believed necessary for all of her children. After working all day, she felt she needed to spend time with the ill infant in the intensive care unit and the healthy toddler sibling. However, the structural environment is not always accommodating, as Tamara describes:

> *I’d like the hospital to have something for the two year old sister to do, like a playroom. I’d think a childrens hospital would have some activities for siblings of these children. When we’re in our own room, the toddler can do whatever she wants to do, but when we’re in the ICU [and multiple babies share a space], it’s a lot harder. I’m on a nervous breakdown because the toddler can only sit there so long.*

Theme 3: “Guide me through the darkness; I am suffering.”—In this theme, parents described their internal processes of grappling with conflicting feelings about the competing demands of all children in the family, the demands of their own intimate relationships, and the desire to come to terms with or find peace in this journey. Parents wanted to understand how this illness situation could affect their other children, what they should try to do about it, and what they actually could do about the family’s situation. As

Jennifer described the experience managing the needs of her infant with a LTI and her healthy children at home:

> "*I'm still sick to my stomach thinking, is this the right thing to do? When she was hospitalized after birth, it was horrible. When the other kids say, mommy, I want you to put me to bed, not Grandma, and knowing I couldn't do that. Then every day leaving the unit, I'd get short of breath and chest pains because I had to leave her.*"

Parents described feeling abandoned, desolate, empty, and alone; on any given day, parents who appeared to be meeting the ever-increasing goals established for them by the ill child's health care team may feel distressed and overwhelmed. As one father noted, "Parents have to have almost this persona. They gotta be the tough, strong parents." Health care providers may contribute to isolation and distress in parents, along with structural barriers, through the implicit and explicit expectations held for parents and the actions for which we applaud them. That is, expectations of health care providers may be unrealistic when considering other parental responsibilities. These barriers or unrealistic expectations can obscure the best "next steps" for a parent to take regarding the care of their ill child and family. Such expectations can be a source of stress and inadvertently send a message that the providers do not fully understand the broader context of family life during pediatric LTI and limit parent engagement instead of inviting it.

While parents' expectations of themselves are rooted in caring for the child with LTI, they welcomed guidance from trusted sources, such as healthcare providers, on managing feelings about the situation with their seriously ill child. They also were acutely aware of their responsibility to meet the demands of their immediate family, especially their other children. Parents viewed healthcare provider recognition of and response to their distressing feelings about the situation as essential. Parents welcomed the opportunity to share their feelings of distress and suffering with a healthcare provider as a way to alleviate the burden of parenting a child with LTI and as a way for them to grow in their capabilities to respond to their own distress. As one parent shared: "When the parent speaks, just hear what they're saying and not just walk away…there's a lot of no communication with each other…we're depending on them to save our kids' lives."

Parents represented their situation as moving through the darkness as they cared for their ill child and other healthy children, and variously acknowledging, minimizing/ignoring, and emphasizing the consequences of the distress for themselves and those around them. Will described his son's questioning about such consequences:

> *Sometimes you are just tired, like last week, it was 8:30 and I said I was heading to bed and my son said, "Dad, why are you tired?" And I tried to explain to him I was up three times last night with your sister and I got four hours of sleep and I am just tired. It gets overwhelming because you want to be home for them. You come home and you're mentally exhausted besides being physically exhausted. You want to give them (siblings) your full attention and sometimes you just don't have it-the fuel tank is empty. It's definitely overwhelming, sometimes, only because you can't do it all (Will).*

Here are Kimberly's insights about the consequences:

> *We don't know when it's going to end and you can't put your hope in the difficulty alleviating because it may not…it's hard because nobody is getting what they need and they won't be (Kimberly).*

Parents suggested meaningful and impactful interventions. Such interventions can illuminate helpful next steps or areas of potential risk by providing parents with a way to identify and act on negative feelings they may experience, as well as help parents formulate concrete strategies to solve problems that increase their demands or diminish their capabilities. Parents suggested that healthcare providers help them normalize their lives. For example, one father mentioned how healthcare providers could help the parents refocus and support their marital relationship by offering an opportunity for them to step away and have dinner together to normalize the importance of maintaining the partnered relationship. The father has a child with a long-standing, life-threatening illness and he enlisted his work collegues to help make this possible:

> *Some health care provider could say… we'll arrange for a sitter to be in the room for you guys for two hours. Even if they just go to the cafeteria with a food voucher. If nothing else I can advocate for, parents need to step away and just be a couple, instead of being mom or dad…otherwise you just hand off to each other (Will).*

Parents also commented that attempts by healthcare providers to help them reframe their situation were also helpful in that it made them feel less isolated (e.g. gently suggesting they have heard similar concerns by other parents; sharing how other families described feeling torn leaving one child to be with another). Reframing family issues in the context of other families may change the perceptions parents have of their demands and capabilities. For example, one mother described feeling less distressed when the nurses caring for her sick infant acknowledged the needs of her toddler for routine and helped her plan accordingly. Healthcare providers can build on parents' capabilities instead of "doing for" parents as they try to care for all of their children and live with life-threatening illness in a way that preserves their family. Another suggestion offered by parents was that nurses or other healthcare providers assist parents to problem-solve and find concrete solutions to their particular challenges. Such problems that parents described in this study, for example, affected parents themselves ("I need food while my child is in the hospital, but I do not want to leave her bedside. My child is terrified"), the child with life –threatening illness ("I want to feel like part of the healthcare team and ensure that my child receives safe care"), and the siblings ("I need physical space to bring in young siblings or to trust that I can leave my child overnight in the hospital and be available at home"). Parents wanted meaningful and helpful support in enacting their role as parent and to meet the goals they have defined for themselves as parents to all of their children.

Discussion

In this study, we explored how parents describe their expectations of healthcare providers and system to support their achievement of parenting goals in pediatric LTI, when they must meet competing demands of caring for all of their children. Three themes emerged, along with several sub-themes that represented relational and instrumental needs to both meet the needs of their children and to meet their internal needs to fulfill their parenting role.

In the first theme, parents expressed desire for support that builds on their capabilities to parent all of their children. The two subthemes focus on the particular needs parents identify: instrumental needs and relational needs. Parents described how their ability to survive the often-lengthy hospitalizations rested on the availability of instrumental support in the forms of food or parking vouchers, dependable childcare for healthy siblings, and flexible work arrangements. This builds on a body of work that describes the financial difficulties parents encounter during a child's hospitalization from advanced, serious illnesses (Bona et al., 2014; Dussel et al., 2011). We described additional instrumental difficulties parents face when caring for a child with LTI, such as safe, secure, affordable childcare arrangements for the healthy siblings that can allow families to connect with both their ill and healthy children and flexible employment options. Parents' description of needs here provides a glimpse into the seemingly small, but cumulative costs they encounter, direct medical costs and also indirect costs related to caring for the ill child, that contribute to loss of family income as reported in the literature (Hechler et al., 2008; Saad, 2008; Tomlinson et al., 2011). Contrary to the tenets of family centered care (Harrison, 2010; Shelton & Stepanek, 1994), our study demonstrates broader cost-related issues may be addressed late or at a point of financial emergency. Cost-related issues, however, contribute to parental distress and the research about these costs must translate into our clinical practice (Christian, 2016a). Assessment and addressing of cost-related issues allows healthcare providers to more comprehensively understand the context in which families care for their children, as well as financial and relational risks for the family. Thus, without a deep understanding of family cost and context, care can never be truly family centered. Similar to other models of universal screening for distress during pediatric LTI, (Kazak, 2006) universal screening for economic and caregiving demands in all families of children affected by LTI is warranted. Screening for financial concerns is consistent with recent guidance published by the American Academy of Pediatrics (AAP) on screening for poverty in all children (AAP, 2016). Communication with families about services and support for those at risk and connection to the healthcare team members who make this element of family-centered care possible is an important step in addressing these instrumental and relational concerns.

In the second sub-theme, parents desired support so that could fully participate in important relationships with their ill child, healthy child(ren), and partner. Parents described feeling pulled between two fronts when one child is hospitalized (Whiting, 2012); yet, parents recognize the context-specific and general needs of their healthy children despite the devastating situation with their ill child (Kamihara, Nyborn, Olcese, Nickerson, & Mack, 2015). Our findings contribute to calls from professional bodies and investigator groups that supporting parents will ultimately benefit ill children and their healthy siblings (Feudtner et al., 2013; Weaver et al., 2016). In our data, the second sub-theme reflects parents' expectations to keep the family together despite difficulties of the life-threatening illness. Parents in this context need help to preserve the family unit; they need to be "supported to be supportive" to their children with LTI (Bruce & Sundin, 2012). Such efforts may also prevent or diminish isolation or emotional burden of the siblings when there is an ill child facing frequent hospitalizations (Bona, Bates, & Wolfe, 2011; Jones, Contro, & Koch, 2014;

Van der Geest et al., 2014; Waldman & Wolfe, 2013). Meaningful support that builds on parental and family strengths and recognizes the real struggles parents experience in trying to meet multiple, yet divergent needs is warranted and has been called for in international undergraduate and generalist nursing training competencies (International Family Nursing Association Nursing Education Committee, 2013).

Supporting the family during a child's life-threatening illness requires complex care planning due to the variety of individual and family-level needs. Consideration of specific family and individual member characteristics beyond the illness efforts itself, including support for daily life routine and siblings' care is necessary (Gerhardt, Lehmann, Long, & Alderfer, 2015; Weaver et al., 2016) and is an internationally-recognized core competency of family nursing (International Family Nursing Association Family Nursing Practice Committee, 2015). This complexity stems from the severity of the illness, its sequalae, and the associated caregiving, in addition to the need to assess and incorporate family-level needs and psychosocial demands into the child's nursing care. The findings of this study can be a helpful source for nurses planning and coordinating care that promotes optimal family functioning because it reveals internal goals that parents perceive as crucial, but may remain unseen or unspoken during the crisis of illness deterioration or hospitalization.

In the second theme, "let's fight this together: please fight alongside me, not against me," parents wanted healthcare professionals caring for their child to demonstrate competence and care that goes beyond completing the task to true acknowledgement of the child and family. This stems from the meaning parents ascribe to the caregiving role. When parents access the healthcare system and seek guidance from healthcare providers, it is an extension of their parenting role to protect the child and show them they are beloved. This contributes to other research in which parents described duties they believe they need to fulfill for their ill children (Feudtner et al., 2015; Hill et al., 2014; Hinds et al., 2009). What our research contributes is how parents believe the healthcare providers and system can help them achieve their self-ascribed parenting duties for both the ill child and the healthy siblings. The healthy siblings may not be "on the radar" of the healthcare providers caring for the ill child as they develop care plans parents are expected to enact, yet weigh on the minds of parents. Parents can simultaneously hold hopes for their ill and healthy children in the face of deterioration in the ill child's health status (Feudtner et al., 2010; Kamihara et al., 2015). Thus, measures to promote communication to support the relationships and the decision-making process are necessary (Weaver et al., 2015; Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). Interventions aimed at training healthcare providers may be the most direct way to change behaviors that create a communication chasm between parents and healthcare providers. In addition, intervention research that centers on teaching parents to be proactive about communicating their needs may be another avenue to cross this communication chasm (Post, Cegala, & Miser, 2002).

In this theme, the relationship is an important focal point of parents' expectations of the healthcare providers and healthcare system caring for the ill child. *Fighting together* highlights the importance of the core concepts of patient and family centered care - collaboration, participation, dignity and respect and information sharing (FCC). Weaver and colleagues (2016) report that the relationship between parents and staff, as well as child and staff, show mutual elements of care, protection, and advocacy. Parents expect a relationship that is rooted in honesty and openness and demonstrated through a caring approach when they face the reality of caring for their sick child. "*Fighting together*" supports and builds on research in which bereaved fathers identified key components of caring health care practice such as: connecting in a human-to-human relationship, being included as team member, and having access to specialized knowledge to help each particular family (Davies et al., 2013). Relationships are the basis of family-centered care and are integral to shared decision-making, as well as patient and family engagement and activation.

In the third theme, parents describe a desire for healthcare providers to "guide me through the darkness." This theme reflects parental desire for support to do the cognitive and emotional work of parenting. It also reflects the internal processes of grappling with the conundrum of meeting the needs of multiple children in a high-stakes situation, as perceived by parents. In our data, parents did not consciously reveal their expectations for guidance and support for their internal feelings that arise during a child's life-threatening illness; they desire to stay strong for their child and at the same time to find strength in caring for the child (Removed for blind review). Yet, parents are physically and emotionally exhausted and seek comfort (Berube, 2014). Parents experience distressing feelings, such as fear, blame, failure related to the child's death, and grief over the loss of normalcy (Berube, 2014; removed for blind review; Bruce & Sundin, 2012; Hurwitz, Duncan, & Wolfe, 2004; O'Shea & Bennett Kanarek, 2013; Penson, Green, Chabner, & Lynch, 2002). Parents describe increased distress when they do not perceive the healthcare providers caring for their child as supportive and describe this as "suffering from care" (Bruce & Sundin, 2012).

Parents' experiences of distress, suffering, and exhaustion may not be outwardly shared with the healthcare team or be visible in parents' behavior. Thus, healthcare providers can create opportunities for distressing feelings and experiences to surface so that parents can access desired support, such as through psychoeducation initiatives that help parents understand trajectories of distress and resilience in LTI and cultivating a clinical culture that sees parent mental health as a priority (Kearney et al., 2015). Other examples of support include creation of parent support-groups, connection to parents who offer to be sources of peer-support, and by creation of space in the parent-clinician relationship for family emotional triage at outpatient visits or during in-patient hospitalizations. Researchers point to the high level of distress experienced by children and their families during cancer treatment, emphasizing the importance of including family voice in routine psychosocial assessment (Kazak et al., 2015). In the midst of such distress, anticipatory guidance may be helpful, as well as support from their child's healthcare providers, family, and social network (Madrigal et al., 2016; Zelcer, Cataudella, Cairney, & Bannister, 2010). The psychosocial assessment tool and the distress thermometer are two possibilities for screening psychosocial symptoms to assist children and families across the continuum of cancer treatment (Kazak et al., 2012). Similar psychosocial screenings are applicable to other subspecialties that care for children with LTI and their families.

Parents sought relationships with healthcare providers that help them help their families, through the provision of support for instrumental or relational needs so that parents could serve their loved ones or through deeper emotional support for the parents, who often felt alone and isolated. They wanted guidance on how to help their family survive, as a unit, a situation without many guideposts. Parents and providers need to establish a helping-trusting relationship (removed for blind review) to reach positive outcomes for the care provided, through their commitment to authentic interaction and shared, broad worldview (Davies et al., 2016). This interpretative analysis shows that through relationships with healthcare providers, parents can feel more confident in their parenting roles and continue to pursue their parenting goals throughout their child's illness. Healthcare providers are pivotal, not only in helping families manage a child's life-threatening illness, but also through their relationships with and concern for parents and siblings.

Implications for Practice

Parents experienced distress as they thought about not being able to meet the needs of each child in their family. This distress can prompt a shift in how nurses and other healthcare providers consider and enact family-centered care in this increasingly complex environment. Healthcare providers can offer meaningful assistance in this regard by broadening the understanding of decisional support beyond the decisions directly related to the care and ongoing life-sustaining interventions for the ill child to a family-based approach, to include more nuanced decisional support of how healthcare-related decisions can affect the entire family. This can build on strategy of offering decisional support to parents as they make healthcare decisions for their seriously ill children (Feudtner, 2007). Nurses can also ask parents what they believe they need from their team to fulfill their multiple roles, both in the healthcare setting and at home (Hinds et al, 2012). Recognition of the multiple stressors that influence family life and the multiple priorities parents contend with is consistent with the commitments of pediatric palliative and hospice care outlined by the American Academy of Pediatrics (Feudtner et al., 2013).

The intensity of the guidance and support that parents sought describes a dovetailing of psychosocial care and palliative care. Adequate support from each of these avenues can scaffold a family as they live with the uncertainty of pediatric LTI, which in turn may strengthen care for the ill child and his or her healthy siblings. Recent work has called for psychosocial assessment of and intervention for the child and family and for palliative care to become standard in pediatric oncology (Gerhardt et al., 2015; Kearney, Salley, & Muriel, 2015; Steele, Mullins, Mullins, & Muriel, 2015; Weaver et al., 2015). Similar standards would be equally beneficial across specialties that care for infants and children with LTI. Supporting parents during this sensitive, trying time in their lives can improve family function and diminish parental distress, which can ultimately affect the health of their children and is consistent with our mandate as pediatric nurses (Christian, 2016b).

Limitations

The limitations and boundaries of this study warrant discussion. Nearly fifty percent of the participants were mothers who identified as White (15/31) which is a limitation. This is similar to limitations in other parenting and palliative care research. We attempted to minimize such limitations and diversify our sample by visiting the participating units across day, evening, and night shifts, as well as during weekdays and weekends and by recruiting a diverse sample. We also included phone interviews as a data collection strategy so that parents could still participate if they needed to return to work or if their child was no longer in the hospital. This did result in an economically diverse sample. In addition, we included only English-speaking participants and, thus, important voices and perspectives may be missing from this analysis. Finally, since this was a secondary analysis, another limitation is that the data were not collected to address the particular research question guiding this study.

Conclusion

Parents are distressed and grapple with conflicting feelings around meeting competing needs of all their children; they want to be available to all of their children, yet may not be able to fulfill the expectations they have imposed on themselves or that are imposed by others. In turn, they look to nurses and other health care providers to help them fulfill some of these expectations, which may or may not be reasonable. Consequently, in order for health care providers to engage with them, parents' expectations of health care providers have to be explicitly understood, acknowledged, and negotiated. Only then is care family-centered (Davies et al., 2013; Feudtner et al., 2013; Baird et al., 2014) and consistent with the guiding principles of palliative care.

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Highlights

1. Parents are distressed and grapple with conflicting feelings about meeting competing needs of their ill and healthy children and the expectations that are held of them as parents.
2. Nurses can influence parents' management of the situation and be a source of support as their parenting role changes over the illness trajectory and children's development.
3. Despite the presence of a child's LTI, parents want pediatric healthcare providers to engage with them and their family to promote survival and growth of family relationships.

Parents: individuals who are biologically or legally related to the child, who live in the same household (full-time or part-time) as the child, and who provide most of the child's care most of the time.

Parenting: A process undertaken with the goal of ferrying children from conception or birth through developmental challenges and life events to adulthood or death. It is a process composed of tasks, roles, rules, communication, resources, and relationships.

Life-threatening illness: serious, chronic medical conditions that are highly likely to cause death in the near future, or medical conditions likely to result in severe disability, medical fragility, or dependency upon medical treatments and technology for survival. Operationalized as an illness state that requires admission to an intensive care unit or in-patient unit for treatment of advanced chronic disease, a life-threatening complication of a chronic illness, or incorporates palliative/hospice care while at home.

Demands: "Comprised of normative and nonnormative stressors, ongoing family strains, and daily hassles" (Patterson, 2002, p. 350).

Capabilities: "Includes tangible and psychosocia resources and coping behaviors" (Patterson, 2002, p. 350).

Figure 1.
Definitions of key terms used in this study

Table 1

Examples of Analytic Processes and Progression

Theme and Subthemes	**Category**	**Codes**
Help me survive this. - Instrumental needs - Family preservation needs	- Needing information - Having social work support	- what is stressful for us - family: what helps or hinders - resources: harder
Let's fight together: Please fight with me and not against me to care for my family.	- healthcare providers who understand - let parents be part of the team	- further guidance: healthcare providers - resources: easier
Guide me through the darkness: I am suffering.	- See beyond what you know	- parenting here and now: what it's like

Table 2

Demographic Data of Participating Families

Demographic Characteristic	**n**
Participating parents	31
Mothers	25
Fathers	6
Families in which 2 parents participated	4
Parent age (range in years)	21–54 (average age 39 years)
Parent race and ethnicity (self-identified)	
African American	4
Asian	1
White	20
More than one race	1
Not reported	4
Unknown	1
Hispanic/Latino	6
Parent highest level of education	
Less than high school	1
High school	6
Some college	6
Associate's degree	2
College graduate	11
Graduate degree	6
Annual family income (range)	<$25,000–>$150,000
Parents who left workforce entirely to care for child with LTI	14
Index children with LTI	28
Age of child with LTI	
less than 1 year of age	10
1–5 years of age	7
6–10 years of age	2
11–15 years of age	4
16–20 years of age	4
21–25 years of age	1
LTI affecting children	
Cancer	4
Congenital heart disease	7
Genetic disorders	5
Prematurity	3
Pulmonary	3
Neurology	4

Demographic Characteristic	**n**
Congenital anomalies	2
Additional chronic illnesses affecting children with LTI	Range 1–7
Number of siblings in family	
1	17
2	8
3	4
4	1
5	2
Number of parents who made an end-of-life decision during study period	11