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Parenting in Childhood Life-Threatening Illness: A Mixed-Methods Study

Kim Mooney-Doyle, PhD, RN, CPNP,[1] Janet A. Deatrick, PhD, RN, FAAN,[2] Connie M. Ulrich, PhD, RN, FAAN,[3] Salimah H. Meghani, PhD, RN, MBE, FAAN,[4] and Chris Feudtner, MD, PhD, MPH[5]

Abstract

Background: Parenting children with life-threatening illness (LTI) and their healthy siblings requires parents to consider their various needs.
Objective and Methods: We conducted a concurrent, cross-sectional mixed-methods study to describe challenges parents face prioritizing tasks and goals for each child with qualitative data, compare parents' tasks and goals for children with LTI and healthy siblings with quantitative data, and describe parenting in terms of the process of prioritizing tasks and goals for all children in the family.
Results: Participants included 31 parents of children with LTI who have healthy siblings and were admitted to a children's hospital. Qualitative interviews revealed how parents managed children's needs and their perceptions of the toll it takes. Quantitative data revealed that parents prioritized ''making sure my child feels loved'' highest for ill and healthy children. Other goals for healthy siblings focused on maintaining emotional connection and regularity within the family and for ill children focused on illness management. Mixed-methods analysis revealed that parents engaged in a process decision making and traded-off competing demands by considering needs which ultimately transformed the meaning of parenting.
Discussion: Future research can further examine trade-offs and associated effects, how to support parent problem-solving and decision-making around trade-offs, and how to best offer social services alongside illness-directed care.

Keywords: mixed-methods research; palliative care; parenting; pediatric

Introduction

Parents of children with life-threatening illness (LTI) manage the needs of their children who are ill and their children who are healthy.[1] In doing so, they balance expectations of themselves and those of others. These expectations shape their beliefs about parenting all of their children and potentially affect child and family adaptation.[2,3] While parents may expect themselves to be ''good parents''[4] to their children, the litmus test for assessing the ability to do so is bifurcated. On one hand, parenting a child with LTI involves focusing largely on illness and survival; successfully managing medical care routines, negotiating with providers, and considering palliative care options.[5–9] Alternatively, parenting their healthy children largely focuses on maintaining normality and reassurance of parental love, availability, and emotional connection.[10]

Parents of children with LTI, confronting not only typical child-rearing challenges but also profound challenges stemming from LTI, described this situation as a ''battleground.''[11] Thus, for thousands of families, caring for healthy siblings adds another front to this battle.[12] Family roles and responsibilities often change because of LTI and meeting new challenges can contribute to distress in the entire family.[13] Thus, while parents strive to be ''good parents'' to their ill children, they are simultaneously learning how to be ''good parents'' to the healthy siblings. Such challenges and disruption can cause parental emotional distress, possibly affecting children's adaptation and family function.[9,14,15] Thus, attention to these multiple stressors and role changes is warranted.

While supporting parents and siblings of children with LTI is a commitment of Pediatric Palliative and Hospice Care (PPHC),[16] expectations parents have for themselves about parenting all of their children remain understudied and poorly

[1]Department of Family and Community Health, School of Nursing, University of Maryland, Baltimore, Maryland.
[2]Department of Family and Community Health, School of Nursing, [3]Department of Biobehavioral Health Sciences, School of Nursing, Center for Medical Ethics, Perelman School of Medicine, [4]Department of Biobehavioral Health Sciences, School of Nursing, [5]Department of General Pediatrics and Pediatric Advanced Care Team, Department of Medical Ethics, The Children's Hospital of Philadelphia, Perelman School of Medicine, University of Pennsylvania, Philadelphia, Pennsylvania.
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understood. In addition, the emotional consequences for parents managing these expectations of self may complicate attempts of providers and others to provide support.[17–20] The aims for this cross-sectional study included (1) describing parents' expectations for themselves in terms of prioritizing tasks and goals for children with LTIs and healthy siblings; (2) comparing parents' tasks and goals for children with LTI and healthy siblings; and (3) describing parenting in terms of the process of prioritizing tasks and goals for children with LTI and healthy siblings.

Methods

We used concurrent mixed methods[21] to gather qualitative data using a semi-structured interview guide (Aim 1 and 3) and quantitative data using a discrete choice experiment (DCE) (Aim 2) to examine perspectives and processes of parenting children with LTI and healthy siblings. Participants were recruited from a large children's hospital. Institutional review board approval was obtained from the hospital and University of Pennsylvania. Pilot testing of data collection methods was conducted before data collection. We created a protocol to address parental distress during the study.

Participants

Inclusion criteria included parents who were over 21 years of age and whose children with LTI lived with them at least part-time (2–3 days/week), were admitted to an inpatient unit for treatment of the LTI or associated complications, and had other children who lived with them at least part-time. Exclusion criteria included parents of children who were previously healthy, but were hospitalized for acute illness or injury. Parents of children with LTI followed by the inpatient palliative care team or admitted to the intensive care units, oncology, or bone marrow transplant units were eligible. Once eligible families were identified, the children's inpatient nurses were asked to identify appropriate timing for screening visits. Recruitment ceased once data saturation was reached.

Procedure

Study recruitment began in February 2013 and concluded in November 2013. We discussed materials with interested parents and obtained informed consent in face-to-face encounters or through telephone with parents who we were unable to meet in the hospital or whose children had been admitted and discharged during the study period. Consistent with parental preferences, we conducted most interviews in person, with parents from the same family interviewed separately. Four parents completed interviews over the telephone.

We used a semi-structured interview guide, informed by an update to Horowitz's conceptualization of parenting work[22,23] and the social ecological model[24,25] that explored the everyday lives of parents affected by childhood LTI.[26,27] Examples of interview questions are: ''Life must get busy caring for your children. How do you juggle or balance everyone's needs?'' and ''Does anything ever have to be put on hold?''

Parents completed a demographic questionnaire about the child with LTI and members of the immediate family and a DCE for their child with LTI and for the healthy sibling.[28,29] The DCE allowed parents to choose good parent attributes (GPAs), which are tasks and goals they believe to be most to least important in parenting a child with LTI.[3] The GPA items were based on previous qualitative research with parents of children with other LTIs.[4] Items were revised based on feedback from interdisciplinary palliative care professionals and parent focus group and have been used in subsequent studies.[3,30] Content validity of the item set was strengthened through previous qualitative research regarding ''good parent beliefs'' in the pediatric oncology setting and pilot testing with the study population.[4] The 12 items can be rank-ordered with data from parental choices among 12 permuted sets of 4 good parent belief attributes, which are rated most to least important.

Analysis

All interviews were digitally recorded, transcribed verbatim, and managed using ATLAS.ti (v.7). Analysis included several iterative steps consistent with principles of thematic content analysis.[31–34] Field notes, reflexivity log, and audit trail were used to strengthen qualitative rigor.[35] Pseudonyms were used to protect participants' identity.

REDCap was used for quantitative data management. Missing data were from three participants who could not be reached after their participation because they relocated internationally or lost their children to LTI (<10% of quantitative data) and were not imputed. Descriptive statistics was generated for demographic variables. Relative ranking and weight for each GPA item was calculated through maximum difference scaling and Hierarchical Bayes (HB) estimation using Sawtooth MaxDiff and Choice-Based Conjoint/HB modules (v. 6).[29] Maximum difference scaling applies multinomial logistic regression to establish the probability of choosing each item (as best to worst) among other items shown in the set.[28] The 12 items are rank-ordered on a relative scale, based on weights each item had in the regression model and in relation to other items. The scores for all items sum to 100 points and represent the strength of the groups.

The purpose of mixed-method analysis was complementarity or seeking ''elaboration, illustration, enhancement, and clarification of findings from one analytic strand with data from another strand.''[36 (p.411)] We followed Onwuegbuzie and Teddlie's analytic process by integrating and analyzing data, synthesizing QUAL/quan findings to form meta-inferences or conclusions. Analytic steps included: data reduction (separate analysis of qualitative [QUAL] and quantitative [quan] data); data display (creation of informational data matrices combining QUAL and quan data about children with LTI and data about healthy siblings); data comparison (comparing QUAL and quan data); and data integration (synthesis into coherent whole to form meta-inferences).[37]

Results

Thirty-one parents from 28 families participated in the interviews and 29 parents provided complete quantitative data (Table 1). Most of the children with LTI were less than five years old (60%) and were admitted to the pediatric intensive care unit (40.0%). The most common childhood LTIs were congenital heart disease (25.0%) and congenital/genetic disorders (24.9%). Most participants were white (64.5%), mothers (78.0%), and cared for two to three children in their family (75.0%). The sample was diverse in socioeconomic status (19.3% reported annual income <$20,000, 30% reported annual income >$100,000) and severity of the child's LTI.

Table 1. Characteristics of Children with Life-Threatening Illnesses and Parents in Study

Characteristic	*No. (%)*
Ill children	$n=28$
Age, years of age	
<1	10 (35.7)
1–10	9 (32.1)
11–20	8 (28.4)
>20	1 (3.5)
Conditions	
Prematurity and neonatal	3 (10.7)
Malignancy/hematologic	4 (14.2)
Cardiovascular	7 (25)
Respiratory	3 (10.7)
Neurologic or neuromuscular	4 (14.2)
Congenital or genetic disorder	7 (24.9)
Parents	$n=31$
Mothers	25
Fathers	6
Average age of parent	39 (21–54)
Highest level of education	
High school or less	7 (22.3)
Some college or associate's degree	8 (25.3)
College	11 (35.4)
Post-college	6 (19.3)
Household income	
<$20,000	6 (19.3)
$20–59,999	3 (9)
$60–99,999	12 (38.6)
>$100,000	10 (32)
Race/ethnicity (self-identified)	
African American	4 (12.9)
Asian	1 (3)
White	20 (64.5)
More than one	1 (3)
Not reported/unknown	5 (15.9)
Hispanic/Latino	6 (19.3)
No. of siblings in family	
1 Sibling	17 (54.8)
2–3 Siblings	12 (38.7)
4–5 Siblings	3 (9)

Qualitative findings

Three themes emerged from parents' descriptions of managing the needs of all their children (Table 2): balancing beliefs; parenting triage; and the toll it takes. In *balancing beliefs*, parents expressed beliefs and philosophies foundational to parenting decisions and goals. This theme included categories related to the primacy of relationships and in-depth knowledge of each child in the family. Regarding relationships, parents were concerned with the parent–child relationship and the sibling–sibling relationships and sought to diminish isolation and negative feelings, while increasing feelings of connection within the family. Parents wanted to convey love and appreciation to children and believed time together was an important avenue for this. They believed, however, illness-related crises took precedence and were challenged finding time together. The finely tuned perceptions about each child's welfare were rooted in the developmental state and age of each child, the illness severity and context, previous experiences with each child, and desire to maintain normality. For example, parents perceived that adolescent siblings ''did not need as much'' from parents, whereas family schedules were arranged around maintaining consistency and normalcy for healthy toddler siblings. Regarding the illness context, parents described the ill child as vulnerable and their health status as a barometer for their own well-being; ''…if she [ill child] is ok, then I'm ok.'' These beliefs propelled parental action.

In *parenting triage*, parents described implementing various strategies to meet the needs of all their children. Parents described triage strategies rooted in beliefs around dealing with things as they come up, focusing on safety, and dividing/conquering. Two categories of specific strategies, essential and relational, helped parents carryout their necessary parenting work. Essential support strategies focused on meeting daily needs to keep the family running and illness managed, such as arranging childcare for siblings, community supports for parent and siblings, parental change of shift (one parent would stay at the bedside and another goes home to the healthy siblings), relocating for the ill child's healthcare, or leaving employment. Relational support strategies focused on fostering connection and decreasing isolation within family relationships and included 1:1 time with each child, honest and reassuring communication with siblings, promoting siblings time together, kangaroo care for ill infants, staying at bedside of ill children, and maintaining normalcy for all children. Strategies changed according to context (e.g., illness severity), but all required decisions to deal with issues immediately or ''place on the back burner.''

In *the toll it takes*, parents describe emotional and relational consequences of agonizing decisions made addressing needs of one family member over needs of another. Parents recognized, and struggled with, individual, dyadic, and family-level consequences of LTI, mostly for themselves and their healthy children. Considering themselves, parents described feeling torn, guilty, overwhelmed, frustrated, afraid, exhausted, and heartbroken. Relational and professional consequences accompanied emotional consequences, namely in disrupted relationships with partners or healthy children and lost professional opportunities. Parents' perceived that siblings often felt left out and received less attention, experienced changes in family relationships, had negative academic effects, and were confused about the gravity of the LTI. Regarding overall family consequences, parents reported disruption, loss of routines, financial burdens, and estrangement from others.

Discrete choice experiment of good parent attributes

The ranks and priorities are displayed in Table 3. The most highly ranked task and priority for children with LTI and their healthy siblings was ''making sure my child feels loved.'' Considering children with LTI, the next five highly ranked items revolved around illness management and addressing healthcare needs. Considering their healthy children, parents chose ''making sure my child feels loved'' almost twice as frequently as the second item, ''focusing on my child's quality of life.'' The remaining items in the top five for healthy children focused on maintaining health and quality of life.

Table 2. Qualitative Findings

Theme	*Category*	*Exemplar quotes pertaining to children with LTI and healthy siblings*
Balancing beliefs	Primacy of relationships	''…we are mothers, we are not quitters.''
		''Samantha is the focus…they know that. We have to get through this stage and get her a new heart.''
		''The most important thing is being her Dad and having fun with her [ill child].''
		''It's a full-time job making sure he's [sibling] OK.''
		''Sometimes I feel like I am abandoning them [siblings].''
		''They all [healthy siblings] need me.''
	In-depth knowledge of each child	''If she's [ill child] ok, then I'm ok.''
		''I study her [ill child].''
		''I told her [sibling]…you're not any less important. Your life is not going to stop because of this situation.''
Parenting triage	Essential support	''When the house is on fire, you don't worry about the wash.''
		''I have to be with the baby [ill child] no matter what.''
		''We decided to home school the older kids so the baby [ill child] wouldn't get more infections.''
		''I'm parenting them [siblings] from the sidelines. I have more of a grandparent role.''
		''They have to miss school because we don't have somebody there that I can say, 'Can you take care of my kids?'…They come with me because they know I'm lonely here with the baby. We are tight and need to be together. My daughter told me 'Mommy, I'm going to miss you.'''
	Relational support	''I'm constantly evaluating quality of life. Is the baby (ill child] going to hate me when he is older because I made these decisions for him?''
		''My husband will kangaroo with Daniel [ill child] when he is in town.''
		''After the hospitalizations, we have to reclaim a stake in our family…We have to reintroduce the kids [ill child and healthy siblings] to each other.''
		''I'm more patient with them…reassuring them about Dylan [ill child] and communicating with them about him.''
The toll it takes	Individual	''It breaks my heart to leave him [ill child], especially being sick.''
		''She's a baby, she might not know if I'm here. If she were older, it would be different.''
		''I was going to law school. I was running marathons. Then I got pregnant with her and it was over. Now it's really over. It's not what I expected, but it's what's expected of me.''
		''If we had more time and resources to devote, we would have done something different with Charles [sibling]. He might be taking college courses now and this is one of those trade-offs that breaks my heart … I will probably be kicking myself for the rest of my life, God forbid, because I think Charles needed more challenge, academic excitement, and we couldn't pull it off.''
		''The boys [siblings] got gypped.''
	Dyadic	''Is she [sibling] going to hate us because we can't go to her soccer games because he can't be around people? I think about her quality of life, too.''
	Family	''Nobody is getting what they need and they won't be for a while.''

LTI, life-threatening illness.

Mixed-methods analysis

Parents engaged in a process of trading-off to manage expectations they had for themselves regarding their children who are ill and healthy (Table 4 and Supplementary Table S1; Supplementary Data are available online at www.liebertpub.com/jpm). The meta-inference of the mixed-methods analysis demonstrated that parental attempts to balance family needs may prompt them to trade-off one child's needs to meet those of another, even if this does not align with their parenting goals. That is, parents may prioritize a child's needs as first, second, and so forth, but the parent may be challenged to carry out their top-rated tasks or meet top-rated goals for each child. This discrepancy may lead parents to believe that they are not fulfilling their definition of ''being a good parent.'' For example, if they cannot stay at the infant's bedside because the toddler sibling needs to run around or if the adolescent sibling is not able to access more education because of financial resources required to manage the LTI, parents may experience distress and perceive that they are not living up to expectations they have for themselves. Thus, the parenting role may reshape into something unrecognizable to them with unintended consequences for themselves and their families.

Discussion

Based on our findings, parents have beliefs undergirding their strategies of managing children's needs, while recognizing potential costs for meeting some needs and not others. The work is consuming because they are simultaneously

Table 3. Relative Ranking and Importance of Good Parent Attributes for Children with Life-Threatening Illnesses and Their Healthy Siblings

Relative ranking	*Good parent attribute: child who is ill*	*Relative importance*	*Good parent attribute: sibling who is healthy*	*Relative importance*
1	Making sure that my child feels loved	15.1	Making sure that my child feels loved	21.2
2	Focusing on my child's health	14.2	Focusing on my child's quality of life	12.8
3	Making informed medical care decisions	12.2	Focusing on my child's health	10.8
4	Advocating for my child with medical staff	10.5	Focusing on my child's comfort	9.4
5	Staying at my child's side	9.5	Spiritual well-being	8.5
6	Putting my child's needs above my own when making medical care decisions	9.1	Keeping a positive outlook	7.1
7	Focusing on my child's quality of life	8.1	Staying at my child's side	6.4
8	Focusing on my child's comfort	7.9	Keeping a realistic outlook	5.5
9	Focusing on my child having a long life	5.9	Focusing on my child having a long life	5.2
10	Keeping a positive outlook	3.3	Putting my child's needs above my own when making medical care decisions	5.2
11	Keeping a realistic outlook	2.9	Making informed medical care decisions	4.7
12	Spiritual well-being	1.2	Advocating for my child with medical staff	3.2

Table 4. Relative Ranking of Good Parent Attribute with Mixed Analysis Matrix for Child with Life-Threatening Illness and Healthy Sibling (Top Five Items for Each Child)

Relative ranking	*Good parent attribute for child with life-threatening illness with qualitative theme and illustrative quote*	*Good parent attribute for healthy sibling with qualitative theme and illustrative quote*
1	Making sure my child feels loved Balancing beliefs: ''Everything is important-her medicines, giving her the best care, but first you got to give her the love and everything else will just fall in place.''—Tamara	Making sure my child feels loved Balancing Beliefs: ''Giving my kids love and support…Just loving my kids and nurturing my kids is first important to me.''—Tamara
2	Focusing on my child's health Balancing beliefs/parenting triage: ''When they're ill we can't see them because of the infection control of Samantha. We can't take the chance. Literally for the last three weeks we haven't had much contact with our other three kids.''—David	Focusing on my child's quality of life Balancing beliefs: ''I'm telling my older daughter, ''you're not any less important.'' We're not going to stop doing things for you; your life is not going to stop because we have this situation. You have to keep on doing your stuff.''—Bianca
3	Making informed medical care decisions Balancing beliefs: ''Making good decisions on his behalf is most important … healthcare, for example, like signing up for Medicare insurance.''—Daren	Focusing on my child's health Parenting triage: ''The elder child, she eats well, she's playing … Is she healthy or not that is why we keep checking. I'm really scared, with one like this it makes you … you always have that in the back of the mind, like is she doing okay.''—Aditi
4	Advocating for my child with medical staff Parenting triage: ''We're pushing medical care to the nth degree. There's not much more that I think we can truly do. Pieces of it totally suck where we are, but we're doing everything.''—David	Focusing on my child's comfort Parenting triage: ''We're trying to make this as comfortable as possible for them, which is kind of difficult because we don't want them to get too disrupted. We don't want them to think that they're any less important.''—Bianca
5	Staying at my child's side Balancing beliefs/parenting triage: ''I am going to spend time with her and be here no matter what. Me and my husband decided to hire a nanny (for the sibling) and in a day or two we thought well whoever is available.''—Aditi	Spiritual well-being Parenting triage: ''In the midst of this when mommy and daddy can't be here, God is always with you. They have a sense of peace.''—Kimberly

parents and caregivers.[9] As such, their work goes beyond normative parenting tasks because it can carry the weight of life or death and may change dramatically over time. Parents can experience both positive and negative effects of this work.[38] Our study corroborates this finding, adding how parents incorporate care of healthy children into family life, consider their needs, and struggle with the impact of LTI. The volume and intensity of parenting work for the ill child may diminish opportunities for communication and connection between parents or between parents and healthy siblings.[9] This may perpetuate important unintended family consequences because parents influence their child's development through communication and relationships.[23,39–41]

The intensive and extraordinary circumstances can prompt parents to redefine parenting, as they manage the ongoing distress of opportunities lost for their children, families, and selves, and consider an uncertain future.[9,42] Redefining parenting in LTI may intensify the perceived cumulative threat of LTI because the conception of parenting they *can* achieve may not align with the conception of parenting they *want* to achieve for their children.[43–44] Parents may be unable to achieve their goal of ''being a good parent'' consistent with the depth of parent and child needs.

Parents endorsed ''making sure my child feels loved'' above other GPAs for their ill and healthy children. The top five GPAs for the child with LTI revolved around illness management, suggesting that parents find managing the illness and its consequences an important way to demonstrate love for the ill child. Parents considered illness management key among their perceived parenting duties, consistent with other studies measuring GPAs.[3,30] Parental GPA rankings for healthy siblings add to this discussion. Parents ranked ''Making sure my child feels loved'' highest and ascribed it nearly twice as much weight as, ''focusing on my child's quality of life,'' reflecting concern for healthy siblings' emotional and physical well-being. There are three possible explanations for this finding. First, parents had fewer options to rank for the healthy sibling. Second, even during crisis and hospitalization of their ill child, parents are deeply concerned about their healthy children, but had fewer ways to demonstrate this. This is supported by other research[45] in which parents expressed hopes for their healthy children as they confronted deterioration in the ill child's health or expressed concern about healthy siblings in PPHC.[46,47] Third, parents may have varying sets of duties for each child and prioritize differently based on these duties. Without understanding the various duties among which parents feel pulled to fulfill, providers may have an incomplete picture of family life and limited understanding of what contributes to parental distress outside the illness.

Trade-offs affect each family member. Parents recognized that trying to balance the needs of all children may come at a cost; less acute needs are triaged and placed on hold during the crisis of hospitalization or go unmet entirely. While trade-offs may seem obvious, effects on the entire family may be overlooked in high-stake clinical environments when a child is ill. Parents may respond to communication with staff that solely focuses on the ill child with their acquired skills, ''putting on a happy face.''[48] The effects of trade-offs on healthy siblings has not been fully explored. Recent studies have demonstrated mixed evidence about the impact of LTI on siblings.[49–57] Quantitative proxy reports revealed that school-aged siblings do not experience more psychological distress than the general population,[58] while qualitative parent-report data reveal parental concerns over sibling well-being in LTI.[10] Data gleaned from siblings themselves, conversely, reveal intrapsychic distress,[59] feeling invisible within the family,[60] perceptions of poor intrafamily communication,[51–52] increased anxiety,[54,55] short and long-term difficulties in psychosocial and physical functioning,[49,61] internalizing and externalizing symptoms and lower self-esteem,[62] lower HRQOL,[63] and improved psychosocial health.[64] Further research on trade-offs and effects on siblings can inform family-focused interventions to support parental decision making, uncover family-level impact,[65,66] and guide efforts to improve relationships and sibling adaptation.[43,67]

Finally, models for addressing social support needs alongside illness-directed care, a major need identified by the Institute of Medicine, are needed.[12] Elucidating the impact of simultaneous stressors[10,67,68] and potential stress-buffering resources[69,70] can inform services geared toward particular family strengths and demands.

Study limitations

While participants were diverse across several demographic categories, the sample did not have racial, ethnic, and gender diversity; important perspectives may be missing. Selection bias was a potential concern since parents who chose to enroll were open to sharing their experiences. Nearly one-third of families approached for enrollment declined participation. Parents who declined had children near death, perceived interviews would be ''too personal or sensitive,'' or were ''too stressed and busy'' because of health, transportation, and work challenges. We attempted to achieve variation in our sample by recruiting families with diverse needs by contacting them across shifts on weekdays and weekends. Finally, while DCE methodology is widely used in economic and health services research and typically does not entail evaluation of a specific experiment's reliability and validity,[71,72] we cannot be sure the degree to which parents might change their preferences (as revealed by their choices) over time, or whether their choices in the experiment would correlate with ''real world'' choices.

Conclusion

Parenting work for children with LTI and healthy siblings remains under-recognized in healthcare encounters, and parents need support to problem solve how to be ''good parents'' to all their children. Trade-offs may be a source of unintended consequences of LTI, perpetuating family distress. Understanding multiple sources of parental distress, in addition to LTI, can help providers evaluate parental needs and create supportive interventions to mitigate detrimental effects on families.

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Address correspondence to:
Kim Mooney-Doyle, PhD, RN, CPNP
University of Maryland School of Nursing
Division of Family and Community Health
655 West Lombard Street, Room 538
Baltimore, MD 21201

E-mail: kemooney@nursing.upenn.edu