

Educational Priorities for Providing End-of-Life Care: Parent Perspectives

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abstract

OBJECTIVES: Partnership with parents is a tenet of pediatric medicine; however, initiatives to include parents in education and research have been limited. Through focus groups, we included parents at the beginning of curriculum development by asking them to identify the priorities, existing supports, and opportunities for improvement in their child's end-of-life (EOL) care.

METHODS: English and Spanish-speaking bereaved parents whose child had been cared for by the palliative care team and had died >18 months before the study initiation were invited to participate. In-person focus groups and a follow-up phone call were used to elicit opinions and capture a diversity of viewpoints. Themes were identified and clustered through an iterative analytic process.

RESULTS: Twenty-seven parents of 17 children participated, with the total sample size determined by thematic saturation. Four themes were identified as important to parents in their child's EOL care: (1) honoring the role of the parent, (2) having confidence in the care team, (3) receiving gestures of love and caring, and (4) navigating logistic challenges.

CONCLUSIONS: We asked parents to be partners in guiding priorities for health care education and professional development to improve pediatric EOL care. In addition to strengthening skills in communication, confidence in the team, and compassion, parents in this study identified a need for hospital staff to anticipate financial and social stressors and provide supportive resources more readily. Additionally, parents described clinical and nonclinical staff as providing support, suggesting that a multidisciplinary and interdisciplinary curriculum be developed to improve pediatric EOL care.



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Drs Arora and Serwint conceptualized and designed the study, drafted the initial manuscript, and reviewed and revised the manuscript; Ms Caliboso designed the data collection instruments, collected the data, conducted the initial analysis, contributed to the initial manuscript, and reviewed and revised the manuscript; Dr Baird, Ms Rusch, Ms Greenman, and Ms Obregon participated in the design of the collection instruments, collected data, reviewed and analyzed the data, and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

DOI: <https://doi.org/10.1542/peds.2021-051379>

Accepted for publication Jun 16, 2021

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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WHAT'S KNOWN ON THIS SUBJECT: Parents have identified important areas in pediatric end-of-life care including symptom management, communication, and bereavement support. Educational sessions involving bereaved parents have strengthened skills. We built on previous work by incorporating parents from the beginning of curriculum development.

WHAT THIS STUDY ADDS: Efforts to strengthen skills in pediatric end-of-life care have been focused on communication and compassion. Parents in this study identified an additional need for guidance on financial and social stressors. Parents also described receiving support from clinical and nonclinical hospital staff.

To cite: Arora G, Caliboso M, Baird J, et al. Educational Priorities for Providing End-of-Life Care: Parent Perspectives. *Pediatrics*. 2021;148(4):e2021051379

Approximately 45 000 infants and children die in the United States each year, and the majority die in hospitals.¹ The words of health practitioners around the time of a child's death influence the parental experience of the death.^{2,3} In past studies, researchers identified parents being helped by health care practitioners who provided compassionate and sensitive care, attended to the needs of their child, offered clear explanations regarding their child's condition, and involved parents in care and decisions.⁴⁻⁶

In qualitative interviews exploring parental perspectives of their child's end-of-life (EOL) care, parents have identified the most important aspects as receiving the following: clear information about their child's condition and care,^{5,7-9} opportunities for parent input in decision-making,⁷ continuity of relationships with health care practitioners,^{7,10} compassionate care,⁵ and confidence that their child was receiving the best care possible.¹⁰ Parents have identified value in pediatric palliative care for symptom management, decision-making, emotional support, and communication.¹¹ These and similar findings have guided pediatric EOL care curricula and trainings to focus on symptom management, communication, and compassion.¹²⁻¹⁴

Although partnership with parents is a tenet of pediatric palliative medicine,¹⁵ initiatives to include the parental perspective in education¹⁶⁻¹⁸ and research¹⁹⁻²¹ have been limited. Bereaved parents have shared their experience through parent panels or single session group discussions,^{13,22-25} with learners identifying these interactions with parents as the most important pedagogical element of the curriculum.²⁶ Role-play scenarios with bereaved parents have

revealed improvement in learner comfort and capacity to communicate with families.^{17,27-29} In curricula and trainings developed to date, medical educators have incorporated the needs of learners, priorities identified through research with bereaved parents, and professional competencies to form content, goals and objectives of learning sessions.^{30,31} In published research on EOL curricula, bereaved parents have not yet been involved from the beginning of curriculum development with the aim of their input to identify learners, guide educational priorities, form learning objectives, and create assessment tools.

Our aim with this study was to coproduce a curriculum with parent partners. We began by asking parents what they want the hospital and hospital staff to know. This question was inspired by the essay "I Wish You Knew" by Anne and Jeff Wills,³² parents who shared their hospital experience and EOL care for their son Ryan. In describing this study as the first step in the development of a patient- and family-centered EOL curriculum, we hoped parents would respond to this aim of amplifying their experience and valuing their collaboration to strengthen the provision of EOL care for other children and their families. In using a focus group format with a semistructured process, we aimed to empower parent participants to build on one another's perspectives, use the parent voice to generate a richer understanding of participants' experiences, and create collective viewpoints to actively guide curriculum development. Using the consolidated criteria for reporting qualitative research (COREQ) guidelines,³³ in this article we report on the first phase of curriculum development, with

parents identifying what is helpful and unhelpful, describing existing supports, and suggesting opportunities for improvement in pediatric EOL care.

METHODS

Research Team

This study was conducted at a pediatric academic medical center where the children of study participants received care. The hospital has a full complement of medical and surgical subspecialties, and a palliative care team provides multidisciplinary care to meet the physical, psychosocial, emotional, and spiritual needs of children and their families.³⁴ The research team included a physician and 2 social workers from the comfort and palliative care team (CPCT) and 2 researchers and a medical interpreter who are not members of the CPCT, all of whom identify as female. Before the study onset, we met as a research team to discuss previous experiences with this topic and to identify personal assumptions. In the initial recruitment call, the CPCT physician described to potential participants that they may have previously interacted with members of CPCT in their child's care and in bereavement follow-up and their input was being sought as part of a study to better understand the parent perspective in pediatric EOL care. Parents who expressed interest in participating in the study received a phone call from the research specialist using a script to provide key details of the study, provide an opportunity to consider voluntary participation with a nonclinician, and schedule the focus group. This research specialist also conducted the in-person consent process with the participants before the start of each focus group. The focus groups were moderated by the CPCT physician and the nurse

researcher to allow probing for additional information facilitated by a clinician known to participants and with a researcher with no previous relationship to participants. The research team met after each focus group to identify and confer on emerging themes.

Study Design

English and Spanish-speaking bereaved parents whose child had received care from the CPCT and whose child died >18 months before study initiation³⁵ were invited to participate. If a parent expressed symptoms of complicated grief in bereavement follow-up or on the initial recruitment call, they

were not approached for study participation and were provided bereavement support resources. A Spanish medical interpreter was present on all phone calls with potential participants whose primary language was Spanish. This study was approved by the hospital institutional review board.

Demographic Survey

A demographic survey was developed by the research team. In this survey, participants were asked about their sex, cultural identity, marital status currently and at the time of their child's death, number of children (including the child who died), and highest level of education

(Table 1). This survey was completed by participants at the focus group and deidentified. In the focus group, participants were asked to share their child's age at the time of death, underlying medical condition, and cause of death.

Focus Groups

In-person focus groups were conducted to obtain opinions and capture a diversity of viewpoints on the care of children and their families at EOL. A semistructured interview guide (Supplemental Materials) was developed and used in each focus group to describe the aim of study, ask the open-ended question of what parent participants wish their health care team knew, and probe by using prompts adapted from the guide.¹⁰

Each focus group was 2 to 3 hours in length, including time for consent, completion of the demographic paper survey, participation in the focus group, and debriefing after the group. Parents were assigned to groups on the basis of their time availability and preference for a group in English or Spanish. All the groups were held in a conference room at the hospital and were moderated by the CPCT physician and nurse researcher. The medical interpreter was present for the focus groups conducted in Spanish. One of the 2 social workers was present at each of the focus groups to provide support and debriefing.

A follow-up phone call with each participant was conducted 3 to 7 days after their focus group. This call allowed parents to provide feedback on their perspectives as participants in the study, for the investigator to share initial themes identified during their focus group, obtain parental input and consensus, and provide the parent additional support if needed. Parents were asked 3 questions related to participation: "What was good about

TABLE 1 Characteristics of Study Participants

Characteristic	Number of Participants
Age of parent, median (range), y	42 (26–52)
Location of child's death, <i>n</i> (%)	
Hospital	12 (70)
Home	4 (24)
Subacute facility	1 (6)
Sex of parent, <i>n</i> (%)	
Female	17 (63)
Male	10 (37)
Marital status at time of child's death, <i>n</i> (%)	
Married	23 (82)
Divorced	2 (7)
Single (never been married)	2 (7)
Living with a partner	1 (4)
Marital status at time of the study, <i>n</i> (%)	
Married	23 (82)
Divorced	2 (7)
Single (never been married)	2 (7)
Living with a partner	1 (4)
Preferred language, <i>n</i> (%)	
English	22 (81)
Spanish	5 (19)
No. children (including child who died), mean	3
Highest level of education, <i>n</i> (%)	
Less than high school	1 (4)
High school diploma or equivalent	2 (7)
Postsecondary nondegree award	1 (4)
Some college, no degree	7 (25)
Associate degree	4 (14)
Bachelor's degree	9 (32)
Master's degree or higher	4 (14)
Population or cultural identification, <i>n</i> (%)	
Asian or Pacific Islander	3 (11)
Black	0 (0)
Hispanic	12 (44)
Native American	0 (0)
White	4 (15)
Other	3 (11)
Decline to state	5 (19)

participating in the focus group?"; "What felt hard?"; and, "Is there anything else you would want us to know?" Written notes of participant responses to initial themes and the above 3 questions were recorded.

Analysis

Each focus group was audio recorded and transcribed verbatim. Transcripts were entered into NVivo 11, a qualitative data management program, and analyzed by using the 6-phase model of thematic analysis.³⁶ The transcripts were reviewed by 2 coders who identified initial codes. The codes were collaboratively reviewed and defined. In cases in which differences occurred, coders developed decision rules and refined definitions. Through an iterative process, codes were clustered into themes to capture the concepts inherent in the narratives. Written notes from follow-up phone calls confirming the initial codes identified in the participant's focus group were used to further inform the development of themes. The themes were reviewed and further interpreted by all the project coinvestigators to reach consensus about major themes and subthemes.

RESULTS

Parents of 58 children were eligible to participate in the study, of which, 38 were reached by the initial recruitment call, and parents of 31 children agreed to a follow-up phone call with the research specialist. Twenty-seven parents of 17 children participated in the

study, with the total sample size determined by thematic saturation. Seven focus groups took place, ranging in size from 2 to 11 participants in each group, with an average of 4 participants per group. The self-reported descriptive data of the 17 mothers and 10 fathers are provided in Table 1. Twenty-five (93%) parents participated in the follow-up phone call.

Of the parents who participated, all but 1 of their children had a chronic medical condition (Table 2). The child with no underlying medical condition was hospitalized for influenza and died after a prolonged intensive care course.

Four themes were identified as important to parents in their child's EOL care. These themes included the following: (1) honoring the role of the parent (Table 3); (2) having confidence in the care team (Table 4); (3) receiving gestures of love and caring from staff (Table 5); and (4) navigating logistic challenges within the hospital and managing daily living (Table 6). Subthemes and participant comments are listed in the tables below.

Honoring the Role of the Parent

Honoring the role of the parent was identified by participants as the knowledge held uniquely by the parent, such as having expertise in their child's needs and medical knowledge about their child's health status and history over time and between different practitioners. Parents described several subthemes under this theme: (1)

parent as the intuitive expert on their child in having a general sense of their child's health and wellbeing, (2) parent as the medical expert about their child across clinical encounters, (3) appreciating that the parent has a perspective that is valued and respected by the medical team, (4) parent as the medical decision-maker, and (5) tasks of parenting, such as feeding, bathing, and diapering.

The subtheme of the parent perspective valued by the medical team was most often elicited in the response to the prompt, "What advice would you give other parents, in similar circumstances, to help them interact with their child's providers?" Parents described being incorporated into the medical team through participating in rounds, having access to an interpreter, and being welcomed to ask questions. Two Spanish-speaking parents in separate focus groups shared occasions when they felt their perspective was not welcomed because of a barrier in language. They described confusion in understanding the medical plan and their continued doubts, wondering, "Why didn't I ask them to do this or do that ... it's hard to understand why I didn't ask that question."

Confidence in the Care Team

In having confidence in the care team, parents identified hospital staff having knowledge about the medical information specific to their child, familiarity with their child's needs and behaviors, and staff having expertise to guide the family about EOL. Parents described the importance of "reading the same file" in ensuring communication between practitioners. In the subtheme of personalization, parents highlighted understanding of practitioners following an algorithm versus an individualized care plan to meet the

TABLE 2 Medical Condition of Child as Described by Patient's Medical Record

Parents Whose Child Had Underlying Condition of the Following	n (%)
Any condition	27 (99.9)
Cancer	5 (18.5)
Congenital heart disease	4 (14.8)
Genetic (lung, metabolic, or neurologic condition)	9 (33.3)
Genetic trisomy (trisomy 13 or 18)	5 (18.5)
Hypoxic ischemic encephalopathy resulting in severe neurologic injury	3 (11.1)
None	1 (3.7)

TABLE 3 Honoring the Role of the Parent

Subtheme	Participant Comments
Parent as the expert on their child	<p>“As a parent, you develop a different sense. You start understanding how to anticipate. You start understanding what they want to communicate to us. You check. Parents see what it means to have a disability. We look into our kids.”</p> <p>“I think as parents you trust doctors, because, obviously, they have the book smarts and the knowledge and it's [their] job, [they] see patients like this every day, similar patients, similar circumstances. So, you trust they know what's best medically, you know? But I think parents, especially moms, you carry them, [so we] just have these gut feeling that you know. A parent responds: Well, it's like, you've carried them from the time they were in your stomach.”</p>
Parent as the medical expert on their child	<p>“Teams are very siloed sometimes, so they may not realize that they just recommended a medicine that is going to counteract with the neuro team and this is coming from the GI team or the pulmonary team . . . I felt that we were the specialists of our children.”</p>
Parent perspective valued and respected	<p>“We felt like everybody really respected our questions and respected our opinions . . . and we were able to contribute to [his] care and we felt like we were an important part of the care team . . . yeah, that really helped, that we were part of the team, not just like parents on the sidelines.”</p>
Parent as medical decision-maker	<p>“I kept telling them all I wanted with my kid was to feel loved. That's all I wanted. I get it, I don't need him to be poked and prodded. I didn't want him to get trached. There are just things that we didn't want.”</p> <p>“If you've made a philosophical decision on what your course of action is gonna be with your child, then everybody should be on board with that.”</p>
Parenting tasks	<p>“As a parent, you just feel helpless . . . your primary job is to protect your child, but, like, you can't if he's sick and there's nothing you can do. I guess that's how I felt in control, that, like, okay, I'm gonna be as knowledgeable as possible and do what I can and pump milk even though he can't drink it and—you know?”</p>

GI, gastrointestinal.

needs of their child, explaining, “Of course there’s always protocol and procedures, but that can’t be the only thing. Like, it can’t be black and white. There has to be a gray area for that. Because that doesn’t necessarily pertain to every single patient that you take care of.” In describing EOL care, parents shared the importance of receiving guidance from hospital staff with regards to medical decision-making, dying, funeral arrangements, and anticipatory grief.

Receiving Gestures of Love and Caring

Gestures of love and caring were coded when parents used the words “love” or “caring” received from hospital staff, separate from attending to the medical needs of the

child. In responding to the prompt of what participants found unhelpful in their child’s care and in what they would want the hospital staff to know, parents shared opportunities for staff to provide compassion.

In describing love and caring, parents received these gestures from varying members of hospital staff, including the following: nurses, physicians, social workers, child life, rehabilitation therapies, interpreters, environmental services, security, spiritual care services, the unit secretary, and the phlebotomist. In support received from staff, parents included those not directly engaged in clinical care, describing the following: the unit secretary who found a meal for the parent whose child was admitted at night, security at the hospital’s front entrance who greeted their family on

every visit, and the person from environmental services who was a consistent comfort while cleaning their room every day for many months.

Logistic Challenges

In describing logistic challenges in their child’s EOL care, parents spoke about the financial stressors of being with their child in the hospital. Parents noted the costs of food, parking, and transportation and identified a lack of support from hospital staff on resources or guidance to navigate financial challenges. In all 7 focus groups, parents brought up the expense of parking and parent meals in the hospital. One parent explained that it felt the hospital did not understand this burden on parents noting, “So, I feel like, you know,

TABLE 4 Confidence in the Care Team

Subtheme	Participant Comments
Reading the same file	"I know the doctors have to switch every week. But one doctor comes and says, 'You know what? We're gonna do this – this week is this treatment,' and then the other comes, 'No, we're gonna change it to another thing.' And the other comes and says, 'You know what? Let's do this.' I think a lot of the times even the doctors were not on the same page. I don't know how much they communicate. I don't feel like they're reading the same file."
Personalization	"There were some [nurses] who were kinda like, 'This is how it's supposed to be.' I know it's how it's supposed to be. But not everybody's the same, and everybody responds really different to things. And we're like, 'No, he's unique. Believe me.' The other 12 nurses and doctors figured that out a while back." "Sometimes I feel like they're telemarketers and they're just answering a script. And they have to go through the steps instead of jumping just up number 5 and save 10 minutes of suffering. I tell them, 'These don't work. Just jump to number 5 and do it.' But they didn't wanna do it."
Familiarity as comfort	"But we had our team on the last day. As hard as it is, we had our team there. I would assume that would be big for any family ... just having a familiar face or some kinda continuity." "And then on the last day, when we decided not to continue, it was like something we are – we were here around 6 weeks. The same nurses, the same doctors were there all the time; the same people. But on that day, nobody we knew was there. Nobody that we knew was there. And I was like, I can't believe this. I couldn't believe it. That none of the people that knew my son were in there. Nobody."
Receiving guidance	"I know [the hospital has] a lot too and they can't hold everybody's hand, [but] sometimes a parent just needs guidance and pointed in which direction to go." "You know, I think prepping families is huge. But especially with the end-of-life piece where prepping for what that last day will look like is big ... just the prepping of 'This is how they might react. This is what their breathing might look like.' I think just a really good walkthrough, and make sure the family is able to, as much as they can, hear it and take that in."

there's just a lack of knowledge, almost, between some of the teams and, you know, we don't want you to have to worry about parking. Like, we don't want you to have to worry about your meals."

Parents described the logistic challenges in their life outside the hospital, including the following: managing work, finances, family and daily living, and care of other children during their child's hospitalization and EOL care. In 2 separate focus groups, 2 parents offered to be "mentors" to help with care of children at home, grocery shopping or meal delivery to families whose children are at EOL, and support in the hospital.

In describing resources that would have been helpful, parents offered that the hospital could provide families with a list of community resources for child care, meal delivery, and financial support.

In describing logistic challenges, within the hospital and outside the hospital, parents shared that information to address these challenges should be offered "without us having to ask." One parent shared, "I think more than offering help ... I didn't know [what] I needed ... I remember [social work] coming in and offering and asking [what help I needed], but I didn't know what I needed."

DISCUSSION

In this study, we asked parents what they wanted the hospital and hospital staff to know on the basis of their perspective as parents whose children received some or all of their EOL care within our hospital. We identified 4 themes from parents as important in their child's EOL care: honoring the role of the parent, having confidence in the care team, receiving gestures of love and caring from staff, and navigating logistic challenges within the hospital and managing daily living. Of the themes identified, partnership with parents, competency of the medical team, and compassion are consistent with previous themes described by parents as important in their child's EOL care.^{37–39}

TABLE 5 Gestures of Love and Caring

Subtheme	Participant Comments
Gestures of love and caring toward parent	<p>“[The nurses] know if you’re having a good day or if you’re having a bad day. And, you know, it’s—they take care of the parents just as much as they take care of the kids.”</p> <p>“We became friends with the chaplain. He’s a very noble person that always lent us a hand. And the cleaning lady that was seeing my child with a lot of love. They helped us.”</p> <p>“... For [the health care team] to continue with that type of love with the kids, but also with the parents, because if the doctor gives you a smile, it’s very beautiful for us. I always received all of that. And it helped me to stand up next to my child’s bed...And a hug from a nurse or like a gesture of love, that encouraged me... I’d liked for my child to survive. But I know the effort from the doctors, from the whole [team], it was the top, it was the best...”</p>
Gestures of love and caring toward the child	<p>“I think that [our children would be] grateful for the care they had. You know they were cared for well and the nurses, you know, loved them, and you know, I think that that’s important... These kids may not feel good, but they know that they’re being taken care of with love and care.”</p> <p>“I would say, it’s nice that everyone got to come and say their goodbyes to her. Which was—I think it was nice for them to just have that opportunity to also, you know, grieve that time and be able to come and see someone that they cared for so much before she passed.”</p>
Gestures received as a lack of compassion	<p>“I would say with doctors, classes for doctors in compassion. Nurses, they’ll kinda listen and they’ll kinda feel bad... doctors are just straight-faced... like, put yourself in [our] shoes. Like, yeah, I understand you have to act a certain way and be a certain—you can’t cry, you can’t sit there and act like it’s your kid. But just compassion and just caring more, and more concern and listening.”</p> <p>“But in the future if they see parents in this situation, I only ask the doctors to have—to explain to [parents] in a way as they were feeling that pain too. I want the doctors to speak softly so they don’t feel like the parents are pushed in a way that you feel that [the doctors] don’t care about the life of the child... Because if—as I told you about the doctor who talked to me very loudly, I didn’t feel the trust of asking him questions. Because I felt like he was answering as he was angry.”</p>

Parental request for guidance in navigating logistic challenges within the hospital and managing daily living have not been previously included in pediatric EOL curricula. Parents described their unanticipated needs, such as non-health care expenses associated with their child’s hospitalization and challenges that limited them from being at the bedside of their hospitalized child. Previous research has revealed hospitalization-related nonmedical costs of lost earnings and expenses such as transportation, meals and child care to be a significant burden for families, highlighting that interventions focused on supporting families should account for

nonmedical cost burdens.⁴⁰ In addition to recognizing the financial burden, parents identified the emotional burden of managing life inside and outside the hospital in describing challenges in activities of daily living, caring for their other children, and working outside the home. Parents expressed a wish that the hospital staff had prepared them for these challenges, providing guidance on the basis of experience with other parents and knowledge of hospital and community resources and not waiting until parents reach out for assistance.

Although not coded as a separate theme, in describing receiving gestures

of love and caring from staff, parents in this study described care received from clinical and nonclinical staff. Hospital staff from a variety of departments may provide important support to patients and families. This included hospital security, interpreters, the unit secretary, and environmental services. This finding suggests that educational efforts to improve coordination, communication, and support in EOL care be delivered in the multidisciplinary manner in which patients and families experience care.

Although thematic saturation was reached, the limitations of this study include our relatively small sample size. Participants’ primary languages were English and Spanish; therefore, our data

TABLE 6 Navigating Logistic Challenges

Subtheme	Participant Comments
Financial stressors associated with additional in-hospital costs	<p>“Some parents don’t eat, then they get crazy—like in a plane, you have to put the oxygen mask on you first to help yourself before you can help [your child].”</p> <p>“Having to worry about something that’s minuscule like [parent meals] when your kid is as sick as our kids have been, I don’t think that’s fair.”</p> <p>“Parking twice a day in and out for both of us, coffee and food when we were at the hospital, and care for our other children...all of these expenses add up and it was hard to ask for help. I wish someone would have told us about these expenses ... without us having to ask.”</p> <p>“It’s like you have to work just to pay for parking.”</p>
Care of other children	<p>“You have to think about how am I supposed to provide care for my 3-year-old? I mean, I’m a stay-at-home mom. Like, where is he supposed to be, exactly?”</p> <p>“I abandoned my other 2 children to completely dedicate myself to him. I left work, house, everything.”</p>
Managing daily living	<p>“I would go to the grocery store and be like, ‘I don’t even know how to make a list.’ My brain was so preoccupied with medications and timers and alarms and catheters and, like, all of these other things that I am now providing for my child, and I can’t think about a list of groceries, you know?”</p>
Guidance	<p>“Social workers need to be more forthcoming with information to help families financially. Because I’m not gonna be like, ‘Oh, hey, we can’t pay our bills!’ But, you know, I’m not gonna—Like, how do you communicate to someone that you—like, not only you don’t wanna communicate that to random people that you barely know, but I feel like there’s no open door.”</p> <p>“Back to social workers ... I get they can’t hold everybody’s hand, but maybe if they can give, like ‘Here’s some resources and, though your world’s upside down, maybe you have a person in your world who’s a little more stable that can go ahead and contact those places for you.’”</p> <p>“Let us know to be patient. Let us know that everything is going to be longer and harder than we think. If your child is here, at this hospital especially in the ICU, it isn’t going to be a quick in and out. Prepare your finances, cancel upcoming vacations, and organize your time off.”</p>

omit the perspectives of parents with other preferred languages. Additionally, >80% of the participants were English speaking. Another limitation in diversity of participants is that no participants self-identified as Black or Native American, although 5 declined to state their cultural identification. This could be attributable to the demographics of the hospital’s patient population as well as the demographics of patients cared for by the CPCT. Because our participant pool was parents whose child had been cared for by the CPCT, nearly all parents had children with chronic underlying illnesses. For parents whose children had been previously healthy and died of an acute event, there may be other important needs that were not identified.

CONCLUSIONS

The themes identified in this study will provide a starting-point for identifying learners, developing objectives, and considering educational modalities for an enhanced curriculum on EOL care. On the basis of this study, it may be that a proactively designed curriculum incorporates communication elements of existing EOL curricula with the addition of identifying financial and social stressors to allow families to explore higher-level emotional concerns. Educational efforts to improve coordination, communication, and support in EOL care should include all staff members from whom parents

identified as receiving support. The experiences of these parents and their active involvement as parent educators will guide priorities for skill strengthening, including the creation of a parent-informed hospital-wide multidisciplinary curriculum to improve the provision of family-centered EOL care.

ABBREVIATIONS

CPCT: comfort and palliative care team
 EOL: end-of-life

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: Funding from the Division of Comfort and Palliative Care was used to support this study. Nonfinancial support was also received through the Academic Pediatric Association Educational Scholars Program, through which the primary author conceptualized and further developed this project. The funder or sponsor did not participate in the work.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

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Pediatrics 2021;148;

DOI: 10.1542/peds.2021-051379 originally published online September 13, 2021;

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