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“I was able to still be her mom” Parenting at end of life in the PICU

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Abstract

Objective—The death of a child in the pediatric intensive care unit (PICU) is perhaps one of the most devastating and challenging experiences a parent can ever endure. This paper examines how parents of children dying in the PICU understood their role and discusses implications for clinical care and policy.

Design—Retrospective, qualitative study

Setting—Two pediatric intensive care units located in children’s hospitals within academic medical centers in the northeastern United States

Subjects—Parents of 18 children who died in the PICU.

Intervention—Semi-structured telephone interviews, digitally recorded and transcribed.

Measurement and Main Results—Many of the factors deemed important by the parents related to their capacity to be a “good parent” to their child throughout his or her stay in the PICU. Specifically, parents sought meaningful ways to express and assert their parenthood across three domains: 1) providing love, comfort and care; 2) creating security and privacy for the family; and 3) exercising responsibility for what happens to one’s child.

Conclusion—Parents’ ability to fulfill the essential features of their role as parents of children dying in the PICU shapes how they perceive the quality of the experience. PICU clinical care and policies can and should uphold and protect these features enabling parents to feel that, despite the outcome, they had done their best on behalf of their children.

Keywords

end-of-life care; pediatric intensive-care unit; parenting; qualitative

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> "I really wanted to bathe her after she passed away. …so, even after she passed away, I was able to still be her mom…So, yeah, I was allowed to be her mommy the whole time, even after she passed away." (P:18)

INTRODUCTION

Confronting the death of a child in the pediatric intensive care unit (PICU) is a challenge to a parent's inner strength and sense of competence. It tests the parent's capacity to nurture and protect the child, to uphold the child's personhood, to hold hope for that child's future, and to come to terms with unbearable loss (1–4). Moreover, the parent must bear this devastating loss within the stressful, bewildering and public environment of the PICU (5–8).

When considering how best to support parents who are confronting the likely death of their child in the PICU, it is useful to bear in mind two dimensions of parent and family needs. The first is the quality of care that clinicians provide to the child, the parents, and other family members surrounding the death. Features of clinical care that are important to parents include: optimal pain management, attention to the child's quality of life, effective communication with practitioners, and opportunities to participate in decision making (3, 9, 10–14). The importance of spiritual and anticipatory bereavement support has also been documented (13, 15). Other studies have emphasized the vital importance of assisting parents in meeting their basic needs and maintaining family life – including adequate nutrition, hygiene, shelter, transportation, and care of other children (2, 5, 16–18).

The second dimension entails enabling parents to fulfill their roles in a capacity that makes sense to them. Researchers have pursued fewer studies on this dimension. Meert and colleagues (3, 19) have described parents' needs to remain connected with their child by maintaining family traditions and cultural practices and to sense that their child is valued as a person by hospital staff. Preserving the integrity of the parent-child relationship (3) and the transcendent quality of the relationship that endures beyond death (15) have also been highlighted.

Family-centered care has emerged over the past two decades as a practice that embodies what many consider to be core elements of care (20). Viewed as being essential to effective and humane pediatric palliative care (8, 9, 18, 21, 22), family centered care recognizes the family's values, beliefs and emotional needs (8). It honors the parents' "commitments to their child" (21), encouraging them to continue actively in their parental role by promoting shared decision making and helping the family to retain their responsibilities throughout a hospitalization (23). However, to best support parents, we need a clear understanding from the perspective of parents as to what they must do to be a "good parent" for their children dying in the PICU (24, 25).

The purpose of this study was to explore in more detail how parents whose children had died in the PICU understood their roles during the time surrounding their children's deaths. The study sought to understand how parents define their most essential activities and responsibilities.

MATERIALS AND METHODS

This study was conducted as the first phase in a larger study designed to develop a pediatric version of the Quality of Death and Dying questionnaire (26–28) to measure parents' and clinicians' perceptions of the quality of dying and death in the PICU (29). As part of the larger study, this qualitative study was designed to elicit information on parents' views about the quality of care during the last three days of their child's life.

Setting

The study was conducted retrospectively at two PICUs located in children's hospitals within academic medical centers in the northeastern United States.

Participants

Using purposive sampling from a review of medical records, we identified the parents of children who had died in the two PICUs between July 2005 and December 2006. Excluded were parents who did not speak English; those who were involved in litigation or mediation with the hospital; and parents in cases where there were allegations of abuse or trauma. Parents were invited to participate by letter followed by a telephone call. Of the 94 deaths that were eligible, 29 parents could not be contacted because of an invalid address and/or telephone number. Of the 65 parents contacted, 18 (28%) were interviewed, 14 (21%) declined to participate, and 33 (51%) did not respond to the letter or telephone message.

The study was approved by the Institutional Review Boards of both hospitals and the research center. Written consent was obtained prior to the interview.

Interviews

Parents were invited to participate in the study six or more months after the death of their child. Interviews were conducted September through November of 2007. Two trained interviewers who were not associated with the hospitals conducted semi-structured telephone interviews, a methodology used successfully in similar studies (30, 13). Questions inquired about experiences in the 72 hours preceding death, what was most difficult for the child or family, what made things easier, and what advice parents would give clinicians and institutions seeking to improve the care provided to other children and families in similar circumstances. The interviews averaged 60 minutes in length and were audio-recorded and transcribed verbatim. De-identified transcripts were used for analysis.

Qualitative Data Analysis

Analytically, a series of iterative steps were employed using Atlas.ti to facilitate the coding (31). Three coders (two authors and a member of the research team who was not involved in the interviews) read the transcripts independently and coded for the QODD domains using a defined list of codes. Differences in the coding were reconciled through regular meetings of the three coders. In addition, the three coders identified emerging concepts that were not anticipated; parenting was one topic that emerged in the first phase of coding. To further explore themes related to parenting, three authors (SM, AB and ECM) read the transcripts for text related to this concept and then identified overarching themes about parenting. Quotations were selected from the transcripts to illustrate the themes related to parenting.

RESULTS

PARTICIPANT CHARACTERISTICS

Characteristics of the 18 decedents are shown in Table 1. The u-shaped distribution of their ages is consistent with the nature of illness among PICU populations with the largest age groups being infants and young adults (9). The seven decedents over age 18 suffered from chronic illnesses, and their parents retained their roles as caregivers. While two (ages 26 and 37) had lived independently in their own apartments for a time, the remainder (ages 19–24) did not appear to have achieved independence. Seventeen of the 18 parents interviewed were mothers.

FINDINGS

Parents emphasized the importance of maintaining their role as parents and being the best parents they could be under the circumstances. One mother said: *"So we definitely took that as our role, to do everything as a parent we could do." (P:11).* Another mother commented on how much she appreciated the PICU staff because *… "they just never made us feel that we were not doing the best that we could do." (P:7)* The parents described how they sought meaningful roles across three domains: providing love, comfort and care; creating security and privacy for the family; and exercising responsibility for what happens to one's child. The domains, key themes within each domain with illustrative quotations, and corresponding implications for practice and policy are summarized in Table 2 and described below.

Providing Love, Comfort and Care—Providing love, comfort and care to their children was at the heart of the parents' desire to be the best parent possible under the circumstances. This encompassed remaining close and connected with their child, providing regular physical care, and seeing their child as a valued individual.

Parents described the benefits of remaining close and connected to their child including touching and holding their children throughout the time in the PICU, as well as when their child was dying:

> "…It sounds so strange but it was one of the most peaceful, beautiful things I've ever seen and ever been a part of. That sounds weird because it's your child. But that's how it started out. It was daddy and I and [my child]. That's how it started. And that's how it ended, with the three of us in a room together. There was something beautiful about that… I was able to get right in that bed with her." (P: 17)

Many parents were reluctant to leave their child's side when they believed death was imminent for fear of not being present at the time of the child's passing. For example, some wished to eat their meals in the room and to hold family meetings at the bedside since time away from the bedside provoked additional stress. One mother described her lingering regrets about being separated from her daughter in order to attend a family meeting, especially when she returned to the room to find her daughter close to death.

> "And when the intensivist wanted to talk to us about what we were going to do next, we were always asked to go into this consult room. And so the whole time I was afraid we weren't going to be in the room with her. …if I had known then I would have said, "No. Can't we just talk about this right here? I want to talk about this right here," if I'd been a little more forceful. But I didn't know I was going to feel like this. (P:18)

For some parents the PICU environment and the distancing effect of the equipment felt intimidating, but they appreciated staff efforts and encouragement to conquer this divide, enabling them to provide the physical care as they wished. One mother said:

> "They let us brush her hair and be right there with her …They let us help them so we could feel a part of what life she had." (P:7)

Similarly, parents of a young infant felt awkward and uncertain in their ability to connect with and comfort their baby, yet the encouraging words and manner of an observant nurse helped them:

> "We kind of felt out of sync with the parent role. We didn't have a chance to bond with him right after the birth because of his situation. All we could really do was to touch him. We …didn't know how to comfort him. He was sedated. You know, the

> thing I remember the most was the one nurse who said that, "He likes to have his head rubbed." That was really important to us." (P:15)

Many mentioned their gratitude when clinicians recognized the child's individual character and interacted with the child as a social being and not simply a patient.

> "They were more engaged in her life than in the fact that she was going to die, which everyone knew. At a certain point, we all knew that…and the other people that were looking after her, knew her as a person and could relate to her". (P2)

Creating security and privacy for the family—Establishing a physical and social space that engendered a sense of security, buffered intrusions, and permitted private time with the child was important. To achieve this, several parents wanted unlimited access to their child. Others adopted a gate-keeping approach, trying to control who entered the space and when, consistent with the parental role of monitoring who enters into their home.

> "And it was constant, constant, constant to that point where she was in tears, "I just need a break." So I would draw all the curtains and put up a big sign but everybody ignored it. I mean if I thought she needed something, I would be the first one to go out and get assistance." (P:1)

This same mother commented that she wished she had more control over the space than she did:

> It would be nice to have a little more say in when things were done, "You know, could you come back in half an hour? We're right in the middle of whatever we were in the middle of…" (P1)

A lack of privacy prevented some parents' expression of emotions and grief, and engendered deep and lasting regrets for some (32). One mother's inhibition about getting into bed with his or her dying child pained her at the time of the interview, many months later:

> "And I think she knew she was going to die because she said, "Will you get in the bed with me?" I couldn't do that with [pause] [crying] all the nurses… Everybody in and out, you can't have those private moments. And I just wished I had got in bed with her one time and gave her that last hug before she became incoherent. I never got that chance because it's so damn busy in there." (P:11)

Another parent remembered the nurse's observations and the watchful eyes of other parents as impediments to the family's privacy and ability to be at ease:

> "The nurse was always there watching. She sat on this high stool through this whole thing. She never took her eyes off of what was going on. And there were other families there with their child. And they were all watching, realizing that this was a critical case. So I would say that there wasn't much privacy at that stage of the game, at the tail end." (P:12)

Exercising responsibility for what happens to one's child—This domain focused on the parents' sense of responsibility and fulfillment of duty. Features of this domain included having detailed information about their child's condition and treatment, advocating for their child's needs, and maintaining vigilance over the quality of the child's care. For many, this meant leaving with the impression that their child had the best care possible under the circumstances:

> "I've seen the best in action. You know, what mother could ask for more? I mean you always want the best for your children and my son had the best. You know, he just had different plans." (P: 10)

A number of parents described the desire to participate in or observe rounds as a way of both keeping informed about, and advocating for, their child's care. In commenting on what advice she might give other parents in a similar situation, one mother said:

> "You know; if you're not sure what they are doing, ask questions. That's the way you get your information. And, I mean, stay in touch with the doctors and the nurses. We would go out in the hall and listen to them round. And ask them questions if we didn't understand what they were talking about or what they thought of situations that they didn't bring up. " (P:3)

For many parents, being an advocate for their child was an essential feature of being a responsible parent. One mother found that being present at rounds was a useful strategy for advocating for her daughter's care:

> "And I think for me the biggest positive impact was being able to be part of rounds and say, "What's best for my daughter?" …You have to be there when they round. You have to be there when there is anything. You just don't leave" (P:11)

For some, being responsible meant remaining vigilant about the quality of the medical care. One mother described chastising a PICU physician because he didn't share information about her daughter's medication with her:

> "And once I explained that I couldn't double check her medications if I didn't know what his orders were. I said, "How am I supposed to prevent a medication error if I don't know what you've ordered." (P:18)

In describing this aspect of their role, some parents noted that the need to exercise this responsibility resulted in their feeling unduly extended in their role beyond that of a parent, "*So you are not only being a parent, you are being like a super parent and that was really brutal." (P:2)* For them, the perceived need to take on a high degree of responsibility created stress and tension.

DISCUSSION

When a child is dying in the PICU the life of the family moves from the home to the unfamiliar and public environment of the ICU. This transition requires parents to adapt by finding new ways to maintain the parent-child relationship and to fulfill their roles (3). For parents who face the death of a child, this can take on existential urgency.

This study offers insight about what matters most to parents in their quest to be the best parents possible when their child is dying in the PICU. Many of the findings can be understood in terms of the need to re-interpret how they would parent their child at home in the radically different PICU environment. Despite the constraints of the PICU environment, our findings suggest that many parents found creative and meaningful ways to continue loving and comforting their child, to establish a sense of security and privacy, and to retain responsibility for what happened to their child. The findings underscore the value of promoting models of family-centered care in the PICU that can preserve parents' rightful place and role as central to their child's life (18).

While parents' recollections suggested that in many cases they felt clinicians encouraged and supported their active involvement in the care of their children, our findings suggest there was room for improvement. These parents might have benefited from more explicit communication with clinicians about what they needed, to fully express and fulfill their parental responsibilities and love for their child (34).

Regarding the need for security and privacy for their family, we found that parents desired a space where they could have unlimited access to their child and time retain some control over the environment. Establishing privacy and being free from intrusions can support a parent's sense of connection and closeness with their child – critical during the intimate unfolding event of a child's death. Clinicians can help by conferring on parents some control over who enters the bed space, particularly when the child's death is imminent. These findings are consistent with those described by Meert et al (13) in their study of the spiritual needs of parents and Meyer et al (3) in their research on parental priorities in the PICU. The solution, of course, is not simply an architectural one – to provide more private physical space, but encompasses broader goals that make parents feel welcomed, valued for their contributions, and respected (3, 24, 35).

The interview data suggest that permitting and encouraging parents to stay at the child's bedside as they wish – including overnight, during rounds, family meetings, shift change, and during invasive procedures – can be enormously helpful to some parents (6, 37, 38). In order to do this well, however, the infrastructure of the hospital, such as the space in the PICU, must enable parents to meet their own instrumental needs (17). Future design of PICU's should take into account parents' need to eat, sleep, shower and attend to their other daily concerns while they remain at their child's side.

With regard to exercising responsibility for what happens to one's child, the interview responses reveal that parents wanted and were capable of claiming a central role in their child's care. For some this focused on involvement in decision making, yet even those who did not wish to be the decision maker clearly showed a desire to be informed and knowledgeable about the care being provided. Although parents must be supported as the primary caregivers for their child, Levine and Zuckerman (36) caution that their role best not expand to supplant the functions of clinicians, since this can present challenges for parents and clinicians alike. This family-staff balance requires negotiation to clarify how parents both want, and are able to participate (20, 23). The concern about parental overburden deserves close attention as the movement to establish a culture of safety and minimize medical error encourages patients and their families to remain vigilant and monitor treatment plans in the hospital. (39)

A possible interpretation of the results overall is that that how parents appraised their ability to be a good parent shaped their feelings and recollection about the circumstances surrounding their child's death. Parents who felt they had done the best they could had the satisfaction of knowing that all that could be done, was done (3). By contrast, parents who were unable to do or accomplish what they believed necessary expressed regrets such as the mother who wished she had gotten into bed with her daughter as she died or the mother who regretted having left the room for a family meeting only to return to find her daughter close to death.

Practitioners can facilitate the parents' role in the PICU when they seek to understand parents' perspectives, incorporate their suggestions, and allow them to take on parental responsibilities. Practice guidelines need to address clinicians' concerns about how to cope with parents whom they feel are overly intrusive, or who question, delay and/or seemingly compromise the care. These guidelines might incorporate an "ethic of accommodation" to help identify and address conflicts when they arise (15, 36)

It is worth noting that while the themes reported reflect commonalities across individuals, each parent has a unique mixture of individual needs and/or wishes essential to fulfilling the sense of being the best parent possible under the circumstances of a child's death in the

PICU. The best family-centered care in the PICU will make it a practice to ascertain these needs and wishes on an individual basis.

Limitations of the study must be acknowledged. Recall bias is a limitation inherent in any retrospective study as is social desirability in semi-structured interviews. Though similar to responses rates of other qualitative studies of death and dying in the PICU (11,13,30,40–47), the response rate for this study is low and raises the possibility of response bias. For reasons of confidentiality, invitations to participate in the study were mailed out by the hospitals and characteristics of the non-responders could not be examined. It is possible that the results of this study under-represent the extent and types of need of the families who did not participate in the study and as such, the results should be interpreted with caution.

Over one-third of the decedents in this study were over age 18 but the reality of the PICU setting is that adults who have pediatric chronic illnesses are treated and die in the PICU. It is important to note that the primary caregiver of the adult-aged decedents in this study were their parents who wanted to continue in this role as their child died – just as did the parents of younger children. Also, the majority of the decedents in this study died of chronic conditions. It is possible the emphasis on themes identified in this study might differ if we had a larger number of families whose child died of an acute illness or trauma or if we had a large percentage of parents of younger decedents represented in the sample. Notably respondents included 17 mothers and one father. The study protocol was to recruit the parent most involved in the child’s care during the last 72 hours of life; however, we cannot know how parents made the decision about who was to complete the interview. With only one father in this study we cannot offer insight into how fathers of a child who dies in the PICU view their child’s death. The sample size was small and drawn from two PICUs both located in the northeastern United States, so these findings cannot be generalized to other settings. Finally, how parents express their love for their child and define their roles is culturally-driven and the findings reported here may not apply across all cultural groups. Despite these limitations, we feel this study offers important insights about the parenting of a child who dies in the PICU based on parents’ own words.

CONCLUSIONS

Three overarching domains characterize essential elements of being a parent of a child who is dying in the PICU: 1) providing love, comfort and care; 2) creating security and privacy for the family; and 3) exercising responsibility for what happens to one’s child. Each domain lends itself to changes in clinical practice and policy. These changes can make an important difference to parents as they recall their child’s end-of-life experience and appraise their worthiness as a parent.

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Table 1

Characteristics of Decedents (N= 18)

Age at death	Median	Range
• Infant (n=6)	3.7 months	(.3–7)
• Toddler/Child (n= 3)	3 years	(1.5–4)
• Pre-teen/adolescent (n =2)	11 years	(10–12)
• Adult (n =7)	23 years	(19–37)
Gender of deceased child; n		
• Male	9	
• Female	9	
Diagnosis; n		
• Leukemia	5	
• Other cancer	4	
• Other	4	
• Congenital diaphragmatic hernia	3	
• Cystic Fibrosis	1	
• Trauma/Burns	1	
Type of condition; n		
• Acute	3	
• Chronic	15	
Length of stay in PICU; n		
• 0–7 days	5	
• 8–14 days	5	
• 15–21 days	2	
• 22–28 days	3	
• 29 days +	3	

Table 2

Domains of Parenting in the PICU: Additional Illustrative Quotations and Implications

Illustrative Quotations Organized by Theme Within Domain	Implications For Policy And Practice
DOMAIN 1: Providing Love, Comfort and Care	
Remaining close and connected to one's child	
• Stay with the child. Don't go home at night and leave them alone. [Name] didn't want to die alone. And I'm sure any child doesn't want to but doesn't know how to say it. So if you can possibly just move in and be there every moment of the day, because they're busy and they don't see every little thing. And you know your child best. So if it is at all possible, someone should be with them 24 hours a day. And don't let the staff boss you around too much. (P: 1) • Well, first of all being able to be in the room all of the time with him. And being able to talk to him. And my husband and I would hold his hand or his feet or whatever was sort of poking out from underneath everything. (P:4) • So we then went back in and it was a matter of about 15 minutes and [Name] was screaming out in pain. And she had been alone during that period while all of this chaos was going on that, frankly, was totally avoidable had we prepared for this adequately. And then they did manage to be moving as quickly as possible. The intensivist was there and the nurse. And they stayed right with her until she died in the next couple of hours. And they immediately got some pain medicine to her. (P:12) • Don't be afraid to spend as much time as you want with your baby or child, after he or she passes away. You know, we never felt like anyone was rushing us. And never felt like we were occupying space and that we needed to hurry up and get out of there because some other child needed the space…But, at the same time, it was two o'clock in the morning when she passed away and I was allowed to bathe her and everything. And then the nurse asked if I wanted to sit and hold her for a little while again and I declined to do that. I said no, that I had done all that I needed to do for her. But then the next day I was really sorry that I didn't stay with her a little longer. I kind of felt like we needed to go on and let the staff there do what they needed to do with her…So I would say, "Take your time and make sure you spend as much time as you want." (P18)	Emphasize and support the importance of parents' love, comfort and presence
Providing physical care to one's child	
• We were able to help dress him, help give a shower. We were kind of a hands on family. We were not afraid of anything, you know, holding the urinal or wiping the butt or anything like that. We did whatever we needed to do and the nurses were great about it. (P:9) • And by now I really want to be a huge part of [Name]'s care. So the nursing staff was awesome. I got to help change diapers. I got to give her a little sponge bath. I got to, you know, of course, hold her hand and play with her feet. But she is heavily sedated and paralyzed that you are not getting too much interaction. (P:14)	Facilitate physical intimacy whenever possible
Seeing one's child appreciated and valued as an individual	
• And I had this photo album. They looked at that. We put pictures up. We decorated his room with some stuffed animals. And we had pictures of him up in different places. And they said the pictures of him that really helped them because they were looking at them and they were like, "Okay. This is what we need right here. We need this little boy sitting in this chair with his eyes open." It really gave them something to work for…It's almost like they took extra special care of him. But I'm sure that every parent felt that way because that's the way it was. They made you feel like you're child is the only one in this entire hospital. And we're giving him 110%. (P16) • I requested that they talk to her even though she probably couldn't hear them. But I just still wanted them to treat her like a person, even though she was-- and they did. They did a great job of that. One of the girls was so young, too. And she was just fabulous, just really giving [Name] what I had wanted for her, the covers in a certain way. You know, it's your own child. (P17)	Encourage, model and help parents to provide appropriate aspects of physical care

Illustrative Quotations Organized by Theme Within Domain	Implications For Policy And Practice
DOMAIN 2: Creating Security and Privacy	
Retaining some control over who enters and what happens in the hospital room	
• …they would knock on the wall or whatever. And so I felt that I had my own little corner there where I could look like whatever I wanted to look like. I could cry if I wanted to. [crying] And they were very kind. Nobody invaded my space at all. I invited them in and they came and they helped me. (P:8) • …But like I said, after I told him that, he didn't come back. So I don't think he liked the way I spoke to him, because he kind of had a cocky attitude, and I was like, "Uh-uh. It's not going to happen…Because I was just like a mother bear hovering over her cub-- You know, you don't mess with me and you don't mess with my child. (P:16)	Provide a comfortable private space; Knock first and seek permission to enter room
Having private, uninterrupted moments one with one's child	
• There was no privacy. There was no peace and quiet. And that is a big, big concern, especially when-- I think if we had known that she was going to die as soon as she did, I would have closed her room off to everybody, including doctors that wanted to come in. They could see everything on the chart. They didn't need to come in and see her. If I had known it was happening that fast, I would have insisted upon no visitors, no doctors, no nurses, except to do what they had to do. There is no privacy. (P:1) • Well, I had wished, maybe--I don't know if this sounds selfish. But he was in a room with three other children and they all were going to live. And I thought to myself it would have been nice, maybe, if he could have a room by himself. But, again, I'm saying that because they knew he wasn't going to live. Maybe they didn't have the space and maybe I am being selfish by saying that. But I had this vision in my head that, "Oh, well, if he could just be in this room by himself, and I can have that time." (P10)	Provide a comfortable private space; Give parents a role in determining others' access to their child; Permit parents unlimited access to their child
DOMAIN 3: Exercising Responsibility	
Being knowledgeable about the child's condition and care	
• My biggest advice is, ask lots of questions and keep asking until you understand it. And keep asking different doctors. Because sometimes you would ask one doctor and get one answer and you would ask another doctor and get another. So it helps you figure out what's really going on. (P:5) • It's very hard to make these kinds of decisions. And I guess for us, the more information we could get, the better we felt we were able to make the decision… Keep pushing and listen to all of them. But at the end of the day, it's your responsibility. (P:12)	Educate parents and provide them with desired information; Invite parents to participate in family meetings & rounds
Advocating for the best possible care for one's child	
• So we were active participants in that [in rounds] … I had no qualms about advocating that…And I think that would be another thing to advise parents is, you have to be your own advocate. You really do. I mean as helpful as they are, if you don't demand it, you're not going to get it. (P:2) • Just know your child's issues better than they do. And become an advocate and make it your full-time priority. Because you can't wait for them to think of everything because they have so many other patients to worry about. You have to become your child's number one advocate and not leave. You have to be there when they round. You have to be there when there is anything. You just don't leave. (P:11) • You know, my son was 21. But it was like he didn't speak up for anything. I took care of everything. Not that he was dumb but he was a mama's boy. Yeah. So you just have to speak up for what you want. (P:13)	Involve parents in decision making; Invite parents to participate in family meetings and rounds.
Noticing and monitoring the quality of care	

Illustrative Quotations Organized by Theme Within Domain	Implications For Policy And Practice
• The only thing I found, like anything, you need to be there all the time because what would happen-- One nurse would take out too much of her medicine. And because they had already taken it out, then it would be short for the next shift. And so the next shift, of course, they came in. And I said, “That’s too much medicine. That’s not right.” And I would check it. And then, of course, the next girl would come in because there weren’t four out of the 12 that should have been there because the other girl took out five. She is now coming with three. And I said, “That’s not the right dosage.” And they didn’t bother to do the math to make sure (P:6) • It seemed we always had new graduates. And my child was very sick. And some of them had never treated a trach. patient or things of that nature. So that was another thing that was always a struggle because we never could feel like we could go downstairs for a soda and feel safe, leaving him in the room. So those kinds of things… But it was just the little things when you didn’t feel confident even looking away because you were afraid they would miss it. Because there was a lot going on. In their defense, there was a whole lot going on. (P:11)	