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Influences on Decision Making Identified by Parents of Children Receiving Pediatric Palliative Care

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Abstract

Background—Parental decision making is a critical component in the provision of palliative and end-of-life care, yet factors that parents perceive as influencing this process, when they are making decisions for their children, have not been well characterized.

Methods—As part of a mixed-methods cohort study, we interviewed 73 parents of 50 pediatric patients who were referred to the hospital's pediatric palliative care service. The semistructured interviews focused on “decision making for your child”; the interviews were recorded and transcribed. A random sample ($n = 13$) was first coded and analyzed for core themes, and these themes were then cross-validated with a second random sample ($n = 3$) of interviews.

Results—Four dominant interrelated themes permeated parents' discussions about the decisions they were making for their children and the process of decision making. First, Orientation and Direction (including the subthemes of Goals and Hopes, Spirituality and Meaning, and Purposeful Effort) connotes the parents' effort to establish and clarify the broad context of decision making. Second, Defining What Is Good for the Child (including the subthemes of Quality of Life and Suffering, and Normalcy and Normalization) conveys how the parents posed questions and pondered what decisions would be in the child's best interests. Third, the entwined theme of Relationships, Communication, and Support reflects how parents reported the social and interactive nature of decision making. Fourth, the theme of Feelings and Personal Accountability focuses inward as parents report efforts to deal with their emotional responses and self-judgments.

Conclusions—Parents report grappling with several influences upon their decision-making processes that extend well beyond the standard discussions of medical information exchanges and the evaluation of risks and benefits. Decision support for these parents should account for these diverse influences.

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Keywords

decision making; decision support; ethics; palliative care; pediatrics; social support

INTRODUCTION

Parental decision making is a critical component in the provision of pediatric palliative and end-of-life care (Field and Behrman 2003; Carter, Levetown et al. 2004; Himmelstein, Hilden et al. 2004; Liben, Papadatou et al. 2008; Mack, Wolfe et al. 2011). The decisions that parents confront are diverse, ranging from deciding whether to issue a do-not-resuscitate or do-not-intubate order, cease some form of technologically sophisticated life-supporting care, limit artificially routed nutrition and hydration (Grubb 1995), or have a child receive a tracheostomy or additional surgery (Montagnino and Mauricio 2004; Patel, Zdanski et al. 2009), to deciding whether to take the child home with hospice (Dominica 1987; Whittle and Cutts 2002; Surkan, Dickman et al. 2006). How this decision-making process operates, though, is not well characterized.

Prior studies in parental end-of-life decision making have largely been based on the reports of bereaved parents, whose experiences have mostly occurred in the settings of the neonatal intensive care unit (NICU), the pediatric intensive care unit (PICU), or pediatric oncology. For example, parents of infants in the NICU have been asked to identify behaviors of nurses that helped to support their decision making (emotional support, provision of information, and the physical care of the infant and family emerged as important factors) (Kavanaugh, Moro et al. 2010). A survey of neonatology fellows found that 40% had had no formal training regarding how to communicate effectively with parents having to make medical decisions (Boss, Hutton et al. 2009). Parents of children in PICUs identified as their key needs honest and compassionate communication with clinicians whom they trust and the receipt of both personal emotional support and professional collaborative teamwork (Meert, Thurston et al. 2000; Meyer, Ritholz et al. 2006; Hsiao, Evan et al. 2007; Meert, Eggly et al. 2008). Parents whose children's cancers had progressed to the terminal stage and the parents had made an "end-of-life" decision cited the following as factors that they took into account when making a decision: wanting to minimize suffering, considering adverse effects of treatment, having "nothing more left to do," "believing that my child could not survive," "feeling that we did all that we could," and "knowing my child's preference" (Hinds, Oakes et al. 2000; Maurer, Hinds et al. 2010). Among parents of children with cancer, factors that have been identified as influencing parental decision making include "information on the health and disease status of the patient," "all curative options attempted," "trusting the healthcare team," and "feeling support from the healthcare provider" (Hinds, Oakes et al. 2001).

Taken together, these studies of parental decision making both underscore and circumscribe the importance placed on the provision of factual diagnostic, therapeutic, and prognostic information regarding the child and the child's care as the key aspect of parental decision support. Yet, there are at least two sets of factors influencing parental decision making that do not fit neatly into the framework of informed consent, which emphasizes the patient's

(or, in this case, the parent's) cognitive comprehension and personal appreciation of potential treatments' benefits and risks (Appelbaum and Grisso 1988), suggesting additional frameworks for studying and providing parental decision support. First, the framework of shared decision making emphasizes collaboration between physicians and parents, paying attention to the multiple persons who contribute to the overall decision-making environment, as well as the particular decision at hand, and addresses the additional issues of role assignment, social support, trust, and communication within the overall framework (Fiks and Jimenez 2010; Kon 2010). Second, a framework of affective processes, based on findings from psychology research and behavioral economics, underscores how people make decisions through a combination of both their thoughts and feelings (Feudtner 2007). These complementary frameworks may be particularly relevant to parents in the midst of making decisions for their children.

We therefore sought to better characterize the decision-making process of parents of children receiving a pediatric palliative care consultation. As part of a larger cohort study, we conducted in-depth interviews with parents inquiring about how they were making decisions for their children.

METHODS

Human Subjects

The conduct of this study was reviewed and approved by the Institutional Review Board of The Children's Hospital of Philadelphia (CHOP).

Setting

Parents included in this qualitative analysis of interview transcripts were enrolled in The Decision Making in Pediatric Palliative Care Study (DPPC), a prospective 6-month cohort study funded by the National Institute of Nursing Research and conducted at CHOP, which provides a broad range of pediatric subspecialty care with specialized intensive care units for neonatal, pediatric, and cardiac patients. CHOP has had a multidisciplinary palliative care consult team since 2003. Enrollment took place from October 2006 to July 2008. Eligibility and other components of the overall study are discussed elsewhere (Feudtner, Carroll et al. 2010).

Data collection

Two of the authors (KC and KH) conducted all 73 interviews, which were audio-recorded and subsequently transcribed. Demographic information was self-reported by parents.

Data analysis

Responses were coded and thematically organized according to the qualitative coding and thematic analysis that underlies grounded theory (Strauss and Corbin 2008). Four reviewers coded interviews in random order until thematic saturation was reached (N=13). Using Atlas.ti 6.0 software, quotes within codes were aggregated to create four major themes with associated subthemes. Additional interviews were then selected and analyzed to cross-validate the achievement of thematic saturation (N=3). After we had concluded our coding,

identification of themes, and cross-validation in the second randomly selected set of interviews, as a further cross-validation, we also examined the transcripts in terms of frequency of the codes to ensure that the corresponding themes were pervasively present in the interviews with the parents.

RESULTS

Both the parents and their children in this study represented a diverse sample of ages, races, and other demographic and clinical characteristics, and the sample of transcripts that were randomly selected for analysis did not differ from those that were not selected in any of these characteristics (Tables 1 and 2).

The parents were asked during the interview to name three “important decisions” they had had to make for their child. They then selected one of these decisions (Table 3) to serve as a focal point for the subsequent interview, which in almost all interviews expanded beyond this particular decision as parents responded to the prompt question: “Is there anything we didn’t discuss that you think is important about making decisions for your child?” Within the transcripts, we identified 83 codes (presented in Figure 1 as a word cloud diagram with size proportionate to the frequency cited in the transcripts). We aggregated these codes into four pervasive themes and several subthemes found throughout the interviews, and present our findings organized by these themes (Figure 2).

Orientation and Direction

When parents of children who are receiving pediatric palliative care are asked about decision making, many comment on the broad context of their decisions, their orientation and direction, most often phrased in terms of goals and hopes, spirituality and meaning, or purposeful effort.

Goals and Hopes—Parents often used the language of goals when talking about their overall orientation for their child’s care. For example, one parent said, “The doctors ask about different decisions for what they can do. It’s very heartbreaking. We want to make her comfortable. That’s our primary goal.” For this parent, making her daughter comfortable is a broad orientation. Another parent spoke about moving away from the importance of schooling for her child by saying, “And the only reason I haven’t addressed school [is that] my goals have changed for her. It’s not really important.” While this second parent does not specify what these larger goals are, they are used to evaluate what this parent considers to be more specific and circumscribed goals, such as education.

When asked about their goals, parents sometimes tried to distinguish between goals they considered realistic and unrealistic. For example, one parent said, “I think an unrealistic goal is to say that they’ll find a cure.” Another parent said, “As far as, like, realistic goals would be to let [my child] have good comfort and just really good care.” When speaking about her goals, a third parent stated that “the other [goals] I have, they’re no longer realistic.”

Hope, like goals, was another general framework that parents used when speaking broadly about their decision making (Feudtner 10 December 2009; Benzein, Norberg et al. 2001;

Feudtner 2005). Unlike when they talked about goals, when parents were speaking of “hopes,” they were less likely to use the adjectives of realistic or unrealistic to modify their words. For example, one parent stated that “I’m always hoping that something will happen that makes this, well, not that [my child] will snap out of it, but, you know.” Another parent said, “I have a lot of hope that [my child] can get better, will get better.” Hope was also something that could be quantified, as having more or less hope. For example, one parent said, “The doctors have always been enthusiastic, and everybody here in the hospital, there’s always been a lot of hope there.” Hope is also something that could be present or absent. For instance, a parent remarked how, “not that the hope isn’t there now, but there was always a hope that his condition wasn’t terminal and wasn’t life-threatening.” Sometimes, parents held conflicting hopes at the same time, as one parent said, “I hope [my child] lives until I die ... sometimes, I hope he doesn’t.”

Spirituality and Meaning—Another general framework parents used to provide orientation and direction was that of spirituality and meaning. For some parents, these two categories were fused using the language of religion. As one parent said, “Praying to God and knowing that there is a God, that gives me peace. And it helps me to deal with the difficult decisions.” For other parents, a more secular language expressed related sentiments. As another parent said, “[My daughter] came along and, you know, it gave me a different perspective in life.”

Purposeful Effort—A third way that parents described their situation was to reference the effort they placed in trying to fight for their child, or to get others to better understand their situation. For example, one parent used the language of fighting by saying, “if [my child] is still fighting, we’re going to keep going.” Also using the fighting metaphor, another parent said, “It’s never nice to know that your child has a life-limiting disease, but, in the same token, we’re not running here, there and everywhere trying to, we’re not in that fight mode, you know?”

Parents also spoke of how difficult it was to have people understand, or even for they themselves to put into words the difficulty of their situation. For example, one parent described the major problem his child was dealing with as, “Being misunderstood. By the world at large.” Another parent said, “I don’t think people really ever got, if you’re not in that world, [my child’s] sensory issues and her whole, they never got what, how much is involved.” And one parent spoke of trying to describe his entire experience as, “It’s hard to say when you’re in the middle of it. It’s just everything.”

Defining What is Good for the Child

One specific theme that parents spoke of frequently when discussing decision making for their child’s care was pondering the child’s best interests and attempting to define what is good for the child.

Quality of Life and Suffering—The specific phrase “quality of life” and more general usage of the words “suffering” and “happiness” provided one common way for parents to evaluate what was good for their child. For example, one parent said, “If there comes a day

when he's not smiling anymore and he's in pain or misery, then the quality of life, we don't want --." Another parent said, "We're not going to make the options so that it might cause [our child] to suffer." Another parent said, "Healthy, to me, is whatever makes [our son] happy."

Normalcy and Normalization—Parents also spoke of having a normal life for their child and their family, and whether or not "normal" should be a goal. Examples of "normal life" included going on vacations and having fun. One parent recounted, "we took [my son] to the beach. He likes the pool, he likes the water." But another parent said, in explaining how their family and social situations had changed after their daughter's diagnosis, "she's got a label now, which is fine with me. Just that she's sick or whatever and I don't think the rules apply to her anymore." A third parent described how they had redefined their expectations of what constituted normal for their child: "We're happy right now, with [our child] knowing who we are and getting a smile out of him."

Relationships, Communication, and Support

Parents also often spoke of their relationships, and the communication and support they received, which reflected the social interactive nature of decision making.

Relationships with Doctors—Doctors who communicated well were much appreciated. For example, one parent said that she was grateful for "having a doctor that you could talk to easily about different options." Another parent described how it was helpful to have her child's doctor explain things in "terms so that we can understand ... like all the side effects, and letting us know that we're kind of making a good decision" because "that way, we can be more comfortable rather than on edge about it." A third parent described how, when they learned that their child had a rare disease and that the doctors were not as knowledgeable about it, that "not too much research was done on [it], we felt kind of, you know, like alone."

Relationships with Family—Family relationships were also of utmost importance. Parents described having different roles, how their roles shifted over time, and the importance of siblings and overall household togetherness.

Within a family, roles were often divided between the mother and father. As one mother said, "I'm the one who gets the supplies, who calls the doctors, takes him to appointments, that kind of thing, and then [my husband] is the one who sat at the bedside endlessly whereas I was always like, I can't sit still." A father described how decision-making roles in his household had shifted over time, distinguishing between earlier and later phases of the child's illness, saying, "At first, the crisis phase, I was letting [my wife] make all the decisions because I just felt comfortable where I could live with the decisions that [she] was going to have to make. But now [as the child became sicker] we're trying to make decisions together." When the parents were not together, other family members were called on to play a supporting role. For example, one parent found more support from her mother, saying "Me and [my mother] have been hand-in-hand since I separated from my husband, because I really didn't have a good, stable relationship. She took on the role of helping us."

Sibling relationships were often very different depending on the age and relationships of the siblings. For example, one parent, distinguishing between two older brothers, said “One wants to be the big brother, he doesn’t want to leave her, he cries all the time before he leaves because he just wants to stay here and protect her.” The other brother, however, is “in the state, ‘Ah, she’s going to heaven. I’m going to see her some day. I’m not worried about it.’ He’s really spiritual, you know what I mean?” Overall, a theme most parents emphasized when talking about family was the importance of togetherness. As one parent summed up: “Whatever comes, we take it together. We are here together to support each other.”

Feelings and Personal Accountability

When talking about decision making for their child, parents also often mentioned their personal responses and self-judgments about the decisions they were confronting, characterizing an inward directed theme that underscores parents’ ongoing efforts to deal with the tumult of their emotions and their perceptions of their role and themselves.

Strong Emotions—Parents described very strong emotions. According to one parent, “it’s an emotional roller coaster. It has been in all different levels since the day [our child] was diagnosed.” Another parent reported how “it’s like you pause, and everything happens all at once, and it’s hitting you right then and there.” Parents also described emotions changing over time. For example, one father describes his initial response to suctioning a breathing tube as, “I couldn’t handle that. I couldn’t stomach it. Even picturing it, I get upset.” Yet this same father described how, over time, his strong emotions had begun to shift: “caring for [my daughter] was very difficult the first two weeks, and the more I started to accept things, the easier it is for me to care for her.”

Responsibility—Parents also often tried to explain how they understood and grappled with their role. One parent described the fundamental ‘choicelessness’ of her situation, saying that “my friends, people who’ve known me the longest time, they say ‘How do you do it?’ I say, ‘What’s the choice?’ I mean, you know, you’re not going to ... you know. I said, ‘She’s my daughter’.” Another parent noted that “we’re doing it because we have to, but we’re doing it, you know, not because we have to, but because we want to, for, you know, for [our child]...It’s as simple as that.” And a third parent described her situation as “that overwhelming feeling of always wondering if you’re doing enough or if you’re doing everything you can. You never want to make the wrong decision.”

DISCUSSION

We found that parents of children who were receiving pediatric palliative care, when interviewed regarding their experiences and thoughts about making decisions for their children, report grappling with several influences upon their decision-making processes that extend well beyond the standard discussions of medical information exchange and evaluation of risks and benefits. We categorized these influences into four major interrelated themes: 1) *Orientation and Direction*, including the subthemes of Spirituality/Meaning, Goals/Hopes and Purposeful Effort, connotes the parents’ effort to establish and clarify the broad context of decision making. 2) *Defining What is Good for the Child*, including the

subthemes of Quality of Life, Suffering, and Normalcy/Normalization, conveys how the parents posed questions and pondered what decisions would be in the child's best interests. 3) *Relationships-Communication-Support* reflects how parents reported the social and interactive nature of decision making. 4) *Feelings and Personal Accountability* focuses inward as parents report efforts to deal with their emotional responses and self-judgments. Absent from this scheme are dedicated categories for medical facts, prognostic estimates of likelihood or duration of survival, or probabilistic assessments of potential benefits or harms of interventions. These elements, when mentioned at all by the parents, almost always figured into their decision-making process as subsidiary to the broader themes we have identified and outlined.

This study has several strengths and limitations that should be kept in mind when considering its findings. First, the interviews were conducted with parents who were still in the midst of making major medical decisions for their children, in contrast with studies of parents who have made a major treatment decision or of bereaved parents. Thus, this study examines an important contemporaneous perspective on factors influencing decision making. Second, we performed in-depth systematic coding by four independent coders, assembled dominant themes from the codes, and then cross-examined our findings in a subsequent set of additional interviews, enhancing the robustness of our qualitative findings. Third, we did interview only parents who were willing to participate in the study and whose children were receiving palliative care consultative services, and our analysis is based on 16 interviews, so generalization of our findings beyond this group of parents should be limited to hypothesis generation for further inquiry.

Our major conclusion in fact can be stated quite clearly as a hypothesis: parental decision-making processes are influenced by factors that extend beyond medical information exchange and evaluation of risk and benefit, including influences arising from their social network of family, friends, and health care professionals that provide support and share in the decision making, and from the parents' thoughts and feelings about their child's wellbeing and their role as a parent. Parents prefer doctors who sit down, look them in the eye, take time to talk in plain language, and show by their demeanor and how they comport themselves that they care about the child as a person. Clinicians, investigators, and ethicists need to broaden – or more aptly said, deepen – their practice and conception of communicating with parents whose children are ill. Decision support for parents of children with serious illnesses should account for these diverse influences in future research and intervention designs.

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References

- Appelbaum PS, Grisso T. Assessing patients' capacities to consent to treatment. *The New England Journal of Medicine*. 1988; 319(25):1635–1638. [PubMed: 3200278]
- Benzein E, Norberg A, et al. The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative medicine*. 2001; 15(2):117–126. [PubMed: 11301662]

- Boss RD, Hutton N, et al. Neonatologist training to guide family decision making for critically ill infants. *Archives of Pediatrics & Adolescent Medicine*. 2009; 163(9):783–788. [PubMed: 19736330]
- Carter, BS.; Levetown, M., et al., editors. *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook*. Baltimore MD: The Johns Hopkins University Press; 2004.
- Dominica F. The role of the hospice for the dying child. *British Journal of Hospital Medicine*. 1987; 38(4):334–336. 340–333. [PubMed: 3676559]
- Feudtner C. The breadth of hopes. *N Engl J Med*. Dec 10; 2009 361(24):2306–2307. [PubMed: 20007559]
- Feudtner C. Hope and the prospects of healing at the end of life. *J Altern Complement Med*. 2005; 11(Suppl 1):S23–30. [PubMed: 16332183]
- Feudtner C. Collaborative communication in pediatric palliative care: a foundation for problem-solving and decision-making. *Pediatric Clinics of North America*. 2007; 54(5):583–607. [PubMed: 17933613]
- Feudtner C, Carroll KW, et al. Parental Hopeful Patterns of Thinking, Emotions, and Pediatric Palliative Care Decision Making. *Arch Pediatr Adolesc Med*. 2010
- Field, MJ.; Behrman, RE., editors. *When children die: improving palliative and end-of-life care for children and their families*. Washington, D.C: National Academy Press; 2003.
- Fiks AG, Jimenez ME. The promise of shared decision-making in paediatrics. *Acta paediatrica*. 2010; 99(10):1464–1466. [PubMed: 21050268]
- Grubb A. Severely disabled child: withdrawal of artificial nutrition and hydration. *Medical Law Review*. 1995; 3(3):316–321. [PubMed: 11657693]
- Himelstein BP, Hilden JM, et al. Pediatric palliative care. *The New England journal of medicine*. 2004; 350(17):1752–1762. [PubMed: 15103002]
- Hinds PS, Oakes L, et al. End-of-life Decision Making by Adolescents, Parents, and Healthcare Providers in Pediatric Oncology. *Cancer Nursing*. 2001; 24(2):122–134. [PubMed: 11318260]
- Hinds PS, Oakes L, et al. An International Feasibility Study of Parental Decision Making in Pediatric Oncology. *Oncology Nursing Forum*. 2000; 27(8):1233–1243. [PubMed: 11013904]
- Hsiao JL, Evan EE, et al. Parent and child perspectives on physician communication in pediatric palliative care. *Palliative & Supportive Care*. 2007; 5(4):355–365. [PubMed: 18044413]
- Kavanaugh K, Moro TT, et al. How nurses assist parents regarding life support decisions for extremely premature infants. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*. 2010; 39(2):147–158.
- Kon AA. The shared decision-making continuum. *Journal of the American Medical Association*. 2010; 304(8):903–904. [PubMed: 20736477]
- Liben S, Papadatou D, et al. Paediatric palliative care: challenges and emerging ideas. *Lancet*. 2008; 371:852–864. [PubMed: 17707080]
- Mack JW, Wolfe J, et al. Parents' roles in decision making for children with cancer in the first year of cancer treatment. *Journal of Clinical Oncology*. 2011; 29(15):2085–2090.
- Maurer SH, Hinds PS, et al. Decision Making by Parents of Children With Incurable Cancer Who Opt for Enrollment on a Phase I Trial Compared With Choosing a Do Not Resuscitate/Terminal Care Option. *Journal of Clinical Oncology*. 2010; 28(20):3292–3298. [PubMed: 20498399]
- Meert KL, Eggly S, et al. Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatric Critical Care Medicine*. 2008; 9(1):2–7. [PubMed: 18477906]
- Meert KL, Thurston CS, et al. End-of-life decision-making and satisfaction with care: parental perspectives. *Pediatric Critical Care Medicine*. 2000; 1(2):179–185. [PubMed: 12813273]
- Meyer EC, Ritholz MD, et al. Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations. *Pediatrics*. 2006; 117(3):649–657. [PubMed: 16510643]
- Montagnino BA, Mauricio RV. The child with a tracheostomy and gastrostomy: parental stress and coping in the home--a pilot study. *Pediatric Nursing*. 2004; 30(5):373–380. 401. [PubMed: 15587530]

- Patel MR, Zdanski CJ, et al. Experience of the school-aged child with tracheostomy. *International Journal of Pediatric Otorhinolaryngology*. 2009; 73(7):975–980. [PubMed: 19403179]
- Strauss, AL.; Corbin, J. *Basics of Qualitative Research Techniques and Procedures for Developing Grounded Theory*. Thousand Oaks, CA: Sage Publications, Inc; 2008.
- Surkan PJ, Dickman PW, et al. Home care of a child dying of a malignancy and parental awareness of a child's impending death. *Palliative Medicine*. 2006; 20(3):161–169. [PubMed: 16764220]
- Whittle M, Cutts S. Time to go home: assisting families to take their child home following a planned hospital or hospice death. *Paediatric Nursing*. 2002; 14(10):24–28. [PubMed: 12520797]

Figure 2. Themes and subthemes in decision making identified by parents of children receiving pediatric palliative care

Table 1

Comparison of demographic and clinical characteristics of children whose parents' transcripts were and were not analyzed.

	Analyzed		p-value
	Yes	No	
	N (%)	N (%)	
	15 (30%)	35 (70%)	
Age			0.48
1 year or less	4 (26.7%)	9 (25.7%)	
1–4 y	4 (26.7%)	11 (31.4%)	
5–9 y	5 (33.3%)	6 (17.1%)	
10–17 y	1 (6.7%)	8 (22.9%)	
18–24 y	1 (6.7%)	1 (2.9%)	
Gender			0.07
Female	5 (33.3%)	22 (62.9%)	
Male	10 (66.7%)	13 (37.1%)	
Race			0.60
White	10 (66.7%)	22 (62.9%)	
African American	3 (20.0%)	8 (22.9%)	
Asian	1 (6.7%)	0 (0.0%)	
More than 1 Race	1 (6.7%)	2 (5.7%)	
Not reported	0 (0.0%)	3 (8.6%)	
Insurance			0.43
Private	8 (53.3%)	12 (34.3%)	
Medicaid	7 (46.7%)	17 (48.6%)	
Other	0 (0.0%)	3 (8.6%)	
Not reported	0 (0.0%)	3 (8.6%)	
Location			0.29
Not in hospital	1 (6.7%)	9 (25.7%)	
Hospital Ward	9 (60.0%)	15 (42.9%)	
Intensive Care Unit	5 (33.3%)	11 (31.4%)	
CCC			0.30
Neuromuscular	4 (26.6%)	10 (28.6%)	
Cardiovascular	0 (0.0%)	1 (2.9%)	
Respiratory	1 (6.7%)	1 (2.9%)	
Gastrointestinal	0 (0.0%)	1 (2.9%)	
Metabolic	7 (46.7%)	6 (17.1%)	
Congenital	2 (13.3%)	7 (20.0%)	
Malignancy	1 (6.7%)	9 (25.7%)	

P-value from Fisher's exact test.

Table 2

Comparison of demographics of parents whose transcripts were and were not analyzed

	Analyzed		p-value
	Yes	No	
	N (%)	N (%)	
	16 (22%)	57 (78%)	
Age			0.41
21–34y	6 (37.5%)	17 (29.8%)	
35–38 y	6 (37.5%)	14 (24.6%)	
39–66 y	2 (12.5%)	19 (33.3%)	
Not reported	2 (12.5%)	7 (12.3%)	
Type			0.56
Mom	9 (56.3%)	36 (63.2%)	
Dad	7 (43.8%)	17 (29.8%)	
Other	0 (0.0%)	4 (7.0%)	
Education			0.71
Graduated High School	4 (25.0%)	10 (17.5%)	
Some or Graduated College	7 (43.8%)	27 (47.4%)	
Some or Graduated Graduate School	4 (25.0%)	11 (19.3%)	
Not reported	1 (6.3%)	9 (15.8%)	
Parent relationship			0.60
Married/Partnered	13 (81.3%)	39 (68.4%)	
Divorced/Separated	3 (18.8%)	8 (14.0%)	
Single	0 (0.0%)	7 (12.3%)	
Other*	0 (0.0%)	1 (1.8%)	
Unknown	0 (0.0%)	2 (3.5%)	

P-value from Fisher's exact test.

* Pertains to an aunt

Table 3

Most important decisions listed by 16 parents of 15 children

Parent	Decision
1*	Whether or not to get anesthesia for G-tube placement.
2*	Whether or not to get G-tube.
3	Whether or not to get to get a second opinion.
4	[No decision specified]
5	Whether or not to do rehabilitation after acute care hospitalization.
6	Where to deliver.
7	Whether or not to allow life extension devices.
8	Whether or not to start radiation.
9	Whether or not to get a transfusion.
10	To give medication for spasms or not.
11	End-of-life Directives.
23	Whether or not to place VP Shunt.
13	Whether or not to admit patient to NICU.
14	Whether or not to have surgery.
15	Whether or not to get G-tube.
16	Which hospital to go to for treatment during this admission.

* These responses were from parents of the same child.