Feature

Parents' Perspectives on Values and Values Conflicts Impacting Shared Decision Making for Critically Ill Neonates

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ABSTRACT

Background

Guidelines from professional societies recommend that, in situations of critically ill neonatal patients, goals-of-care decisions be approached jointly by physicians and parents and be based on medical information and parents' values. How to effectively engage in shared decision making in this context is debated, however, and emerging evidence suggests that clinicians and parents perceive these decisions and their roles in decision making very differently.

Methods

Semistructured interviews were conducted with parents (n = 15) who had been given a critical antenatal diagnosis and faced difficult decisions about their child's care goals. Parents of infants with a broad range of diagnoses, expected poor prognoses, medical/surgical therapies, and medical outcomes were enrolled. A coding scheme was developed through an iterative process of reading transcripts and team meetings. Each transcript was coded by two team members who met to reconcile discrepancies.

Results

Parents reported many considerations when they made goals-of-care decisions, including weighing the chances of survival and acceptable quality of life, avoiding suffering, ensuring all options were tried, remaining hopeful, and being a good parent. Although most parents trusted their care team, many reported their values were in conflict with their clinicians' and that impacted their decision-making experience and generated negative emotions and distrust.

Conclusions

Parents of critically ill neonates consider a number of values when making goals-of-care decisions for their infants.

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When parents' and clinicians' values differ, conflicts arise that can result in negative experiences and distrust. Better understanding of parents' values by clinicians may reduce conflicts and support shared decision making.

INTRODUCTION

Technological advances in newborn critical care have improved survival among infants with complex, life-threatening conditions, but continued difficulty remains in predicting which infants will not survive, or will survive with lifelong developmental impairments. When outcomes are uncertain, professional guidelines recommend that goals-of-care decisions be made jointly by physicians and parents, based on medical information and parents' values.[1] How to best achieve this in practice remains unclear, and neonatologists struggle to effectively engage in shared decision making in these contexts.[2] Evidence suggests that clinicians and parents perceive these decisions and their roles in decision making differently,[3] and that clinicians are poor at gauging parents' preferences for how much responsibility for decisions parents wish to bear.[4] Likewise, clinicians and parents may hold starkly different personal values that frame whether or not they perceive a possible medical outcome as acceptable.[5]

Because goals-of-care decision making in the neonatal intensive care unit (NICU) is stressful and emotionally charged, conflict within and between families and clinicians often occurs.[6] Disagreements about which course of action aligns with the best interests of the infant can be escalated by poor communication.[7] Failure to listen and engage in discussion about differing perspectives and values not only negatively impact parents' NICU experience—perhaps their only memories of their child's time alive—it can lead to mistrust of the care team. Additionally, when a care decision does not align with parents' values, a plan may be implemented that fails to prioritize the outcomes they find most important.[8] This can lead to serious long-term implications for parents, including grief, decisional conflict, and regret.[9]

To expand on the body of evidence regarding parents' perspectives on, and experience with, complex decision making in the NICU, we sought to investigate the values parents said affected goals-of-care decisions when their infant was hospitalized after a poor antenatal prognosis. We also characterized parents' perceptions of how the medical team elicited, understood, and incorporated parental values into decision making and how perceived parent/clinician disagreements affected parental decision making, experiences, and trust in their clinicians.

PATIENTS AND METHODS

Recruitment

We conducted semistructured interviews, until thematic saturation was reached, with 15 parents from 2017 to 2018. There were 14 interviews in total (including one wife-husband dyad). Participants were identified through the University of Michigan Health System parent host email list, a voluntary list of parents who have had infants in the NICU in the past and are open to receiving correspondence; this approach was selected to reduce the possibility of harm to potential participants by exacerbating the emotional distress they experienced with their child's NICU hospitalization. Parents were emailed, and those interested responded with details about their child's case and NICU stay. Parents who met inclusion criteria were contacted to schedule an interview. Participants signed an informed consent form at the time of the interview and received a $50 gift card. This study was approved by the University of Michigan Medical School Institutional Review Board (HUM00118383).

Semistructured Interviews and Materials

The interviews were in person, except for three conducted via telephone because of travel constraints. Given the variation in clinical course and how long the participants wanted to discuss their experience, the duration of interviews varied substantially, ranging from a half hour to almost three hours. The interview guide was developed and refined with input from of the all authors and focused on events surrounding the parents' NICU stay, how decisions regarding their infant's care were made, the values that informed those decisions, and how they felt about the experience in retrospect. The interviews were audio recorded and transcribed.

Data Analysis

De-identified interview transcripts were imported into Microsoft Excel (2016) for coding, and descriptive statistics were completed by authors CK and SK (see table 1). Constructionist thematic analysis of the data was conducted using Braun and Clark's approach.[10] This type of analysis considers themes robust when they are distinct, coherent, and cohesive, relative to the coded extracts and the entire data set.[11] Codes and themes were identified and refined by the primary researchers (CK and SK) and refined through discussion with all team members. All interviews were independently read and coded by two researchers (CK and SK); discrepancies were reconciled at regular intervals by these team members, with any remaining inconsistencies resolved through discussion with the full research team.

Research Team and Reflexivity

To ensure reflexivity, the research team was comprised of interdisciplinary members, including a practicing neonatologist and bioethicist (SK), a lawyer and bioethicist (KSB), a professor of learning health sciences and expert in qualitative research (RDV), and a research associate in bioethics with a background in sociology (CK).

RESULTS

Participants' demographics and summary case data are presented in table 1. Additional context and overviews of case details (as described by parents) are provided in table 2. Many parents were transferred to, or from, another health system and shared their experiences across multiple health systems. We identified several themes when parental values played a central role: chance of survival, quality of life, avoiding suffering, ensuring all options were tried, and being a good parent. We also detected themes related to the friction between parents

TABLE 1. Demographics and case details (*n* = 15)

Demographic	*n*	%
Gender		
Parent females (by parent)	14	93
Neonate females (by neonate)	7	33
Age (by parent); mean = 34; SD = 5.4		
21 - 30	4	27
31 - 40	8	53
> 40	3	20
Race (by parent)		
White	14	93
Multi-racial	1	7
Education level (by parent)		
Some college/associates degree	2	13
College degree	5	33
Advanced degree	1	7
Studying for college or advanced degree	3	20
Not disclosed	4	27
Employment status (by parent)		
Employed	6	40
Not employed	2	13
Not disclosed	7	47
Weeks of pregnancy at birth (by case)		
23 - 24	3	21
25 - 26	4	28
27 - 28	3	21
29 - 30	1	7
31 - 32	1	7
37 - 40	1	7
C-sections (by case)	11	79
Singleton versus twin (by case)		
Singleton	7	50
Twins	7	50
Outcomes (by case)		
Singleton—survived	3	21
Singleton—died	4	29
Twins—both survived	2	14
Twins—1 survived, 1 died	5	36
Home medical needs (by surviving infant)		
Tracheostomy with home mechanical ventilation	3	25
G-tube feeds	2	17
Ages of surviving children (by surviving infant)		
< 1 year	3	25
2 years	2	17
3 years	1	8
4 years	3	25
6 years	1	8
> 10 years	1	8

NOTE

There were 14 cases/interviews, including one wife and husband pair, 21 neonates, and 7 pairs of twins. There were 12 surviving infants.

and clinicians caused by perceived differences in values and in the (un)cer-tainty of prognoses. Many parents felt that their opinion on the role their values should play in the decision-making process differed from the opinion of the medical team. Parents reported feeling that their clinicians focused too narrowly on chance of survival, quality of life outcomes, and suffering, and dismissed the importance of the other values parents held in making decisions. This difference led to conflict, mistrust, and negative experiences for parents. Additionally, parents often felt judged by their medical team. Several recalled clinicians labeling them as "selfish," "in denial," and "inhumane" for making choices different than what were recommended. Major themes are depicted in figure 1.

Parents' Values Around Chance of Survival

Parents often described wanting to know their infant's chance of survival when faced with goals-of-care decisions:

> As a data person, that's the first thing I wanted to hear. Like, what is the data? What are the statistics? What are the outcomes? And the outcomes were very poor. . . . They gave us a 3 percent chance [of survival]. And even with that, it would have been [with] catastrophic disabilities. [. . .] And so, I read the studies, and I also just met with a lot of women who were in the same experience as I was with early water breaking, or PPROM [preterm premature rupture of the membranes], and some of them had positive outcomes and so we decided to move forward. [Parent 7]

Although some parents acknowledged that outcome data were an important consideration, many reported that a low probability of survival did not dissuade them from choosing to continue the pregnancy or opting for a trial of therapy. They reported valuing outcomes like meeting their baby alive, having time with their baby, and pursuing an opportunity that offered a chance of survival. Parents also described making decisions to maximize the chance of these outcomes even when it incurred risk of maternal health complications:

> And I said, "I get your reasoning, [a C-section is] a major surgery and whatnot, but I want the best possible chance to meet him alive." [Parent 1]

Values Conflicts Around Chance of Survival

When parents chose to pursue therapies that offered the opportunity for survival and the chance to meet their child alive when physicians recommended comfort care, parents were frustrated when they felt their physicians misattributed their goals to poor comprehension of survival probabilities. When there were disagreements, parents reported that physicians exhibited behaviors that were dismissive, rude, and interfered with the therapeutic relationship:

> The doctors were not supportive of the decision [to continue the pregnancy], no. They were very clear that we should terminate. That that's what the protocol stated. [. . .] Based on the data they had and the survivability of both of us, or either of us, I understand logically where it was, but it felt more like, just check the box. "Okay, she's [ruptured at] 18 weeks, this is protocol, just go." And that part, I think, felt dismissive. [Parent 7]

Parents' Values Around Quality of Life

All parents discussed quality of life as a factor in their decisions around goals of care at delivery and in the NICU, but held varying perspectives on what they considered acceptable. Some parents expressed that they just wanted their child to be happy, or a part of their family, even if they had significant deficits:

> I just said to God . . . I don't care if he is a baby that drools the rest of his life, and that's all I get to do. I want to care for him. [Parent 5]

Other parents had clear limitations on what neurodevelopmental outcomes or long-term technology needs they prospectively considered to be a substantive quality of life, although the thresholds they described varied between parents:

> We made the conscious decision of we didn't want a child that was dependent on

TABLE 2. Overview of case diagnoses, therapies, and outcomes: 14 cases/interviews, 15 parents, 21 neonates

ID	Diagnoses	Complications	Resuscitation plan at delivery	Outcomes
P01	Trisomy 18; born at 37 weeks	Cardiac defect with single ventricle palliation, renal failure, respiratory failure with tracheostomy	Full resuscitation	Died at 3 months, after transition to comfort care goals
P02	Twins: TTTS that prompted preterm delivery at 27 weeks	Neonate 1: Bronchomalacia, RDS/BPD, growth restriction, RDS/BPD, growth restriction Neonate 2: Pulmonary stenosis, RDS	Neonate 1: Full resuscitation Neonate 2: Trial of therapy	Neonate 1: Survived Neonate 2: Died at 5 days after transition to comfort care goals
P03	PPROM that prompted preterm delivery at 25 weeks	RDS/BPD, PDA with surgical closure	Full resuscitation	Survived
P04	Twins: PE, TTTS with ligohydramnios, polyhydramnios, twin anemia/polycythemia that prompted preterm delivery at 27 weeks	Neonate 1: Internal bleeding, RDS/BPD, and tracheobronchomalacia with tracheostomy and home mechanical ventilation Neonate 2: Sepsis with multi-organ failure, endocarditis, pulmonary embolism, RDS	Full resuscitation	Neonate 1: Survived Neonate 2: Died at 2 months after transition to comfort care goals
P05	Twins: Cervical insufficiency, chorioamnionitis that prompted preterm delivery at 23 weeks care	Neonate 1: PDA with surgical closure, intracranial hemorrhage with post-hemorrhagic hydrocephalus with a VP shunt, seizures, RDS/BPD, NEC, paralyzed vocal cord and sub-glottic stenosis with surgical ablation, growth failure with feeding tube Neonate 2: RDS, BPD, NEC with bowel obstruction, sepsis	Full resuscitation	Neonate 1: Survived Neonate 2: Died at 6 days after transition to comfort goals
P06	Polyhydramnios and placental abruption that prompted preterm delivery at 31 weeks, multiple congenital anomalies	VACTERL association, tracheoesophageal fistula with esophageal atresia, duodenal atresia, imperforate anus, limb deformity, bowel obstruction, brain bleed, cardiorespiratory failure	Full resuscitation	Died at 15 days after transition to comfort care goals
P07	PPROM at 18 weeks that prompted premature delivery at 26 weeks	NEC with perforation with resection and ostomy, RDS/BPD, pulmonary hypertension, pneumonia, osteopenia with femur fracture, intracranial hemorrhage with cerebral palsy, total parenteral nutrition cholestasis	Trial of therapy	Survived
P08	Traumatic fall with placental abruption that prompted premature delivery at 24 weeks	RDS/BPD, pneumothorax with chest tube, PDA with surgical closure	Trial of therapy	Survived

P09	Maternal PE with HELLP syndrome, fetal intrauterine growth restriction with absent diastolic blood flow that prompted preterm delivery at 24 weeks	RDS/BPD, NEC with surgical resection	Trial of therapy	Died at 21 days after transition to comfort care goals
P10	Twins: PPROM and chorioamnionitis that prompted premature delivery at 25 weeks	Neonate 1: RDS/BPD, intracranial hemorrhage, seizures, pulmonary hypertension, sepsis, pneumothorax with chest tube, PDA with surgical closure Neonate 2: RDS, fungal sepsis	Full resuscitation	Neonate 1: Survived Neonate 2: Died at 20 days after transition to comfort care goals
P11	Twins: TTTS, polyhydramnios that required anmioreduction, absent end-diastolic flow, and growth discordance that prompted preterm delivery at 27 weeks	Neonate 1: Hydrops with cardiac dysfunction, RDS/BPD, NEC with 3 recurrences, intestinal stricture that required surgical resection Neonate 2: Growth restriction, cardiac dysfunction, RDS/BPD	Full resuscitation	Both survived
P12	Twins: Growth discordance with severe growth restriction of one fetus, severe PE that prompted emergent delivery at 30 weeks	Neonate 1: Severe growth restriction, RDS/BPD, severe hypercapnia, tracheobronchomalacia with tracheostomy and home mechanical ventilation, feeding difficulties with G-tube placement and home G-tube feeding Neonate 2: Uncomplicated NICU course	Neonate 1: Trial of therapy Neonate 2: Full resuscitation	Both survived
P13	Twins: Cervical insufficiency with vaginal bleeding, preterm labor that prompted delivery at 25 weeks	Neonate 1: RDS, pseudomonas sepsis Neonate 2: RDS/BPD, Pneumonia, pneumothorax with chest tube, PDA with surgical closure, bronchomalacia with tracheostomy and home mechanical ventilation, cleft lip	Full resuscitation	Neonate 1: Died at 1 week after transition to comfort care goals Neonate 2: Survived
P14/ P15	Antenatally diagnosed severe intracranial anomaly; born at 40 weeks	Microcephaly, encephalocele	Comfort care	Died at 3 days

NOTE: Not all parents were offered full resuscitation based on anticipated infant prognosis

KEY: BPD = bronchopulmonary dysplasia
G-tube = gastrostomy tube
HELLP = hemolysis, elevated liver enzymes, low platelet count;
NEC = necrotizing enterocolitis
RDS = respiratory distress syndrome
PDA = patent ductus arteriosus
PE = pre-eclampsia
PPROM = preterm premature rupture of membranes
TTTS = twin-twin transfusion syndrome
VACTERL = a spectrum of anomalies—vertebral anomalies, anorectal anomalies (anal atresia), cardiac anomalies, tracheoesophageal fistula or atresia, renal anomalies, and limb anomalies
VP = ventriculoperitoneal

> machines to live their life because in our opinion that was no way to live. [Parent 9]

Values Conflicts Around Quality of Life

Parents generally said that they believed the medical team's predictions and had realistic expectations for their child's quality of life, and emphasized that these aspects were carefully weighed as they made decisions. Thus, parents were distressed when they felt that their clinicians assumed that they failed to understand, acknowledge, or thoughtfully consider quality of life:

> Two weeks after [Baby 2] died, we were sat down at one of our meetings and we were told that we were being selfish. That [Baby 1] would have no quality of life. That . . . the only reason [Baby 1] was still on a ventilator in the NICU was because we didn't want to feel the pain of losing another child. . . . At the time there was a 35 percent chance of survival at 23 weeks and there was a 95 percent chance of life-altering disability. We were told "never walk, never talk, never see, never hear." Furthermore, he will never be out of a medical facility, off of a ventilator ever in his life . . . we were just being selfish to not [choose comfort care]. [Parent 5]

Parents' Values Around Avoiding Suffering

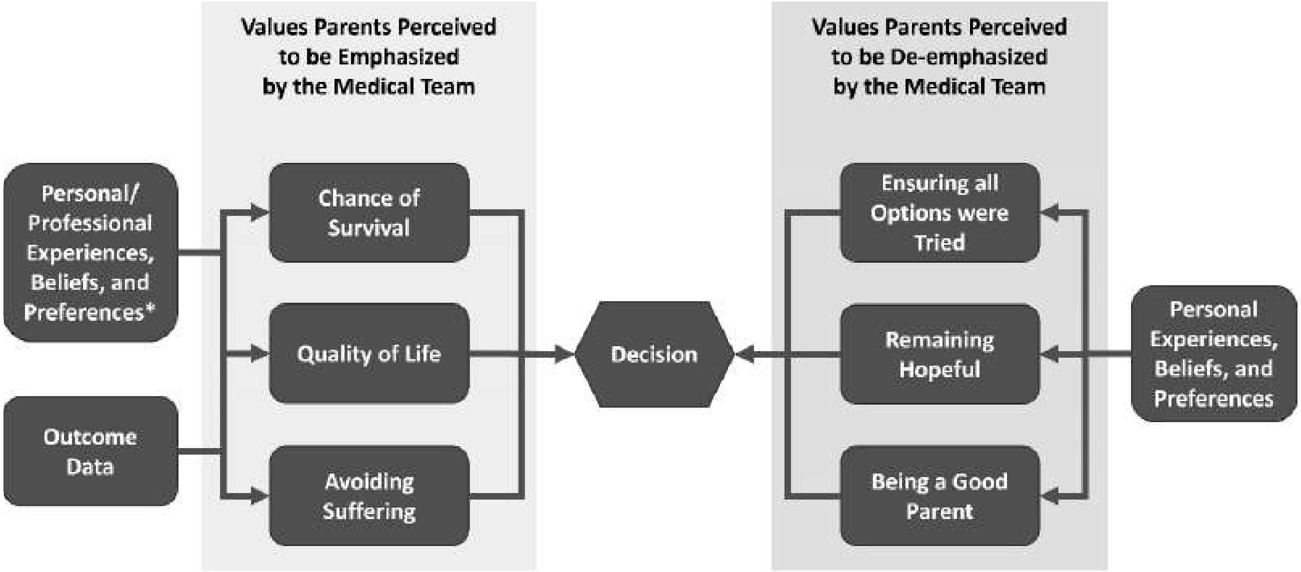
Parents described the desire to avoid suffering as one of many value-laden considerations they had to balance in their decision-making process:

> I think right then we were put into that moment of this might not be a survivable thing and if it's not, do we want to just draw it out if he's suffering? I think almost from day one we were thinking about we don't want him to suffer. [Patient 6]

Notably, in most cases, when parents observed or believed that their infant was in pain, they made decisions to not pursue additional intensive therapies to avoid prolonging suffering:

> My friend had said, "When they start doing things to your son and you cry because it bothers you or your child cries in pain, then you know," and that time had come. I just

FIGURE 1. Values-based considerations, and emphasis by parents in clinicians, as reported by parents for goals-of-care decision making for their critically ill infant



* Experiences, beliefs, and preferences that affect values around "chance of survival," "quality of life," and "avoiding suffering" differ between clinicians on the medical teams and parents.

> knew more poking, prodding, and dialysis; it just was not the right thing. . . . [Patient 1]

Values Conflicts Around Avoiding Suffering

Parents also often felt that the clinical team did not realize how seriously they had considered their child's suffering. Parents felt judged when they felt that clinicians chastised them for making decisions that did not prioritize their child's comfort:

> One of the surgeons came in and said, "I have kids, and I would never do this to my child if I knew I was gonna put them through a painful open heart surgery, and they were gonna die anyways. I think I would do the humane thing." [Parent 1]

Parents' Values Around Ensuring All Options Were Tried

Many parents expressed that they wanted to ensure that all reasonable options to give their child a chance of survival were tried.

> I felt like if there was any kind of chance, it was worth trying. [Parent 4]

Parents sometimes pursued these options to avoid any lingering doubts. This helped parents when they were making decisions to focus on comfort care goals and allowed them to manage regret:

> So we have no regrets, we did everything we could. . . . We didn't say, "Oh, I wonder if we would've done that [surgery]?" There is none, we are 100 percent solid. [Parent 1]

Values Conflicts Around Ensuring All Options Were Tried

Many parents reported conflicts arose when members of the care team did not understand or honor their request to ensure all options were tried. At times, parents perceived that their physician's excessive focus on the low probability of survival signified that they were no longer trying to achieve the same care goals. This affected parents' trust in the medical care team:

> And they just kept saying, "We just don't think she's going to make it." [. . .] My problem is that they never—because they thought she was going to die—they did not fight hard to find out why her CO_2 was 200. [Parent 12]

Likewise, they became frustrated when members of the care team pushed for redirection of care before all options had been tried:

> So I just flat out asked him. I'm like, so are you at the point that if we don't agree to take him off the ventilator, that he's dying anyway? . . . if we say, no, are we at a point that you could take us to court and get him removed? . . . This doctor leans back and goes, "oh no, we're not there, but we just need you to know." I'm like, "don't you ever come back to me again and tell me to take him off the ventilator until we are there." [Parent 5]

Parents' Values Around Remaining Hopeful

Nearly all parents described that continuing to remain hopeful for their child was very important to them. Often, parents hoped that their child would have a good outcome even if they were told it was unlikely or impossible. Parents articulated that this hope was not rooted in misunderstanding or denial of the prognosis, but rather in loving their child:

> Hope is all you have. I will never regret, even if she had passed, *never* regret having hope that she wouldn't. [Parent 12]

Values Conflicts Around Remaining Hopeful

Several parents described negative interactions with the medical team when they felt their clinicians were not engaging in, or were actively discouraging, their hopefulness. They felt clinicians misattributed their continued hope to denial:

> They did not want to talk about [Baby 2]. They kind of made me feel like I was in denial about him surviving, so I forced them into the conversation anyway, even though they didn't want to talk about it . . . they kind of entertained it a little bit, but not really. I remember specifically saying, you know, when [Baby 2] shocks you all, and pulls through this, and I had said something

> about [his life] in the future. They just kind of chuckled and then went back to [Baby 1]. [Parent 4]

Parents' Values Around Being a "Good Parent"

Interwoven with many of the values mentioned above were reports that being a "good parent" to their child was important in making medical decisions around goals of care. Parents described what a parents' role for a critically ill newborn entailed, including advocating for their child as an individual; loving, caring, for or sacrificing for their child; and not "giving up" on their child (see table 3).

Values Conflicts Around Being a "Good Parent"

Several parents remarked that when they perceived values differences between themselves and clinicians, it was their responsibility as "a good parent" to advocate for their child's best interest. They recalled these interactions as tense and sometimes adversarial.

> I think I made a name for myself in that NICU a little bit, because I got very edgy at that point. [. . .] I didn't care anymore, and I didn't hold back and I didn't let them shut me down on my ideas anymore. I really fought for him. [Parent 4]

DISCUSSION

Our study eliciting parents' values on complex decision making for infants in the NICU who were anticipated to have poor prognosis adds to the growing body of literature on this topic. Additionally, it characterizes how clinicians' failure to understand and acknowledge the importance of parents' values creates conflict and hinders shared decision making in goals-of-care decisions. These themes provide a unique window into how parents bring their values to these decisions and how they perceive values conflicts with clinicians. For example, parents reported feeling dismissed or judged when their values did not align with those of their child's clinicians, and that this impacted their trust in the team and experience in the NICU. These findings have broad implications for how neonatal clinicians may better engage parents in shared decision making for goals of care in these situations.

Parents in our study reported they weighed a variety of factors when they faced making decisions, including chance of survival, quality of life, avoiding suffering, ensuring all options were tried, having as much time with their child as possible, remaining hopeful, and being a good parent. Prognostic predictions regarding survival and long-term morbidity were appreciated by parents in our study, but their decisions often were ultimately guided by other considerations. A systematic review of parents' communication needs for antenatal counseling for extreme prematurity by Kharrat and colleagues noted that multiple studies of parents reported that parents expect to receive this morbidity and mortality risk information.[12] Decisions to provide resuscitation at delivery or to continue supportive therapies and interventions were often made even when prognosis was poor, and parents noted that their consideration of a low chance of survival was tempered against their values of "remaining hopeful" and "ensuring all options were tried." A qualitative study by Arnolds and colleagues noted that when parents were optimistic and hopeful, it did not reflect a failure to understand their child's risk of death.[13] A feeling that it is unacceptable to give up a chance at life has been reported in other studies of parents of critically ill children.[14] Brooten and colleagues found that parents whose child had died were comforted by the knowledge that "everything" was tried.[15] Our data further support the observation that outcome data may be more helpful to parents in framing expectations than in making decisions.[16]

Quality of life was noted as influential in decision making by all of the parents in our study, although parents differed in what they considered to be acceptable. When they perceived conflicts with clinicians, it was generally that they found potential outcomes more acceptable than their clinicians did. This is consistent with the findings of Saigal and colleagues, who noted that clinicians rated disabled states worse than death more often than parents did.[17] Ferrand and colleagues found that parents project a good quality of life for their infants that is independent of the risk of disability, and that attending school, building friendships, and building a family were more important considerations than physical illness, neurodevelopmental impairment, or decreased life expectancy.[18] While parents in our study valued avoiding suffering for their infant, this was balanced against their desire to have more time with their infant.

TABLE 3. Quotes on being a "good parent"

Advocating for child as an individual

You know, the medical staff all had the statistics and the numbers and the data and the protocols, but our kid was unique and we just wanted to make sure we were representing him as an individual. [. . .] It just goes back, like I said, **you are your child's advocate**. And being present. [Parent 7]

Loving, caring for, and making sacrifices for child

[The doctor] said, "**You just be mom**. That's all you need to be is be mom and love him and kiss him and touch him." I think that was great advice to give to any parent. Just be mom and dad. You'll never regret that. [Parent 6]

[Mother on bedrest]: Just sit still. Just don't do anything. Like, just sit, like never again. You are going to be nursing; you're going to be bottle feeding [. . .] you're going to take them to school; you're going to go to basketball. That's what shifted my mind. Like I can lay here**, I can lay there for them, like this is going to be what I do for them.** [Parent 5]

Not giving up on child

They said there's only a 15 percent chance of them coming out with no issue after a grade four [brain bleed], that's relatively low. **How do you make a decision like that?** [. . .] If someone can't tell us [definitively] that she's going to be a vegetable, [. . .] and there's still hope that she can relatively have somewhat of a normal life, **how do you make a decision and say pull the plug? I'm your child, how do you do that?** [Parent 10]

So the day went on, and around 8:30 PM, they told us it was time to come in and say goodbye. We would have to tell them, basically, when to turn the machine off, which was something I was not ready or willing to do. But we did get to hold him. We had some family with us. **We actually did not have to turn the machine off**. He passed on his own while he was on the ventilator. So **we felt really lucky for that. Very, very lucky.** [Parent 13]

Parents in our study described the importance of being a good parent when they faced complex decisions in the NICU, which included "loving, caring, and sacrificing for," "advocating for," and "not giving up on one's child." While these subthemes overlap with similar ones identified in studies of good-parent beliefs in parents of seriously ill pediatric patients,[19] there are some nuanced differences between those and our findings. Loving and caring for their seriously ill child was emphasized by parents as important in fulfilling the parental role, similar to the parents in other studies.[20] While these studies have noted "putting my child's needs above my own when making healthcare decisions" as a consideration, this differs somewhat from the situations described as "sacrificing for one's child" described by parents in our study. Since only limited studies have focused on parents' fetal and neonatal decision making, rarely have the parents faced situations when they could make decisions to imperil their own health for the sake of their children. Expectant parents may face decisions during pregnancy, such as whether to pursue fetal interventions and surgery, or when and how to deliver, in which risks to the pregnant person's own health may be weighed against potential benefits to their unborn child. The impact of good-parent beliefs on these decisions warrants further study in this population.

The subtheme of "not giving up on one's child" was emphasized by parents in our study as an obligation of being a good parent to their child, distinct from their desire "to ensure all options were tried" for their own piece of mind or for their ability to cope with the death of their child in the long term. This has similarities to the attribute of "focusing on my child having as long a life as possible," which was identified in previous studies of good-parent beliefs,[21] but not ranked among the highest priority good-parent attributes by parents.[22] Lastly, "advocating for one's child" has been noted in the past as central to the good-parent role,[23] but in our study parents described their advocacy role less in terms of getting the medical team to fulfill their child's wants and needs, and more ins regard to pushing for their values and considerations to be central in goals-of-care decision making, especially when they felt the medical team imposed conflicting values. For this reason, the importance of good-parent beliefs and their relationship to parental coping in situations of values conflicts between families and medical care teams in the NICU should be further explored. Clinicians may give such factors—more informed by parents' individual values than clinical data—relatively little consideration, making them a possible locus of values conflicts. Several studies of parents and clinicians have observed that physicians provide information in counseling that focuses on the medical outcome of the infant rather than values about those impacts within the context of the family.[24] Additionally, clinicians focus on outcomes derived from research studies that evaluate the efficacy of therapies that may not be meaningful to parents.[25]

Parents who perceive that their clinicians are withholding information, or are presenting unfounded, overly optimistic, or pessimistic survival predictions, feel manipulated and lose trust in their care team.[26] Each of these problems—and efforts to resolve them—may be exacerbated if parents believe clinicians have dismissed their goals as the product of ignorance or selfishness (as reported by several parents in our study). Although there has been limited exploration of the role of values conflicts on parents' experiences with decision making in the NICU, several past studies have noted that trust can be undermined or facilitated by communication around decision making.[27] Our findings reinforce the importance of collaborative communication centered around values in decision making, and lend support for an individualized, values-based approach to counseling. Counseling should consider the unique characteristics of the infant and the specific circumstances of the pregnancy/delivery and hospitalization and use sensitive and supportive language and behaviors with families in the NICU.[28]

Our findings reinforce the importance of collaborative communication centered around values in decision making, and lend support for an individualized, values-based approach to counseling.

Our study has limitations, particularly regarding potential recruitment and participation biases in our methods. We recruited from parents who were willing to stay engaged in the hospital's parent host program, and enrolled those willing to speak with us about their experiences and values in an effort to protect vulnerable patients. Despite this, we were able to achieve our recruitment goal of parents of infants with diverse diagnoses with serious prognoses. Nearly half of the infants died, and several of the survivors were unaffected or less-affected twins; 10 of the 15 parents interviewed experienced death of at least one of their newborns, and three of the 12 survivors went home on mechanical ventilation. This recruitment strategy, however, may have limited our ability to enroll patients of diverse backgrounds. Participants in our study were largely White, educated at a college level or higher, and all English speaking. Although our participants were demographically similar to our hospital NICU patient/family population, which more than 70 percent White, the growing body of evidence regarding how clinician/family relationships impact neonatal outcomes,[29] coupled with barriers to building collaborative relationships[30] created by the complex relationship between race, language, and other demographic factors, make it imperative to identify whether value conflicts are escalated in situations when families differ from their clinicians racially or culturally. Our finding that parents experience values conflicts that resulted in mistrust in the care team, even when they were not of racially minoritized or historically marginalized background, is perplexing, and we speculate that these barriers to collaborative care may be worse in other populations. Additionally, all but one of our participants were mothers, which limited our findings' generalizability to shed insight into the experiences of men/fathers in these situations.

For some participants, considerable time had elapsed since their hospitalization, and their recollections from their NICU experience may be inaccurate and altered by their reflections since their child's discharge or death. Ultimately, it is parents who must live with the memories of their child's time in the NICU, and how they recall decision making and their interactions with the medical team around decision making may be more important to understanding the experience of parents in these situations than objective specifics of what actually happened. We also did not query the perspective of the clinicians who worked with these patients to better understand their perceptions of the conflicts that were reported by parents. If parents—the ones who must live with these decisions and memories—feel unsupported, that is a problem whether or not clinicians contest the etymology of this feeling. A larger, multisite recruitment and recruitment of parent-clinician dyads may address some of these challenges in future research. Additional research is also needed to gain insight into clinicians' perspectives and how they align with those of parents and to examine how parents' values may change over time—prior to, during, and after their experience in the NICU.

While we cannot generalize these exploratory qualitative findings to the broader population of parents who have had critically ill neonates, we did find that, despite having diverse experiences, our participants converged on many of the same values and themes, and that these themes reflected previous findings in the literature about parents' values.

RECOMMENDATIONS FOR PRACTICE

Based on these findings, we recommend that clinicians who engage in counseling and goals-of-care decision making for critically ill neonates antenatally and throughout the NICU course should:

1. Self-reflect to identify their own values and consider how these values may bias how they perceive possible outcomes, counsel about these outcomes in decision making, and make recommendations to parents in goals-of-care decisions.
2. Recognize the plurality of values and perspectives considered in decision making and the broad range of what outcomes individuals may consider acceptable in care decisions for critically ill neonates.
3. Acknowledge uncertainty and limitations to prognostic prediction with humility and provide honest counseling that encourages parents to consider the possibility that certain outcomes will occur, and what these possible outcomes might mean for their child and family.
4. Offer parents all ethically permissible treatment options as warranted by the situation and accept their decisions, even if they are counter to medical recommendations.
5. Communicate respectfully, with empathy, and support parents' hope and their ability to feel they are being "good parents."

CONCLUSION

Parents identify chance of survival, quality of life, avoiding suffering, ensuring that all options were tried, and being a good parent as important in considering medical decisions for their infants. While parents will have different perspectives on what outcomes are acceptable based on their values, nearly all of the parents we interviewed considered a similar set of values when they made decisions. Conflicts arose when parents felt their clinicians failed to understand, acknowledge, or incorporate their values in goals-of-care decision making. Medical decisions for critically ill neonatal patients must align with parents' values. A thorough understanding of parents' values, as well as identification and self-reflection about clinicians' own values and how they impact these conversations, are necessary to support engagement in these challenging situations.

CONTRIBUTORS' STATEMENT

Dr. Kukora conceptualized and designed the project, codeveloped the interview guide and coding scheme, performed qualitative analysis, wrote the initial draft, and revised the article. Mr. Krenz interviewed the majority of participants, codeveloped the coding scheme, performed qualitative analysis, and revised the article. Professors Spector-Bagdady and De Vries interviewed participants, codeveloped the interview guide and coding scheme, assisted with qualitative analysis, and critically revised the article. All of the authors approved the final article as submitted and agree to be accountable for all aspects of the work.

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