

# Worth a Try? Describing the Experiences of Families during the Course of Care in the Neonatal Intensive Care Unit When the Prognosis is Poor

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**Objective** To determine how parents of infants in the neonatal intensive care unit with a poor or uncertain prognosis view their experience, and whether they view their choices as “worth it,” regardless of outcome.

**Study design** Parents of eligible neonates at 2 institutions underwent audiotaped, semistructured interviews while their infants were still in the hospital and then again 6 months to 1 year after discharge or death. Interviews were transcribed and data were analyzed using thematic analysis. Two authors independently reviewed and coded each interview and discrepancies were resolved by consensus.

**Results** Twenty-six families were interviewed in the initial group and 17 families were interviewed in the follow-up group. The most common themes identified included realism about death (24 families), appreciation for the infant’s care team (23 families), and optimism and hope (22 families). Overall themes were very similar across both centers, and among parents of infants who died and those who survived. Themes of regret, futility, distrust of care team, and infant pain were brought up infrequently or not at all.

**Conclusions** No family believed that the care being provided to their infant was futile; rather, parents were grateful for the care provided to their infant, regardless of outcome. Even in the case of a poor prognosis or the death of an infant, families in our study viewed their infant’s stay in the neonatal intensive care unit favorably. (*J Pediatr* 2017;■■:■■-■■).

Advances in technology have given neonatologists the ability to provide care to increasingly smaller and sicker neonates. Literature has shown that parents and physicians place different values on outcomes of death vs disability and have different feelings on the resuscitation of premature infants and infants with severe congenital anomalies.<sup>1-4</sup> The parental choice to provide intensive care to an infant in the gray zone or with severe congenital anomalies is at times in conflict with the attitudes of healthcare professionals and can generate moral distress.<sup>5-7</sup>

Prior studies have indicated that, during their child’s stay in the neonatal intensive care unit (NICU), parents experience a variety of both positive and negative emotions.<sup>8-10</sup> However, these studies have focused primarily on 1 time point and little is known about how parents view their child’s hospitalization while they are in the NICU and if parents, over time, begin to experience distress or regret over the pursuit of aggressive medical intervention for their infant. We envisioned that parents might reflect on their experience in several possible ways. On one end of the spectrum, parents might see the heroic attempts to save their babies in the face of poor prognosis as “opportunism overwhelming compassion,”<sup>11</sup> or as the medical team prolonging suffering in their baby to continue to push forward toward technological progress or to avoid death at all costs. Alternatively, a family might appreciate the medical care provided to their infant, even if the baby did not survive or survived with a disability, or have mixed emotions about their child’s care.

In this study, we describe parental experiences surrounding the care of the sickest infants in the NICU, regardless of outcome. This study illuminates the experience of families during an infant’s admission as well as after discharge or death. We were interested in the frequency with which different emotions occur in parents of extremely ill neonates, and how the baby’s outcome influences the variety of emotions that parents feel.

## Methods

This longitudinal, semistructured, qualitative interview study was conducted at 2 centers; the University of Chicago (U of C) Comer NICU, which is a tertiary care center with the capacity for 70 beds serving a primarily low-income, African American population, and the Evanston Infant Special Care Unit, a tertiary care center with capacity for 44 beds serving a population with a greater proportion of Caucasian patients. The institutional review board at both centers approved the study.

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NICU Neonatal intensive care unit  
U of C University of Chicago

Basic demographic data along with reason for admission and outcome at discharge were recorded for each family enrolled.

Parents were approached for consent for the study if their infants were  $\geq 5$  days old and met any of the following enrollment criteria, aimed at identifying the sickest infants: (1) gestational age at birth of  $\leq 25$  weeks, (2) grade 3-4 intraventricular hemorrhage diagnosed by head ultrasound examination, (3)  $>60\%$   $\text{FiO}_2$  and still intubated at  $>1$  month of age, (4) a history of extracorporeal membrane oxygenation, or (5) trisomy 13 or 18. Parents were excluded from the study if they were non-English speaking. Parents were interviewed both in the hospital and again 6-12 months after discharge or death. Enrollment was stopped when the study reached thematic saturation in the initial interview group, and this same cohort of 26 families was subsequently contacted for a follow-up interview.

The initial interview was conducted in person with semistructured, open-ended questions aimed at evaluating the parents' experience of their child being in the NICU, including how they understood their child's illness, how they felt about/coped with the experience of having a sick infant, and what issues they were thinking about going forward. The semistructured interview questions can be found in **Table I** (available at [www.jpeds.com](http://www.jpeds.com)). All interviews were digitally audio recorded, transcribed and checked for accuracy and imported into qualitative research software (NVivo 11, QSR, International, Burlington, Massachusetts). When possible, both parents were interviewed together.

The second interview was conducted either in person or over the phone  $\geq 6$  months after discharge or death. The interview was also semistructured with a script of open-ended questions (**Table I**). Inquiries targeted the current medical status of the babies and then asked parents to look back on their NICU experience, consider the decisions they made and the feelings they had at the time, and reflect on how they feel both about their NICU and post-NICU experience. All follow-up interviews were digitally audio recorded, transcribed and checked for accuracy and imported into qualitative research software (NVivo 11, QSR, International).

## Statistical Analyses

Initial codes were determined a priori based on interviews conducted during a prior study done by our group.<sup>8</sup> We used an iterative process whereby subsequent codes were added when new themes were identified and interviews were recoded for added themes. Thematic saturation was reached after the enrollment of 26 families in the initial interview group and recruitment was ended. For the follow-up interviews, codes were carried over from the initial interview group and subsequent codes were added when common themes were identified. Two members of the research team independently coded each interview, and codes were checked to ensure accuracy.<sup>12</sup> Any discrepancies in coding were resolved by consensus.

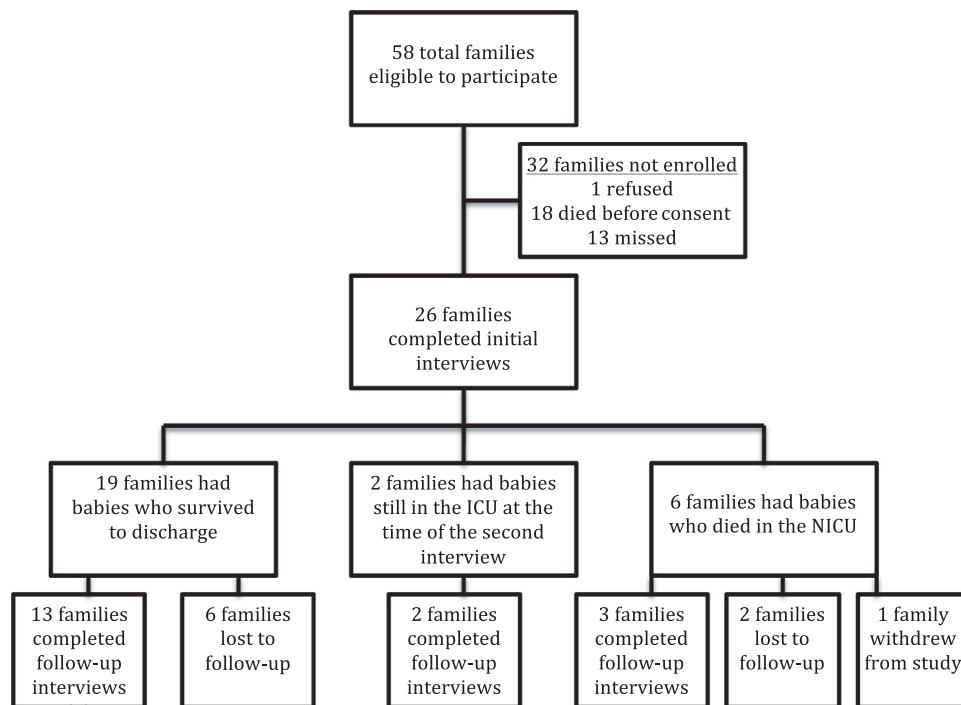
## Results

Of the 28 families approached for consent, 27 families consented to participate in the study and 26 families were inter-

viewed (**Figure**). Of the 38 eligible families, 17 were interviewed at the U of C over the study period (June 2014-June 2015) and 9 families out of 20 eligible families were interviewed at Evanston Hospital over the study period (November 2014-November 2015). Of the families eligible for interviews, 17 patients at U of C (45%) and 6 families at Evanston (30%) had an infant who died in the NICU. The most common reasons for not conducting an initial interview were that the infant died before being able to contact the family or an interviewer was unable to connect with a family at the bedside. Only 1 family refused to be interviewed. Of the 26 families who participated, both parents were interviewed together in 10 of the interviews (38%) and only the mother was interviewed in the other 16 interviews (62%). The most common inclusion criterion was extreme prematurity (21 babies [70%]), followed by extracorporeal membrane oxygenation (5 babies [17%]), severe intraventricular hemorrhage (2 babies [7%]), trisomy 13 (1 baby [3%]), and mechanical ventilation on  $\geq 60\%$   $\text{FiO}_2$  at  $>1$  month of age (1 baby [3%]). The average time to the first interview was 46 days of life (range, 5-170 days of life). There were an equal number of white ( $n = 10$  [39%]) and African American ( $n = 10$  [39%]) families interviewed, with a smaller number of Hispanic, Asian, and mixed race families ( $n = 6$  [22%]). Of the babies that are included in the study, 22 (73%) survived to discharge, 6 (20%) died before discharge, and 2 (7%) had never left the hospital at the time of the follow-up interview (**Table II**).

Every family who completed an initial interview was contacted for a follow-up interview. Seventeen families (65%) could be reached for follow-up interviews and all families who were reached completed the follow-up interview. One family withdrew from the study after the death of their child and the other 8 families were lost to follow-up. The proportion of families from each site was similar to the initial interview group. Follow-up interviews were completed at an average of 435 days of life (range, 259-750 days). The majority of parents met criteria because they were parents of extremely preterm babies ( $n = 17$  [80%]), which was consistent with the initial interview group. In the follow-up group, the majority of infants had survived with 3 infants dying before discharge and 2 infants still in the hospital at the time of follow-up. Of those surviving at 1 year, about one-third survived with a disability or significant medical complexity. Only mothers were available for follow-up interviews (**Table II**).

During the initial interviews, a total of 25 themes were catalogued. The 5 most common themes included realism about death ( $n = 24$ ), appreciation for care team ( $n = 23$ ), optimism and hope ( $n = 22$ ), stress ( $n = 18$ ), and fear ( $n = 17$ ). In contrast, uncommon themes included futility ( $n = 0$ ), suffering ( $n = 0$ ), and parental guilt ( $n = 2$ ). In the follow-up interviews, a total of 32 themes emerged. The 5 most common themes were appreciation for care team ( $n = 17$ ), no regrets ( $n = 16$ ), infant bonding ( $n = 14$ ), coping with medical illness ( $n = 12$ ), and authoritative knowledge ( $n = 12$ ). Some of the least common themes in the follow-up group were futility ( $n = 0$ ), regret ( $n = 1$ ), lack of optimism and hope from parents ( $n = 1$ ), and infant pain ( $n = 2$ ; **Table III**). Illustrative quotes from families are presented in **Table IV**.



**Figure.** Families eligible for participation in the study. One family of multiples was a family of a child who died and a child who survived.

Our 2 sites were demographically different. The families from the U of C were predominately ethnic minorities (12 families [76%] were African American or Hispanic), whereas the families at Evanston were largely ethnic majorities (5 families were white [55%] and 2 families were African American or Hispanic [22%]; **Table II**). Despite these differences, there was considerable overlap in the themes that emerged when families talked about their experience. The themes of realism about death, appreciation for care team, optimism and hope, fear, and stress were all common themes in both initial interview groups. One exception was the finding of a much greater reliance on “faith” among the U of C families, in that 15 families (88%) spoke of their reliance on faith vs only 2 Evanston families (22%). Another difference between the 2 centers was a greater focus on the theme of future disability among the Evanston group, with 6 Evanston families (66%) referencing this theme vs 5 U of C families (29%). These trends remained true in the follow-up interviews, where the themes of appreciation for care team, no regrets, infant bonding, and coping with medical illness were among the top common themes in both groups. Again, references to faith, coping with disability or developmental delay, and concern about future development were different in the follow-up groups, with only 1 Evanston family (16%) talking about the role of faith in their experience vs 5 U of C families (45%). Also consistent with the initial interviews, 5 Evanston families (83%) referenced the theme coping with disability or developmental delay vs 5 U of C families (45%); 5 Evanston families (83%) referenced the theme of concern about future development vs 4 U of C families (36%; **Table V**; available at [www.jpeds.com](http://www.jpeds.com)).

In the initial interview group, there were 6 families whose children died in the NICU. Although the families experienced very different outcomes, the themes of appreciation for care team, no regrets, and infant bonding were among the top themes among both parents of infants who died and parents of babies who survived. In the follow-up group, there were only 3 families of infants who died who could be reached for an interview and all 3 families voiced themes of appreciation for care team, sadness, and no regrets. Families of babies who survived expressed themes relating to the reality of caring for a child with a difficult NICU course, including coping with medical illness, and coping with disability or developmental delay; they also spoke more about optimism and hope (**Table VI**; available at [www.jpeds.com](http://www.jpeds.com)). Overall, the parents of babies who did not survive seemed to look back on that time as incredibly sad and difficult, but also as a time that held a special meaning for them and their family:

“This is something that was for us very special in the way that I mean I went through sometime because it was a time of suffering for us and also for L and because it was something that we didn’t expect it about all the issue with the trisomy. It was a very very painful time but as well it was a time of strength because we had a lot of people praying for us and it was also a time, so sometimes we use as a source of strength.”

In the follow-up interviews, 5 families were living with children who survived with disability/medical complexity and 10 families were living with children who are noncomplex medically with typical development. Appreciation for the care team was the most common theme in both groups. Interestingly, no regrets was a common theme in both categories (n = 4 of 5

**Table II.** Study participants and infant characteristics

	In-hospital families (n = 26)	Follow-up (n = 17)	In hospital (%)	Follow-up (%)
Site				
Evanston	9	6	35	35
U of C	17	11	65	65
Race/ethnicity				
White	10	6	39	35
African American	10	7	39	41
Hispanic	4	3	15	18
Asian	1	0	4	0
Mixed race	1	1	4	6
Who was interviewed				
Mother	16	17	62	100
Father	0	0	0	0
Both	10	0	38	0
Time to interview (days of life)	46 (5-170)	435 (259-750)		
	In-hospital babies (n = 30)	Follow-up (n = 21)	In hospital (%)	Follow-up (%)
Sex				
Male	11	8	37	38
Female	19	13	63	62
Entry criteria				
≤25 weeks	21	17	70	80
Extracorporeal membrane oxygenation	5	1	17	5
Grade 3-4 intraventricular hemorrhage	2	1	7	5
Trisomy 13	1	1	3	5
>60% FiO <sub>2</sub> and intubated at 1 mo	1	1	3	5
Outcome				
Survival to discharge	22	16	73	76
Died in hospital	6	3	20	14
Never discharged	2	2	7	10

disabled vs 10 of 10 not disabled): “She was behind on crawling and walking, because she doesn’t have good balance. But she is getting therapy, so they are working with her on that. Just one of the big things that you know, they kept her alive though, and that is what I’m most grateful for.” Important differences were also noted. Parents of typically developing children spoke more about infant bonding, stress, and optimism and hope (Table VII; available at [www.jpeds.com](http://www.jpeds.com)).

## Discussion

Parents experiencing the imminent birth of an infant with a poor or uncertain prognosis are faced with a series of difficult decisions of whether to proceed with intensive care or choose comfort care at delivery. During these difficult conversations, physicians are often encouraged to partner with parents to help them understand the data, make informed decisions, and attempt to prepare them for the road ahead. Physicians and parents each come with their own unique sets of beliefs, experiences, and values and, although they may be dedicated to the best interests of a child, when a parent makes the decision to continue intensive care for their infant with a poor or uncertain prognosis, the healthcare team may question the decision given the possibility of death, disability, and fear of doing harm.

Moral distress, defined by Jameton as a phenomenon in which one knows the right action to take, but is constrained

from taking it,<sup>13</sup> has been well-described in the literature around the care of infants in the NICU.<sup>5,6,14,15</sup> The feeling that the patient has not been best served by those making the decisions can lead to feelings of moral distress among the healthcare team tasked with taking care of these fragile babies. One question we sought to answer in this study was whether parents felt that the intensive care being provided to their baby was somehow experimental or inappropriate. No family we interviewed endorsed these feelings. On the contrary, parents were overwhelmingly grateful to the team providing care to their baby. We found this interesting and surprising, given the moral distress that has been described around the care of these infants from the perspective of the medical team. Our interviews with families who chose resuscitation revealed that these parents felt grateful and remained optimistic even in the midst of a stressful NICU admission, and even in the face of real or anticipated developmental and medical challenges.

Literature is emerging as to how families make such decisions regarding beginning or withholding resuscitation in the delivery room<sup>16</sup> and how they feel about the information given to them and their experience in the NICU.<sup>17,18</sup> Certainly, no 2 families are exactly alike and care should always be taken to make the conversation as individualized as possible.<sup>19</sup> As physicians, we tend to rely on statistics as a way to ensure that parents have been fully informed and have realistic ideas of what to expect while their child is in the NICU,<sup>20</sup> but we need to be aware that these statistics may not have the same kind of importance to families.<sup>9</sup> Families may understand the sta-

**Table III.** All themes catalogued from interviews with families

Themes	Interviews	Total codes
<b>Initial interview (n = 26)</b>		
Realism about death	24	50
Appreciation for care team	23	60
Optimism and hope	22	52
Stress	18	29
Fear	17	44
Faith	17	38
Trust in care team	17	34
Infant bonding	13	22
Authoritative knowledge	13	18
Roller coaster	13	13
Sadness	12	21
Future disability	11	18
No regrets	10	10
Staying strong	9	16
Baby as fighter	8	10
Infant pain	8	8
Do not give up	7	8
Best interest	6	10
Optimism from care team	6	9
No fault	3	4
Distrust of care team	3	3
Parental guilt	2	2
Lack of optimism from caregiver	1	5
Futility	0	0
Suffering	0	0
<b>Follow-up interview (n = 17)</b>		
Appreciation for care team	17	48
No regrets	16	30
Infant bonding	14	22
Coping with medical illness	12	26
Authoritative knowledge	12	25
Optimism and hope	11	22
Coping with disability or developmental delay	10	17
Stress	9	18
Concern about future development	9	12
Trust in care team	8	13
One day at a time	7	8
Faith	6	12
Sadness	6	10
Roller coaster	6	6
Realism about death	5	9
Fear	4	9
Baby as fighter	4	6
Optimism from care team	4	5
Parental guilt	4	5
Staying strong	4	5
Do not give up	3	5
Suffering	3	5
Best interest	2	3
Needing more time	2	3
Be patient	2	2
Distrust of care team	1	7
Lack of optimism and hope from care team	1	4
Infant pain	1	2
Lack of optimism and hope from parents	1	1
Regret	1	1
Futility	0	0
No fault	0	0

tistics yet remain hopeful that their child will be part of that small percentage that thrives. In this study, realism about death was the most common overall theme, brought up by 24 families (92%) during interviews, which suggests that these fami-

lies did have an understanding of the possibility of death that their infants faced. Despite this understanding, another theme brought up by 22 families (84%) was optimism and hope, suggesting that families are able to remain hopeful when faced with the possibility of death or disability for their child. The theme of holding onto hope when faced with a poor or even terminal prognosis is not unique to the NICU literature, and has also been described in the field of oncology and adult medicine.<sup>21,22</sup> Furthermore, the families we interviewed whose infants died or survived with a disability recalled the admission to the NICU with many positive feelings, because it was a time for them to bond with and parent their baby. This finding supports the already published literature that parents of disabled children tend to view quality of life with disability as better than the medical team does.<sup>23,24</sup> Another interesting finding was that the 2 major differences in parental themes between families surveyed at different sites centered on themes of faith and future disability/coping with disability. In this study, the U of C group referenced faith more often and disability less often compared with the Evanston group, and this trend continued upon review of the follow-up interviews. This finding supports published literature demonstrating that a family's religious beliefs affect the way that they view pivotal risk for different disability states in children.<sup>3</sup>

Finally, having no regrets was a common theme among the families interviewed in the NICU (10 of 26 families) and especially in the follow-up group where 16 of 17 families brought up having no regrets. This finding is consistent with a recent study demonstrating low rates of decisional regret among parents who decided for resuscitation vs nonresuscitation of infants in the gray zone.<sup>25</sup> Additionally, the literature has shown that clinician involvement in shared decision making can affect perception of guilt or regret.<sup>26,27</sup> It is unknown whether the parents in our study had low rates of reported regret owing to these factors or owing to, as some authors have described,<sup>28</sup> parental rationalization of prior decisions as a coping mechanism or underreporting of difficulties in living with a disability.

There are some limitations to this study. We were interested in interviewing a vulnerable population of families with critically ill children, and the families interviewed were a convenience sample of parents who could be interviewed at the bedside (for the initial interview). One-third of the families interviewed in the initial group could not be reached for a second interview, and only one-half of the families of infants who died could be reached for follow-up interviews. A large portion of families who were not interviewed were "missed" because their infant died before the initial interview. All interviews were conducted with either mothers or both parents together. No single fathers could be interviewed for the study, and this study may not adequately reflect the important feelings of fathers in the NICU. We did not interview families who chose palliative care at delivery. A parent's decision to resuscitate their baby at delivery, or to choose palliative care, is complex, as are the feelings of healthcare providers who care for these babies and families, and those families likely would voice important themes, which are not captured here. Finally, the families we interviewed were cared for by a variety of

**Table IV. Illustrative quotes from parents**

Themes	Interviews (n = 26)	References	Illustrative quote
<b>Initial interview</b>			
Realism about death	24	50	"I was like oh my god, this gonna be a long week. I hope she make it. You know, that was just my main—that was the only time I feel like, she's not going to make it."
Appreciation for care team	23	60	"I'm just grateful that she was able to be born at 25 weeks I mean I don't know if that would always happen, I mean if you were born 100 years ago."
Optimism and hope	22	52	"I mean if there is like a 0.25% chance I believe in it. . . never lose hope."
Stress	18	29	"My anxiety is through the roof. I worry about, I think about every mom or parent probably goes through the same worries I do about their kids but tacked on top of that I always worry about her developmental, her development."
Fear	17	44	"We need a miracle. Like A is gonna have to decide on—she's controlling the will so you know and that's scary—you feel helpless."
<b>Follow-up interview</b>			
Theme	Interviews (n = 17)	References	Illustrative quote
Appreciation for care team	17	48	"I'm proud of everything that her and I went through together and I'm so grateful for the team there and everything we went through and it was a huge life experience."
No regrets	16	30	"Was I selfish to choose—you know am I making her—doing more harm than good? You know you gotta but when I look at it now I don't have any regrets. . . after I see how beautiful she is how well she blossomed I'd say I'm happy I made it with the trach."
Infant bonding	14	22	"Being able to see her every day gave me hope, you know? Being around her and spend time with her and everything—it just gave me a lot, so much to look forward to."
Coping with medical illness	12	26	"I worry a little bit about her lungs because it does seem like whenever she gets sick—she's gotten sick maybe 3 times, which isn't bad—but when she gets sick her breathing deteriorates pretty quickly and it makes me nervous a little bit."
Authoritative knowledge	12	25	"Know your baby and trust that you know what's best for him. P always tells us when it's too much and he always lets us know so feel comfortable in your decision and know that you know what's best for your baby."

different clinicians and we did not record physician–parent conversations. We acknowledge that physician bias and framing affects the way in which decision makers make decisions for and feel about the status of their critically ill loved ones.<sup>29,30</sup>

In conclusion, we interviewed parents of high-risk infants in the NICU in the hospital and again 6-12 months after discharge to determine how they felt about their experience. We have enhanced our understanding of how some families of infants with a poor or uncertain prognosis feel about their NICU stay, regardless of outcome. Although the discussion with families about whether to choose palliative care at delivery versus attempt resuscitation should be individualized, and the ultimate decision made by a family respected, the data presented here demonstrate that these parents who opted for a trial of therapy in the NICU viewed their decision favorably, and the families in our study remind physicians of the value families may find in a stressful NICU admission. ■

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**Table I. Semistructured interview questions**

## Interview template (before discharge)

1. I'd like to start by learning a little about you. Can you tell me a little about yourself and your family?
2. How did things go during the pregnancy? Did you think about the possibility of your baby being in the NICU before delivery?
3. How do you think your baby is doing?
4. Can you tell me about your experience with the NICU so far?
5. Tell me about any other experiences you've had in an intensive care unit.
6. What has happened to \_\_\_\_\_ since he/she was admitted to the NICU?
7. What kind of fears or concerns have you had since \_\_\_\_\_ was admitted?
8. Where have you gotten most of your information on \_\_\_\_\_'s medical condition since he/she has been admitted to the NICU?
9. Has there been a time during this hospitalization when you thought that \_\_\_\_\_ might not survive?
10. Who do you turn to for emotional support when \_\_\_\_\_ is sick?
11. How do you go about making decisions about your baby's care? Who do you turn to to help you make decisions for \_\_\_\_\_?
12. Are there any circumstances under which you would consider stopping the medicines and machines, even if it meant that \_\_\_\_\_ would not survive?
13. Later on when you are looking back, how do you think you will see this experience of \_\_\_\_\_ being in the NICU?
14. Do you have any advice for other parents whose infants are in the NICU?
15. Is there anything that we haven't discussed that you would like to talk about?

## Interview template (after discharge)

## (Baby is alive)

1. How are things going at home?
2. How old is your child now?
3. How is your child doing medically? Have they needed to come back to the hospital?
4. How has your child been doing developmentally, what milestones have they reached?
5. Do you ever think back to when your baby was in the NICU?
6. When you think back to your time in the NICU, how would you describe it?
7. When you think back to the choices you made in the NICU (read choices back to family), how do you feel about them? Do you think you would make the same choices again?
8. What were the best parts about your baby's stay in the NICU?
9. What was most meaningful, what made you hopeful?
10. What were the worst parts about your baby's stay in the NICU?
11. Do you have any regrets about your child's NICU stay?
12. What concerns do you have about your child?
13. What are your hopes/plans for your child's future?
14. Do you have advice for other parents whose infants have graduated from the NICU?

## (Baby is deceased)

1. How are things going at home?
2. Do you ever think back to when your baby was in the NICU?
3. When you think back to your time in the NICU, how would you describe it?
4. When you think back to the choices you made in the NICU (read choices back to family), how do you feel about them? Do you think you would make the same choices again?
5. What were the best parts about your baby's stay in the NICU?
6. What was most meaningful, what made you hopeful?
7. What were the worst parts about your baby's stay in the NICU?
8. Do you have any regrets about your child's stay in the NICU?
9. Do you have any advice for other parents whose infants have passed away in the NICU?



**Table V.** Comparing themes from the U of C vs Evanston Hospital

Themes	No. of interviews (%)	No. of interviews (%)
<b>Initial interview</b>		
<b>N</b>	<b>17</b>	<b>9</b>
Realism about death	16 (94)	8 (88)
Faith	15 (88)	2 (22)
Appreciation for care team	14 (82)	9 (100)
Optimism and hope	13 (76)	9 (100)
Fear	11 (64)	6 (66)
Stress	11 (64)	7 (77)
Trust in care team	10 (58)	7 (77)
Authoritative knowledge	10 (58)	3 (33)
Sadness	8 (47)	4 (44)
Infant bonding	7 (41)	6 (66)
Staying strong	7 (41)	2 (22)
No regrets	7 (41)	3 (33)
Roller coaster	7 (41)	6 (66)
Best interest	6 (35)	0 (0)
Don't give up	6 (35)	1 (11)
Baby as fighter	5 (29)	3 (33)
Future disability	5 (29)	6 (66)
Infant pain	5 (29)	3 (33)
Needing more time	3 (17)	1 (11)
Optimism from care team	3 (17)	3 (33)
No fault	2 (11)	1 (11)
Distrust of care team	2 (11)	1 (11)
Lack of optimism and hope from care team	1 (5)	0 (0)
Parental guilt	1 (5)	1 (11)
Futility	0 (0)	0 (0)
Suffering	0 (0)	0 (0)
<b>Follow-up interview</b>		
<b>N</b>	<b>11</b>	<b>6</b>
Appreciation for care team	11 (100)	6 (100)
No regrets	10 (90)	6 (100)
Infant bonding	9 (81)	5 (83)
Authoritative knowledge	8 (72)	4 (66)
Optimism and hope	7 (63)	4 (66)
Coping with medical illness	7 (63)	5 (83)
Trust in care team	6 (54)	2 (33)
Stress	5 (45)	4 (66)
Faith	5 (45)	1 (16)
Coping with disability or developmental delay	5 (45)	5 (83)
Sadness	4 (36)	2 (33)
Baby as fighter	4 (36)	0 (0)
Concern about future development	4 (36)	5 (83)
One day at a time	4 (36)	3 (50)
Fear	3 (27)	1 (16)
Realism about death	3 (27)	2 (33)
Optimism from care team	3 (27)	1 (16)
Staying strong	3 (27)	1 (16)
Roller coaster	3 (27)	3 (50)
Parental guilt	2 (18)	2 (33)
Don't give up	2 (18)	1 (16)
Distrust of care team	1 (9)	0 (0)
Lack of optimism and hope from care team	1 (9)	0 (0)
Best interest	1 (9)	1 (16)
Needing more time	1 (9)	1 (16)
Suffering	1 (9)	2 (33)
Be patient	1 (9)	1 (16)
Lack of optimism and hope from parents	1 (9)	0 (0)
Futility	0 (0)	0 (0)
Infant pain	0 (0)	1 (16)
No fault	0 (0)	0 (0)
Regret	0 (0)	1 (16)

**Table VI.** Comparing families of infants who died vs those who survived

Themes	Died No. of interviews (%)	Survived No. of interviews (%)
<b>N</b>	<b>3</b>	<b>15</b>
Appreciation for care team	3 (100)	15 (100)
Sadness	3 (100)	4 (26)
No regrets	3 (100)	14 (93)
Infant bonding	2 (66)	13 (86)
Suffering	2 (66)	2 (13)
Best interest	2 (66)	1 (7)
Trust in care team	2 (66)	7 (46)
Authoritative knowledge	1 (33)	12 (80)
Faith	1 (33)	5 (33)
Concern about future development	1 (33)	9 (60)
Coping with disability or developmental delay	1 (33)	10 (66)
Coping with medical illness	1 (33)	12 (80)
Needing more time	1 (33)	2 (13)
Optimism and hope	1 (33)	10 (66)
Regret	1 (33)	1 (7)
Stress	1 (33)	9 (60)
Baby as fighter	0 (0)	4 (26)
Be patient	0 (0)	2 (13)
Distrust of care team	0 (0)	1 (7)
Don't give up	0 (0)	3 (20)
Fear	0 (0)	4 (26)
Futility	0 (0)	0 (0)
Infant pain	0 (0)	1 (7)
Lack of optimism and hope from care team	0 (0)	1 (7)
Lack of optimism and hope from parents	0 (0)	1 (7)
No fault	0 (0)	0 (0)
One day at a time	0 (0)	7 (46)
Optimism from care team	0 (0)	4 (26)
Parental guilt	0 (0)	4 (26)
Roller coaster	0 (0)	6 (40)
Realism about death	0 (0)	5 (33)
Staying strong	0 (0)	4 (26)

**Table VII.** Comparing families with infants who survived with developmental delay and medical complexity vs those who survived with typical development

Follow-up interviews	Developmental delay/medically complex (n = 5)	Typical development (n = 10)
Code	No. of interviews (%)	No. of interviews (%)
Appreciation for care team	5 (100)	10 (100)
Coping with medical illness	5 (100)	7 (70)
Coping with disability or developmental delay	4 (80)	6 (60)
No regrets	4 (80)	10 (100)
Authoritative knowledge	3 (60)	9 (90)
Realism about death	3 (60)	2 (20)
Infant bonding	3 (60)	10 (100)
Concern about future development	3 (60)	6 (60)
Baby as fighter	3 (60)	2 (20)
One day at a time	3 (60)	4 (40)
Optimism from care team	3 (60)	1 (10)
Fear	2 (40)	2 (20)
Optimism and hope	2 (40)	8 (80)
Staying strong	2 (40)	2 (20)
Roller coaster	2 (40)	4 (40)
Distrust of care team	1 (20)	0 (0)
Lack of optimism and hope from care team	1 (20)	1 (10)
Stress	1 (20)	8 (80)
Trust in care team	1 (20)	6 (60)
Needing more time	1 (20)	1 (10)
Infant pain	1 (20)	0 (0)
Don't give up	1 (20)	2 (20)
Parental guilt	1 (20)	3 (30)
Suffering	1 (20)	1 (10)
Be patient	0 (0)	2 (20)
Best interest	0 (0)	1 (10)
Faith	0 (0)	5 (50)
Futility	0 (0)	0 (0)
Helplessness	0 (0)	0 (0)
Lack of optimism and hope from parent	0 (0)	1 (10)
No fault	0 (0)	0 (0)
Regret	0 (0)	1 (10)
Sadness	0 (0)	4 (40)