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Decisional Satisfaction, Regret, and Conflict Among Parents of Infants with Neurologic Conditions

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Abstract

Objectives—To characterize decisional satisfaction, regret, and conflict among parents of critically ill infants with neurologic conditions.

Study design—In this prospective cohort study, we enrolled parents of infants with neurologic conditions in the intensive care unit (ICU). Hospital discharge surveys included the validated

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Prior presentation: An abstract and poster from this project was presented at the Medical Student Research Symposium at Duke University School of Medicine in August 2021 and at the Child Neurology Society annual meeting in September 2021. An abstract and poster from this project will be presented at the Newborn Brain Conference in February 2022.

Family Satisfaction with the ICU (FS-ICU) decision-making subscale, Decision Regret Scale (DRS), and Decisional Conflict Scale (DCS). We defined high satisfaction with decision-making as FS-ICU score ≥ 75 , high decisional regret/conflict as DRS/DCS score > 25 , and within-couple disagreement as a difference between scores of at least 25 points.

Results: We enrolled 61 parents of 40 infants (n = 40 mothers, n = 21 fathers); 35 mothers and 15 fathers completed surveys. Most mothers reported high satisfaction with decision-making (n = 27/35, 77%) and low decision regret (n = 28/35, 80%); 40% reported high decisional conflict (n = 14/35). Mothers and fathers reported higher decisional conflict in the domains of uncertainty and values clarity as compared with the domain of effective decision-making (Bonferroni-corrected p-values < 0.05). There were no differences in decision outcomes between paired mothers and fathers. However, within any given couple, there were numerous instances of disagreement (n = 7/15 for decision regret and n = 5/15 for decisional conflict).

Conclusions—Many parents experience decisional conflict even if they ultimately have high satisfaction and low regret, underscoring the need for decision aids targeting uncertainty and values clarity. Couples frequently experience different levels of decisional regret and conflict.

Keywords

Neonatology; Neurology; Critical Care

Up to one-third of patients in the neonatal intensive care unit have or are at significant risk for brain injury.¹ Parents caring for these infants may face complex and tragic choices about care.^{2, 3} The stakes of these decisions can be high; existing data suggest that death for infants with neurologic conditions most commonly occurs after a decision to limit life-sustaining treatment.^{2, 3} Despite the high stakes of decision-making for infants with neurologic conditions, little is known about the decision-making experience of their parents. Important outcomes of decision-making include decisional satisfaction, regret, and conflict.

Studies in adult critical care suggest that family members of adults in the intensive care unit (ICU) have high satisfaction,^{4–8} low regret,^{9, 10} and low conflict about the decision-making process.^{10, 11} In pediatric critical care, studies have found high levels of satisfaction with decision-making¹² and moderate levels of decisional conflict.¹³ In non-intensive care pediatric settings, surrogate decision-makers have low decision regret^{14–16} and low decisional conflict.^{14, 17–19} However, as studies of surrogate decision-makers have shown higher levels of decisional conflict for end-of-life decisions than other medical decisions,⁵ results from other pediatric settings cannot necessarily be generalized to this context.

Parents of critically ill infants differ from surrogate decision makers for adults in important ways. Parents of infants are unable to rely on the patient's previously stated values or quality of life before they became ill. Infants with critical illness often have two default decision-makers. Existing data suggest that mothers and fathers often differ in the way they report information about their child^{20, 21} and have different perspectives on quality of life, disability, and death.^{22, 23}

To understand and improve the decision-making experience of parents of critically ill infants, we must understand whether they are satisfied with the decision-making process,

regret their decisions, or are conflicted about their decisions. The aims of this study were to characterize decisional satisfaction, regret, and conflict in parents of critically ill infants with neurologic conditions and characterize the relationship between parental decision outcomes.

Materials & Methods

Data Collection

A convenience sample of parents of infants with neurologic conditions was recruited between September 2018 and September 2020. Recruitment was paused due to the COVID-19 pandemic between mid-March and mid-June 2020. Parents of infants who met the following inclusion criteria were approached for enrollment: (1) age less than one year old, (2) presence of a neurologic condition, (3) presence of an upcoming goals of care discussion, and (4) current hospitalization in the neonatal, pediatric, or pediatric cardiac ICU at Duke University Hospital. A goals of care discussion was defined as a discussion about withdrawal of life-sustaining care or initiation of long-term medical technology to sustain life. The exclusion criteria were: (1) maternal age less than 18 years old, (2) maternal speech or hearing impairment, and (3) preferred language other than English. The Duke University Health System institutional review board approved this study.

Baseline parent demographic information was collected by survey at time of enrollment. Additional surveys measuring decisional satisfaction, regret, and conflict were administered within one week of discharge from the hospital. The surveys were not administered immediately following infant death due to concerns about parental distress. Parental data was collected between September 2018 and September 2020.

Infant characteristics were collected by electronic medical record review. Infant SNAPPE-II score²⁴ was calculated through retrospective chart review, using data from the first 12 hours of infant hospitalization in the ICU at the study center.

Measures

Satisfaction with decision-making, decision regret, and decisional conflict were measured using the validated Family Satisfaction with the ICU (FS-ICU) decision-making subscale,^{5, 8, 12} the Decision Regret Scale (DRS),²⁵ and the Decisional Conflict Scale (DCS),^{17, 26, 27} respectively. All surveys utilize items with a five-point Likert scale. In accordance with each survey's user manual and other studies, we converted all item responses to integers from 0 to 4, calculated the average, and multiplied by 25 to give a final score from 0 to 100.^{28–30} Within-couple disagreement was defined as a difference between parent scores of more than 25 points.

Family Satisfaction with the ICU—The Family Satisfaction with the ICU (FS-ICU) decision-making subscale^{5, 8, 12} is a 10-item survey designed to measure family surrogates' satisfaction with the decision-making process in the ICU. It has been shown to have an internal consistency of $\alpha = 0.95$ in when administered to white, English-speaking caregivers of children admitted to the ICU.¹² Families are asked to rate their satisfaction with communication from members of the care team (“How satisfied are you with how often doctors communicated to you about your child's condition?”), the quality of the

information provided (“How satisfied are you with how well the ICU staff provided you with explanations that you understood?”), their inclusion in the decision-making process (“Did you feel you had control over the care of your child?”), and how supported they felt (“Did you feel supported during the decision-making process?”). As has been done in prior studies,^{5, 6} parents were considered to have high satisfaction with decision-making if their Family Satisfaction with the ICU decision-making subscale scores were ≥ 75 .

Decision Regret Scale—The Decision Regret Scale (DRS)²⁵ is a 5-item survey designed to measure distress or remorse following a health-care decision. It has been shown to have an internal consistency of $\alpha = 0.81 - 0.92$ when administered to English-speaking adult decision-makers.²⁵ Decision makers are asked to rate their agreement with statements expressing the absence (“I would make the same choices if I had to do it over again”) or presence (“The choices did my child a lot of harm”) of regret. As has been done in prior studies,^{9, 14–16, 31} parents were considered to have high decision regret if their Decision Regret Scale scores were > 25 .

Decisional Conflict Scale—The Decisional Conflict Scale (DCS)^{17, 26, 27} is a 16-item survey designed to measure uncertainty about making health-care decisions. It has been shown to have an internal consistency of $\alpha = 0.85 - 0.92$ when administered to English and Spanish speaking parents of children eligible for a palliative care program.¹⁷ Decision makers are asked to rate their agreement with statements related to five domains of decisional conflict: effective decision-making (“I expect to stick with my decisions”), being informed (“I felt like I knew the benefits of the choices regarding my child’s care”), support (“I had the right amount of support from others in making these choices”), uncertainty (“I was unsure what to do in these decisions”), and values clarity (“It was hard to decide if the benefits were more important than the risks, or if the risks were more important than the benefits”). Single-word substitutions were used to convert survey items to past tense. As has been done in prior studies,^{14, 19} parents were considered to have high decisional conflict if their Decisional Conflict Scale score was > 25 .

Statistical Analysis

Statistical analysis was performed using R version 4.0.3. Subscale scores were compared using a Friedman test and post-hoc analysis was performed using a series of Wilcoxon signed-rank tests with a Bonferroni correction. Kendalls tau was used to describe correlations between different survey outcomes and between parental outcomes on the same survey. When comparing parental scores, a paired t-test was used to investigate agreement after a Shapiro-Wilk test confirmed that the differences between scores were normally distributed.

Results

Infant and Parent Characteristics

Parents of 80 infants were eligible for enrollment; 61 parents (n = 40 mothers, n = 21 fathers) of 40 infants were enrolled in the study, resulting in an enrollment rate of 50%. Discharge surveys were collected from 35 of 40 enrolled mothers and 15 of 21 enrolled

fathers, reflecting a response rate of 90% and 75%, respectively (Figure 1; available at www.jpeds.com). For all enrolled infants, one enrolled parent identified themselves as the infant's mother. In all cases in which a second parent was enrolled, they identified themselves as the infant's father. In one case, there was no attempt to collect discharge surveys due to infant death. In another case, discharge surveys were collected at the time of planned discharge, and the infant died in between survey collection and leaving the hospital. Three infants were enrolled after pausing recruitment in the context of the COVID-19 pandemic.

Parents who completed surveys had a median age of 31.5 (range: 19 – 46) and half identified as Black (Table I: Maternal Demographics and Infant Characteristics) (Table II: Paternal Demographics; available at www.jpeds.com). Nearly half of mothers reported that their highest level of education was some college or less and nearly half of fathers reported that their highest level of education was high school, GED, or less than high school. The median annual family income was \$25,000 – \$34,999, with nearly one-third of parents reporting an annual family income of less than \$25,000. The majority of parents described themselves as strongly or somewhat spiritual.

Infants who had at least one parent complete surveys had a median length of stay of 76 days (range: 8 – 344) (Table I: Maternal Demographics and Infant Characteristics). Nearly half were born prematurely; the median gestational age was 37 weeks and 0 days (range: 22 weeks 3 days - 40 weeks 4 days). The most common diagnoses were genetic conditions, brain malformations, intraventricular hemorrhages, and seizures, with just over one-quarter of infants carrying each diagnosis. Over three-quarters of infants whose parent(s) completed surveys received mechanical ventilation during their hospitalization and almost half had a feeding tube placed. Nearly one-quarter of these infants had a code event and one died during admission.

Maternal Decision Outcomes

Over three-quarters of mothers reported high satisfaction with decision-making ($n = 27/35$, 77%). The median Family Satisfaction with the ICU decision-making subscale score was 87.5 (range: 2.5 – 100). One-fifth of mothers reported high decision regret ($n = 7/35$). The median Decision Regret Scale score was 10 (range: 0 – 90). Forty percent of mothers reported high decisional conflict ($n = 14/35$). The median Decisional Conflict Scale score was 23.4 (range: 0 – 78.1) (Figure 2). Maternal satisfaction with decision-making was moderately negatively correlated with decision regret ($\tau = -0.58$, $p < 0.001$) and decisional conflict ($\tau = -0.64$, $p < 0.001$). Maternal decision regret and decisional conflict were moderately positively correlated ($\tau = 0.71$, $p < 0.001$).

Among the five Decisional Conflict Scale subscales, mothers experienced significantly less conflict related to making effective decisions or being informed than they did related to support, uncertainty, and values clarity (Bonferroni-corrected p -values all < 0.05) (Figure 3).

Paternal Decision Outcomes and Agreement Between Parent-Parent Dyads

Just over half of fathers reported high satisfaction with decision-making ($n = 8/15$, 53%). The median Family Satisfaction with the ICU decision-making subscale score was 77.5

(range: 10 – 100); 40% of fathers reported high decision regret ($n = 6/15$). The median Decision Regret Scale score was 25 (range: 0 – 55); 60% of fathers reported high decisional conflict ($n = 9/15$). The median Decisional Conflict Scale score was 29.7 (range: 0 – 54.7) (Figure 4; available at www.jpeds.com).

Among the five Decisional Conflict Scale subscales, fathers experienced significantly less conflict related to making effective decisions than they did related to uncertainty and values clarity (Bonferroni-corrected p -values all < 0.05) (Figure 5; available at www.jpeds.com).

When comparing the 15 fathers who responded to surveys to the 15 mothers of their infants, there were no significant average differences in Family Satisfaction with the ICU decision-making subscale score, Decision Regret Scale score, or Decisional Conflict Scale score (all paired t -tests $p > 0.05$) (Figure 6). Although maternal and paternal scores were moderately positively correlated for the Family Satisfaction with the ICU decision-making subscale ($\tau = 0.59$, $p = 0.004$), there was no statistically significant correlation between maternal and paternal scores for the Decision Regret Scale or Decisional Conflict Scale (Figure 7; available at www.jpeds.com).

Within-couple disagreement, defined as a difference between parental scores of at least 25 points, was uncommon for the Family Satisfaction with the ICU decision-making subscale ($n = 2/15$, 13%). Nearly half of couples had disagreement between Decision Regret Scale scores ($n = 7/15$, 47%) and one-third had disagreement between Decisional Conflict Scale scores ($n = 5/15$).

Negative Parental Decision Outcomes

eight mothers reported low satisfaction with decision-making. The median Family Satisfaction with the ICU decision-making subscale score among these mothers was 40 (range: 2.5 – 70). Three-quarters of the mothers who had low satisfaction with decision-making had high decision regret and all had high decisional conflict. Of the eight mothers with low satisfaction with decision-making, seven had the father of their infant enrolled in the study, and five of those fathers also experienced low satisfaction with decision-making. Seven total fathers reported low satisfaction with decision-making. The median Family Satisfaction with the ICU decision-making subscale score among these fathers was 55 (range: 10 – 72.5). Six of the seven fathers who had low satisfaction with decision-making had high decision regret and all had high decisional conflict. Low satisfaction with decision-making was present across all ages and demographic groups, with parents identifying as white, Black, Asian, and multiracial, reporting annual family incomes in all categories, and having educational backgrounds ranging from having completed less than high school to having completed a graduate/professional degree.

seven mothers reported high decision regret. The median Decision Regret Scale score among these mothers was 50 (range: 30 – 90). Six of the seven mothers who had high decision regret had low satisfaction with decision-making and all had high decisional conflict. Of the seven mothers with high decision regret, six had the father of their infant enrolled in the study, and five of those fathers also experienced high decision regret. Six total fathers reported high decision regret. The median Decision Regret Scale score among these

fathers was 42.5 (range: 30 – 55). All of the fathers who had high decision regret had low satisfaction with decision-making and high decisional conflict. High decision regret was present across all ages and demographic groups.

a total of 14 mothers reported high decisional conflict. The median Decisional Conflict Scale score among these mothers was 42.7 (range: 26.6 – 78.1). Over half of the mothers who had high decisional conflict had low satisfaction with decision-making and half had high decision regret. Of the 14 mothers with high decisional conflict, nine had the father of their infant enrolled in the study, and six of those fathers also experienced high decisional conflict. Nine total fathers reported high decisional conflict. The median Decisional Conflict Scale score among these fathers was 45.3 (range: 28.3 – 54.7). Seven of the nine fathers who had high decisional conflict had low satisfaction with decision-making and six had high decision regret. High decisional conflict was present across all ages and demographic groups.

Discussion

we characterized the satisfaction with decision-making, decision regret, and decisional conflict of parents of critically ill infants with neurologic conditions. Our findings are consistent with previous work, identifying high rates of satisfaction with decision-making^{4-8, 12} and low rates of decision regret.^{9, 10, 14-16, 31} A significant proportion of parents experienced decisional conflict, particularly in the domains of uncertainty and values clarity. These results are also consistent with previous studies.^{10, 11, 14, 17-19, 26, 32} We highlight three ways in which these findings can be used to inform the development of decision-making interventions for parents of critically ill infants.

Many parents in this cohort experienced high levels of decisional conflict. Decision aids have been shown to reduce decisional conflict in a variety of disciplines.³²⁻⁴⁰ The majority of existing decision aids focus on low-stakes decisions in outpatient settings;^{32, 34-37, 39} few are designed for surrogate decision-makers. a decision aid has been developed for surrogate decision makers contemplating prolonged mechanical ventilation for their adult family members in the ICU.³³ Several decision aids have additionally been developed for pregnant women facing extreme premature delivery.^{38, 41-46} The majority of existing tools place high emphasis on helping patients or surrogates gain information.^{33, 35, 36, 40} Our data suggest that mothers were not distressed about lacking information; instead, support, uncertainty, and values clarity are areas in most need of intervention. Similarly, our data suggest that fathers were more distressed about uncertainty and values clarity than making effective decisions. Sometimes, parent decisional conflict related to values clarity occurs alongside parent-clinician conflict; in these situations, leveraging palliative care or clinical ethics consultation services can provide support to both parents and clinicians. Other times, parents may have difficulty elucidating their values. Tools have been developed to improve values clarity among patients with serious illness³⁷ and among parents considering newborn genomic sequencing.⁴⁷ The development and promotion of such tools for parents of critically ill infants is an important future step in improving decision outcomes.

The secondary goal of this study was to compare the decisional satisfaction, regret, and conflict between parent-parent dyads. We found that there was no significant difference on average between paired mothers and fathers for any decision outcome, which is consistent with previous studies.^{4, 14, 19, 27} That is, even though there were disagreements between mothers and fathers, there was no consistent pattern (e.g., mothers tending to have higher scores than fathers on a decision outcome). The finding that nearly half of couples had disagreement about decision regret and one-third had disagreement about decisional conflict was surprising, as was the lack of correlation between these scores. Our results suggest that the internal decision-making experiences of parents of the same infant frequently differ in important ways. Although these differences are not inherently problematic, our findings suggest that using a single parent's survey outcomes to measure the decision-making experience of the couple is insufficient. Decision aids aimed at improving decision outcomes in parents, therefore, may require distinct development, implementation, and measurement between parents.

Finally, even though we lacked the statistical power to assess which factors were associated with low satisfaction with decision-making, high decision regret, or high decisional conflict, it is notable that all demographic groups experienced low satisfaction with decision-making. Although some previous studies have found characteristics of the patient, surrogate, or clinical environment to be associated with differences in decisional satisfaction,^{4, 6} regret,^{14–16, 25, 31} or conflict,^{10, 13, 14, 17–19} many of the associations are not replicated in other studies and some studies find no significant associations at all.^{10, 27} Taken together, these data suggest that it is difficult to predict who is at highest risk for low satisfaction with decision-making, high decision regret, or high decisional conflict. Therefore, all parents should be screened for these outcomes regardless of infant or parent characteristics.

This study had several limitations. These results represent data from a single institution. We did not collect information about ICU type, which limits our ability to assess differences in parent experience based on individual ICU care practices. Although the enrolled parents were from diverse racial, educational, and socioeconomic backgrounds, there was little ethnic diversity, which was likely related to the exclusion of patients who did not speak English. Although the psychometric properties of each measure have been evaluated in similar contexts, future work should re-assess these properties in diverse pediatric settings. Because parents were not asked to fill out surveys immediately following infant death, information about the experience of parents whose infants died is limited. Similarly, even though our enrollment rate is not unusual in the context of recruiting parents whose children are critically ill, our study captures half of the population eligible for enrollment. Although precautions such as waiting until discharge to collect surveys were taken to reduce response bias, it is impossible to know how candid parents were when filling out surveys. Medical mistrust and fear that survey responses would influence the future care of their child may have had an effect on parental responses. Finally, as parents were surveyed at discharge from a hospitalization in which numerous decisions were made, the ability to make inferences about specific decisions is limited. As parents face a variety of concurrent, longitudinal decisions during their infant's hospitalization, our approach of collective recollection instead provides a holistic picture of the decision-making experience.

Although most parents of critically ill infants with neurologic conditions have high satisfaction with decision-making and low decision regret, a significant proportion experience high levels of decisional conflict. These results suggest that decision-making interventions for this context should target parents individually and address the domains of support, uncertainty, and values clarity.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations and acronyms:

ICU	Intensive Care Unit
FS-ICU	Family Satisfaction with the ICU
DRS	Decision Regret Scale
DCS	Decisional Conflict Scale

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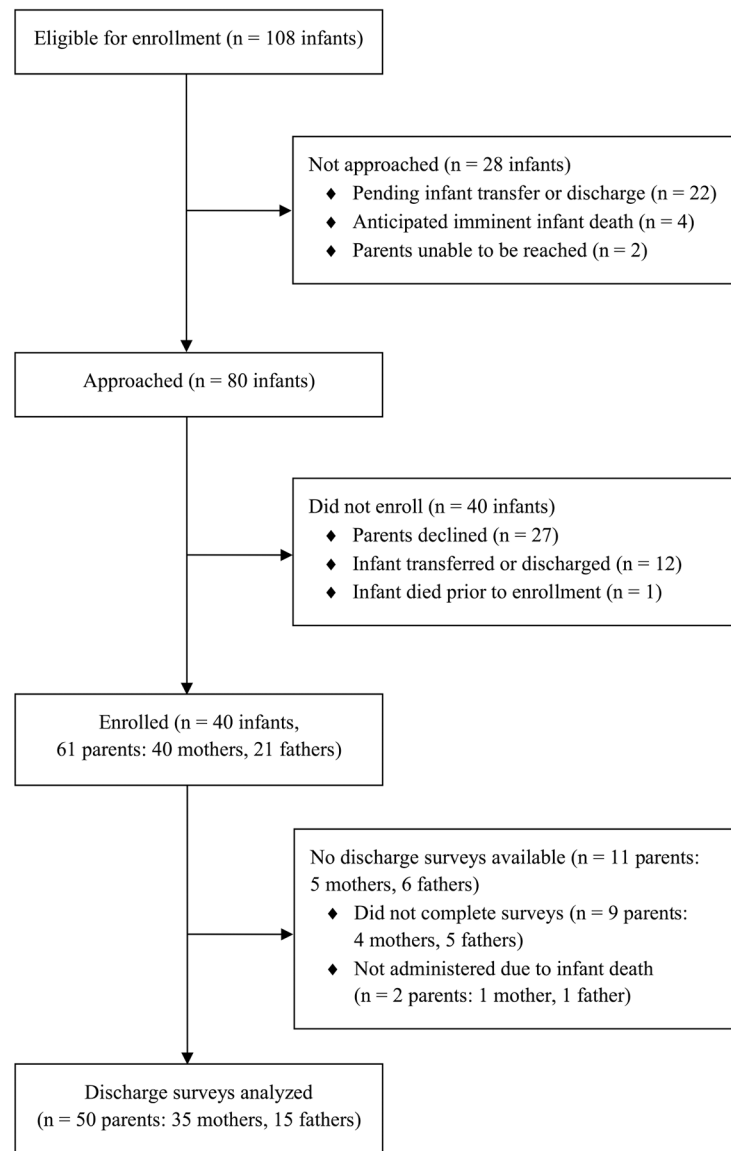


Figure 1.

The number of infants at each stage of the study. A total of 108 infants were eligible for enrollment during the study period. The parents of 80 infants were approached for enrollment and 61 parents of 40 infants were enrolled. The completed discharge surveys of 50 parents of 35 infants were analyzed.

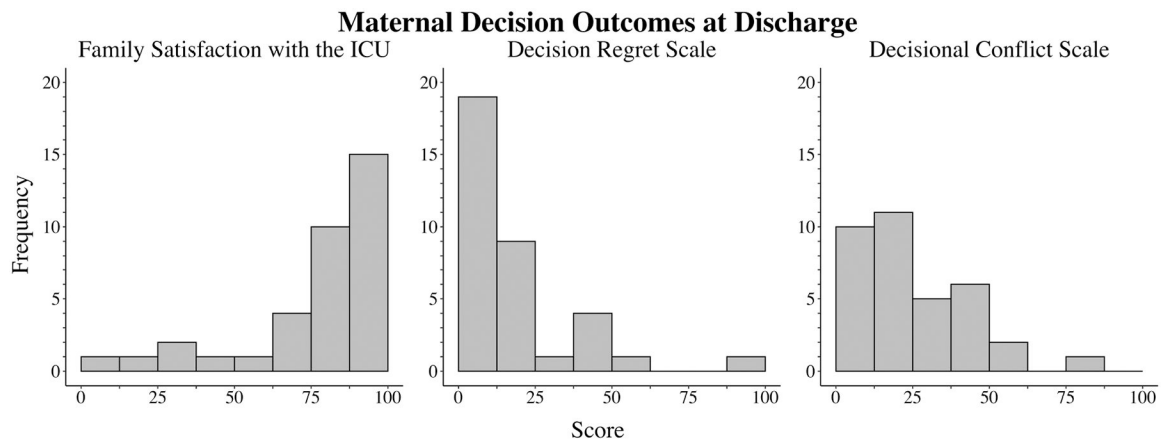


Figure 2. Distribution of maternal Family Satisfaction with the ICU decision-making subscale scores, Decision Regret Scale scores, and Decisional Conflict Scale scores at discharge. In these histograms, each bar represents the number of mothers whose decision-making scale scores fell within the corresponding 12.5-point interval. The majority of mothers report high satisfaction with decision-making (score ≥ 75), low decision regret (score ≤ 25), and low decisional conflict (score ≤ 25).

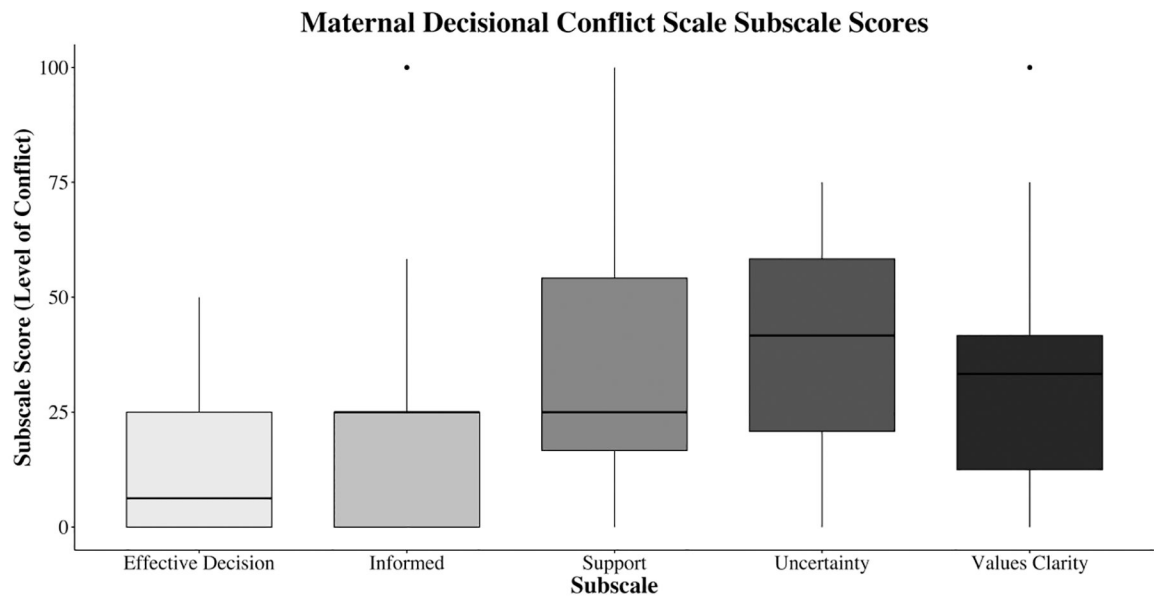


Figure 3.

Maternal Decisional Conflict Scale subscale scores at discharge. Boxes display the 25th (lower boundary), 50th (horizontal line), and 75th (upper boundary) percentile values, and vertical lines extend from the box to the most extreme value within one-and-a-half times the interquartile range below or above the 25th and 75th quartiles, respectively. Outliers are denoted with a point. Like the overall score, subscale scores are considered to reflect high conflict if they are greater than 25. Mothers experienced the least decisional conflict related to making effective decisions and being informed. Mothers experienced significantly higher levels of decisional conflict related to support, uncertainty, and values clarity (Bonferroni-corrected p -values < 0.05).

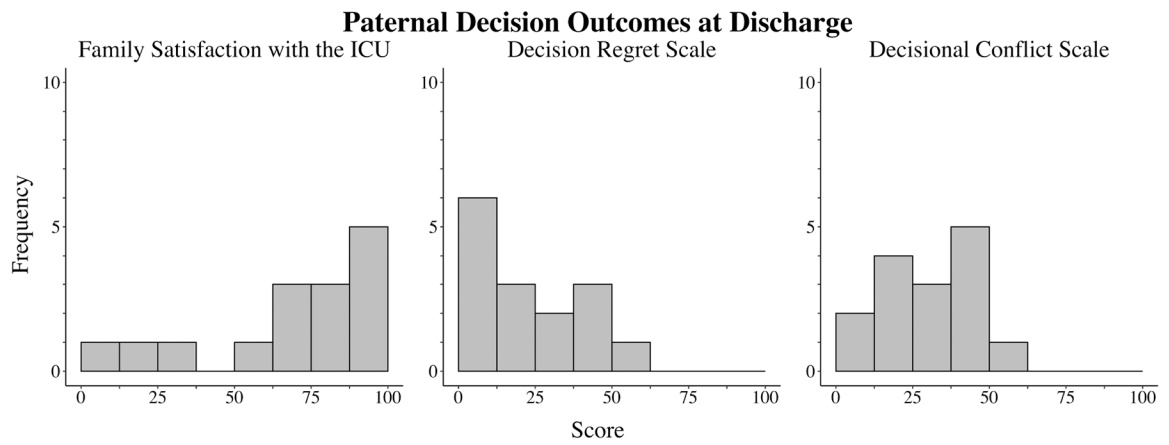


Figure 4. Distribution of paternal Family Satisfaction with the ICU decision-making subscale scores, Decision Regret Scale scores, and Decisional Conflict Scale scores at discharge. In these histograms, each bar represents the number of fathers whose decision-making scale scores fell within the corresponding 12.5-point interval. The majority of fathers report high satisfaction with decision-making (score ≥ 75) and low decision regret (score ≤ 25).

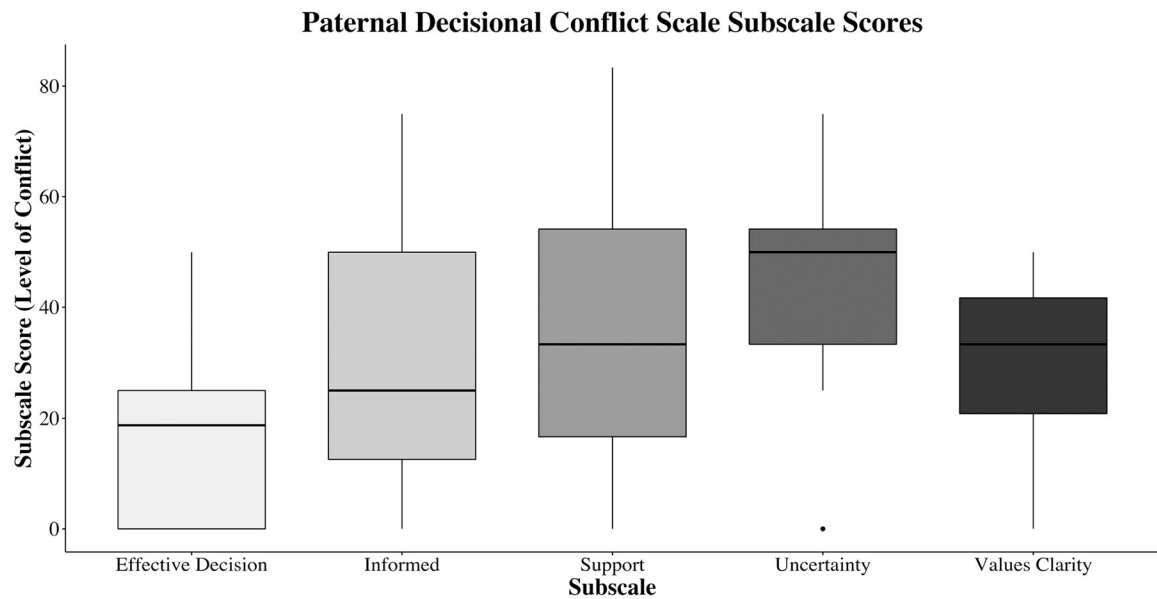


Figure 5. Paternal Decisional Conflict Scale subscale scores at discharge. Boxes display the 25th (lower boundary), 50th (horizontal line), and 75th (upper boundary) percentile values, and vertical lines extend from the box to the most extreme value within one-and-a-half times the interquartile range below or above the 25th and 75th quartiles, respectively. Outliers are denoted with a point. Like the overall score, subscale scores are considered to reflect high conflict if they are greater than 25. Fathers experienced less decisional conflict related to making effective decisions than they did related to uncertainty and values clarity (Bonferroni-corrected p -values < 0.05).

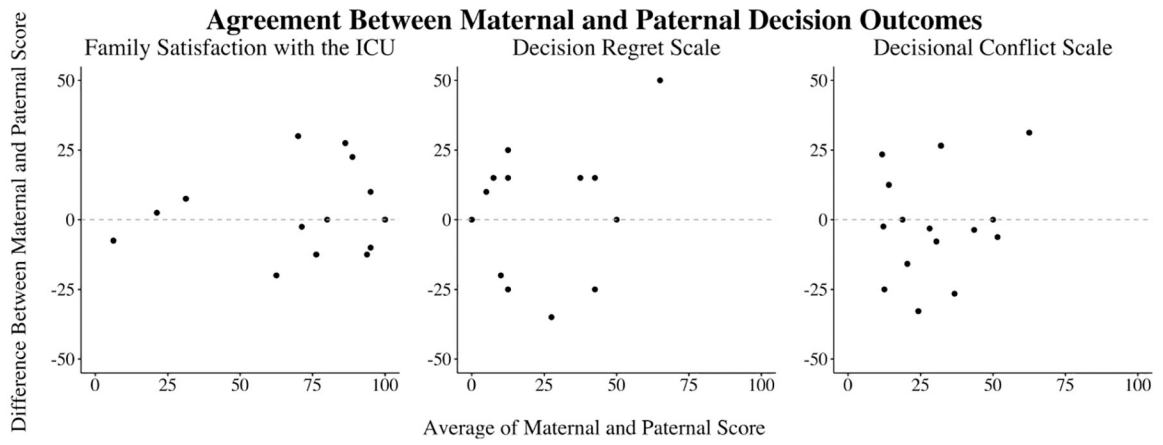


Figure 6. Bland-Altman plots for maternal and paternal Family Satisfaction with the ICU decision-making subscale, Decision Regret Scale, and Decisional Conflict Scale scores at discharge. Although there were substantial differences in score within individual couples for all three surveys, there was not a significant difference in the average scores between mothers and fathers as a whole. There was one set of couples with identical average scores and differences between scores for decisional satisfaction (average scores 100, difference between scores 0) and two sets of couples with identical average scores and differences between scores for decision regret (average scores 12.5, difference between scores +25 and -25).

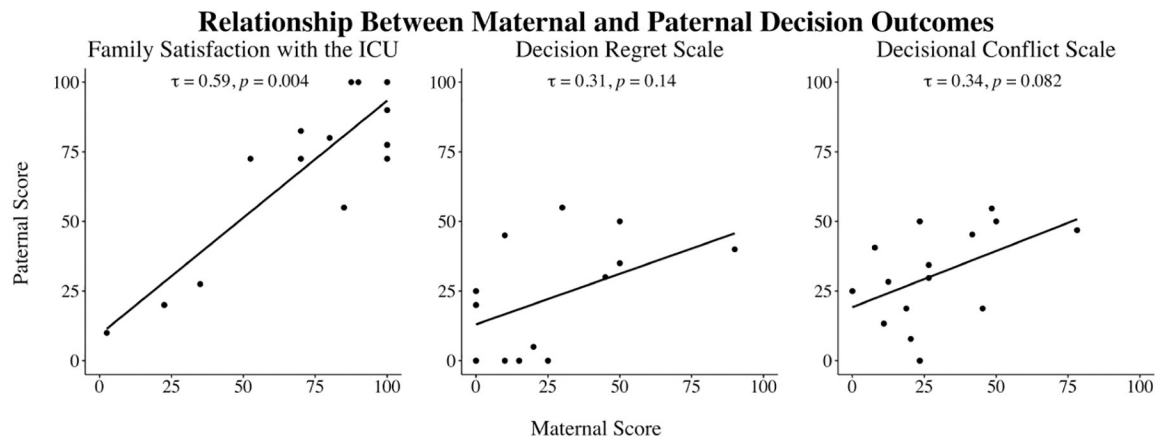


Figure 7. Maternal and paternal Family Satisfaction with the ICU decision-making subscale scores were moderately positively correlated at discharge. Maternal and paternal Decision Regret Scale and Decisional Conflict Scale scores were not statistically significantly correlated.

Table 1.**Maternal Demographics and Infant Characteristics**

	All enrolled (N = 40)	Completed surveys (N = 35)
Maternal Demographics		
Median age (range)	30 (19 – 43)	31 (19 – 43)
Father also enrolled (%)	21/40 (53)	19/35 (54)
Race (%)		
Black	21/40 (53)	19/35 (54)
White	16/40 (40)	14/35 (40)
Asian	3/40 (8)	2/35 (6)
Multiracial	2/40 (5)	2/35 (6)
Other	2/40 (5)	1/35 (3)
Hispanic ethnicity (%)	3/40 (8)	2/35 (6)
Education (%)		
Less than high school	2/40 (5)	1/35 (3)
High school/GED	7/40 (18)	6/35 (17)
Some college	13/40 (33)	10/35 (29)
Associate's/technical	3/40 (8)	3/35 (9)
Bachelor's degree	6/40 (15)	6/35 (17)
Graduate/professional	9/40 (23)	9/35 (26)
Family income (%)		
< \$25,000	13/39 (33)	10/34 (29)
\$25,000 – \$34,999	9/39 (23)	8/34 (24)
\$35,000 – \$49,999	3/39 (8)	2/34 (6)
\$50,000 – \$74,999	4/39 (10)	4/34 (12)
\$75,000 – \$99,999	2/39 (5)	2/34 (6)
\$100,000 – \$149,999	6/39 (15)	6/34 (18)
\$150,000	2/39 (5)	2/34 (6)
Spirituality (%)		
Not at all	2/40 (5)	2/35 (6)
Slightly	5/40 (13)	5/35 (14)
Somewhat	14/40 (35)	11/35 (31)
Strongly	19/40 (48)	17/35 (49)
Infant Characteristics		
Female sex (%)	22/40 (55)	20/35 (57)
Born prematurely (%)	19/40 (48)	16/35 (46)
Median gestational age (range)	36w6d (22w3d – 40w4d)	37w0d (22w3d – 40w4d)
Median length of stay (range)	76 days(8 – 344)	76 days (8 – 344)
Median SNAPPE-II score, (range)	22 (0 – 102)	23 (0 – 102)
Diagnosis (%)		

	All enrolled (N = 40)	Completed surveys (N = 35)
Genetic condition	13/40 (33)	9/35 (26)
Brain malformation	11/40 (28)	9/35 (26)
PVL	5/40 (13)	5/35 (14)
Stroke	7/40 (18)	5/35 (14)
IVH	10/40 (25)	9/35 (26)
Grade 3	4/10 (40)	4/9 (44)
Grade 4	5/10 (50)	5/9 (56)
HIE	7/40 (18)	6/35 (17)
Seizures	13/40 (33)	9/35 (26)
Interventions (%)		
Therapeutic hypothermia	6/40 (15)	6/35 (17)
Mechanical ventilation	31/40 (78)	28/35 (80)
Feeding tube placement	18/40 (45)	16/35 (46)
Tracheostomy	7/40 (18)	6/35 (17)
CSF diversion	9/40 (23)	8/35 (23)
Palliative care consult	17/40 (43)	14/35 (40)
Pastoral care consult	20/40 (50)	17/35 (49)
Chest compressions	10/40 (25)	8/35 (23)
DNAR Order	6/40 (15)	5/35 (14)
Death during hospitalization (%) *	2/40 (5)	1/35 (3)

* Surveys were not administered immediately following infant death due to concerns about parental distress. In one case, there was no attempt to collect discharge surveys due to infant death. In another case, discharge surveys were collected at the time of planned discharge, and the infant died in between survey collection and leaving the hospital.

Table 2.

Paternal Demographics

	All enrolled (N = 21)	Completed surveys (N = 15)
Median age (range)	32 (20 – 46)	33 (20 – 46)
Mother also enrolled (%)	21/21 (100)	15/15 (100)
Race (%)		
Black	8/21 (38)	6/15 (40)
White	9/21 (43)	6/15 (40)
Asian	1/21 (5)	1/15 (7)
Multiracial	2/21 (10)	1/15 (7)
Other	1/21 (5)	1/15 (7)
Hispanic ethnicity (%)	2/21 (10)	2/15 (13)
Education (%)		
Less than high school	1/21 (5)	1/15 (7)
High school/GED	9/21 (43)	6/15 (40)
Some college	1/21 (5)	0/15 (0)
Associate's/technical	2/21 (10)	1/15 (7)
Bachelor's degree	4/21 (19)	4/15 (27)
Graduate/professional	4/21 (19)	3/15 (20)
Family income (%)		
< \$25,000	5/21 (24)	4/15 (27)
\$25,000 – \$34,999	2/21 (10)	1/15 (7)
\$35,000 – \$49,999	3/21 (14)	1/15 (7)
\$50,000 – \$74,999	2/21 (10)	1/15 (7)
\$75,000 – \$99,999	3/21 (14)	3/15 (20)
\$100,000 – \$149,999	2/21 (10)	1/15 (7)
\$150,000	4/21 (19)	4/15 (27)
Spirituality (%)		
Not at all	3/21 (14)	3/15 (20)
Slightly	2/21 (10)	2/15 (13)
Somewhat	5/21 (24)	2/15 (13)
Strongly	11/21 (52)	8/15 (53)