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# Parental Perspective on Shared Decision-Making of Extremely Premature Infants

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**Article**

**Keywords:**

**Posted Date:** September 20th, 2026

**DOI:** https://doi.org/10.21203/rs.3.rs-10843523/v1

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**Additional Declarations:** There is **NO** conflict of interest to disclose.

## Abstract

# Objective

To evaluate decisional conflict and perceptions of shared-decision making among caregivers of extremely premature infants during the first week of life in the NICU.

# Study Design:

This multicenter, cross-sectional study enrolled caregivers of infants born at $22^0$-$27^6$ weeks' gestation across three NICUs (October 2024-October 2025). Surveys were administered during the infant's second or third week of life. The primary outcome was decisional conflict (SURE test, score < 4). Generalized linear mixed models compared outcomes between periviable versus later extremely premature infants.

# Results

Sixty-five families completed 119 completed surveys; 36.9% periviable. Overall, 16.9% of caregivers and 27.7% of families screened positive for decisional conflict, not differing from non-NICU estimates (p = 0.48; p = 0.16) or by gestational subgroup (difference 0.8%; p = 0.9). Engagement was high: 79.8% active participants, 79.0% shared responsibility, and 91.6% received sufficient information.

# Conclusion

Most caregivers reported low decisional conflict and high shared decision-making engagement, without gestational-age differences, suggesting NICU shared decision-making effectively supports caregivers.

## Introduction

For many caregivers, NICU admission is unexpected, particularly when it occurs early in the pregnancy (< 28 weeks' gestation).(1) Caregivers of NICU infants are faced with making decisions within an unfamiliar, frightening, and stressful environment. While this may be true for many NICU caregivers, caregivers of infants born extremely prematurely (< 28 weeks' of gestation) may face even more critical decisions given the high risk of morbidity and mortality within this population.(2, 3) In fact, in scenarios in which an infant is born < 25 weeks' gestation, caregivers are asked to decide whether or not to pursue resuscitation efforts.(4) These decisions are often made in the setting of significant prognostic uncertainty and ethical complexity, making shared decision-making particularly important in this population.

Neonatologists are tasked with providing medical insight and explaining complex medical concepts in a way that caregivers, who serve as proxy decision-makers for their infants, can understand. Establishing

open and effective communication between the medical team and family is critical(3), as caregivers are often asked to make decisions in situations in which there is no clear “right” answer, but rather a “best” answer tailored to the family’s beliefs, values, and the infant’s clinical condition.

Caregivers have expressed a preference to have an active role in their child’s treatment course.(5, 6) Shared decision-making involves collaboration between providers and caregivers to incorporate caregiver values and preferences alongside medical recommendations in order to determine the treatment course that best serves the patient’s interests.(5, 7, 8) Shared decision-making is recommended in NICU care by the American Academy of Pediatrics(5, 9) and has been associated with decreased caregiver regret regarding medical decisions(6).

Many studies have examined the role of shared decision-making within the NICU, including its role during prenatal counseling(1, 10–13), the importance of communication style(8, 10, 14, 15), caregiver preference for the extent of engagement depending on the type of decision(6, 10, 16), and barriers to implementing shared decision-making(17, 18). However, few studies have evaluated caregiver perceptions of shared decision-making during the earliest phase of NICU hospitalization for extremely premature infants, particularly using real-time assessment methods. This study is innovative because it examines caregiver perception of shared decision-making during the infant’s first 7 days of life (with the day of birth defined as day of life (DOL) 0) assessed in near real-time during the second or third week of the infant’s life. This timing allows caregivers some distance from the initial emotional shock, while remaining close enough for more immediate recall and potentially more accurate reporting. This first week of life requires frequent, clear communication to establish rapport amongst families and providers to have effective shared decision-making throughout the infant’s NICU course. To our knowledge, there is no established literature examining the real-time perception of caregivers when it comes to shared decision-making of extremely preterm infants during their first week of life. The SURE test is a 4-question survey derived from the Decisional Conflict Scale that has been validated to assess caregiver decisional conflict when making medical decisions for their children(19–21). It has been used in various settings, including primary care and prenatal consultations; however, its use within the NICU caregiver population has not been well studied.

The objective of this study was to evaluate caregiver perceptions of shared decision-making during the first week of life for extremely premature infants admitted to the NICU using the SURE test. We hypothesized that caregiver perceptions of shared decision-making would vary based on gestational age of the infant, elicitation of beliefs/values system, and overall there would be higher rates of decisional conflict within the NICU setting compared to other areas of pediatric care.

## Materials and Methods

# Participants

From October 2024 to October 2025, caregivers - defined as one of two primary caregivers of the infant (including birthing parent, non-birthing parent, foster parent, or adoptive parent) - were screened from two Level III NICUs and one Level IV NICU. During this period, 105 infants were born and admitted to these NICUs based on gestational age at birth of $22^0$ – $27^6$ weeks. Inclusion criteria for participation in this study was as follows: (1) infant between DOL 8–21 at time of enrollment; (2) caregivers were English speaking and literate in English; and (3) caregiver ≥ 18 years of age. Of these 105 infants, 15 families (14%) were excluded from participation due to: neonatal death prior to DOL 7 (n = 3), non-English speaking (n = 6), caregiver < 18 years of age) (n = 3), and inability to obtain consent due to family extremis (n = 3) (e.g., parental hospitalization). Of those remaining eligible (n = 90), 25 families (28%) were unable to be contacted within study timeframe (n = 15) or declined participation (n-10). The final participating sample included parents of 65 infants (62%), yielding 119 completed caregiver surveys (Fig. 1).

## Procedures

# Enrollment

Caregivers of infants born at $22^0$-$27^6$ completed weeks' gestation were screened daily at two Level III delivery NICUs and one Level IV referral center (non-delivery) NICU. Eligible caregivers were approached by members of the research team, including members from the Ohio Perinatal Research Network (OPRN) team. Participants were approached during the infant's second or third week of life (DOL 8–21) either in-person or via telephone for enrollment. If a caregiver agreed to enroll, they received a $20 gift card in exchange for completion of the survey.

A standardized waiver of consent was approved through the Institutional Review Board for the purpose of this study. Participants were provided with a research information form outlining the study purpose, the voluntary nature of participation, and contact information for the research team.

## Survey and SURE Test

The survey used in this study was developed by the research team to assess caregiver perceptions of SDM. The survey was comprised of the 4 SURE questions embedded within it, as well as multiple choice questions, Likert-scale questions, and optional open-ended questions for a total of 40 (or 41) questions.

The SURE test is a 4-item questionnaire screening tool that was formed from the full 16-item Decisional Conflict Scale. The acronym is derived from the 4 questions which address themes such as "**S**ure of myself," "**U**nderstand information," "**R**isk-benefit ratio," and "**E**ncouragement." Each item is scored as a "yes" or "no," where a yes scores 1 point and a no scores 0 points. A score of 4 means no decisional conflict detected, whereas a score of ≤ 3 is a positive screen for clinically significant decisional conflict. (21)

## Data Collection/Management

All data were collected and managed using REDCap (Research Electronic Data Capture) tools.(22, 23) Upon enrollment, participants were assigned a unique study identifier automatically generated within REDCap. Caregivers had the option to complete the survey electronically or on paper. Electronic surveys were completed via a secure link on a personal device or using a study-provided tablet. Paper surveys were labeled with the participant's unique study identifier and entered into REDCap by study staff, with double data entry performed for all paper surveys to ensure accuracy.

Infant demographic and clinical data were abstracted from the electronic medical record (EMR) and manually entered into REDCap (including gestational age at birth, birthweight, biological sex, head ultrasound results, and the type of respiratory support). All study personnel completed required institutional training, including Collaborative Institutional Training Initiative (CITI) certification, and were granted access to both the REDCap database and the EMR. All data analysis were conducted in R version 4.5.2 (R Core Team).(24)

# Statistical Analysis

Demographic and baseline characteristics were summarized with count (percent) for categorical variables and mean (standard deviation) or median (25th and 75th percentiles) for continuous variables.

The primary outcome was caregiver decisional conflict as measured by the SURE score. To assess SURE scores of caregivers of extremely preterm infants in the NICU and determine the prevalence of clinically significant decisional conflict, the proportion of caregivers with decisional conflict was compared with published population estimates using a one-sample test for proportions with the normal approximation. The SURE survey consists of four "yes" or "no" questions. A "yes" is scored as 1, whereas a "no" is scored as 0. Scores < 4 were considered a positive indicator for decisional conflict. Assuming a decisional conflict prevalence of 20% in the population, as assessed from prior studies(19, 25), we estimated that 80 families would provide 80% power to detect an *a priori* clinically meaningful difference of 11.4% at a significance level of 0.05.

To compare SURE scores for caregivers of infants born at $22^0$-$24^6$ weeks' gestation and those born at $25^0$-$27^6$ weeks' gestation, generalized linear mixed models with a logit link and random effect for the unique family were used. Odds ratios and differences in proportions, along with 95% confidence intervals, were estimated from this regression model. We estimated 30 families with infants born $22^0$-$24^6$ weeks' gestation and 50 families with infants born $25^0$-$27^6$ weeks' gestation would provide 80% power to detect a 22.5% difference in SURE scores at a significance level of 0.05.

## Results

# Participant Characteristics

# Infant Characteristics

Infant characteristics are detailed in Table 1. In total, 105 infants were screened, and 65 were enrolled in the study. Periviable infants ($22^0$-$24^6$ weeks' gestation) accounted for 36.9% (n = 24) of the study population. The mean birth weight of infants was 797g, with 52.3% (n = 34) of the sample being female infants. The majority of infants were White (53.8%, n = 35), with the next most common racial groups being Black or African American (15.4%, n = 10) and multiracial (15.4%, n = 10), as identified by caregiver report. In terms of severity of medical condition, 63.1% (n = 41) of infants had no identifiable intraventricular hemorrhage on head ultrasound, and only 10.8% (n = 7) had a severe hemorrhage (considered Grade III/IV intraventricular hemorrhage). Additionally, 52.3% (n = 34) of infants were mechanically ventilated. These numbers are consistent with those infants who were eligible but not enrolled in the study **(see Supplementary Table S1).**

Table 1
Infant Characteristics by Gestational Age Group

| Characteristic | Overall (N = 65) | 22–24 weeks (N = 24) | 25–27 weeks (N = 41) |
|---|---|---|---|
| **Birthweight (g)** | | | |
| Mean (SD) | 797 (189) | 642 (127) | 888 (158) |
| Median (Q1, Q3) | 790 (660, 910) | 608 (560, 745) | 890 (790, 1,000) |
| Min, Max | 430, 1,210 | 430, 900 | 620, 1,210 |
| **Infant Sex** | | | |
| Female | 52.3% (34/65) | 50.0% (12/24) | 53.7% (22/41) |
| Male | 47.7% (31/65) | 50.0% (12/24) | 46.3% (19/41) |
| **Infant Race** | | | |
| White or Caucasian | 53.8% (35/65) | 50.0% (12/24) | 56.1% (23/41) |
| Black or African American | 15.4% (10/65) | 29.2% (7/24) | 7.3% (3/41) |
| Biracial or Multiracial | 15.4% (10/65) | 8.3% (2/24) | 19.5% (8/41) |
| Other* | 15.4% (10/65) | 12.5% (3/24) | 17.1% (7/41) |
| **Head Ultrasound Results** | | | |
| No bleed (No IVH) | 63.1% (41/65) | — | — |
| Small bleed (Grade I-II IVH) | 26.2% (17/65) | — | — |
| Large bleed (Grade III + IVH) | 10.8% (7/65) | — | — |
| **Respiratory Support** | | | |
| Mechanical Ventilation | 52.3% (34/65) | — | — |
| Non-invasive Support† | 47.7% (31/65) | — | — |

*Other includes: African, Asian, Latino/Hispanic Black, Latino/Hispanic Unspecified, and Latino/Hispanic White.

†Non-invasive support includes CPAP, NIPPV, NAVA, and NIV-NAVA.

Abbreviation: IVH, intraventricular hemorrhage.

# Caregiver Characteristics

Caregiver characteristics are detailed in Table 2. Overall of the 119 completed surveys, 54.6% (n = 65) of caregivers identified as the birthing parent, and the most frequently represented age group was 31–40 years old. Most participants identified as White/Caucasian (62.2%, n = 74), followed by Black/African American (19.3%, n = 23). In terms of educational attainment, 34.5% (n = 41) reported a high school diploma or equivalent as their highest level of education, 10.9% (n = 13) had not completed a high school diploma or equivalent, and 22.7% (n = 27) held a bachelor's degree or higher.

Table 2
Caregiver Characteristics Stratified by Gestational Age Group

| Characteristic | Overall (N = 119) | 22–24 weeks (N = 42) | 25–27 weeks (N = 77) |
|---|---|---|---|
| **Caregiver Relationship to Child** | | | |
| Birthing parent | 54.6% (65/119) | 57.1% (24/42) | 53.2% (41/77) |
| Non-birthing parent | 45.4% (54/119) | 42.9% (18/42) | 46.8% (36/77) |
| **Caregiver Age** | | | |
| < 20 years | 4.2% (5/119) | 7.1% (3/42) | 2.6% (2/77) |
| 20–30 years | 39.5% (47/119) | 42.9% (18/42) | 37.7% (29/77) |
| 31–40 years | 43.7% (52/119) | 35.7% (15/42) | 48.1% (37/77) |
| 41–50 years | 12.6% (15/119) | 14.3% (6/42) | 11.7% (9/77) |
| **Caregiver Education** | | | |
| No high school diploma/GED | 10.9% (13/119) | 14.3% (6/42) | 9.1% (7/77) |
| High school diploma/GED | 34.5% (41/119) | 40.5% (17/42) | 31.2% (24/77) |
| Some college but no college degree | 31.9% (38/119) | 35.7% (15/42) | 29.9% (23/77) |
| Bachelor's degree or above | 22.7% (27/119) | 9.5% (4/42) | 29.9% (23/77) |
| **Caregiver Race** | | | |
| White or Caucasian | 62.2% (74/119) | 54.8% (23/42) | 66.2% (51/77) |
| Black or African American | 19.3% (23/119) | 26.2% (11/42) | 15.6% (12/77) |
| Biracial or Multiracial | 4.2% (5/119) | 2.4% (1/42) | 5.2% (4/77) |
| Other* | 14.3% (17/119) | 16.7% (7/42) | 13.0% (10/77) |

*Other includes: African, Asian, Latino/Hispanic Black, Latino/Hispanic Unspecified, and Latino/Hispanic White.

# Decisional Conflict

Among the 65 enrolled infants, 18 families had at least one caregiver with a SURE score indicating potential decisional conflict (Table 3). The estimated prevalence of decisional conflict with at least one affected caregiver was 27.7% (95% CI: 17.7, 40.4). This prevalence was not significantly different from published estimates in non-NICU populations (p = 0.16). Across all caregivers, the prevalence of decisional conflict was 16.9% (95% CI: 10.9, 25.2). Similarly, this prevalence did not differ significantly from published estimates in non-NICU populations (p = 0.48). The difference in decisional conflict among caregivers of infants born at $22^0$-$24^6$ weeks' gestation compared with those born at $25^0$-$27^6$ weeks' gestation was − 3.4% (95% CI: -17.9%, 11.1%, p = 0.9) [Odds ratio 0.8, 95% CI (0.25, 2.34)].

Table 3
SURE Responses and Decisional Conflict Stratified by Gestational Age Group

| Characteristic | Overall (N = 119) | 22–24 weeks (N = 42) | 25–27 weeks (N = 77) |
|---|---|---|---|
| **SURE Item Responses** | | | |
| Sure about the best choice for your child | 95.0% (113/119) | 95.2% (40/42) | 94.8% (73/77) |
| Know the benefits and risks of each option | 89.9% (107/119) | 85.7% (36/42) | 92.2% (71/77) |
| Clear about which benefits and risks matter most | 89.9% (107/119) | 90.5% (38/42) | 89.6% (69/77) |
| Enough support and advice to make a choice | 95.0% (113/119) | 95.2% (40/42) | 94.8% (73/77) |
| **Total SURE Score** | | | |
| 1 | 2.5% (3/119) | 2.4% (1/42) | 2.6% (2/77) |
| 2 | 8.4% (10/119) | 9.5% (4/42) | 7.8% (6/77) |
| 3 | 5.9% (7/119) | 7.1% (3/42) | 5.2% (4/77) |
| 4 | 83.2% (99/119) | 81.0% (34/42) | 84.4% (65/77) |
| **Decisional Conflict** | | | |
| No decisional conflict | 83.2% (99/119) | 81.0% (34/42) | 84.4% (65/77) |
| Possible decisional conflict | 16.8% (20/119) | 19.0% (8/42) | 15.6% (12/77) |

Possible decisional conflict was defined as a SURE score < 4. The prevalence of possible decisional conflict did not differ significantly between caregivers of infants born at $22^0$-$24^6$ weeks' and those born at $25^0$-$27^6$ weeks' gestation (difference − 3.4%, 95% CI − 17.9% to 11.1%; p = 0.60; odds ratio 0.8, 95% CI 0.6–1.9).

Abbreviation: SURE = Sure of myself, Understand information, Risk-benefit ratio, Encouragement.

# Post-Hoc Analyses

Given the absence of a gestational age effect, we conducted several post-hoc analyses to explore whether other factors might be associated with decisional conflict. Three variables were examined including: birthing versus non-birthing caregiver status, caregiver race, and markers of infant illness severity such as respiratory status (specifically mechanical ventilation versus non-invasive support), and head ultrasound results.

The difference in decisional conflict amongst the birthing caregiver group compared to the non-birthing caregiver group was − 12.9% (95% CI: -25.6%, -0.2%, p = 0.05) [Odds ratio 0.3, 95% CI (0.09, 1.0)]. This is representative of decisional conflict being present in 23% of birthing caregivers compared to 9% in the non-birth caregiver population.

The difference in SURE scores between White caregivers (n = 45) and Black or African American caregivers (n = 23), was − 4.9% (95% CI -18.3%, 8.5%, p = 0.5) [Odds ratio 0.7, 95% CI (0.23, 2.0)]. Infant illness severity was examined by two proxies including level respiratory support and head ultrasound results. The difference in decisional conflict amongst caregivers of mechanically ventilated infants (n = 61) compared to those on non-invasive respiratory support (n = 58) was 4.3% (95% CI -9.2%, 17.8%, p = 0.5) [Odds ratio 1.4, 95% CI (0.47, 4.28)]. Similarly, when examining difference in decisional conflict amongst caregivers of infants with “large bleeds” (defined as grade III or higher intraventricular hemorrhage (IVH)) to those of infants with “small bleed or no bleed” (defined as grade II IVH or less), the difference was − 2.0% (CI -24.5%, 20.5%, p = 0.9) [Odds ratio 0.8, 95% CI (0.13, 5.2)].

# Caregiver Perceptions of Inclusion in Shared Decision-Making

Overall, caregivers described high levels of engagement in shared decision-making, with 79.8% identifying as active participants, 79.0% feeling they shared responsibility with the medical team when making decisions, and 91.6% reported receiving sufficient information to make informed decisions. Most caregivers reported being asked about their religions/personal belief systems during the NICU course (61.3%); however, nearly half (52.1%) indicated that these beliefs did not influence the care they felt was appropriate for their infant. Additionally, 80.7% of caregivers expressed satisfaction with the bond they were able to establish with their infant during the first week of life.

## Discussion

This study examined the near real-time perspective of caregivers on shared decision-making during the first week of life for extremely premature infants, a period that has not been previously studied using validated decisional conflict screening tools. The findings suggest that most caregivers of extremely preterm infants do not experience clinically significant decisional conflict as measured by the SURE test, and that caregivers report high levels of engagement in shared decision-making during this critical early period.

# Decisional Conflict in the NICU Population

The overall rate of decisional conflict among caregivers in this study (16.9% at the individual level; 27.7% at the family level) was not statistically different from published estimates in non-NICU populations. This finding is notable given the high-acuity, emotionally charged nature of the NICU and the gravity of decisions facing this population. In primary care settings, the prevalence of clinically significant decisional conflict using the Decisional Conflict Scale has been reported to range from 10.3% to 31.3%, depending on the type of decision and patient characteristics.(25) In a pediatric tertiary care setting using the SURE test, Boland et al. found that 23% of parents screened positive for decisional conflict after ambulatory or emergency department visits.(19) The comparable rates observed in the present study may reflect effective communication and shared decision-making practices at the participating NICU centers, or alternatively, may reflect limitations of the SURE test in capturing the full spectrum of decisional conflict in this population, as it is not yet a validated tool within the NICU.

It is important to contextualize these findings alongside studies using the full Decisional Conflict Scale in ICU populations. Barlet et al. reported that 40% of mothers of critically ill infants with neurologic conditions experienced high decisional conflict, even when most reported high satisfaction with decision-making and low decisional regret.(26) The discordance between decisional conflict and satisfaction underscores the idea that conflict may be an inherent feature of high-stakes surrogate decision-making rather than a marker of inadequate communication.

# Absence of Gestational Age-Based Differences

A key finding was the absence of a significant difference in reported decisional conflict between caregivers of periviable infants ($22^0$-$24^6$ weeks' gestation) and those of infants born between $25^0$-$27^6$ weeks' gestation (difference of 0.8%, $p = 0.9$). This was unexpected, as periviable infants face substantially higher morbidity and mortality(2, 3), and caregivers of these infants are often confronted with decisions regarding resuscitation(4, 27). One possible explanation is that the shared decision-making process during prenatal counseling and the early postnatal period may adequately address caregiver concerns regardless of gestational age. Prior literature emphasizes that effective shared decision-making in the NICU requires eliciting parental values and using those to guide decision-making rather than solely providing prognostic data.(28) In this study, 64.3% of caregivers of periviable infants and 59.7% of caregivers of non-periviable infants reported that they were asked about their values or belief systems during the first week of their infant's life. However, only 21.4% and 27.2% from periviable and non-periviable caregivers, respectively, reported that these beliefs influenced the care they felt was appropriate for their infant. With the majority of caregivers being approached regarding their values, it may have attenuated gestational age-related differences in decisional conflict. Values elicitation may be one of the key mechanisms by which shared decision-making reduces conflict - by enabling early alignment between the medical team and the family. Additionally, the study may have been underpowered to detect a difference between these subgroups, as the enrollment included fewer periviable infants (36.9% of the cohort) than originally targeted.

# Examining Post-Hoc Analyses

Given the absence of gestational age-based differences, it stands to reason that the quality of the shared decision-making process may matter more than the severity of the clinical situation. This is further supported by no evidence of differences in post-hoc analyses of decisional conflict amongst caregivers of infants considered more critically ill (mechanical ventilation, large IVH), however the differences were all close to 1 and confidence intervals were wide. Effective SDM could mitigate factors such as gestational age and severity illness of infant. Additionally, during the first week of life, families may be processing the overall experience of having an infant in the NICU rather than differentiating between specific clinical markers. Whether the baby is requiring invasive or non-invasive support may matter more to clinicians in the moment than to families.

The post-hoc analysis finding of a statistically significant difference in presence of decisional conflict amongst birthing caregivers compared to non-birthing caregivers, (24.1% vs. 9.3%, $p = 0.05$) needs to be interpreted cautiously, however, the finding is hypothesis forming. The birthing parent is both patient and surrogate decision-maker simultaneously - recovering from delivery while being asked to process complex prognostic information. That dual role may limit their capacity to fully engage in SDM during the first week. This suggests that medical teams should assess readiness before launching into complex conversations to allow more time for processing, consider earlier psychology or social work involvement, and make sure non-birthing caregivers are included as true partners in decision-making and not just observers. This is an area that demands larger, adequately powered studies.

# Caregiver Engagement in Shared Decision-Making

The high rates of perceived engagement in shared-decision making reported in this study, 79.8% identifying as active participants, 79.0% feeling shared responsibility, and 91.6% reporting sufficient information, are encouraging and align with the growing emphasis on family-centered care in neonatology. These findings are consistent with prior work demonstrating that most parents prefer an active or shared role in NICU decision-making. Soltys et al. found that 52.3% of NICU parents preferred an active role and 34.3% preferred a shared role, and that shared decision-making was associated with less decisional regret.(6) Turley et al. similarly reported that 89% of parents in “NICU grey-zone decisions” wanted to be very involved in shared-decision making, though only 63% felt included.(29) The higher rates of perceived inclusion in the present study (80%) may reflect differences in study populations, timing of assessment, or institutional culture, and warrant further investigation.

However, the finding that over half of caregivers (52.1%) indicated that their personal values or belief systems did not influence the care they felt was appropriate for their infant is notable. This contrasts with literature suggesting that spirituality, hope, and religious beliefs are highly influential in parental decision-making for critically ill infants.(28, 30) In this study, 61.3% of caregivers reported being asked about their personal views/belief systems, suggesting that this aspect of shared decision-making was addressed in the majority of cases, potentially allowing alignment of care plans with family values early in the NICU course. It is also possible that caregivers did not perceive a conflict between their beliefs and the recommended medical course.

# Timing of Assessment and Methodological Considerations

A key feature of this study is the near real-time assessment of decisional conflict and shared decision-making perception during DOL 8–21. Most prior studies have assessed these constructs either prenatally, at hospital discharge, or retrospectively months to years after NICU discharge.(6, 26, 30) The timing chosen for this study represents a deliberate balance between allowing sufficient time for the acute emotional impact of delivery to subside while still capturing perceptions close enough to the events for recall accuracy. This approach addresses a recognized limitation in the literature, as the Decisional Conflict Scale anniversary review noted that most studies fail to report when decisional conflict was measured during the decision-making process, making scores difficult to interpret.(31) The near real-time assessment may also capture a more dynamic picture of the decision-making experience, consistent with calls for models of shared decision-making that acknowledge evolving prognostic clarity and emotional complexity over time.(32)

# The SURE Test in the NICU

This study represents the first application of the SURE test in the NICU caregiver population. The SURE test was originally validated in primary care for detecting clinically significant decisional conflict, demonstrating high sensitivity (94.1%) and specificity (89.8%) against the full Decisional Conflict Scale.(21) It has since been validated for use with parents making surrogate health decisions for their children, though with lower sensitivity (32%).(20) The brevity of the SURE test (4 items) makes it practical for use in the NICU, where caregivers face significant emotional and cognitive burden. However, lower sensitivity in parental populations suggests that the SURE test may underestimate the true prevalence of decisional conflict in this study. Furthermore, while the SURE test is not validated in the NICU, the present findings suggest feasibility for future validation studies in this population. Future studies should consider pairing the SURE test with the full Decisional Conflict Scale to determine validity in this population. Qualitative interviews may also be considered in addition to decisional conflict screening to provide a more comprehensive assessment of caregiver decisional conflict in the NICU.

# Limitations

This study has several limitations. Restriction of enrollment to English-literate caregivers excludes a population that may experience high levels of decisional conflict and lower engagement in shared decision-making when care is delivered in a non-primary language. Language barriers are known to significantly impact communication quality, trust, and parental participation in NICU decision-making for families with limited English proficiency.(33) Additionally, participants of this study predominantly identified as White (62%), which limits external generalizability of the findings. Future studies should prioritize multilingual enrollment and culturally adapted assessment tools to capture the experiences of these underrepresented families.

The inclusion of up to two caregivers per infant introduces potential bias from within-family correlation, as paired caregivers share the same infant, clinical context, and medical team. This was addressed

statistically using generalized linear mixed models for gestational age comparisons and a family-level sensitivity analysis for decisional conflict prevalence. Notably, however, prior work has shown that caregivers within the same family may experience different levels of decisional conflict, underscoring the importance of assessing each caregiver individually.(26)

The sample included fewer periviable infants than originally targeted, reflecting the lower incidence of births at these gestational ages. This limited the statistical power to detect differences between gestational age subgroups. Finally, participants received compensation in the form of a $20 gift card, which may have influenced participation and selection bias.

## Conclusion

This study is the first to apply the SURE test to assess decisional conflict among caregivers of extremely preterm infants during the first week of life in near real-time. The majority of caregivers reported low decisional conflict and high levels of engagement in shared decision-making, with no significant difference between caregivers of periviable ($22^0$-$24^6$ weeks' gestation) and later extremely preterm infants ($25^0$-$27^6$ weeks' gestation).

These findings carry several implications for clinical practice. First, the relatively low rates of decisional conflict and high perceived engagement suggest that structured shared decision-making during the first week of life can effectively support caregivers of extremely preterm infants, consistent with evidence that clear and compassionate communication is a key facilitator of shared decision-making in neonatal medicine.(17) Second, the absence of gestational age-based difference in decisional conflict suggests that the quality of the shared decision-making process may matter more than illness severity in shaping caregiver experience. Third, the finding that a meaningful minority of caregivers experience decisional conflict (approximately 17–28%) highlights the need for routine screening and targeted interventions to support these families.

Future research should prioritize multilingual enrollment and culturally adapted tools to capture the experiences of non-English speaking families, longitudinal assessment of decisional conflict throughout the NICU course as feelings of engagement and role in SDM make change throughout an admission, and formal validation of the SURE test against the full Decisional Conflict Scale within the NICU population. Additionally, studies examining the relationship between early shared decision-making, caregiver mental health, and long-term decisional regret would further inform best practices for family-centered neonatal care.

## Declarations

# Conflict of Interest

The authors declare no competing financial interests. A standardized waiver of consent was approved through the Institutional Review Board for the purpose of this study (IRB Reference # STUDY00004272). This study was performed in accordance with the Declaration of Helsinki.

# Availability of Data and Materials

*Funding*

Funding for this project was granted through an institutional grant; Nationwide Children's Hospital Intramural Funding Grant (Award Reference # IFPAWRI242024).

# Author Contributions

Rebecca R. Saliga, MD contributed to the design, acquisition, interpretation of data, and drafting the manuscript. Susan M. Lopata, MD, helped with analysis and interpretation of data, and editing the manuscript. Amy Baughcum, PhD, helped with study design, analysis and interpretation of data, and editing the manuscript. Sara Conroy, PhD, helped with study design, statistical analysis, interpretation of data, and editing the manuscript. Zachary Farmer, MD, helped with study design, interpretation of data, and editing the manuscript. Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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# Figures

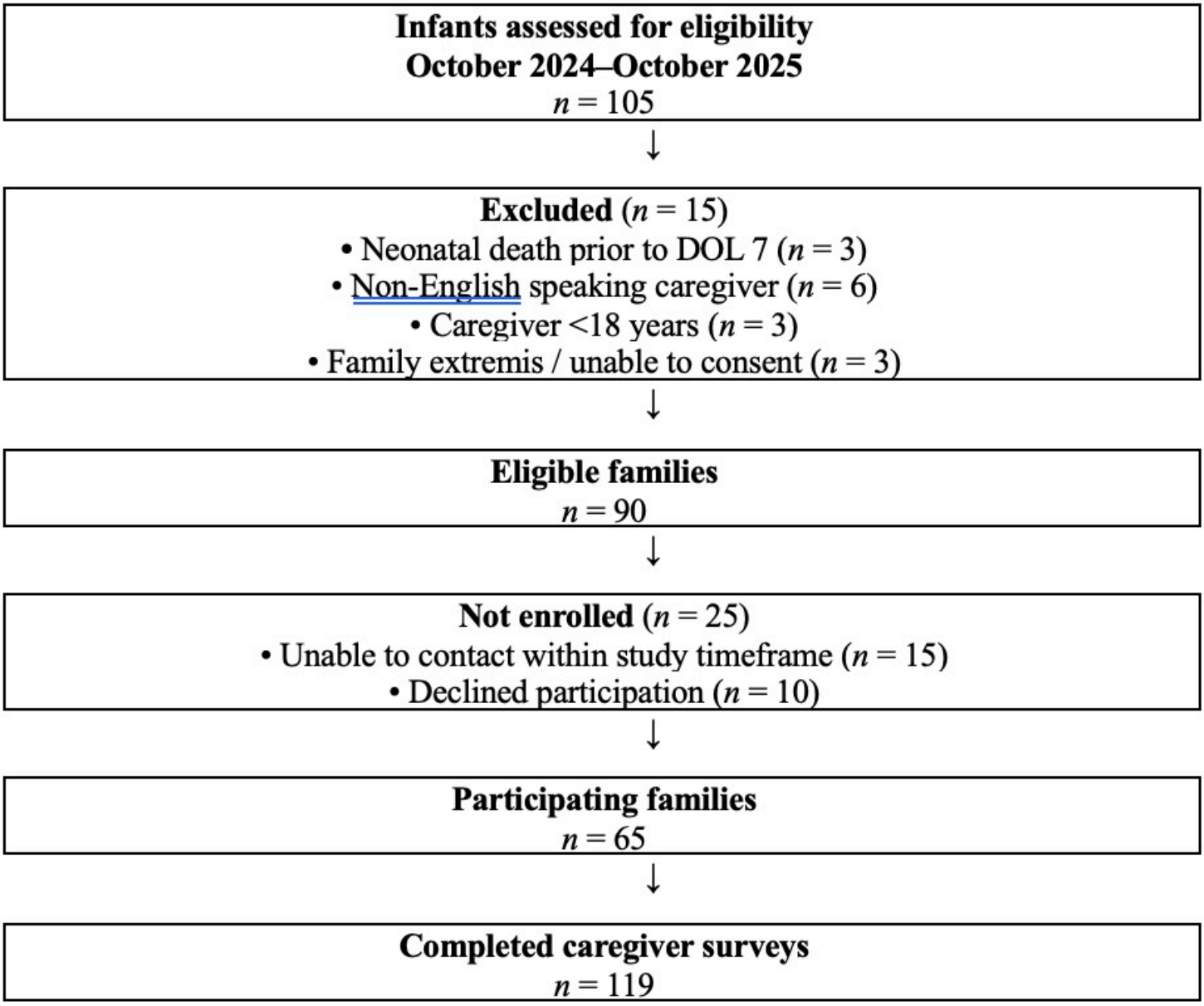



**Figure 1.** Caregiver Enrollment and Participation Flow Diagram

**Figure 1**

See image above for figure legend.

## Supplementary Files

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- SuppTable1.jpg