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# Shared Decision Making in the NICU

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## Abstract

The ethical dilemmas and predominant frameworks surrounding decision making for critically ill newborns have evolved substantially over the last 40 years. A shared decision-making approach is now favored, involving an exchange of information between parents and clinicians that emphasizes parental values and preferences, resulting in a personalized approach to decision making. In this review, we summarize the history of clinical decision making with a focus on the NICU, highlight different models of decision making, describe the advantages and current limitations of shared decision making, and discuss the ongoing and future challenges of decision making in the NICU amidst medical innovations and emerging technologies.

## INTRODUCTION

### Case 1

A 28-year-old woman is admitted to the labor and delivery service for premature labor and premature rupture of membranes at 23 weeks' gestation. The neonatologist is called for a prenatal consultation, because the obstetrician believes she may deliver imminently. The neonatologist meets with the pregnant woman alone to discuss the prognosis and delivery plan, providing information about prematurity and possible complications, likely need for intubation and mechanical ventilation, estimated length of NICU stay, and long-term risk of neuro-developmental impairment. The neonatologist then asks if she prefers attempted resuscitation in the delivery room or comfort care, given this information.

### Case 2

A female infant is born at 32 weeks' gestation because of acute placental abruption requiring resuscitation in the delivery room. Three days after birth, the infant is found to have large bilateral intraventricular and parenchymal hemorrhages with evidence of extensive ischemia on brain magnetic resonance imaging. The neonatologist reports these findings to the family including the possibility that their daughter may be significantly neurologically impaired. The infant's parents worry about her quality of life in the future but are hopeful that her prognosis will improve. The neonatologist asks the family if, given this information, they would like to dis-continue life support.

Neonatologists are often asked to counsel families in the wake of uncertainty in rapidly evolving situations. Parents are then often asked to make a decision, typically after a rapid overview of complex medical information and its potential long-term consequences, while trying to cope with unanticipated events and their new role as a parent. These cases demonstrate many of these practical and ethical challenges. How much information should

clinicians provide to parents? What options should parents be given? What is important to families? Who should make the final decision? These cases, though hypothetical, are plausible, and highlight opportunities for improved shared decision making and the challenges surrounding such an approach.

Shared decision making, an established element of family-centered care in pediatrics, is now included in several policy statements surrounding care for critically ill infants. (1)(2) Yet, how to optimally apply shared decision making in the NICU remains an ongoing challenge. Many decisions in the NICU involve a substantial level of uncertainty, creating moral dilemmas for both parents and clinicians. These “gray zone” decisions are complicated; they are dependent on parent and clinician experiences, values, and goals. In this review, we examine the history of clinical decision making, with a focus on the NICU; highlight different models of decision making; describe the advantages and current limitations of shared decision making; and discuss the ongoing and future challenges of decision making in the NICU amidst medical innovations and emerging technologies.

## HISTORY OF CLINICAL DECISION MAKING

In its early days, the field of neonatology was characterized by rapid innovation in therapies for premature infants, including the institution of antenatal steroids, fetal surfactant administration, and advancements in ventilation. (3) Advancements in the field of bioethics occurred simulta-neously as existing models of decision making (physician authority and paternalism) were challenged. Patients and parents advocated for a seat at the table in the decision-making process and the right to proceed with or decline treatment when given options. As such, medical decision making in the United States largely shifted away from paternalistic practices, swinging toward patient autonomy.

In the NICU specifically, parental authority in decision making became increasingly important. With advancing technology, infants at younger gestational ages were being resuscitated and there was increasing evidence about risks of disabilities in survivors. (4) In 1973, the practice of withdrawing or withholding life-sustaining technology from certain neonates based on poor prognosis and parental wishes in an institution was first described in the *New England Journal of Medicine*, gaining widespread attention and invigorating ethical debate. (5)(6) A decade later, the case of “Baby Doe,” an infant born with trisomy 21 whose parents declined surgical treatment of a tracheoesophageal fistula ultimately allowing him to die in infancy, questioned the right to nonintervention when a certain technology or surgery was available. This case was ultimately settled in court in favor of the parents. (7)

In the wake of these cases and in promotion of patient-centered care and decision making, the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research was created in 1982. (8) The report endorsed the creation of institutional ethics committees, initially proposed as a way to review decisions surrounding the use of life-sustaining interventions in seriously ill adults, children, and newborns. (9) The report also explicated shared decision making for the first time as an evolution of respect for autonomy and informed consent.(8) In this commission, treatment options for seriously ill newborns were recommended to be assessed by the physician as *clearly*

*beneficial*, when there is medical consensus that there is a net benefit to the child; *futile*, when there is no therapy that can benefit an infant; or *uncertain*, when it is difficult to assess whether the treatments available will confer benefit. (8) When uncertainty exists regarding the potential benefit of a specific therapy, ethicists recommended a shared decision-making approach. (8) With this change, attention shifted toward the *process* by which decisions were made, rather than the *result* of the decision. (10) Figure 1 highlights such important time points in the history of clinical decision making.

Over the last 2 decades, shared decision making has become the preferred method of physician-patient partnership. Recently, the National Quality Forum released a call to action to health-care providers and organizations to adopt a shared decision-making approach in their clinical practices. (11) Publications with the keywords “shared decision making” have increased substantially in the last 10 years. Shared decision-making approaches, in the context of patient decision aids, have been linked to improvements in decision quality with an alignment between values and choices. (12)

In its policy statements, the American Academy of Pediatrics has increasingly advocated for a shared decision-making model involving physicians and parents when there is uncertainty surrounding prognosis or benefits of a given treatment. (1)(2)(13) The momentum for family-centered care and information sharing is also growing internationally, with many industrialized nations incorporating tenets of shared decision making into neonatal care guidelines. (14)(15) Many of these reports provide recommendations on what types of information should be provided to families, but only recently did the current guidelines on antenatal counseling for extreme prematurity mention the importance of considering parental values in these conversations. (1)

## WHAT IS SHARED DECISION MAKING?

The shared decision-making process functions as an intermediary between the extremes on the decision-making spectrum of physician paternalism and patient autonomy. (16) It involves a reciprocal exchange of information between parties with the goal of facilitating medical decisions that align with patient or surrogate preferences, values, and goals. (11)(15)(17) The National Quality Forum report, through a multidisciplinary group, arrived at a consensus definition of shared decision making: “a process of communication in which clinicians and patients work together to make optimal healthcare decisions that align with what matters most to patients.”(11) The report describes 3 required components:

1. clear, accurate, and unbiased medical evidence about reasonable alternatives—including no intervention—and the risks and benefits of each
2. clinician expertise in communicating and tailoring that evidence to individual patients
3. patient values, goals, informed preferences, and concerns, which may include treatment burdens (11)

There is an intimate connection among respect for autonomy, informed consent, and shared decision making. Informed consent relies on 5 agreed-upon elements: 1) competence, 2)

disclosure, 3) understanding, 4) voluntariness, and 5) consent. (18) Shared decision making incorporates these principles with the added valuable element of the exchange of information. While informed consent implies autonomous decision making without physician recommendation (or in the case of pediatrics, parental authority to make a decision), in shared decision making, the physician assumes some decisional responsibility by providing recommendations based on patient or parental values, preferences, or moral frameworks. (19) Thus, in a shared decision-making model, there is a shift from physicians as mere providers of information leaving parents to decide on their own, to a focus on physicians' need to help parents clarify parental values while incorporating relevant information to make decisions together.

## SHARED DECISION-MAKING FRAMEWORKS

The literature surrounding models of shared decision making is largely limited to the adult population and mainly centers on the effect of decision aids. (20) Decision aids have been explored in antenatal counseling but have focused primarily on informational comprehension of prematurity and its complications, rather than the processes of eliciting parental perspectives and values examination. (4)(21) None-theless, a recent randomized trial using decision aids in counseling at extreme prematurity found significantly improved knowledge of complications of extreme prematurity without any effect on parental decision conflict. (21)

Some have suggested a framework founded in "communicative ethics" to be paramount in any shared decision-making model. (22) Applied to shared decision making, communicative ethics emphasizes the communication process used to reach a decision as an integral part of the actual treatment decision. The framework encourages clinicians to recognize and encourage all stakeholders' participation in the discussion and to accept that all stakeholders are morally equivalent to one another to promote open and honest communication to reach a decision. (22) Table 1 highlights practical suggestions for communicating with parents about making difficult decisions. Similarly, the model of relational autonomy emphasizes the importance of relationships and situational awareness in forming identities. (23)(24) Relational autonomy models encourage clinicians to engage with patients and families, to acknowledge emotions, and to consider the consequences of their illness or condition in offering guidance on decision making. (23)

One framework proposed by Haward et al and Janvier et al for end-of-life discussions and prenatal consultations in the NICU uses the mnemonic "SOBPIE" to help guide such encounters. (4)(25) The elements suggest that clinicians assess the *situation* by gathering information and determining what, if any, decision needs to be made. *Opinions* and biases should be recognized by health-care professionals. Clinicians should practice *b*asic politeness by reducing distractions, meeting in private locations, and being sensitive. *P*arents' concerns and needs should be addressed with *information* tailored toward these needs, individualized for the infant's condition and goals of consultation. *Emotions* should be supported and serve as a vehicle for building trust. (4)(25)

Haward et al suggested that a personalized decision-making approach is more appropriate for the antenatal consultation because shared decision making implies that parents desire collaboration with their physicians in these decisions. (4) Some parents prefer to make decisions on their own, others prefer to have clinicians make the decision for them, while others prefer a balanced approach. Although there is significant heterogeneity in parental desire for decision making, eliciting preferences, including degree of desired involvement, is a vital part of a shared decision-making approach.

Figure 2 represents a framework to optimally incorporate these strategies into a shared decision-making approach in the NICU. (10) Phase 1 emphasizes the preparation for any encounter with a family in the NICU with an important emphasis on acknowledging personal bias, putting personal views aside, and being nonjudgmental. Phase 2 describes basic etiquette and techniques to increase trust with families. Phase 3 is a continuous process that involves eliciting parental hopes and values while acknowledging emotion to tailor shared information to move toward a shared decision. (10)

## DECISION-MAKING PREFERENCES

Many decisions in the NICU fall into the “gray zone”: resuscitation of infants at extreme prematurity, withdrawing and withholding life-sustaining interventions, and interventions for infants with trisomy 13 and 18 are just a few. Parental decision-making preferences can vary in the amount and type of information desired, preferred processes for consideration of options, need for emotional support, and share in the decisional responsibility. (4)(26) Preferences for decision-making involvement vary significantly among parents, but physicians are typically poor at identifying which decision-making style parents prefer. (21)(27)

Such discordance between desired and actual decision-making preferences can have consequences. When parents perceive a decision-making style that differs from their expectations and does not address their values, they are less confident about their decisions, report a solitary process, and have difficulty integrating the event into their own narrative. (28) Parents in the NICU often identify religious faith, hope, and a personal connection with their physician as central to their decision making regarding delivery room resuscitation. (28)(29) However, these preferences often differ from what physicians identify as most important, (28)(30) resulting in a potential barrier to effective communication.

Studies have shown that parents prefer to make certain types of decisions while delegating others to the neonatal clinicians. (31)(32) For example, parents often prefer to delegate to the physician team decisions requiring a high degree of urgency and medical expertise or are technical in nature. (31) Parents, on the other hand, typically prefer to make decisions surrounding big picture goals, high parental familiarity, high perceived risk, and part of a normal parental role, such as feeding. (31)(32)

Some clinicians and ethicists worry that the emotional burden of making some decisions, particularly end-of-life decisions, may be too psychologically distressing for parents. (33) However, studies analyzing decision making surrounding treatment limitations in the NICU

found that most parents believed that they should be actively involved, and it was their responsibility to take part in such decisions.(29)(34)(35) In fact, when parents were asked about their perceived role in the decision-making process after the death of their child in the NICU, most parents preferred decision making they perceived as shared, and such a perception was associated with lower long-term grief scores.(26)(36) Parents of infants in the NICU should be engaged in the decision-making process for their infant that matches their desired level of involvement to best support their needs and to facilitate parent-physician partnership.

## CHALLENGES OF SHARED DECISION MAKING IN THE NICU

### Surrogate Decision Makers and Parental Sense of Duty

Although there is general agreement that neonatal clinicians and parents should engage in shared decision making to the degree parents desire, the application of shared decision making in the NICU remains an ongoing challenge. Shared decision making, as it was originally designed, was created to enhance communication between physicians and their patients in the outpatient setting. (37) In pediatrics and neonatology, however, there is a limitation on decision-making authority for surrogate decision makers, which are generally accepted to be the infant's parents, except in certain scenarios. The proposed qualifications for surrogate decision makers are to have the ability to make reasoned judgments, possess adequate knowledge and information, be committed to the infant's interests, all while being emotionally stable. (18) Physicians have a duty to ensure parents have adequate information to make a decision; however, there is a significant emotional burden of decision making for parents. Having an infant in the NICU is a stressful experience for a parent and having to make decisions with potentially lifelong consequences for their infant while trying to understand and interpret information and long-term outcomes is undoubtedly challenging. Parents similarly feel a sense of personal duty to fulfill their role as a "good parent." (38) These "good-parent beliefs" come from a set of responsibilities that parents identify as important to support their child. With these beliefs, parents form their personal sense of duty which can meaningfully affect their decision making. Parents may struggle to weigh options and engage in shared decision making in light of these values as they grapple with the question of what constitutes a good parent for their critically ill child. (38)

### The Best Interest Standard and the Harm Principle

Traditionally, in the case of a neonate, whose wishes are unknown, the "best interest standard," defined as "the best estimate of what reasonable persons would consider the highest net benefit among the available options," has been argued to be the most appropriate standard for surrogate decision making. (18) This approach, however, has been recently challenged by some ethicists as being problematic, because it may be subjective and intolerant of differing values and perspectives. (39)(40) Determining an infant's best interests can be complex, and is typically done by considering the potential benefits and burdens of the available options. (18)(41) However, many of these determinations are subjective and related to perceptions of quality of life and potential burdens of disability. Parents and those with disabilities have been shown to be more accepting of possible severe disability than most health professionals.(42) As such, the "harm principle," which focuses

on whether the child will be harmed by a decision, has been more recently championed by many ethicists because it allows a wider range for parental discretion. (39)(40) This principle has been argued to primarily focus on decisions in which parental views on treatment differ from those of the medical team and there is uncertainty on what is optimal for the child, thus termed the "zone of parental discretion." (39) In these scenarios, the tenets of shared decision making remain paramount.

## Conflicting Values and Priorities

Although shared decision making, in theory, has the potential to enhance ethical decision making in the NICU, many neonatologists are not implementing this approach in practice. In a survey of practicing neonatologists, many endorsed the idea of shared decision making in practice, but the majority admitted to making most decisions themselves.(30) In addition, despite evidence that spirituality and hope were central in guiding parental decision making in the NICU, many neonatologists report rarely discussing parental religious or spiritual beliefs during prenatal consultation.(29)(30) Compounding this, most neonatologists still view their primary role in the prenatal consultation as providers of factual information, which contrasts with data from families that numerical predictions of morbidity and mortality were not as important as spirituality, religious beliefs, and input from other family members. (30)(43)

## Unconscious Biases

Beyond this, inherent differences between parent and clinician values, personal experience, and even interpretation of medical data may influence definitions of "best interests," and ultimately decision making. Physicians may also in-advertently frame certain facts based on their own biases that may sway parental decision making. This process, in which facts are framed in communication, has been labeled "choice architecture." (10) Neonatologists should be aware of their potential role as choice architects while counseling parents in the NICU. This can lead to a framing effect, a bias whereby decisions may be influenced by how options are presented (positive or negative semantics), which, in addition to other biases (eg, availability bias, anchoring bias, optimism bias, implicit bias) have been demonstrated to affect patients' preferences and decisions (Table 2). (44)(45) In the context of perinatal counseling, presenting mortality percentages or survival percentages (45) may reflect the biases of the medical provider, rather than accurate parental preferences, potentially influencing decision making. These biases are not just related to framing effects but may be unconscious as well, related to disability, educational level, sexual orientation, and other factors, and may alter the clinicians' perceptions of parental values. (10)

In addition, the facts presented to families are often technical in nature and are chosen by clinicians without eliciting parental input, thus often resulting in a failure to determine what decisions matter most to a family. Rather than simply provide facts to parents, clinicians should help parents clarify their values and goals when possible, then present these balanced facts in a way that parents may find useful. (10)

## CONCLUSIONS

Decisions for infants in the NICU are made every day by parents and clinicians, often in difficult situations. As exemplified by the cases presented in the introduction, suboptimal interactions between neonatologists and families may result in poor understanding and decision making, and may potentially even lead to decisional regret by already vulnerable families. A shared decision-making approach emphasizes the importance of eliciting parental beliefs, values, and desired degree of decisional responsibility while compassionately communicating essential information for reaching a decision. As the gray zones in neonatology continue to shift, so do opportunities for improved shared decision making. In addition, emerging technologies will continue to play a major role in perinatal decision making as parents face increasingly complex choices in pre- and post-natal treatment options. Further research on shared decision making is needed to evaluate what information is relevant to parents, what factors influence parental decisions, and how clinicians can collaborate with families to most effectively participate in the decision-making process. Finally, further education is needed for clinicians to learn and refine their communication and counseling skills to engage parents in the decision-making process that best suits their needs.

## AUTHOR DISCLOSURE

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## Objectives

After completing this article, readers should be able to:

1. Define shared decision making and its role in the NICU.
2. Describe frameworks and strategies to apply shared decision making in the NICU.
3. Identify the unique challenges of shared decision making relevant to neonates.

**American Board of Pediatrics Neonatal-Perinatal Content Specifications**

- Recognize the controversies associated with treating extremely premature infants.
- Know the evolving issues of maternal versus fetal rights.

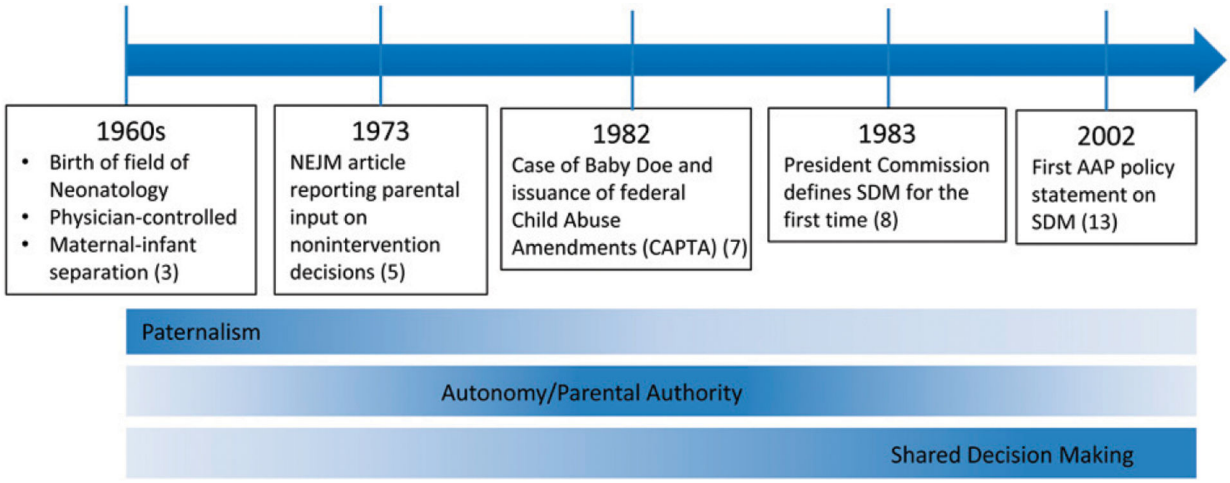


**Figure 1.**

Timeline of clinical decision making in the NICU. AAP=American Academy of Pediatrics; CAPTA: Child Abuse Prevention and Treatment Act; NEJM= *New England Journal of Medicine*; SDM=shared decision making.

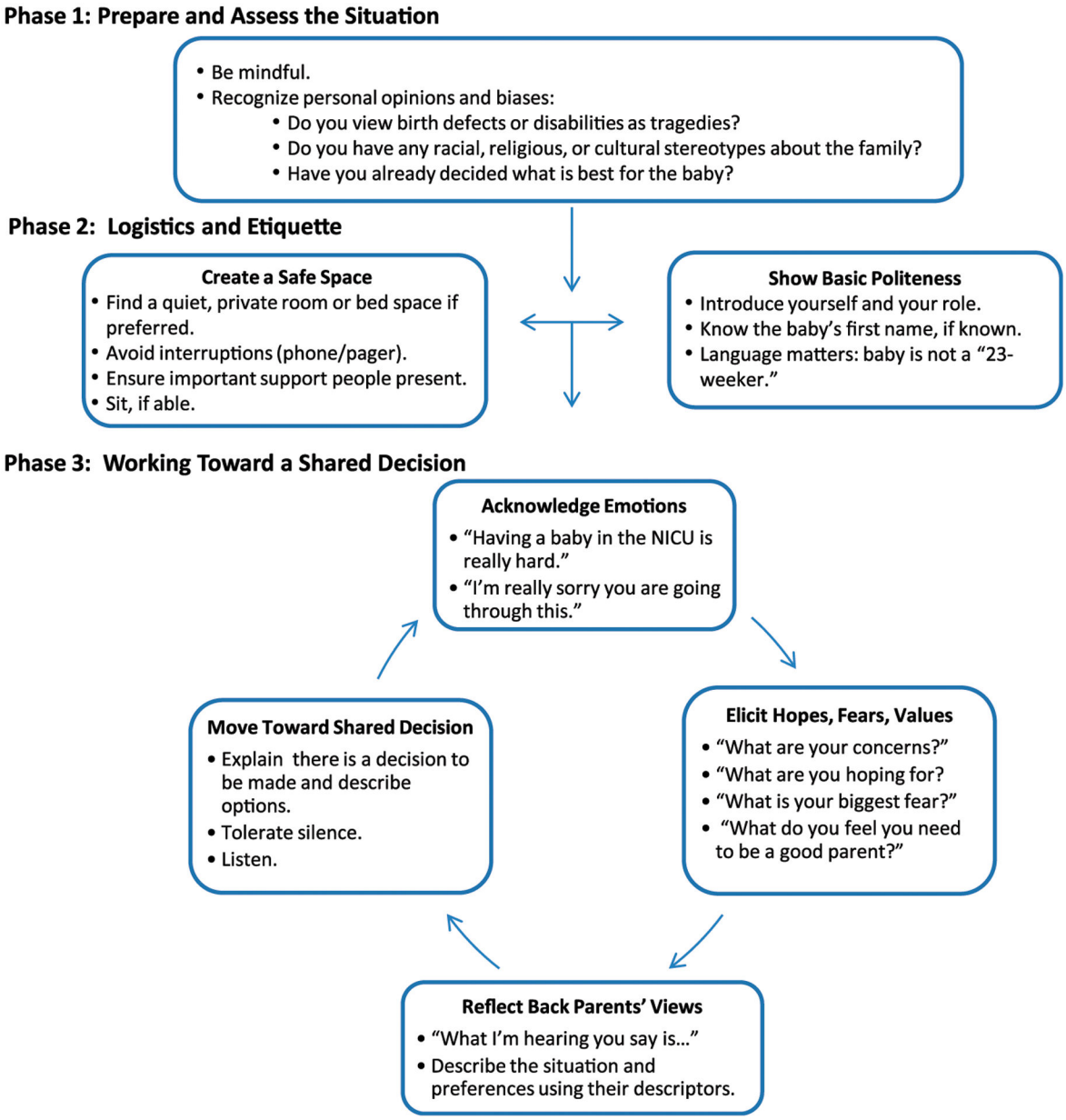


**Figure 2.**

Framework for shared decision making in the NICU. Adapted with permission from Lantos JD. Ethical problems in decision making in the neonatal ICU. *N Engl J Med*. 2018;379(19):1851–1860. (10)

**TABLE 1.**

Communication Strategies to Engage Families in Shared Decision Making (10)(20)(22)(25)(38)

| SHARED DECISION-MAKING ITEM | APPROACH (EXAMPLE) |
|---|---|
| Assess understanding | “What do you understand about the situation now?” “Would it be ok to talk about some of the options we have now moving forward?” |
| Examine value system | “What are your hopes for your baby/[child’s name]? What are you most concerned about?” “Are there things we should know about your family, such as beliefs or faith, that may help us?” “What does it mean to you to be a good parent?” |
| Sharing information | “To help make decisions, some parents want to know statistics, others want to know the big picture, while some want to know both the details and the summary—what kind of parent are you?” |
| Determine parental decision-making style | “Each family makes decisions for their child differently. Some parents prefer to make decisions on their own, some with input or recommendations from their doctor, and some prefer the doctor to make the decision with their input. What kind of parent are you?” “What do you think is most important to focus on?” |
| Validate emotions | “I can only imagine how difficult it must be to make these decisions.” “Many loving parents facing this decision feeloverwhelmed.” |
| Provide support and follow-up | “How can we best help you?” “What can we do more to support you through this?” “Let’s set up another time to talk after you’ve had the chance to discuss with your family and think some more.” |

**TABLE 2.**

Potential Biases Affecting Decision Making in the NICU (44)(46)(47)

| BIAS | EXPLANATION | EXAMPLE | COUNTER[a] |
|---|---|---|---|
| Framing effect | Decision based on information presented with positive or negative connotations | Presentation of only survival or mortality statistics during prenatal consultation | Offer balanced data (positives/negatives) |
| Availability bias | Decision based on most easily recalled and/or available information | Parental declination of a standard treatment (vaccine, vitamin K) based on recent story in media about isolated poor outcome related to treatment | Provide evidence-based research and guidelines |
| Anchoring bias | Decision that relies too heavily on one value or initial piece of information | Physician recommendation to withdraw life-sustaining technology based on intraventricular hemorrhage | Seek second opinion from relevant stakeholders (eg, family, colleagues, institution, ethics committee) |
| Optimism bias | Tendency to believe one is less likely to experience a negative outcome | Parental belief that their child will not develop cerebral palsy despite significant parenchymal hemorrhage | Provide facts while acknowledging uncertainty and nurturing hope |
| Implicit bias | Unconscious attribution of particular quality to certain social/ethnic/racial group | Offering or withholding a specific management/treatment option (eg, resuscitation at extreme prematurity, surfactant) | Use consensus-driven and evidence-based guidelines |

[a]The suggestions included are meant to counter potential biases found in practice.