Decision Making in the NICU —
Strategies, Statistics, and “Satisficing”

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As science progresses, new issues in bioethics grab the headlines, but in neonatal medicine communication and decision making for sick and premature infants is as important today as it was thirty years ago. Decisions have to be made and made well, despite suboptimal time, data, or knowledge. To this end, the authors propose good communication and a cooperative model as key to interpreting the best interest standard in a way that respects parental rights and responsibility and allows best interest to be decided from an amalgam of medical facts and human values.

While new issues in bioethics tend to grab the headlines and demand attention as science progresses, some older issues in interpersonal dynamics, communication, and decision making remain for clinicians who make daily judgments at the bedside. In the field of neonatal medicine, an issue that remains relevant and requires attention by all clinicians entering the field (whether as physicians, nurses, nurse practitioners, or others) is that of communication and decision making for sick and premature infants with their parents.

Decision making in medicine, particularly pediatric medicine, has long been recognized as fraught with uncertainty. The nature of clinical decision making in the neonatal intensive care unit (NICU) is that one operates with some uncertainties at all times. How will this baby respond to this therapy? What are the long-term benefits, or side-effects? And if this particular disorder is present now, what is the likely outcome or effect when the child is two years old? Five years old? A young adult?

Clinicians strive to reduce uncertainties by assembling facts as they relate to the case at hand. These facts include medically relevant physiologic and pharmacologic conditions and the best understanding of disease processes in a developmentally sensitive manner. That is, a twenty-five-week gestation infant’s response to a particular condition (e.g., respiratory distress, infection, acid-base perturbation) is understandably different from that of a thirty-five-week gestation infant. In the end, however, these medically relevant facts often fail to clarify the uncertainty. The medical facts do not provide decision makers with a crystal ball, but a fuzzy lens that simply allows for a best guess. Because of this fuzziness,

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clinicians also need to make additional considerations related to human values and the concerns of the parents or guardians. This process requires
a readiness to communicate openly with parents and families to ascertain their goals in caring for their infant.

The healthcare professionals' perceptions of parents help shape the propensity to address and consider parental input (Silverman 1983). Parents and clinicians are likely to perceive things differently, including the risk associated with a particular treatment or course of therapy. Parents may be viewed as more subjective and human relations oriented, often considering their own fears, guilt, or the emotional impact of their decisions rather than some rational or objective calculus of risk. They tend to be risk averse, typically proceeding along lines of a more decided or certain course with relatively known, or quantifiable, outcomes.

Clinicians, who are sometimes described as being “rescue” oriented, objective, and scientific, often poorly receive such a basis for decision making. Physicians, in particular, may be acculturated to give more heed to statistics than emotions as they are trained in the rigors of the scientific method.

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Physicians, in particular, may be acculturated to give more heed to statistics than emotions as they are trained in the rigors of the scientific method. They may also tend to be more risk seeking: they may be willing to try something even if the potential for gain is unknown or relatively small. Specialty nurses, who spend hours at the bedside of critically ill newborns, may contribute information that is beneficial to both physicians and parents. Parental perceptions of these nurses vary: they may be seen as advocates, educators, or simply as other faces in a team of rescuers.

In addressing the role of emotions in decision making, Callahan (1988) wrote:

One conclusion I would have to draw, however, is that I must respect the differing moral sentiments of others. Just as in my reasoning I would be open to correction from better arguments, so I should be open to the possibility that the moral emotions of others may be more valid and more morally sound than my own. . . . I would be especially slow to label the moral sentiments or responses of others as squeamishness, or sentimentality, or irrationality. I would be especially aware that graver moral danger arises from a deficit of moral emotion than from emotional excess.

Some parents have described decision making to be hard, demanding more than they might be willing to deal with amid crisis in the NICU (Anderson 1995). They may feel isolated, ostracized, misunderstood, overwhelmed, and under pressure to “give in” to powerful professionals that have institutional resources behind them. Yet such imbalances can be reconciled using good communication, transparency in decision making, shared determination of goals and decision making, advocacy or support groups, and family resource centers. As has been noted over the years, deferring to parental judgment whenever possible may be the single most important maxim for clinicians.

What continues to be necessary on the part of clinical decision makers in the NICU is a balance of these medical and human value considerations and a more complete understanding of the various stakeholders’ perspectives. Additionally, there needs to be some recognition that decision-making processes that are undertaken amid uncertainty may result in outcomes that are tragic or “undesirable.” That the outcome itself may lead someone
to judge the decision as having been “wrong” is not sufficient to indict decision makers who have endeavored to use rational means even while operating in uncertainty and under the pressure of time.

All parties must learn to accept the tragic tension created between what may be called right versus rational decisions (that is, decisions judged retrospectively to be right after reflection, when the outcome is obvious — and it is desired, or good — versus decisions that are judged prospectively to have been made well, despite suboptimal time, data, or knowledge, having been made in a rational manner — and defensibly so) regardless of the ultimate outcome.

**The Best Interest Standard**

One manner in which the burden of uncertainty is addressed is to focus decision making on the perceived (hypothesized) best interest of the child.

The best interest standard focuses on what the infant/child stands to benefit from treatment (i.e., what is perceived to be in his or her best interest). Such interests may be perceived as medical or physiologic, social or relational, or moral or spiritual. Parents should be trusted to speak to these interests as they will generally confer the values and interests that shape the child over his or her development and rearing. Nonetheless, clinicians have responsibilities to reveal medical facts and relate them in the context of a particular family’s values. This task requires dialogue and discernment (AAP 1995; AAP and ACOG 1995; AAP 1996).

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**Parental rights**

The parental right to decide for their infant is grounded in the value of parenting or in the private loving relationship between parent and child (Downie 1997). However, if parental decision-making rights stem from the value of parenting, that value also entails the parents’ responsibility to act in the child’s best interest. In this light, however, the child’s best interest includes the family relationships and not simply his or her medical health. Not only must the medical diagnosis and prognosis be determined, but also the anticipated quality of life and the best possible upbringing for the infant require consideration.

Parents share their lives with their children. They live, play, travel, eat, holiday, entertain, and

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worship together. The choice a parent makes for his or her child is also a choice of what kind of person the parent wants to be. The parent’s right to rear their children with their values is an extension of their own right to live by these same values.

Best interest decisions are therefore driven by a combination of medical and moral values. It follows that the burden of proof for difficult decisions (e.g., withholding or withdrawing treatments, subjecting infants to burdensome or experimental care, or weighing parental input against the healthcare team’s perception of beneficial care) ought to lie with those who would override the parent’s decision.
But it is also because of parental responsibility to consider best interest that the right to decide for the child is not absolute. Parental love can have different motives and potential pathology, creating conflict between the medical team and the parent. Fost (1981) has stated, “when the child is seen as presenting a great burden to the parent, there is an obvious conflict of interest which may make the parent unable to put the child’s best interest first.” Yet interests in research, medical knowledge, and avoidance of medical-legal ramifications may complicate a clinician’s evaluation of what constitutes the infant’s best interest. Conflicts of interest can appear everywhere. And, for some tragically brain-injured infants, a best-interest standard may not obtain (Morris 2001).

Facing uncertainty
What likely introduces conflict in these gray areas, however, is not parental or clinician pathology, but different viewpoints on, or assigned meanings to, uncertain medical options and outcomes. These views are shaped by the different stakeholders’ perspectives and values. “Best interest” is not objective but obscure. As a result, the collaborative relationship between clinician and parent is key:

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Distinguishing the improper imposition of values on parents from a proper commitment to a child’s best interest is possible only when physicians share compassionately in the experience of the parents and child as they confront the meaning and reality of illness (Nelson 1992).

When faced with uncertainty, the clinician must form a partnership with the parents, explore clinician and family values, and negotiate the meaning of an infant’s best interest. A negotiated model encourages an enhanced autonomy that consists of listening to and sharing perspectives, accepting the clinician’s authority to offer recommendations, and obligating clinicians to fully understand parental reasoning. In doing so, the child is fully valued, not simply his or her biologic life.

It should be acknowledged that there is more at stake than simply the best interest of the child. Fost (1986) argues that even if we could define what best interest meant, we wouldn’t want to structure our society in a way that placed that value above all others. “[P]arenting is difficult enough. We can make it more difficult, less effective, and less attractive by questioning every parental move and motive” (ibid).

Against the Grain —
Cases of Unilateral Decision Making
The need for mutually derived goals of care should be apparent having considered the foregoing statements. Shared decision making is the standard that the American Academy of Pediatrics invites its members to model. The Miller case is one of many cases that illustrate a lack of shared decision making (Paris 1997; Montalvo and Vila 1999; Stinson and Stinson 1992; and Paris, Goldsmith, and Cimperman 1998). In this case, an ad hoc ethics committee made up of a group of healthcare professionals and administrators unilaterally told the Millers that they were required by law to resuscitate their infant. This advice, of course, came from the institution whose physicians had earlier told the Millers that their experience was an unfortunate “late miscarriage” and resuscitation was not recommended. Although informed and asked to give their opinion about resuscitation, the Millers were excluded from the final decision in deference to an expert medical panel.

Similarly, the Messenger infant was resuscitated when a physician unilaterally decided it had to be done in order to evaluate the infant, despite the family specifically asking that resuscitation not be done. The parents then independently withdrew life-support, for which they were later prosecuted and acquitted. The Vila parents claimed that the
same type of unilateral decision making limited their parental autonomy to make a decision as they had not provided informed consent to resuscitate their extremely premature infant. The MacDonald case took a different twist. The physician began resuscitating, then stopped when he felt it was not working. The infant was found to be still alive later, and treatment began again. Thereafter, the physician was acquitted of negligence.

A common theme of all these cases is that the courts have never held the prosecuted party responsible for the decision made. No matter what their eventual outcome, these cases are in the courts because they exemplify unilateral decision making. Thus, they are also an illustration that good communication and shared decision making may have prevented the trials in the first place.

Negotiated Model of Best Interest
One role of parental decision making, based on a child's best interest, is to maximize the developing autonomy of the child who lacks full autonomy but nevertheless has legitimate interests. Because the values of the child may not be known, deference is given to families to be proxy decision makers for their child. But how is this "best interest" to

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be understood? Whether a medical procedure is good for a patient involves an assessment of the benefits and burdens of the procedure, or whether the procedure offers the patient an acceptable quality of life.

There are at least two aspects to best interest. The first aspect is objective or medical; it concerns such issues as what the procedure can and cannot do, what risks there are, and the available outcome data. The second aspect of best interest is the subjective or moral aspect concerning the value or meaning of the objective components for the patient.

A negotiated model of best interest incorporates both the objective and the subjective aspects into the concept of best interest (Leuthner 2001). Parents must be allowed to interpret the meaning of the prognosis given to them by the clinical team and thereby make decisions for their children. Clinicians must recognize their moral agency. They may agree or disagree with parental values, but must work with parents within societal and professional rules and norms in deciding what actions determine best interest. This notion is consistent with a negotiated model of best interest.

Strategies
Statistical prognostic strategy
This strategy for decision making uses birth weight or other parameters to define a category of patients for whom NICU care is deemed futile. Based on certain statistics generated from a given population clinicians attempt to identify some threshold for anticipated (intact) survival. Problems arise when these population-derived parameters are from populations not representative of those a local service may care for (e.g., data from the northeastern United States may not fit populations in the southwest). Other problems may exist when large population derived data are applied to an individual patient. Finally, data will become outdated as advances in clinical care continue, and lags in NICU outcome data occur. This method usually disallows parental considerations as statistics (i.e., the medical establishment) determines what is best.

Waiting for (near) certainty
This strategy usually implies the application of all therapies available to every patient, in order to save as many as possible. It is sometimes called the technological imperative, and it largely disregards the patient's quality of life, suffering, or disproportionate bearing of burdens over any actual or potential benefits of continued intervention. Interventions continue until there is nearly certain grave morbidity or impending death. While a parent may choose to follow this strategy, it actu-
ally disallows parental input, or views parental decisions to cease or forgo certain therapies as other than “best interest” oriented.

**Individualized prognostic strategy**
As proposed by Nancy Rhoden (1986), the individualized prognostic strategy is a way to approach uncertainty through continued clinical evaluation and continued communication between clinician and parent about what that information means, therefore maximizing parental values. This trend is a recent one in the United States and involves the initial provision of care with frequent reassessments to ascertain the real benefits or burdens accruing to the patient from such care.

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**Good communication is fundamental to understanding what is in an infant’s best interest.**

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and decisional strategies. It provides a means for withdrawing from trials of care when it becomes evident that the patient is not benefiting from them, or that the outcomes will be so grave as to be viewed by reasonable persons (especially parents) as not in the patient’s best interest.

One needs to be careful with this strategy because it can easily slip into the wait-until-certainty strategy. The danger of this slippage depends on how one determines when it is evident that the patient is not benefiting. If one’s values are particularly vitalistic, the evidence is present only when one is certain of severe morbidity or mortality. And that, of course, equates to the wait-until-certainty strategy. Thus, these strategies are more or less on a continuum.

The individualized prognostic strategy can be very helpful in clinical situations in which statistics favor initial resuscitation, such as at twenty-three to twenty-five weeks’ gestation, but in which clinicians may need to reconsider continuation of therapy. It is psychologically helpful when things are looking bad, because clinicians can say that they gave the baby a chance. But is it truly helpful in the gray area? The reality is that a baby doing “well” at twenty-three to twenty-four weeks, can still suffer a disaster later or have late appearing developmental problems, so that only a slight predictive value for the future has been gained. Uncertainty in long-term survival and outcome can never really be clarified objectively. Consequently, is there not a false sense of security in saying that treatment will begin? If decision making is truly individualized, thorough discussion ahead of time may provide an answer before any actions are taken.

In each of these strategies, principles may be used to inform clinical judgment and guide clinicians’ actions. Autonomy may only be approached for the neonate through an individualized respect of persons, best seen in attempts to ascertain and act on a child’s best interest. Great deference is generally given to parents as previously noted, the better to protect the young child’s future autonomy. Beneficence is generally used to guide actions that are perceived to be directed toward accomplishing some good. This principle is also addressed through the best interest standard. Nonmaleficence, avoiding harm, is at times problematic because burdens (e.g., suffering) associated with intensive care are weighed in the context of anticipated or potential outcomes. To uphold this principle, the burdens of care should not outweigh the benefits of care.

In the end, these first three principles only clarify decision making if stakeholders remain open to the obscure yet robust meaning of “best interest” and burdens. A fourth principle, justice or fairness, directs clinicians, parents, institutions, and society to treat similar cases similarly and to provide for an equitable distribution of goods and services for the newborn and his family. When clinicians, an institution, or a society (via the courts) demand continued aggressive NICU treatments with highly probable or foreseeable long-term morbidities without similarly providing the resources and means for continuing care at home or in an
appropriate care setting for the disabled child, the demand is neither just nor equitable.

**Communication**
If it is accepted that best interest is a robust concept of medical fact and human value, then it should be accepted that good communication is fundamental to the understanding of what is in an infant's best interest. The first responsibility of the clinician is to provide recurring assessments and prognostication in view of new facts, the patient's responsiveness to therapies, and evolving morbidity concerns. Healthcare professionals, however, often view communication as "I presented the facts and options on rounds at the bedside, and the parents understand and agree to the medical treatment." The deeper reality of that statement may be that "we overwhelmed the family with language about medical facts that forced them to cave in to our technology."

What is missing in this form of communication is listening to the family and exploring with them their values and goals for their child and family. Needed are ongoing, often daily, conversations of asking questions, such as,

- What are your goals for your child?
- How do you think your child is doing?
- What do you think about or what do you understand the future might be for your child?
- What are your hopes and fears?"
- Who helps and supports you during difficult decisions or times in your life?"

Good communication then entails listening to the responses, allowing one to understand the family's perspective. One can then correct any misunderstanding of medical facts and explore further any conflicting or agreeable values and goals. Good communication entails that both clinicians and parents understand the same clinical facts and different human perspectives, so that both parties can move to a mutual understanding of what is best for the individual child.

**Statistics**
Clinicians and parents must recognize that statistical data are generally derived from small populations and may not be generalizable to their specific institution. Yet statistics do inform decisions and may be called on in communicating with peers, colleagues, and families. At least three categories of statistics warrant attention.

Local institutional morbidity and mortality data are important for healthcare professionals to know and impart to their local service area. They may reflect local demographic variables and biases, population specific health conditions, access or quality issues. They may also allow comparison to other institutions deemed appropriate for benchmarking outcomes.

Regional outcome data may be useful in knowing what geographically or politically defined regional perinatal center outcomes are. These may be linked to specific centers and the subspecialty services provided in them — to both local and geographically dispersed populations. Such data are often forthcoming from follow-up clinics and may be tabulated at the state level.

National reference data from other centers and the medical literature (perhaps seen as "what can be" rather than "what should be expected") provide some guidance for families and professionals alike.

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An example of the need to look at statistics carefully may be seen in the outcome for a twenty-four-week gestation infant. National data suggest
that at twenty-four weeks’ gestation, the chance of survival is 40 to 60 percent (but it may be lower if one includes stillbirths in the analysis). Local outcomes and regional data may reflect otherwise.

At Vanderbilt University, survival for this category of patients is 45 percent, but those who were born outside the medical center (in community hospitals) and transported to Vanderbilt fared much more poorly than those born at Vanderbilt. Further, local and national data reveal that from one-third to one-half of the survivors at 24 weeks’ gestation have major neurologic sequelae, such as mental retardation, cerebral palsy, visual or other sensorineural deficits (Fanaroff 1995, Hack 1994, McCormick 1992).

It is important that all stakeholders recognize that moral judgment may be obscured through an appeal to “objective” outcome data. Such an appeal leads to committing the “technical criteria fallacy” first noted by Veatch (1977). He appropriately points out that clinician’s and society’s infatuation with technical abilities, data collection, and scoring systems leads to misunderstanding the nature of these decisions. It may be presumed that decisions are made on the basis of a prognosis, when in fact they are based on the meaning of that prognosis. He argues that the search for technical criteria leads to medicalizing value decisions. Outcome data can only provide a parent with some risk assessment for their child to be. People have different risk-taking behavior based on their values.

The perspective of those judging the outcome further complicates assessing the quality of outcomes. Saigal’s work on quality-of-life for NICU survivors as judged by the patients themselves versus their parents or doctors and nurses is revealing (Saigal 1999). Her work looks at more than the objective outcome data to consider the potential meaning behind the outcome. While criticized by some who recognize the limitations of this study design; that is, that it allows only the “best” of the surviving preterm infants to participate in her qualitative assessment (e.g., survivors who can communicate), these data still bear consideration.

“Satisficing”
In looking for helpful models of difficult decision making, the work of Nobel Prize Laureate Herbert Simon in economics, and subsequently in cognitive theory, can provide some assistance, or at least a balm for those burdened with uncertainty and tragedy. Simon’s notion of “satisficing” has been adapted into many fields beyond his original use of the term in economics. When dealing with hard choices, satisficing allows one to consider decisions that, while not perfect and not leaving one completely satisfied, satisfy to some extent and “suffice,” given the constraints made on the decision-making process. In an economic sense, they do not maximize utility by producing the biggest or best outcome. They are “good enough” decisions that recognize the very real-world problems of uncertainty and value conflict.

How can this model assist clinical decision makers? By adopting an approach that accepts the finite limit of what can be known at any given moment, uncertainty is less than formidable. A truly “best” or “right” decision might be unknowable, but a satisfactory one can be made using a rational process that considers all pertinent facts and submits them to critical judgment. Such judgment is beyond intuition, statistical analysis, and even reflection. It is a deliberative process “characterized by the moral question of ‘What ought I to do now’ and aimed at the good of the patient (Coles 2002).
Conclusion
Clinicians must engage patients and families in communication to elaborate and gain insights into understanding their values and goals. In the NICU, this entails a shared decision-making approach between parents and clinicians striving to address the newborn patient’s best interests. In so doing they may enlist the help of colleagues in clinical ethics. Provided they are educated and experienced in making professional judgments that are both reflective and deliberate, these same clinicians can make decisions for their tiny patients and with their parents. Such decision making will satisfice.

References