

## REVIEW ARTICLE

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# Ethical Problems in Decision Making in the Neonatal ICU

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IN THE NEONATAL INTENSIVE CARE UNIT (NICU), DISAGREEMENTS ABOUT whether life-sustaining treatment can ethically be withheld or withdrawn are not uncommon. Usually, the dilemma comes down to questions about the value of life with severe physical or cognitive impairments. Disagreements can go in both directions. Sometimes, doctors recommend treatments and parents refuse. Sometimes, parents request continued treatment that doctors think inappropriate. Such conflicts have occurred in cases of hypoxic encephalopathy,<sup>1</sup> degenerative neurologic diseases,<sup>2</sup> and even brain death.<sup>3</sup> These disagreements can cause moral distress among doctors and nurses and debates about the ethical justifiability of unilateral decisions that treatment is futile and should be withdrawn.<sup>4-6</sup> Usually, disagreements are resolved by ongoing discussion between doctors and parents, by bringing in other family members, or by consulting an ethics committee.<sup>7</sup> Most intensivists learn how to negotiate with families in these situations.

Occasionally, disagreements become intractable, and cases end up in court. Some states have statutes in place that guide judicial decisions.<sup>8</sup> Laws in Texas, California, and Virginia empower doctors to withdraw life-sustaining treatment unilaterally.<sup>9-11</sup> By contrast, laws in Kansas, Oklahoma, and New York empower patients and families to prevail in disagreements.<sup>12-14</sup>

Ethicists have developed a general framework for balancing the child's interests with the scope of parental authority. That framework, first articulated by a presidential commission on bioethics in 1983, was based on the view that doctors have a responsibility to decide whether treatment is clearly beneficial, futile, or somewhere in between.<sup>15</sup> When, according to medical expertise, treatment is clearly beneficial, the baby's right to treatment outweighs the parents' rights to make medical decisions for their baby. When the benefits of treatment are less clear, ethicists (and courts) defer to parental choices. This general framework acknowledges the inevitability of a gray zone — that is, situations in which many options are legal, reasonable people disagree about the right thing to do, and a decision must be made. Much has been written about how to define gray zones. I do not define them here but simply acknowledge that they exist. The purpose of this review is to describe and analyze various strategies for improving the process by which physicians work with parents to make decisions about societally defined gray-zone cases.

Although intractable disagreements make dramatic news stories, most disagreements are not intractable. Instead, in most cases, doctors and parents struggle together to figure out what is best for them in the dilemma in which they are immersed. In such situations, all the options are legally permissible and ethically defensible. The goal of ethical analysis in such cases is to help both doctors and parents make difficult decisions within the ethical gray zone.

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Attention to the process by which decisions are made, rather than to the result of the decision-making process, has changed the way we think about both the goal of neonatal bioethics and the role of doctors as they counsel parents in these situations. Until recently, doctors saw their primary role as providing parents with detailed, objective information about treatment choices and likely outcomes. A newer approach recommends that doctors help parents discern their own values and ethical commitments as they face an unanticipated situation and a series of life-altering decisions.<sup>16</sup> The shift of focus from result to process is subtle but important; instead of an ethics of conflict resolution, this approach requires an ethics of value clarification (Fig. 1).

In this review, I examine reasons for the shift from the older approach to the emerging paradigm for shared decision making. Then I explain how advances in both prenatal diagnosis and neonatal therapeutics change our understanding of what parents need in the NICU. Finally, I discuss some current innovations that will probably become important tests of this approach in the future.

#### DOCTORS AS INFORMATION PROVIDERS

The early days of neonatology were characterized by exuberant medical innovation.<sup>18-20</sup> New approaches to the treatment of premature babies were introduced at such a rapid pace that outcome studies were often obsolete by the time they were completed and published. Anecdotal evidence and descriptive studies suggested that the innovations were working.<sup>21</sup> Most doctors were excited and optimistic about these successes.<sup>22,23</sup>

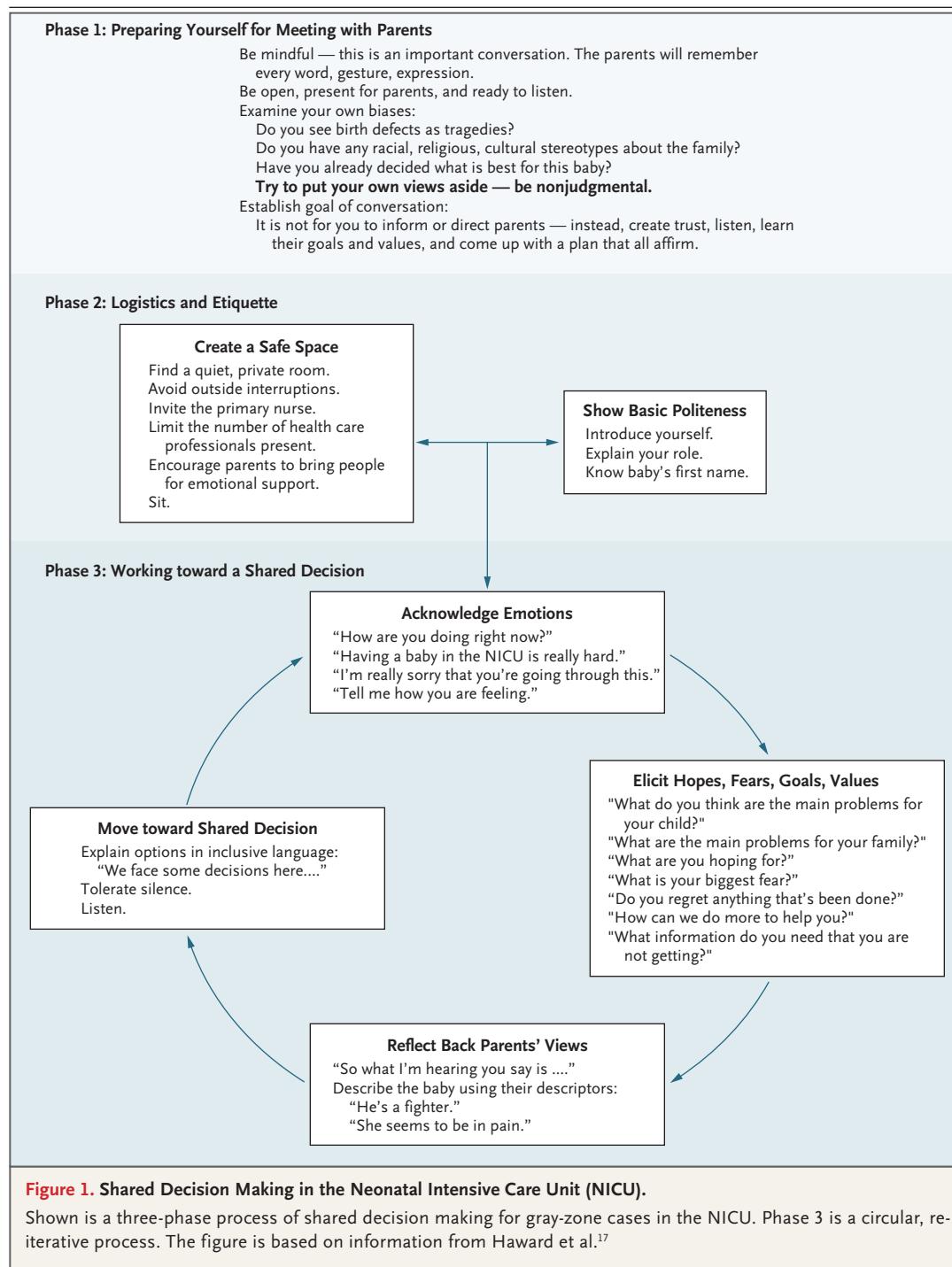
Some doctors and parents, however, worried that the benefits of neonatal intensive care had been oversold and the downsides underappreciated.<sup>24</sup> They criticized the innovators for irresponsibly ignoring troublesome long-term outcomes for NICU survivors, suggesting that, in some cases, doctors withheld bleak clinical information from parents in order to curtail discussions about withdrawing life support.<sup>25</sup> One parent recounted, "The NICU staff members went out of their way to hide information from us about the likelihood that David would have neurologic damage."<sup>26</sup> Another said, "Pessimistic assessments of Andrew's condition and prognosis had been made

by the Neurology Department, though they were never mentioned to us by anyone."<sup>27</sup> A doctor wrote, "Now that the very smallest, marginally viable neonates are rescued routinely, troubling questions have surfaced about the long-term biological and social consequences of the immediate technical triumphs."<sup>28</sup>

These critics focused on parents' need for information and parents' right to refuse unwanted treatment. A group of parents advocated for what they called "family-centered care." They wrote, "Fully informed parents should have the right to make decisions regarding aggressive treatment for their infants."<sup>29</sup> To do so, "they must have available to them the same facts and interpretation of those facts as the professionals."

Doctors took these critiques seriously. They adopted as a professional standard the obligation to give parents detailed information about possible outcomes for their babies. A 2002 policy report by the American Academy of Pediatrics (AAP) stated, "Family members should be provided with an overview of the potential complications of extreme prematurity and prolonged intensive care. They should be informed of the range of survival rates and of the types and rates of long-term disabilities that can be expected."<sup>30</sup> Over the years, the AAP has reiterated this approach. A 2009 statement read, "The purpose of antenatal counseling is to inform parents and assist with decision-making. . . . Parents should be given the most accurate prognostic morbidity and mortality data available for their infant."<sup>31</sup>

Soon, however, both doctors and parents noticed serious problems with simply giving the parents detailed facts about outcomes. One problem was that the facts themselves were not always well known or straightforward. Different centers reported strikingly different outcomes for similar babies. For example, for babies born at a gestational age of 24 weeks in the late 1980s, reported survival rates ranged from 10 to 57%.<sup>32</sup> Haward et al. wrote, "Suggesting a standardized set of facts is too simplistic. Decision making is multifaceted, and understanding risk information is dependent on relationships, trust, balances between cognitive and affective elements, life experiences, subjective interpretations of decisional outcomes, tolerance of risk/uncertainty, and other personal factors."<sup>17</sup> Benham, the parent of an infant in the NICU, wrote about the com-



plex realities of parent–professional relationships in the NICU: “Critically sick babies are cared for by a constantly rotating team of doctors, nurses, nurse practitioners, residents and specialists. . . . Some treat aggressively and some don’t.

One doctor is pro-life. One has disabled kids. One was unexpectedly widowed. All of these factors influence how they talk to parents, how they assess quality of life and how they interpret risk.”<sup>33</sup> Thus, an approach focused on transparency

**Table 1. Comparison between Data-Guided Parental Choice and Shared Decision Making in the NICU.\*****An approach focused on the process of shared decision making**

Start with open-ended invitations:

- Is now a good time to talk?
- Tell me how you're feeling today.
- How does your child look to you?
- Tell me more.

Let parents tell you what they know and how they feel:

- What have other doctors and nurses told you about your child?
- What do you fear?
- What do you hope for?

Stop talking.

Let parents speak.

Listen actively.

Make eye contact, nod head, and focus on person speaking.

Circle back: "What I'm hearing you say is.... Did I get that right?"

Find common ground; use "we":

- "We are both hoping for that goal!"
- "Here are some of the options and the decisions that we have to make."

**An approach focused on giving parents information and asking for a decision**

For each gestational age, provide parents with data in an "outcome-by-gestational-age" format for babies born at 22, 23, and 24 weeks.

## Short-term outcomes

- Percent of babies who survive
- Percent of babies who leave the NICU with respiratory problems
- Percent of babies with abnormal findings on ultrasonography of the head
- Percent of babies with jaundice requiring phototherapy
- Average number of days in hospital

## Long-term outcomes

- Percent of babies who need tracheostomy
- Percent of babies who need gastrostomy tube
- Percent of babies with cerebral palsy
- Percent of babies with cognitive impairment
- Percent of babies with visual impairment

Ask the parents whether, given the information provided, they want to choose life-sustaining treatment or comfort care only.

the shortcomings of that approach led researchers to study other aspects of shared decision making in order to develop better ways for doctors and parents to work together to make difficult ethical decisions for critically ill babies.

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 SHARED DECISION MAKING  
 AS A NEW APPROACH
 

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A new way of approaching ethically charged decisions in the NICU began to emerge in the early 2000s.<sup>36,37</sup> This new approach was stimulated by two lines of research showing that the old ways were not working. It was also prompted by research in psychology and behavioral economics suggesting more effective ways to help parents participate in decision making for their babies (Table 1).

The first line of research undermining the old approach comes from studies showing that, contrary to some widely held beliefs, most disagreements between doctors and parents about treatment choices do not arise because doctors hide bleak information that would lead parents to request withdrawal of treatment (Table 2).<sup>40</sup> Instead, disagreements occur because, even when parents are given information about the possibility of bleak outcomes, most parents want treatment that doctors think is inappropriate or futile.<sup>41</sup> Parents are more accepting of severe disability among surviving babies than are most health professionals.<sup>41,42</sup> The recent case of Charlie Gard in the United Kingdom epitomizes this type of disagreement.<sup>2</sup> Fost summarized the implications of these studies: "The gap between the views of the physicians and nurses on the one hand and the parents and adolescents on the other should be a useful starting point for health professionals who want to work collaboratively with parents."<sup>43</sup>

A second important line of research shows that most neonatologists are neither skilled at nor committed to a process of shared decision making. Although shared decision making is the ethically preferred approach (as opposed to pure parental autonomy or pure medical paternalism) in the gray zone of ethical ambiguity,<sup>44</sup> most neonatologists do not share decision making well. Only a minority of neonatologists, in a small number of clinical circumstances, allow parental preference to determine whether tiny premature babies are resuscitated.<sup>45</sup> Even though doctors

and information was neither sufficient nor necessarily empowering.<sup>34</sup> Indeed, given a physician's general approach to communication, some wondered whether transparent discussion of objective information was even possible.<sup>35</sup> Appreciation of

\* The description of shared decision making is adapted from Madrigal and Kelly.<sup>38</sup> The description of data-guided parental choice is adapted from Koh et al.<sup>39</sup> NICU denotes neonatal intensive care unit.

endorse the idea of shared decisions, in practice they make most decisions themselves.<sup>46</sup>

Another line of research that has led to new thinking about the microethics of shared decision making comes from behavioral economics.<sup>47</sup> Decades ago, Simon showed that people do not make decisions the way many philosophers and economists imagine they do. Instead, “actual human rationality can at best be an extremely crude and simplified approximation to the kind of human rationality that is implied, for example, by game-theoretical models.”<sup>48</sup> Further research has shown that framing effects, availability bias, and dozens of other predictably irrational thought patterns are an inherent part of the way our minds work.<sup>49,50</sup> These new understandings make it clear that there is no simple way to present facts (Table 2).<sup>51,52</sup>

Facts do not speak for themselves. They are always and inevitably communicated in ways that subtly shape how people interpret them and thus subtly shape the decisions that follow. The process by which facts are communicated, or framed, has been called “choice architecture.”<sup>53</sup>

People’s decisions are shaped by the ways in which choices are presented. Fifty years ago, Beecher wrote, “Patients will, if they trust their doctor, accede to almost any request he cares to make.”<sup>54</sup> Choice architecture is unavoidable when one person has the knowledge and information that another person needs in order to make a decision.<sup>55</sup> It is especially relevant and powerful in the medical context because of the imbalance in knowledge between doctor and patient.<sup>56</sup> Recognition of the role that doctors play as choice architects suggests that there might be new ways to think about the ethical responsibilities that go along with that role.

#### THE ETHICS OF CHOICE ARCHITECTURE

Doctors who counsel parents about choices for a sick baby in the NICU have a responsibility to be aware of the ethical complexity of their role as choice architects.<sup>57</sup> This responsibility holds true for neonatologists and for specialists in palliative care. Their goal should be not just to help parents understand their child’s clinical situation and prognosis but also to help parents understand the meaning of the choices they face in light of that clinical situation. Therefore, doctors

**Table 2. Three Important Domains of Research about Ethical Decisions in the NICU.**

Most disagreements that arise are unrelated to doctors’ withholding bleak information.
Parents want honesty but tempered with hope.
Parents generally are more accepting of disability than are health professionals.
Most disagreements arise when parents demand treatment that doctors think is inappropriate, not when parents refuse treatment.
Neonatologists endorse shared decision making but do not practice it.
Few neonatologists allow parents’ preferences to prevail.
Parents want to participate but also want doctors’ help.
People do not usually base decisions on objective data alone.
Many known biases lead people to make decisions that contradict their own values.
Facts are inevitably framed in a way that shapes choices.
Doctors’ biases might lead them to frame the facts in a way that inadvertently sways parents.

must first help parents articulate their own hopes, fears, and value commitments — and then connect those to the decisions at hand.<sup>58</sup> See Case 1 and Case 2 for examples of how physicians can use the shared decision-making approach to address difficult questions about neonatal treatment.

The task is particularly tricky because parents in the NICU are in the grip of very strong emotions. Parents have described how these emotions change their ways of thinking.<sup>61</sup> Forman described her experience after the birth of premature twins: “The world receded; everything took place in slow motion and was viewed as if down the wrong end of a very long telescope. So much was unfamiliar that if I was asked my name, I had to think for long moments.”<sup>62</sup> Benham recalled her racing thoughts after she first saw her baby, who had been born at a gestational age of 23 weeks: “I had crazy thoughts. Should we prepare a birth announcement? What would we name her? If she died, would we get a birth certificate? Would there be a funeral? Would we get a box of ashes, and if so, what size box?”<sup>63</sup> The strong emotions that are evoked by the NICU experience make it difficult for most parents to understand and interpret information about the complex probabilities of various outcomes.

Strong emotions lead to a distinctive set of thought processes. Parents of critically ill babies generally do not make decisions by carefully

## Case 1

A neonatologist went to speak to the teenage parents of a premature baby, Gabriel, who had been born at a gestational age of 27 weeks.<sup>59</sup> The parents were married and had two other children. Neither parent had finished high school.

By day 3 of life, Gabriel had pulmonary and intraventricular hemorrhages. After reviewing these findings, the doctor spoke with the parents about their baby's condition and poor prognosis. She was going to recommend discontinuation of life support. Instead, she asked if they had any questions. The father asked, "Will I be able to love him, even if he is handicapped?" The doctor reassured the father that Gabriel would be very lovable. The mother asked, "Will he be able to love us?" The doctor replied, "He will love you as much as any other child, probably more."

The father told the doctor that they had a nephew with Down's syndrome whom they adored. He asked if Gabriel would be like that nephew. The doctor told them that it was too early to predict the long-term effects of Gabriel's brain hemorrhage. She promised to meet with the parents every morning and update them on his condition and prognosis. The discussion never explicitly addressed questions about whether to discontinue life support. But the doctor got a good sense of the parents' values, and the discussion built a basis for trust.

## Case 2

A neonatologist was called for a prenatal consultation concerning a woman with premature rupture of membranes who was in labor at 25 weeks of gestation. The obstetricians said that she would deliver within the next few hours. The pregnancy was complicated by a prenatal diagnosis of a large omphalocele on an ultrasound examination performed at 18 weeks of gestation. The parents said they wanted everything done to save the baby. The neonatologist was tempted to simply tell the parents that treatment would be futile and that the only option was comfort care. Instead, he asked them what it was like when they first heard the diagnosis of omphalocele. He asked what they were hoping for and what they feared most. The mother expressed her shock, confusion, and grief. She wondered whether she had done something wrong to cause the baby's problems. The doctor assured her that she had not. The father wondered whether treatment in the NICU would cause pain. The doctor said that they do their best to control pain but that it would depend on how sick the baby was and what interventions were needed. Together, the parents and doctor agreed not to make any decision until the baby was born.

At birth, the baby had a heart rate of 50 beats per minute, a large omphalocele, and physical findings consistent with a gestational age of 25 weeks. The doctor told the parents that their baby could not be saved. The mother asked to hold her baby. The neonatologist wrapped the motionless and apneic baby in a warm blanket. A few minutes later, the infant was pronounced dead. The neonatologist's focus on the parents' emotional state, rather than on the futility of treatment, helped build the trust that enabled a shared decision to be made in the delivery room.<sup>60</sup>

calculating the likelihood of achieving various specific outcomes. Instead, they try to figure out what it means to be a good parent for their critically ill babies. For some parents, this effort leads to determined advocacy for or against particular interventions. For others, it means focusing on their family or religious beliefs.<sup>64</sup> Kukora and Boss note that for many parents, "hope, spirituality, compassion, input from other family members, and religious beliefs are highly influential factors when making life-and-death decisions for their infants."<sup>65</sup>

Facts are also important, but they need to be framed and contextualized to make sense in the context of other powerful concerns. Too often, doctors think that facts are not just necessary but also sufficient to guide parents' decisions. They are not. Doctors need to help distressed parents use the facts by first helping them understand and clarify their goals, values, and priorities. Only then can the doctors contextualize the facts in a way that will make them useful. If the ultimate goal for doctors is to empower parents to make decisions in gray-zone situations, then doctors must recognize the importance of choice architecture in nudging parents in one direction or another.

Because the role of the choice architect in nudging parents toward a particular decision seems to require a hefty dose of paternalism, doctors' responsibilities as choice architects may seem paradoxical or inconsistent with autonomy. This apparent contradiction has been noted in other contexts in which the philosophy of choice architecture has been called "libertarian paternalism."<sup>66</sup> The task of choice architects is paradoxical only if we assume that there is a neutral position that does not frame or shape choices and if we have a narrow view of autonomy. This narrow view interprets autonomy as a sort of rugged individualism by which each person reasons his or her way to conclusions and choices without the help of others. From another perspective, however, autonomy is realized and exercised only through caring relationships; people need the help of others to act autonomously. This view seems particularly relevant to medical contexts in which doctors' specialized knowledge, information, and communication skills are essential to help patients or parents understand the meaning of their situation and the choices they face.

The crucial role of doctors is to promote "relational autonomy,"<sup>67</sup> which begins with the assumption that our identities are formed and fully realized only through relationships. We become who we are with the help of others. Mackenzie and Stoljar describe the way relational autonomy works: "The relational autonomy model provides clinicians with ethical justification for directly engaging families in difficult conversations that acknowledge emotions and for offering parents guidance on the breadth of decisions."<sup>68</sup> According to Gaucher and Payot, a model of relational autonomy recognizes that people are "rational,

emotional, creative and interdependent”; by recognizing and affirming these aspects of parents’ experience, the physician “establishes the beginnings of a trusting relationship with the health-care team, which may last throughout the baby’s hospitalization and care, benefitting all parties involved.”<sup>69</sup>

Few people imagine what they would do if faced with a tragic situation involving their newborn baby. Most people in such situations flounder as they try to understand what it means to be a good parent and what decision is best for their baby. They need help. An empathic doctor, like a good psychotherapist, can help them clarify their own values and thereby make more authentic choices.<sup>70</sup>

How can doctors help parents make authentic choices? The first step is the hardest. Doctors must become aware of their own beliefs and unconscious biases. These may relate to disability; to the allocation of scarce resources; to parental ethnic background, educational level, sexual orientation, and socioeconomic status; or to other factors. Such beliefs and biases could cloud physicians’ perceptions of what parents want and need. The second step in helping parents is to learn to ask them open-ended questions about their hopes, fears, goals, and values and then listen carefully for key elements of the answers (Fig. 1).<sup>71</sup>

Through such questions and answers, doctors can sense what parents need. Some parents want detailed statistics, and others do not.<sup>72</sup> Some parents are angry, and others are sad. Some are in spiritual crisis, whereas others are primarily concerned about the well-being of other family members. Doctors who first explore the reasons behind the parents’ emotions, hopes, and fears can better counsel the parents to make the best decision for their child and their family.<sup>73</sup> Doctors need to learn to listen carefully (i.e., actively and intensely) to the cues and clues that parents give about their primary concerns, hopes, and fears. Such conversations take time. But time spent in such conversations up front may avoid the need for much more time-consuming and difficult conversations later in a baby’s hospital course (see Cases 1 and 2).

This approach to shared decision making will not always lead to decisions that doctors or nurses would prefer. Sometimes, parents’ values are different from those of professionals. Such differences can lead to moral distress on the

part of health care providers, especially nurses, who may find themselves required to deliver treatments that they find morally troubling.<sup>74,75</sup> When decisions about treatment fall within the zone of parental discretion, however, parents’ preferences ought to prevail. The approach recommended here helps doctors and nurses elicit parental preferences and helps parents articulate them. It does not offer a solution to the moral distress that arises from deep value differences.

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#### WHAT ABOUT RIGHT AND WRONG?

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A focus on the microethics of shared decision making may give the impression that any decision is ethically defensible. Such is not the case. The zone of parental discretion is delineated by society’s complex legal, political, economic, and cultural crosscurrents. These define the limits of the gray zone within which parental values are permitted to shape decisions. We try to do what is best for children.<sup>76</sup> If we are not certain what is best, we try to do what causes the least harm.<sup>77</sup> These principles lead to clear conclusions in most cases. When they do not, parents are empowered to make decisions.<sup>78</sup>

The boundaries of the zone of parental discretion reflect a complex mix of factors that include the current state of medical technology, prevailing and sometimes shifting cultural attitudes, and societal resources. In numerous areas of pediatrics, the gray zone has shifted. For example, surgery for correctable anatomical malformations in babies with trisomy 21 used to be within the zone of parental discretion.<sup>79,80</sup> In the 1970s, only a small minority of doctors would have sought protective custody to operate on a baby with Down’s syndrome.<sup>80</sup> By the late 1980s, two thirds of doctors would have done so.<sup>81</sup> As recently as 1981, courts sided with parents who did not consent to surgical repair of esophageal atresia because the baby had Down’s syndrome.<sup>82</sup> It is unlikely that courts would reach that conclusion today.<sup>83</sup> The shift came about only after a vigorous societal debate took place in the courts, the media, and academia about the limits of parents’ rights to refuse medically recommended treatments.<sup>84-86</sup> Along the same lines, treatment of illness in babies with trisomy 18 used to be considered futile.<sup>87</sup> Such treatment has now moved to the zone of parental discretion.

Similarly, the zone of parental discretion for babies born at the borderline of viability has

shifted over the past decades, and the shift has occurred in different ways in different places.<sup>88</sup> Some centers treat all babies born at a gestational age of at least 22 weeks. Other centers accept parental refusal of treatment for babies born at a gestational age of 24 weeks. The detailed process by which such shifts took place is beyond the scope of this article but includes technological advances such as prenatal diagnosis, legal changes such as the legalization of abortion, and changes in societal attitudes toward people with disabilities. Through this complex process, we have many widely agreed-on national standards for deciding when treatment is obligatory. At the edges, in the gray zones, individual centers develop their own guidelines.<sup>89</sup> Clinicians work with ethics committees and hospital legal counsel to define the boundaries of the gray zone at each medical center.<sup>90</sup>

#### TOWARD THE FUTURE

The central argument of this review is that an important and necessary shift is occurring in the focus of neonatal bioethics. The focus used to be on empowering parents by giving them information and on rule making to define the zone of parental discretion. Today, the focus is shifting toward an ethics of relational autonomy. Doctors need to develop new communication skills to help parents clarify their values. Doctors must also be aware of their own values as they design the choice architecture within which parents will be empowered to make choices. This self-awareness and these communication skills will be especially important as pediatrics changes and decisions become even more complex and value-laden.

Three emerging technologies are likely to loom large in the future of neonatal bioethics, testing doctors' skills in helping parents make good decisions. First, we will see continued advances in prenatal diagnosis and fetal therapy.<sup>91</sup> Genomic testing with the use of cell-free fetal DNA in maternal serum will allow more and more fetal anomalies to be diagnosed early in pregnancy. Parents will then face more complex choices than they do today about terminating pregnancy, trying innovative fetal therapy, or waiting for postnatal treatment options.<sup>92,93</sup> Many parents choose to terminate pregnancies after severe fetal

anomalies have been diagnosed, but others choose to continue their pregnancies.<sup>94-96</sup> The likely effect of better prenatal diagnosis will be that parents who learn that the fetus has congenital anomalies and who choose not to terminate the pregnancy will want treatment in the NICU for their babies. This effect could increase the number of situations in which doctors recommend withholding treatment but parents request it.<sup>97</sup>

The second looming change in neonatal bioethics involves the gradually shifting boundary of viability. Until 10 years ago, most centers were not offering resuscitation for babies born at a gestational age of 22 or 23 weeks. Now, some centers (and some countries) are reporting survival rates of 30 to 50% for babies born at a gestational age of 22 weeks and 60 to 70% for babies born at 23 weeks.<sup>98</sup> If these results are replicated at other centers and if the long-term outcomes are similar to those for babies born at a gestational age of 24 or 25 weeks, then more centers will begin offering treatment at earlier gestational ages. That will require better cooperation between neonatologists and specialists in maternal fetal medicine to ensure that pregnant women are given accurate information about options and counseling to help them make decisions.

Finally, recent research on an artificial placenta might change the way we think about treatment for the tiniest babies. To date, the artificial placenta has been used only in sheep models, but the results are impressive.<sup>99</sup> Clinical trials are likely to start soon.

Each of these developments will change the ways that we think about the boundary between fetus and infant, between acceptable and unacceptable quality of life, and between viable and nonviable newborns. Each technological change will alter the calculus by which doctors categorize treatment as beneficial, futile, or somewhere in between. Doctors will need to learn new skills in order to help parents understand the choices that they face, clarify their own values, and make good decisions. The recent turn away from rare and controversial cases and toward the microethics of everyday practice will prove to be crucial because choices are likely to become even more complex than they are now.

Disclosure forms provided by the author are available with the full text of this article at NEJM.org.

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