

## Session 12. Critically Ill Newborns

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### Overview

The newborn intensive care unit (NICU) is a common setting for difficult ethical challenges, often involving life-and-death decisions. These may include withholding treatment such as resuscitation, mechanical ventilation, or surgery or withdrawing life-sustaining medical treatment such as mechanical ventilation and artificial nutrition and hydration. Such decisions are frequently faced because of the high morbidity and mortality of some conditions commonly encountered in this setting, such as extreme prematurity, perinatal asphyxia, and major congenital anomalies. Who should decide when a treatment should be withheld or withdrawn? Ideally, decisions are made by the parents, physicians, and nurses working together, but on what basis should decisions be made? And what is to be done when they disagree? A careful ethical analysis should be carried out, based on solid clinical and prognostic data and the values of those involved in making the decision. In reality, however, data are often vague and values are often not shared in common. But a decision must, nevertheless, be reached.

Such critical ethical decisions may be more common in the NICU than in other pediatric settings, but they are certainly not unique to the NICU. Nonetheless, is there something unique about ethical problems encountered with this patient population? For example, is borderline viability based on extreme prematurity a unique situation in pediatrics, or is it analogous to other problems sometimes encountered in the care of older children? Are clinicians more willing to withdraw or withhold life-sustaining treatment for this patient population than for others in pediatrics or adult medicine? If so, is this justified?

In this teaching module, participants will examine these questions in the setting of specific case examples. The primary case involves resuscitation of a newborn infant born at borderline gestational age, but the questions and principles identified are relevant to a wider range of issues in the NICU.

### Instructor's Guide

- Case Summary
- Alternative Cases
- Learning Objectives
- Suggested Reading for Instructor
- Further Reading
- Case Discussion
- Conclusions and Suggestions

## Case Summary

A 36-year-old woman who has been pregnant 3 times but has no living children presents to the hospital in active labor with ruptured membranes at 22 weeks and 5 days' gestation. The fetus is a female singleton, the product of *in vitro* fertilization. Pregnancy was otherwise unremarkable, including several normal ultrasounds. Estimated fetal weight is 530 g. On physical examination, the cervix is dilated and the obstetrician believes that delivery will occur within the next several hours. The pediatric team meets with the woman and her husband to share information, answer questions, and discuss the plan.

- What options should be offered to the parents for resuscitation and treatment?
- If informed parents request resuscitation and intensive care, but the clinical team feels they are inappropriate, is the team nevertheless obligated to provide it?
- If informed parents decline resuscitation and intensive care measures, but the clinical team feels it is inappropriate to withhold those measures, is the team nevertheless obligated to withhold those treatments?
- What ethical principles or approaches can be applied to guide clinicians and parents through decisions regarding the care provided to this child?

## Alternative Cases

1. A woman is in labor at 32 weeks' gestation with a fetus known to have trisomy 13, including congenital heart disease. This diagnosis carries with it a high probability of death in the first weeks or months of life and profound cognitive impairment among those who survive longer. In the event of respiratory failure, should the parents be offered resuscitation? Mechanical ventilation? Should cardiac surgery be made available for this child if requested by parents?
2. A child is born at term with hypoplastic left heart syndrome. He is initially stable and placed on a prostaglandin infusion to maintain systemic blood flow. Parents are informed that there is roughly a 75% chance of survival at 5 years, but this will require at least 3 separate surgical procedures and extensive hospital time. Some neurologic disability, although probably not severe, is likely should he survive, and there is a small chance of significant neurologic disability. In addition, should he survive, there is a possibility that he might require a heart transplant later in life. The cardiology service has recommended that the surgery be performed, but the parents have requested that the prostaglandin infusion be stopped and the child be allowed to die. How should the clinical team proceed? Are they obligated to withdraw support as requested by parents, even if they disagree with the parents, and believe surgery is the appropriate course of action?
3. A full-term baby is delivered by cesarean section for severe fetal bradycardia. She requires extensive resuscitation in the delivery room, including intubation, positive-pressure ventilation, chest compressions, and epinephrine. Her Apgar scores are 1, 2, and 4 at 1, 5, and 10 minutes, respectively. The cord pH is 6.70/6.85. Early course in the NICU is notable for severe lung disease, hypotension, disseminated intravascular

coagulation, and seizures. At 7 days of age, she is minimally responsive to tactile stimulation, is ventilator dependent but with some spontaneous effort, and has magnetic resonance imaging evidence of severe ischemic changes of the brain and a markedly abnormal EEG consistent with hypoxic-ischemic encephalopathy. What options should be offered to the parents? What should the clinical team do if the parents insist on maximal efforts but the team feels this would be inappropriate?

### **Learning Objectives**

1. Understand the major components of honest disclosure when presenting options to parents.
2. Understand ethical considerations in withdrawing or withholding a specific therapy from a critically ill newborn infant.
3. Understand the parents' right to decide and limitations of that parental right, based on the rights of the newborn, including the patient's best interests.
4. Understand the roles of the parents and of the physician in critical decision making in the NICU.

### **Suggested Reading for Instructor**

American Academy of Pediatrics, Committee on Bioethics. Guidelines on forgoing life-sustaining medical treatment. *Pediatrics*. 1994;93(3):532–536

American Academy of Pediatrics, Committee on Fetus and Newborn. Noninitiation or withdrawal of intensive care for high-risk newborns. *Pediatrics*. 2007;119(2):401–403

### **Further Reading**

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## Case Discussion

### ***What should the parents be told by the pediatric team?***

After appropriate introductions, parents should be given the relevant information about likelihood of survival and long-term disability as well as anticipated clinical course should their daughter survive (eg, duration of NICU stay and common major problems). It is important to be honest with the parents and with ourselves about the degree of uncertainty of outcome data. For example, in this case the gestational age is certain because of *in vitro* fertilization, but often obstetric estimates of gestational age may be 10 to 14 days high or low, which would yield a wide range in the predicted chance of survival. Depending on the certainty of the gestational age, it may be more appropriate to speak in terms of a range of predicted outcomes rather than a specific number. Although it is important to be honest with parents with regard to the precision (or lack thereof) of the data used to present likelihood of survival and disability, one must also be cautious not to overemphasize one end or the other of the range of predicted outcomes in order to “sell” the parents on a decision one way or the other.

The predicted chance of survival may also be center dependent; simply quoting center-specific survival statistics may be inadequate. For example, some centers may never attempt resuscitation earlier than 23 weeks, tell parents that they have never had a survivor at 22 weeks, and remain unwilling to try on that basis. This reasoning is circular, creating a self-fulfilling prophecy, and thus is invalid. The appropriate question to be addressed is, what percentage of newborn infants in this situation survive when maximum efforts are made? If one does not have those data, it would be best to say so. Survival data from centers more aggressive with a given diagnosis (eg, 22 weeks’ gestation) are significantly different than from less aggressive centers.<sup>1</sup>

The conversation with parents should be based on our obligation to tell the truth and to provide them, as the surrogate decision-makers for the child, with relevant data so they can make their best decision. This recognizes their rights as parents and the child's right to have decisions made in good faith on her behalf by appropriate surrogate decision makers.

***What options should parents be given for resuscitation?***

In general, parents have a right to make the decision on their child's behalf. If there is no chance of success, however, the physician is not obligated to provide a procedure or to offer it. No newborn infant should be made to undergo a procedure, particularly an invasive or potentially painful one that offers no chance of benefit. This would include attempted resuscitation, but one needs to be sure that prognostic information is up to date. Some believe there is no chance of survival after birth at 22 weeks' gestation, but in fact, data have shown that with aggressive treatment, survival is unlikely but nevertheless possible. This possibility, in itself, does not prove that resuscitation at 22 weeks' gestation should be performed or even offered, only that a decision not to offer resuscitation cannot be justified by impossibility (or physiologic futility).

As a reasonable rule of thumb, resuscitation for this (or any) newborn infant should be offered to the parents unless there is virtually no chance of success or if providing the procedure would clearly be opposed to the child's best interest (American Academy of Pediatrics Committee on Bioethics); that is, the burdens of the procedure to the child would clearly outweigh the benefits. Burdens taken into account could be short term (eg, pain) or long term (eg, disability). Benefits might include the chance for survival and the potential happiness that life could bring to the child. Of course, this will often be a largely subjective judgment, and the balance of benefit and burden are not always clear, in which case the judgment and values of the parents should usually be determinative. Thus, unless it is clearly opposed to the child's interest (ie, there is virtually no chance of survival), resuscitation should be discussed with the parents. At present, the recommendation of the American Academy of Pediatrics, based on this approach and the currently available data, is that resuscitation should generally be considered and discussed (although not necessarily recommended) with parents of infants born at 22 weeks' gestation.<sup>2,3,4</sup>

A physician is not morally obligated to do whatever parents ask, but if the physician does refuse a request for any treatment, including resuscitation, there should be a valid moral justification for that refusal. Simply referring to hospital policy or standard of care does not in itself qualify as a valid moral argument. Any standard or policy is only as defensible as the ethical reasoning behind it.

***If the physician would recommend against a procedure (eg, resuscitation) but would be willing to provide it if requested by the parents, should the physician mention it if the parents do not?***

Parents should be made aware of their options, whether or not they know enough to ask. They should not have to be savvy enough to ask to be given that right. A counterargument might be that once they are given the option, they might feel obligated to choose aggressive care even if it is not what they truly want. Perhaps this places an impossible burden on parents and potentially a sense of guilt that could last throughout their lives, should they choose to forego resuscitation. There is often tension between the physician's obligation to fully inform parents (and give them

maximal latitude in decision making) and to minimize their suffering. Respect for autonomy is a core principle of modern biomedical ethics (as are beneficence, nonmaleficence, and justice), but this can come into conflict with paternalistic tendencies from medical professionals who desire to limit information sharing, perhaps at least in part in an effort to reduce this potential parental suffering.<sup>5</sup> These tensions should be discussed in the seminar.

***What if the physician believes the procedure (eg, attempted resuscitation) should be performed, but the parents refuse?***

Parents should be given a great deal of discretion in making such decisions, and even if the physician believes the procedure in question should be performed, an informed parent's refusal should generally be respected. There will be some threshold, however, beyond which the child has a clear right to the procedure. That threshold should be determined by the child's prognosis; that is, at some point, the chance of a good outcome with the procedure is so high that it is clearly in the child's best interest to undergo the procedure (eg, neonatal resuscitation), and it should be carried out regardless of parental preference. It could be said that at this point, the child's best interests trump, or outweigh, the parents' right to decide. Just as there may be a lower threshold of prognosis below which the neonatologist would refuse to attempt resuscitation, there should be an upper threshold above which the physician is obligated to try. In such a case, it would be disingenuous to offer the parents options if there is only one choice the medical team is willing to consider. Participants should discuss how good a prognosis should have to be to make attempts at resuscitation obligatory.

***Is it appropriate for hospitals to have policies or guidelines addressing which newborn infants should be resuscitated?***

It seems very reasonable for the appropriate clinical group (eg, a hospital's neonatology section, perhaps with input from others such as the ethics committee) to have discussed and agreed on guidelines as to which patients are candidates for resuscitation and to have shared them with obstetricians at the facility. The existence of such guidelines will avoid the problem of changes in plan or options available to parents as responsibility is handed off between neonatologists. It would seem unfair that the parents of a child born on Monday are given a choice that parents of a similar child born on Tuesday are denied, just because a different physician is on call (Mercurio 2009). Additionally, hospital-wide policies encourage consistent communication from both the obstetrician and neonatologist to families about their available options.

***How should such guidelines be developed?***

Guidelines should be based on a good understanding of the relevant data and their weaknesses, as well as sound ethical reasoning. For any group who share a diagnosis in common (eg, extreme prematurity, major congenital anomaly), considerations such as the patient's best interest, fairness, and transparency are essential. Also, guidelines should avoid grouping together newborn infants who may have very different prognoses. In the case of extreme prematurity, for example, it has been well demonstrated that there is a wide range of predicted survival for a given gestational age, depending on other factors such as gender, size, antenatal steroids, and multiple gestation.<sup>6,7</sup> Data clearly show that a larger girl born at 22 weeks' gestational could have a better chance of survival, and intact survival, than a smaller boy born at 23 weeks' gestation.<sup>6</sup> Thus, it makes little sense (and would be unjust) to offer resuscitation to the 23-week boy's

parents but not the 22-week girl's parents. Policies based on gestational age alone greatly increase the likelihood of such injustice. A similar problem may be found with congenital anomalies, such as severe congenital heart disease, if patients are inappropriately considered together despite very different prognoses.

Overall, it would seem preferable to base resuscitation policies on prognosis, recognizing that the numbers provided in the literature will often be approximations. It also seems reasonable to allow discretion within those guidelines to the physician on the scene. National and international organizations (including the American Academy of Pediatrics and the Nuffield Council on Bioethics) have created guidelines that may prove helpful. Perhaps it would be ideal if there were, with allowance for physician discretion and exceptions, one policy for all hospitals in a given region or country. This could avoid the injustice of offering parents of similar babies in nearby facilities very different options. Here again, a defensible policy would be grounded in deliberation based on applying sound ethical principles to available data.

***Should resuscitation be less obligatory for a newborn infant compared with older children? Should parents be given more latitude in deciding whether resuscitation is performed in the case of a newborn infant, compared with an older child with a similar prognosis?***

It is often stated that all children deserve equal consideration when such decisions are made, but in practice, physicians might consider resuscitation or other life-saving procedures as more “optional” for a newborn infant than for an older child with a similar prognosis for survival and disability. Although this would be difficult to prove, survey data support this supposition, particularly in the case of premature newborn infants.<sup>8</sup> A possible explanation (although not necessarily a moral justification) for this differential treatment by medical providers might be that the newborn infant has not yet developed interpersonal relationships with parents to the extent that older children, even older infants, have. Participants should discuss whether a different (less obligatory, more permissible) approach to resuscitation should exist for newborn infants and what possible ethical justifications there would be for that difference. It is here suggested that unless a valid ethical justification can be identified, different criteria for resuscitation specifically for the case of newborn infants should not be permissible. This same question can be discussed for the example of artificial nutrition and hydration or for surgical intervention.

***If the patient is resuscitated and placed on a mechanical ventilator, is it morally permissible to later withdraw the endotracheal tube or other life-sustaining treatment, thus allowing the baby to die?***

Many ethicists have suggested that if it was permissible not to place the endotracheal tube, it would be equally permissible to withdraw it (ie, withdrawing life-sustaining support is morally equivalent to withholding that support). In some situations, withdrawing might even be preferable to withholding from an ethical standpoint, because clinicians may have more prognostic information than was available at birth. Thus, parents are often given the option of attempted resuscitation and beginning intensive care and then deciding whether to continue. Two important caveats should be considered: (1) although it may be equally permissible from an ethical standpoint, it may be psychologically more difficult for parents or staff to withdraw interventions once they have been initiated; and (2) the acceptability of withholding intubation or resuscitation is based on prognosis, and if prognosis changes for the better (eg, the patient does

significantly better than was anticipated), at some point it may no longer be appropriate to withdraw intensive care measures.

## Conclusions and Suggestions

Physicians should be familiar with current outcomes data, and the limitations of those data, before making decisions or policies regarding newborn resuscitation. Each facility that provides medical care for critically ill newborn infants should discuss the data, as well as the relevant ethical and practical considerations, to develop a general approach to newborn resuscitation. The primary consideration in developing such a policy should be the patient's prognosis.

Parents have a right to know all information relevant to major decisions concerning their child, and it is the obligation of the physician to provide that information honestly, even if parents do not think to ask.

After sharing the relevant information, physicians should work with parents to determine a plan for their child. In general, the wishes of parents should prevail, but there will be rare circumstances wherein the parents' right to decide will be limited by the rights and best interests of the child.

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