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CLINICAL CASE

Physician and Parental Decision Making in Newborn Resuscitation

Commentary by Eric C. Eichenwald, MD, Frank A. Chervenak, MD, and
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An ultrasound performed on a woman who was 23-weeks pregnant revealed multiple findings suspicious for trisomy 21 syndrome, (Down syndrome). The woman and her husband were devastated, saying they could not possibly raise a child with mental retardation and physical anomalies, and they requested a termination. The obstetrician recommended amniocentesis for chromosomal analysis that would give definitive diagnosis of trisomy 21, and the test was performed. The parents said they planned to terminate the pregnancy if the results of the chromosome analysis confirmed Down syndrome.

Before the results were returned, the woman arrived at the labor and delivery unit with a tender abdomen, purulent discharge from the cervix, and high fever. She appeared to have an acute intrauterine infection from the amniocentesis procedure. Antibiotics were started, but it soon became clear that the woman was becoming septic; the obstetrician on call recommended rapid delivery of the fetus. The woman and her husband again clearly stated that they wanted no resuscitation performed on the infant after delivery. The couple and the physicians agreed that, given the probability of a severely anomalous infant, the plan would be to provide only comfort care measures.

The woman's labor was induced and she delivered a liveborn female infant, surprisingly robust. The infant had a strong cry, kicked vigorously, and was much larger than anticipated. The neonatologists examining the infant found themselves reconsidering their decision to withhold resuscitation. Suddenly the seemingly certain prenatal diagnosis of Down syndrome appeared implausible, given the appearance of a strong infant without apparent anomalies. The NICU team realized that, under any other circumstance, resuscitation measures would be well under way; they became uneasy as they watched the premature infant's forceful kicking and energetic cries. Within minutes to hours the female infant's lungs would tire and she would die without respiratory support.

The physicians announced to the parents their decision to reverse their previous plan to withhold care based on the healthy appearance of the neonate. The neonatologist described the resuscitation measures they planned to begin. The parents were infuriated. "We had an agreement," the father retorted. "My wife and I made it very clear to you that we cannot manage an impaired child. This is our decision to make—we're the parents, and it is your duty to respect our wishes."

Commentary 1

by Eric C. Eichenwald, MD

Decisions about whether to provide intensive care to periviable infants remain some of the most difficult in neonatology. These decisions do not occur in a vacuum; rather they are complex interactions among parental concerns and rights; societal norms, which may be regional rather than national; and the neonatologist's opinions about viability and medical futility. The case presented is an excellent example of the potential conflicts among these competing demands, and it helps focus some of the issues surrounding prenatal consultation and parental decision making.

Clinical Facts

So, what are the facts about outcomes of extreme prematurity? We know that below a certain gestational age (approximately 22 weeks), because of immaturity of the major organ systems, death is certain even with aggressive care—hence, providing intensive care is medically futile. With advancing gestational age, the chances of survival increase, though this may come at the cost of significant long-term morbidity, especially in those infants born between 23 and 24 weeks' gestation. For example, in the Vermont Oxford Network (a voluntary network for data collection in more than 650 neonatal intensive care units in the U.S. and abroad), among infants born between 1996 and 2000 with a birth weight of 401 to 500 grams and a mean gestational age of 23.2 weeks, mortality was 83 percent, and survivors often had serious short-term medical complications [1]. The EPICure study reported outcomes for all infants born at a gestational age of 20 to 25 weeks over a 10-month period in 1995 in the U.K. and Ireland. Only 811 of the 4,004 infants (20 percent) received intensive care, and 39 percent of those survived to discharge [2]. Of the survivors, 16.5 percent had ultrasonographic evidence of severe brain injury. Of these surviving infants who were evaluated at 30 months of age, half had a motor, cognitive, or neurosensory disability; in approximately one quarter of the children, the disability was considered severe.

The National Institutes of Child Health and Development Neonatal Research Network recently analyzed outcomes at 18 to 22 months of age of 4,446 infants born between 22 to 25 weeks' gestation at 19 centers in the United States [3]. Of these, 83 percent received intensive care in the form of mechanical ventilation. Of the infants for whom outcome could be determined, 49 percent died, 61 percent died or had profound impairment, and 73 percent died or had impairment (defined as mental retardation, moderate or severe cerebral palsy, blindness, or deafness). Factors in addition to gestational age that were found to affect a favorable outcome to intensive care included being female, exposure to antenatal corticosteroids, singleton gestation, and birth weight. A web-based tool to approximate survival without impairment based on these data is available at the National Institutes of Health web site [4].

How Neonatologists Act on These Facts

How do neonatologists interpret these data when it comes to decisions in the delivery room about resuscitation of an individual infant? A cross-sectional survey of 149 practicing neonatologists in six New England states queried attitudes about whether intensive care was beneficial at different gestational ages [5]. At or below 23-0/7 weeks gestation, 93 percent of the reporting neonatologists considered treatment futile. In contrast, at 24-1/7 to 24-6/7 weeks and 25-1/7 to 25-6/7 weeks' gestation, 41 percent and 84 percent of respondents, respectively, considered treatment beneficial. When asked to consider parental requests, 91 percent of the neonatologists responding reported that they would resuscitate in the delivery room despite parental requests to withhold treatment if they considered treatment to be clearly beneficial.

When respondents considered treatment to be of uncertain benefit, 100 percent reported that they would resuscitate if parents requested, 98 percent reported that they would resuscitate if parents were unsure, and 76 percent reported that they would follow parental requests to withhold. Thus, while parents' requests about their infant's resuscitation influence the neonatologist's decision making in the delivery room, these decisions are also heavily influenced by the physicians' beliefs about the gestational age bounds of clearly beneficial care, which are strikingly variable among physicians.

These data reinforce the need for prenatal consultation with parents prior to the expected delivery of an extremely preterm infant. In the same survey of New England neonatologists, respondents were queried as to the content of prenatal consultation [6]. The results showed that neonatologists consistently discussed the clinical issues anticipated with the expectant parents, but they varied when it came to discussing the social and ethical issues surrounding an extreme preterm birth. Of note, while 77 percent of the neonatologists surveyed indicated they thought that decisions about withholding resuscitation should be made jointly with parents, only 40 percent said that the decision is made by both parties in actual practice.

While it is clear that the consulting neonatologist's beliefs about the benefits of providing intensive care influence how the consultation is performed, it is also evident that how the message is framed to parents influences decisions. In a survey of adult volunteers, a hypothetical vignette of a threatened delivery at a gestational age of 23 weeks was given to participants [7]. Respondents were randomly assigned to receive the same prognostic outcome information framed as either likelihood of survival with lack of disability (positive frame) or the chance of dying and likelihood of disability (negative frame), and asked to decide on resuscitation or comfort care. Overall, 24 percent of respondents chose comfort care, and 76 percent chose resuscitation. More participants chose to provide comfort care rather than resuscitation when the vignette was presented in a negative frame.

In practice, because of the uncertainty surrounding outcomes in periviable infants, after prenatal consultation even, many parents are unable to state definitively

whether they desire resuscitation or not. In these circumstances, it is left to the neonatologist to decide whether to intervene in the delivery room. Many neonatologists use their initial assessment of the infant at birth and the response to initial resuscitative efforts to help them decide whether to proceed with further intensive care. In a study of outcomes of infants with a birth weight equal to or less than 750 grams, proxy measures of “how the infant looked” in the delivery room (Apgar scores and heart rate at one and five minutes) were neither sensitive to nor predictive of death before discharge, survival with neurologic disability, or intact neurologic survival [8].

Guiding Principles for Decision Making

Where are we left with these difficult decisions about what to do in the delivery room when a periviable infant is born? First, prenatal consultation should provide the expectant parents with factual information about survival and outcomes, unfettered by the neonatologist’s personal beliefs. Second, it is essential that the parents’ beliefs and attitudes about quality of life be sought and understood. Finally, respect for the parents as decision makers for their unborn infant must form the basis for these conversations. It must remain clear, however, that after the infant’s birth, the neonatologist’s first duty is to his or her patient—the newly born infant. While the judgment to offer resuscitation to an individual infant should be heavily influenced by the parents’ wishes, if clinical circumstances are found to be different after birth than was expected, the physician must first consider the rights of the baby.

This case presents exactly that dilemma—a prenatal diagnosis which is unconfirmed, and an infant perhaps more mature and vigorous than expected. Here, several errors may have been made which influenced the parental decisions. It is unclear whether the parents were provided a sense of the uncertainty of the diagnosis of trisomy 21 based on the ultrasound findings. Many findings “associated” with an aneuploidy may also be seen in a normal fetus. When the mother developed chorioamnionitis after the amniocentesis, the decision to resuscitate the infant needed to be reconsidered and discussed with the parents in the context of what to do if the diagnosis of trisomy 21 was incorrect. It is possible that the parents, when provided with the full information about the outcomes of extreme prematurity, might have chosen resuscitation in the absence of a chromosomal abnormality.

Lastly, as is true for any prenatal consultation, uncertainty about the gestational age needs to be clarified—it is clear that differences of 1 week of gestation can profoundly alter outcome and influence the decision to provide intensive care. While the neonatologist does indeed have a duty to respect the parents’ wishes, he or she also has an obligation to provide care that is, in his or her opinion, beneficial to the baby. I would argue in this case, since the gestational age of the infant is certain to be 23 weeks or less, our knowledge of outcomes would swing the first duty to the parent’s strongly expressed wishes for no resuscitation, and, regardless of the condition of the infant after birth, comfort care would be appropriate.

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Commentary 2

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This case involves the physician’s ethical obligations to a pregnant woman and her husband during pregnancy and also the physician’s ethical obligations to a neonatal patient and its parents after liveborn delivery. The difference between these two sets of ethical obligations is crucial for understanding how the team should respond to the refusal of intervention by the child’s parents.

The Pregnant Woman as a Patient

The physician’s ethical obligations to a pregnant woman are both beneficence-based and autonomy-based. As her fiduciary, i.e., a professional committed to protect and promote her health-related interests, the physician has a beneficence-based obligation to offer, recommend, and perform clinical interventions that are reliably expected to result in the greater balance of clinical goods over clinical harms for the woman in the course of her pregnancy. Pregnant women have their own perspective on health-related and other interests, and the ethical principle of respect for patient autonomy obligates the physician to provide the pregnant woman with the

information relevant to her decisions about the clinical management of her pregnancy and then to implement only those clinical interventions that she authorizes as a result of the informed consent process [1].

The Fetus as a Patient

The physician also has beneficence-based obligations to protect and promote the health-related interests of the fetus, but only when the fetus is a patient. The physician does not have autonomy-based obligations to any fetus, because its developmental state does not support the complex psychosocial functioning by virtue of which an individual generates its own moral status. In the language of ethics, the fetus is not capable of generating independent moral status or rights, hence the concept and discourse of fetal rights are best avoided in determining a physician's ethical obligations to a pregnant woman.

The fetus is a patient when it is presented to a physician or other health care professional for clinical interventions. In the language of ethics, the fetus has dependent moral status when there are links between its current existence in utero and its later becoming a child. Before viability (the ability of the fetus to survive ex utero with full technological support) the only link between a fetus and its later becoming a child is the pregnant woman's autonomous decision to confer the dependent moral status of being a patient on her fetus. Prior to viability the pregnant woman is free to withhold conferring moral status or, having conferred it, to withdraw it.

When a woman presents herself to a physician or other health care professional after viability (typically after 24 weeks' completed gestation by reliable ultrasound dating), the fetus is a patient, and the physician has beneficence-based obligations to protect and promote its health-related interests. We emphasize that the fetus is not a separate patient, because these beneficence-based obligations must always be balanced against the physician's autonomy-based and beneficence-based obligations to the pregnant woman [1].

It is well accepted in obstetric ethics that a pregnant woman is free to withdraw the conferred moral status of being a patient from a previable fetus whether the fetus has an anomaly or not. Therefore, a woman is free to continue or end her pregnancy in either case. When there is a suspicion of trisomy 21 with ultrasound late in the second trimester, the obstetrician should attempt to resolve this uncertainty as expeditiously as possible with invasive genetic diagnosis.

In this case scenario, the physician would have been ethically justified to offer the pregnant woman invasive intervention to cause in utero fetal death by intracardiac potassium chloride injection before labor was induced [2]. A major preventive ethics aspect of this case, unmentioned in the scenario, is that this option should have been discussed with the parents by the physician. Because the fetus is previable, the pregnant woman's autonomous decision making determines whether or not it has conferred status as a patient. Had she decided to withdraw the status of being a

patient from her fetus at that time, it would no longer have been a patient. Terminating the life of a previable fetus in utero does not violate any professional, beneficence-based obligations to a fetal patient and is therefore permissible in obstetric ethics.

If her pregnancy had continued to viability, then the fetus would have become a patient. We have argued elsewhere that it is permissible to perform an abortion of a viable fetus but only when one of two conditions is met: “a very high probability of a correct diagnosis...[with] either (a) a very high probability of death as an outcome of the anomaly diagnosed or (b) a very high probability of severe irreversible deficit of cognitive developmental capacity as a result of the anomaly diagnosed” [3]. Neither condition, we emphasize, can be competently judged to be met by presence of Down syndrome, much less the increased risk of Down syndrome. Therefore it would be unethical to perform termination of a viable pregnancy in this context.

The Neonate as a Patient

A fundamental component of the ethical concept of the previable fetus as a patient is that this moral status is a function of the pregnant woman’s autonomous decision to confer it. In contrast, infants born alive in the presence of health care professionals become patients independently of the autonomy of their parents. This is because the general ethical concept of being a patient requires only that the human being in question be presented to a physician or other health care professional and that there exist clinical interventions that are reliably expected to result in the greater balance of clinical goods over clinical harms to that human being. Moreover, parents of a liveborn infant become his or her moral fiduciaries, and they, too, are obligated to protect and promote the health-related interests of their child. Thus, a liveborn infant simultaneously acquires two kinds of mutually reinforcing moral status—one as a patient of health care professionals to whom the infant is presented and a second as a child of his or her parents. As their child’s fiduciaries, parents have a beneficence-based obligation to authorize clinical intervention when their child’s health care professionals have beneficence-based obligations to intervene [4].

Neonatal resuscitation and subsequent neonatal critical care management are understood to be trials of intervention. They are undertaken to achieve the short-term goal of preventing imminent death and the long-term goal of an acceptable clinical outcome. For infants, acceptable outcomes should be understood from a clinical perspective: is continued critical-care intervention reliably expected to preserve some interactive capacity that will support some psychosocial development that is not overwhelmed by the child’s condition or the iatrogenic complications of treatment?

The ethical analysis of the neonate’s status as a patient has important clinical implications in this case. The outcomes for infants born at reliably estimated 23 weeks’ gestation vary according to the infant’s sex, its singleton versus multiple status, and administration of steroids [5]. Outcomes also vary by the presence and severity of anomalies [6, 7].

Resuscitation and transfer to the neonatal intensive care unit (NICU) is reliably expected to prevent this neonate's imminent death, hence the short-term goal of clinical intervention, preventing imminent demise, can be reasonably expected to be achieved for this patient.

Concerning the long-term goal of achieving an acceptable clinical outcome, we note that this infant was a singleton and is female, factors that increase her chance of survival and decrease the risk of developmental impairment. In addition, no anomalies have been identified. Even if trisomy 21 had been confirmed by genetic evaluation, that anomaly cannot be reliably predicted to eliminate interactive capacity and psychosocial development; most infants with Down syndrome have mild or moderate mental retardation, both of which are compatible with significant psychosocial development.

The father's express concern that he and his wife are not able to manage an impaired child has uncertain bearing on decision making at this time, because a prediction that their child would be significantly developmentally impaired as a result of extreme prematurity is uncertain. It is ethically impermissible for the team to discontinue clinical management of this neonatal patient at this time, because it cannot be reliably expected that the second goal of critical care intervention—an acceptable clinical outcome—will not be achieved.

The judgment that there is sufficient clinical and ethical justification to resuscitate and transfer the infant to the NICU should be explained to both parents. They should be counseled about continuing clinical management as a trial of intervention that will be reconsidered should evidence-based clinical reasoning subsequently support a prognosis of imminent death that cannot be prevented or of irreversible, profound loss of developmental capacity from the child's condition or iatrogenic complications.

Another preventive ethics aspect of this case is that both parents should be informed prior to birth, that when physicians and other health care professionals have a fiduciary, beneficence-based obligation to continue clinical management, parents have a directly parallel fiduciary responsibility to authorize such management. The goal of the discussion should be to prepare the parents for the shift from obstetric to neonatal ethics and the relatively diminished force of parental autonomy in the latter circumstance. We have argued that these parallel and mutually reinforcing fiduciary obligations are still substantial despite predicted caregiving burdens [1, 3].

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