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CLINICAL CASE
Reframing Neutral Counseling
Commentary by Anne Drapkin Lyerly, MD, MA

A 19-year-old woman who said she was 25 weeks' pregnant was rushed into labor and delivery crying from the pain of regular uterine contractions. Her cervix was dilated to 3 cm, and she was diagnosed with premature rupture of membranes and preterm labor. An ultrasound revealed a fetus measuring 21 weeks' gestation in vertex position. The woman had had no ultrasound during her pregnancy but stated that she was sure of the date of her last period. Fetal heart tracing was suspicious for acute fetal distress, and the obstetrician worried that the woman's due date was not accurate and that the fetus might be too preterm to have any chance at resuscitation. The woman begged the obstetrician, "Please save my baby."

The obstetrician knew that a classic cesarean section with a vertical incision on the uterus would be the least traumatic means of delivery for the infant. Very premature infants with thin epidermis and partially ossified skulls are at risk for major intracranial bleeding and tissue ecchymosis from passage through the birth canal. A vertical uterine incision, however, would make future vaginal deliveries impossible for the woman due to the risk for uterine rupture with a future labor. The obstetrician knew further that the emergency induction of general anesthesia needed for immediate delivery of the distressed fetus places pregnant women at particularly high risk for serious respiratory complications. Given the conflict between the mother's statement and the ultrasound report, the fetus could be 21 weeks old and not yet viable, or it could be a growth-restricted 25-week fetus.

Knowing the risks of both courses of action, the obstetrician counseled the mother on her options: (1) a classic cesarean section under general anesthesia with serious short- and long-term risks to the mother and baby that may not survive, or (2) labor with likely birth trauma to an extremely preterm fetus already in severe distress. The obstetrician considered the unwritten rule that seemed to shroud these situations. The move toward nondirective counseling had been so roundly endorsed that physicians felt unable to share their years of experience with patients out of fear of inappropriately influencing patient decisions. Patients, lacking preparation or experience to make such difficult decisions, routinely asked for advice about how to proceed. Neutral counseling, now mandated by hospital policy, left the obstetrician with little comfort, feeling that mothers were increasingly undergoing invasive interventions to save impaired infants with marginal chances at normal lives, in large part because they were ill-equipped to make the decisions.

Commentary

Decisions at the threshold of viability are some of the most difficult in perinatal medicine. Like other thresholds, the space of questioned viability is fraught with ambiguity—about the roles of obstetricians and neonatologists, responsibilities of pregnant women and their partners to the life they have created, and the fine line between the maintenance of hope and imposition of harmful interventions at what may well be the inevitable end of a life.

Oftentimes the angst associated with these decisions stems from uncertainty about the optimal course of action—whether, for example, cesarean delivery or aggressive resuscitation would be beneficial. This case poses a very specific challenge, since the optimal clinical course, expectant management and vaginal delivery, is clear. Consider first the question of gestational age. Is this fetus a previable 21-week fetus or a growth-restricted 25-week fetus, as menstrual dating suggests? According to the American College of Obstetricians and Gynecologists (ACOG), most ultrasound fetal-weight formulas estimate gestational age within two weeks of menstrual dating [1]. With a discrepancy of more than two weeks between the ultrasound and menstrual dating, the ultrasound estimate is used, signifying that 21 weeks is the correct gestational age—an age at which there is no chance of resuscitation, and no reason for surgical intervention.

What about the possibility, however slim, that the dating discrepancy is the result of severe fetal growth restriction and the fetus's gestational age is 25 weeks—clearly beyond the critical threshold of viability? Like gestational-age estimates, weight estimates strongly urge expectant management: neonatal survival at an estimated fetal weight of less than 400 grams (estimated fetal weight for a 21-week fetus is 360 grams) is not reported [1]. Again, the facts leave us without a good reason for aggressive intervention.

According to the case narrative, the obstetrician "knows" that a classic cesarean would be the least traumatic means of delivering the infant, but the facts, again, suggest otherwise. Although some clinicians cautiously raise the possibility of a role for surgery in cases of extreme prematurity with fetal growth restriction [2], ACOG points out that numerous retrospective, nonrandomized studies have failed to demonstrate a benefit of cesarean delivery for an extremely preterm fetus [1, 2]. It can also be argued that what is lost in a cesarean delivery —a gentle vaginal birth and the opportunity for a premature infant to be held in the minutes or hours before its inevitable death— constitutes significant trauma in itself.

The loss of opportunities to deliver future children vaginally and potential for complications during future pregnancies as a result of the vertical uterine scar are added costs borne by the woman. It is difficult to resist intervening in circumstances that appear dire, but the facts tell us this is exactly what we should do.

Nondirective Counseling

What the case facts don't tell us is how to counsel the patient. In many areas of reproductive medicine (and of medicine generally) neutrality in counseling has been advocated. For prenatal counseling, the commitment to nondirectiveness stems in part from the troubling legacy of eugenic movements in the early decades of the 20th century. In nondirective counseling [3], statistical probabilities are presented as neutrally as possible so that both continued gestation and pregnancy termination of a chromosomally (or otherwise) abnormal fetus appear to be reasonable options, depending on a patient's values and life context. The goal of nondirective or neutral counseling is to promote patient autonomy, or self rule, by avoiding the undue influence of another's values. But in the case at hand, what might seem to be neutral or nondirective counseling has a very different effect.

Consider what nondirective counseling might entail in this case. The physician would present the options: expectant management and vaginal birth versus classic cesarean delivery aimed at maximizing any chance of saving the fetus. Inasmuch as the evidence does not support the latter, the real difference between the two options is the level of risk to the woman. What the patient hears in this neutral presentation, however, is that the option that poses an increased risk to her holds greater promise of saving her baby. Many obstetricians will attest that most women will make the only choice they can as mothers-to-be—accepting the risk to "save the baby." Despite nondirective counseling, only one choice emerges as reasonable.

Here we see the limitations of nondirectiveness. Two questions arise: (1) is the pregnant woman's choice to accept risk the better clinical choice? And (2) is her decision truly autonomous? The literature and statistics reviewed above suggest strongly that the answer to the former question is no. For an answer to the latter, we can look to the work of scholars who have recently investigated whether decision making following neutral disclosure of information can ever, in fact, be autonomous. Bioethicist Rebecca Kukla argues that "respecting autonomy has more to do with the overall shape and meaning of [patients'] health care regimes" than ensuring that patients "make their own decisions" [4]. According to Kukla, the practitioner's responsibility is not simply to disclose relevant information, but to be aware of the ways that this information is understood and acted upon.

In a society that valorizes maternal sacrifice and the miracle babies of modern neonatal medicine, many patients find it morally reprehensible to decline a cesarean delivery, even in the face of impossible odds presented accurately. If the physician wants (as she should) to make the option of nonintervention reasonable or reachable for this patient, something else is needed.

The Importance of Framing

In this and many other cases, that something else is framing, presenting options to patients in a way that is meaningful and understandable in the context of their lives as patients, aspiring parents, and moral agents. Framing is not accomplished by informing patients of probabilities, however accurate, of morbidity associated with expectant management and vaginal birth versus classical cesarean. For one thing,

such disclosure implies that the question of delivery mode is reasonably open, when, clinically, it is not. Rather, framing requires communicating effectively that this woman's fetus has an incalculably small chance of survival, pursuing that chance would come at a dear cost to woman and fetus alike, and expectant management is a medically and morally appropriate approach.

How might framing be accomplished for the perinatologist who is much more familiar with welcoming life than bidding it farewell? For one, the physician should take great care not to frame the decision about the delivery mode in terms of providing or withholding technology. The decision to proceed with expectant management and vaginal delivery at the threshold of viability is often framed as withholding treatment, which makes the decision to resist the use of technology counterintuitive if not inexcusable to a parent-to-be.

The sense of moral wrongness associated with withholding treatment from one's newborn undermines the goal of nondirective counseling, which is to assure meaningful, uncoerced informed consent. Instead it calls into question the very meaning of autonomous decision making and the circumstances that, as Kukla points out, foster autonomy. The choice of vaginal delivery should be framed as a good, compassionate option, and one that a loving mother could choose. Cesarean delivery should be described as a medical intervention that carries costs to the woman and infant alike, and one without clinical evidence to support its use; it should not be framed as an act of hero(ine)ism.

If a patient proceeds with vaginal birth, she and the physician may call the impending delivery what it is—a miscarriage. As a technical medical term, "miscarriage" is often reserved for fetuses born prior to 20 weeks' gestation. But this cut-off point is used to denote an inevitable delivery at a gestational age at which the neonate is incapable of surviving—circumstances that apply in the case we are discussing. Moreover, the term miscarriage has profound cultural and social meanings that transcend its clinical denotation. It names a process that is inevitable and sad. Use of the term creates space for mourning and reverence and directs others toward the task at hand, which is to care for the pregnant woman as she undergoes the loss of a desired pregnancy.

Some will debate the use of the term miscarriage in this setting, but the lesson is less contestable. At the threshold of viability, neutral disclosure of probabilities associated with cesarean and vaginal delivery restricts true autonomy by forcefully setting as a default the use of technology and surgical intervention. To present an expectant mother whose fetus is in danger with the option of assuming risk to herself to increase the chances of her infant's survival, when the latter is not supported by clinical evidence, is neither responsible nor nondirective. Instead, it directs most women to choose an option that imposes loss without benefit and removes a choice in which many women would find meaning. Rather than detached objectivity, the task of compassionate obstetrical care is to accompany patients through the weighty

decisions, transformations, and (all too often) the mourning that choices at the threshold of viability entail.

References

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

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