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Ethical challenges in the new world of maternal–fetal surgery

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ABSTRACT

This article explores some of the complex ethical challenges that exist in the field of fetal diagnosis and treatment, especially surrounding maternal–fetal surgery. The rise of these new treatments force us to reconsider who or what is the fetus, what are our obligations to the fetus, and what are the limits to those obligations. In addition, we will consider provider and professional biases, disability issues, and how maternal–fetal surgery has, for a select group of women, changed the very experience of motherhood.

Fetal diagnosis has always been medically complex and ethically controversial. Rapid advances in molecular genetics and advanced imaging technologies have given clinicians an unprecedented look into the womb. Until recently, however, advanced diagnostics were used primarily for decision-making around pregnancy termination and preparing for postnatal treatment. But now a selected group of women have a third option. What was once considered, science fiction has become a reality—surgery on the fetus. Harrison et al.[1] at the University of California, San Francisco pioneered open fetal surgery in the 1980s. The theory was simple: if an intervention for congenital anomalies took place prior to birth, one might be able to cure, or at least mitigate, the negative consequences that would be inevitable if surgery was delayed until the fetus was delivered.

The pace of medical and social developments in this arena is dizzying. Consider that in the early 1980s standard treatment was withheld from more than half of infants with a myelomeningocele.[2] After the Baby-Doe controversy, postnatal treatment of spina bifida came to be understood as mandatory.[3] And today eligible women are offered prenatal repair of their fetus' myelomeningocele.[4] In the wake of these rapid societal shifts precipitated by technological advancements, a new set of ethical challenges has surfaced. For what is both morally important and problematic, is precisely that the procedure is not, properly understood, "fetal" surgery. It is more appropriately termed "maternal–fetal" surgery: both the fetus and the mother undergo surgery. Significantly, such a surgery poses physical harm and offers no direct physical benefits to the mother.

The purpose of this article is not to provide an overarching ethical framework to guide prenatal decision-making. Instead, my aim is far less ambitious: to provide an overview of some of the major ethical questions that underlie the challenges for the physicians face when caring for pregnant women and ill fetuses. Questions such as: who is the patient (the pregnant woman, the fetus, or both) and how ought we navigate the tradeoffs, which invasive procedures yield each individual? Are there specialty-specific biases and commitments that unduly influence the counseling process? How have fetal diagnostics and interventions changed the very experience of motherhood? Is the risk of fetal death associated with maternal–fetal surgery for nonlethal conditions discriminatory against people with disabilities? And finally, should pregnant women be obligated to undergo surgery in order to benefit their fetuses?

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But who is the patient?

The majority of fetuses prenatally diagnosed with congenital anomalies now have a physician monitoring them before they are born. With evolving technology, many diagnosed fetuses are not just monitored but also undergo treatment in utero. These treatments vary from minimally invasive blood transfusions for fetal anemia to more invasive fetoscopic procedures for twin-to-twin transfusion syndrome to open surgical repairs for spina bifida. In this current age of medicine, most would argue that the fetus has become a patient.[5]

McCullough and Chervenak[6] explicate the fetus as patient idea.[7,8] They strategically bypass any discussion about fetal personhood given the deep-seated metaphysical disagreements surrounding the moral status of the fetus. Instead, they focus on the concept of patienthood. The previable fetus becomes a patient, they argue, when (1) the mother presents her to the physician and (2) when there exists a clinical intervention to benefit the fetus. They argue that the fetus has no intrinsic moral status but rather a "dependent moral status," which is conferred upon the fetus only when the pregnant woman presents the fetus to the physician. In this paradigm, the status of the fetus as patient is only ever contingent: if the mother desires the fetus to be viewed as a patient, her "thinking makes it so."[9] The physician does have beneficence-based obligations to protect and to promote the best interest of the fetus but only if it is brought to her. They reject that fetal patienthood necessarily implies that the pregnant woman and fetus are separate patients.

On the other hand, Lyerly et al.[10] argue that fetal patienthood will encourage viewing the pregnant woman as simply the fetal environment, thus obliterating her own identity. The authors acknowledge that both physicians and pregnant women have beneficence-based obligations toward the fetus. They cite taking prenatal vitamins to prevent birth defects as one example. Yet, they believe that the "concept of fetus as patient" will animate conceptualizations of the fetus and pregnant woman as two separate patients. This could result in physicians regarding "their obligations to and the value of each of their patients as equal." Instead, Lyerly et al. argue for a single patient, the pregnant woman.

This emphasis on symbiosis is helpful for a field marred with a feto-centric history.[11] Fetuses are not separable from pregnant women. Yet, the fetus is also not reducible to the pregnant woman—not merely an extension of her flesh analogous to a kidney. Rich[12] describes the fetus as "something inside and of me, yet becoming hourly and daily more separate." Young[13] recollects fetal movements as "belonging to another, another that is nevertheless my body." Understanding pregnancy as a separate existence or as a single existence fails to accurately account for the phenomenon at hand. Pregnancy is experienced as "the splitting of the subject: redoubling up of the body, separation and *coexistence* of the self and another."[14]

Lyerly et al.[10] take a surprising turn when they insist on self-sufficiency and detachment as prerequisites for patienthood. The "paradigmatic patient" is one who is "fully separate from others." Defining the "paradigmatic patient" in such a way may protect the normative asymmetry Lyerly is arguing for—the primacy of the clinician's duties to the pregnant woman—yet the definition itself is problematic. The concept of the patient as a self-sufficient, independent, and fully autonomous being is an illusion, the byproduct of a post-enlightenment, patriarchal American culture. What makes certain decisions in medicine so difficult and often heartrending—whether parents should stop life-sustaining treatment for their baby in the NICU, whether a sister should donate a kidney to her younger sister, or whether your father with advanced Alzheimer's disease should undergo surgery for his newly diagnosed cancer—is that we are intimately connected to others. Yet, the overarching framework of discussions on personhood, and now patienthood, is obsessively individualistic. The particular emphasis on separateness does violence to the moral and emotional commitments that arise out of intimate relationships.

Debates over personhood, and now patienthood, are controversial because they are often seen as the basis of morality. We believe that persons, and patients, deserve to be treated in certain ways. It is thought that if we can determine the capacities or criteria that constitute personhood (or patienthood), then we will know who is worthy of fundamental rights and our moral respect. Lindemann[15] takes the opposite approach. She argues that personhood is something that we do. Someone is not a person because I *think* she is a person, but rather because I *treat* her as a person. Thus, personhood, and I would argue patienthood, is dependent on a moral community recognizing and responding to the other. And for many women, pregnancy is the very active process of beginning to initiate the fetus into personhood. Lindemann writes:

> In nonhuman animals, for all we can tell, pregnancy is a process that, occurs in the female without any purposive contributions on her part: she passively suffers the fetus to grow in her rather than actively, shaping it, so the relationship that ensues is a purely biological one. In human pregnancies, by contrast, what begins as a purely biological, relationship is transformed into a recognizably human one because, by what the woman does in word, deed, and imagination, she calls, her fetus into personhood. She now not only bears the identity of a pregnant woman but also becomes a particular kind of pregnant woman: she is an expectant mother.

The decision to undergo maternal–fetal surgery is not premised on whether the fetus is a person, but rather it depends on our attitude toward the fetus, perceptions of ourselves as parents, and the belief that medical interventions are one form of caring for children and even our future children. Hauerwas[16] writes, "We seldom decide to treat or not treat (someone) because they have or have not yet passed some line that makes them a person or nonperson. Rather, we care or do not care for them because they are Uncle Charlie, or my father, or a good friend." A fetus is a patient because we treat her as a patient.

Tradeoffs

Despite great advances in obstetrical care, pregnancy is risky. Pregnant women are at increased risk for both morbidity and