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How to value patient values: Cesarean sections for the periviable fetus, and home births

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A B S T R A C T

Respect for patient autonomy involves providing sufficient information to patients to allow them to make informed decisions, and then honoring their requests unless they are unethical or futile. At times, the factors that patients consider may not be purely biologic ones but rather will include “spiritual” factors (a sense of control in a home birth). When patients balance biologic risks against spiritual gain, physicians may not be comfortable giving deference to patients' choice. In order to explicate this issue we explore two clinical scenarios: home birth, and cesarean section for a periviable fetus; and we consider futility and limits on affirmative autonomy. We argue that bodily integrity must remain inviolate. However, conversations regarding a patient's affirmative rights invoke the moral agency of both patient and provider. Those conversations must include considerations of patient values as well as medical facts. Physicians' values are also part of counseling, but they are appropriately considered only when they are medical values (beneficence, truth telling), not personal beliefs (e.g., children with impairments should have, or not have, a ‘do not resuscitate’ order). Physicians have the right to refuse to participate if they think that the biologic risk overwhelms a potential value-based benefit, but they should be loath to do so if the balance is anywhere close to equipoise, and the patient's values are deeply held.

Almost all physicians are familiar with the basic liturgy of informed consent; capacity, disclosure, comprehension, voluntariness and consent. In many cases the disclosure process, albeit challenging, is straightforward (i.e., risks, benefits, alternatives, recommendations). For example, a woman considering a trial of labor after a cesarean section (TOLAC) would be informed, among many other things, that TOLAC is associated with a risk of uterine rupture of approximately one in 200, and with a benefit of potentially avoiding a future repeat cesarean section with its increased risk of abnormal placentation. The manner in which patients weigh these and other factors will vary from individual to individual. At times, the factors that patients consider may be purely biologic, such as the risks and consequences of uterine rupture or placenta accreta, but at other times will include “spiritual” factors (non-physical; e.g., the perceived psychologic benefits of going through labor and having a vaginal birth). When patients take on biologic risks in order to achieve spiritual gain, physicians may be less comfortable accepting the patient's choice than when the patient chooses the clinical path posing the least biologic peril. An example of the former is home birth, with some women valuing the process of giving birth in a familiar setting over the risks of sudden bleeding or fetal distress, which most physicians believe they could better handle in a hospital. Another dilemma that occasionally confronts physicians is women's requests for cesarean sections for periviable fetuses, even those with abysmal prognoses, in order that they can feel that they have done “everything possible” for their child. In this piece, we will discuss the manner in which physicians should consider patient values when determining the appropriateness of pursuing a clinical course favored by a patient, one with clear biologic risks that women and their physicians must balance against patient-perceived, non-biologic, benefits. First, we will discuss maternal requests for cesarean section for the periviable fetus.

Some might view a physician's decision to accede to a woman's wishes, and to perform a cesarean section for a fetus whose mode of delivery will not materially alter its prognosis, as a simple reflection of the physician's increasing understanding of, and deference to, patient autonomy. But autonomy has its limits, especially when it involves a request (positive autonomy), rather than a refusal (negative autonomy). In the first instance, as we have

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previously noted in the context of cesarean section on maternal request, "the physician is obligated to ensure that the woman understands the risks …, appreciates that those risks could indeed occur, and makes a voluntary decision. … The physician should also ask her to reconsider her decision. Referral for a second opinion would surely be justified as an important quality assurance strategy. If the patient persists in her request and her request reflects deeply held values that she reaffirms, then it meets the test of being well supported in autonomy-based clinical judgment. We emphasize that spontaneous, uninformed, or unreflective requests fail to meet this demanding ethical standard." [1].

However, even if a patient's comprehension of the clinical consequences of her decision, and her commitment to her choice, have been assured, the physician need not necessarily honor her request. At least that is the supposition reflected in a formulation of professionalism that many leading medical organizations, including the European Federation of Internal Medicine, The American College of Physicians, and the American Board of Internal Medicine, have endorsed [2]. In their document, they describe autonomy as a process of providing patients with the information they need to make an informed decision, and then respecting those decisions. However, they explicitly set limits on autonomy by going on to cite instances in which autonomy would not be controlling, noting that physicians should consent to patient requests, "as long as those decisions are in keeping with ethical practice and do not lead to demands for inappropriate care." Thus, whereas, in almost in all circumstances, a physician should honor a patient's decision to forgo a recommended procedure, that same patient's request for surgery is more contingent.

Before focusing on that contingent nature of affirmative autonomy, it is important to distinguish it (affirmative autonomy) from negative autonomy if only to stress the basis for the greater deference given to that aspect of autonomy. Respect for a pregnant woman's right to refuse obstetrical interventions is an established principle of obstetrical ethics, one that the American College of Obstetricians and Gynecologists has championed [3,4]. It reflects the prevailing understanding of human rights, that bodily integrity is a foundational right that the English have written into their law for more than a century, and that has been enshrined in the UN charter since shortly after the World War II [5]. Although physicians have occasionally raised legal challenges to women's unencumbered right to refuse interventions [6], the courts have struck them down. In those cases brought before the courts, they have most frequently found that criminal sanctions lacked legislative foundations [7]. Although there are dissenters who feel that overriding obligations to a fetus should temper a mother's right to refuse, those voices are not representative of mainstream ethical thought. Opinions rendered by ACOG's Committee on Ethics, and the British National Institute for Health and Care Excellence, which continue to hold that negative autonomy is essentially unassailable, reflect that belief [4,8].

Affirmative autonomy is less controlling. Indeed, constraints on maternal autonomy are, in some circumstances, quite reasonable and may reflect a balance a physician strikes between the risks to the mother and the potential goods or harms that could obtain to the fetus. For example, an obstetrician would be justified in refusing to perform an elective repeat cesarean section at 32 weeks that a woman requested at that point in gestation merely because her relative would be visiting from out of town. Here risks to the fetus are sufficiently concerning to justify physicians exercising their own right of conscious refusal. In the case of a maternal request for cesarean section in the setting of a periviable fetus, a physician might believe that maternal risks of surgery are determinative since neonatal benefits from such an intervention would be *de minimis*. Hence, they might reject all requests for surgery since no good could obtain to the fetus, and the mother's risks might be consequential. However, we would argue that a decision to evoke conscious refusal by the physician would not be as justifiable as in the case above (elective delivery at 32 weeks). In the first instance, whereas no benefit to the periviable fetus may accrue, no harm would accrue either. As for surgical risks to the mother, the point at which a physician's concerns about them should supersede patient autonomy is unclear, particularly when a woman is adequately informed and is willing to accept them. The American obstetrical community has, in the case of term pregnancy, accepted (albeit not uniformly) that a woman's informed request for a cesarean can be granted even in the absence of a standard obstetrical indication [9]; in other words, in circumstances in which evidence of benefit to the fetus is lacking. So what could justify a physician's refusal to perform a requested cesarean section simply because the fetus's likelihood of survival dips below either a local or an organizational standard? [10] One answer is futility.

As noted above, a consortium of medical organizations has defined autonomy in a manner that makes it clear that there are times when it is ethical to pierce the shield of patient autonomy. They explain that when a patient makes a choice, a physician should honor that decision, unless it is unethical or futile [2]. Thus if the intervention would be harmful, or if it falls outside either a physician's expertise or the boundaries of appropriate medical care, or when a request for care is futile, a physician's refusal to participate would be warranted.

It is the latter, the question of futility, which often animates conversations about cesarean sections for fetuses with poor/abysmal prognoses. Kasman has defined medical futility as a clinical action serving no useful purpose in attaining a specified goal for a given patient [11]. Perhaps most fundamental to decisions about delivery, indeed the issue that must be interrogated before others such as patient values, cost, societal interests, and burdens associated with a life of profound impairment of the periviable fetus, is whether surgery would be futile. But first, let us dissect the concept of futility further.

Not surprisingly, much of the ethical dialogue around futility has focused on the other margin of life, i.e., the role of aggressive interventions versus palliative care at the end of life. Trotter has offered the following definition of futility [12]:

1. There is a goal.
2. There is an action and activity aimed at achieving this goal.
3. There is virtual certainty that the action will fail in achieving this goal.

For the obstetrician and the pregnant woman considering management options, it is the third consideration that is often the most challenging. While a goal can be defined (e.g., a child without profound impairment for some, without moderate impairment for others), and, in a hypothetical case such as a prolapsed cord, the action is definable (a cesarean section followed by all appropriate neonatal care), defining "virtual certainty" is more problematic. In reality, Trotter's guidance is honored largely in the breach since neither organizational guidelines nor common practice demonstrate a willingness to intervene even when the likelihood of failure to achieve the goal is substantially less than virtual certainty. According to NICHD data [10], at 23 weeks there is a 29% survival rate for males and 34% for females; survival rates at slightly less than those numbers (e.g., at between 22 weeks and 23 weeks) are clearly not the equivalent of a virtual certainty of death. Yet most published guidelines recommend against surgical intervention even at 22 weeks and six days [10]. Why?

In the first instance, it may be the widely shared dread of bringing into the world a child with severe disabilities. Indeed,

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