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Pediatric obstetrical ethics: Medical decisionmaking by, with, and for pregnant early adolescents



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ABSTRACT

Pregnancy in an early adolescent carries with it specific ethical considerations, in some ways different from pregnancy in an adult and from medical care of a non-pregnant adolescent. Obstetrical ethics emphasizes the right of the patient to autonomy and bodily integrity, including the right to refuse medical intervention. Pediatric ethics recognizes the right of parents, within limits, to make medical decisions for their children, and the right of a child to receive medical or surgical interventions likely to be of benefit to her, sometimes over her own objections. As the child gets older, and particularly during the years of adolescence, there is also a recognition of the right to an increasingly prominent role in decisions about her own healthcare. Pediatric obstetrical ethics, referring to ethical decisions made by, with, and for pregnant early adolescents, represents the intersection of these different cultures. Principles and approaches from both obstetrical and pediatric ethics, as well as a unified understanding of rights, obligations, and practical considerations, will be needed.

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Introduction

The principle of respect for patient autonomy is widely recognized as central to modern medical ethics. This is understood as an obligation on the part of physicians and other healthcare providers to support the patient's self-determination with regard to medical care, within certain limits, and in particular to respect the patient's bodily integrity. Central to this understanding is the doctrine of informed consent, and an appreciation of the patient's right to refuse medical intervention, even potentially life-saving intervention.

Pediatric medical ethics adds a layer of complexity, in that the patient commonly lacks the capacity to make critical medical decisions, and thus such decisions are made by a surrogate decision maker, typically one or both parents. Of course, the development of that capacity does not occur suddenly, such as on a person's 18th birthday, though legal rights often do. Rather, for most people, the ability to make important decisions develops gradually over childhood, adolescence, and early adulthood. The time when one might be considered capable of making a decision will depend in part on the nature and gravity of the decision; a small child may not be competent to decide whether to receive intravenous antibiotics, but quite capable of deciding which arm should be used. For decisions of major importance, adolescents are generally perceived as still needing some guidance. Pediatric ethics is a discipline unto itself within the broader field of medical ethics, and carries with it specific concerns about the unique needs of children, the gradual development of decision-making competence, the rights of children, the rights of parents, and the obligation of physicians to weigh all of these in their medical management decisions. While

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there is no universal agreement on all questions of pediatric ethics, there is a widely accepted general framework.

Obstetrical ethics is also a discipline unto itself within medical ethics. Considerations such as the rights of the woman, the rights of the fetus and/or the future child, as well as the role of the family, and the obligations of the physician in this unique setting may all be brought to bear. By the lights of some, there are at some point two patients involved,¹ in a setting that is clearly unique in medical care. Rarely, a physician might perceive that a pregnant woman's decisions are not consistent with the needs of the fetus or future child. Once again, it would be a mistake to assume consensus on all of the ethical questions in obstetrics, but there is considerable literature in this area, and there are general approaches and principles that are widely, if perhaps not universally, seen to apply. Notable among these is the right of the pregnant woman to bodily integrity, and her right to refuse medical or surgical intervention.

Much less explored is the field of what shall here be called pediatric obstetrical ethics: when disagreement and/or ethical concerns arise in the setting of pregnancy in an early adolescent. Those more familiar with obstetrical ethics may see things very differently from those schooled in pediatric ethics, though the principles and practical considerations of each might apply. And, importantly, application of those two approaches could yield very different conclusions about the recommended course of action in clinical situations. A unified understanding of rights, obligations, and practical considerations is needed. What follows is an ethical analysis of pediatric obstetrical ethics in the setting of a clinical case, including practical recommendations regarding how to proceed. Legal advice might at times also prove helpful, and is recommended in settings of uncertainty, but is beyond the scope of this article and the expertise of the author.

Case discussion

A 15-year-old girl with insulin-dependent diabetes mellitus, and a history of diabetic ketoacidosis episodes, was admitted to the hospital at 33 weeks in preterm labor. Her pregnancy is otherwise unremarkable, and, aside from being large for gestational age, the fetus appears normal by ultrasound. Some concerning decelerations in the fetal heart rate have been noted since admission. From the time of admission she has been quiet, reluctant to speak with staff, and resistant to interventions including fetal monitoring, ultrasound, and blood tests, including glucose monitoring. In addition, she has made it clear that she will refuse cesarean delivery under any circumstance. The patient's mother, with whom she lives and appears to have a good relationship, has tried without success to convince her to cooperate with medical management. Her mother has asked the staff, "Please do whatever you have to do for the safety of my daughter and my grandchild." The patient's father is not involved in her life. Staff are increasingly concerned about the status of this young woman and her fetus, and, in the setting of her resistance, are unsure of how to proceed with diabetes monitoring, fetal monitoring, and interventions.

This analysis will include four components: fundamental medical ethics, obstetrical ethical principles and approaches, relevant pediatric ethical principles, and finally a discussion of pediatric obstetrical ethics, including practical recommendations. Clearly, a comprehensive review of any one of the first three is beyond the scope of this article, but some basic aspects of each will be explored, particularly with regard to how they might inform judgment for the case at hand.

Fundamental medical ethics and the right to refuse treatment

The right of a patient (at least an adult of sound mind) to refuse medical treatment is at the heart of our understanding of patient autonomy, and the Doctrine of Informed Consent. This concept is not unique to contemporary ethics, nor to medical ethics, and was perhaps best articulated by the philosopher John Stuart Mill over a century ago: "The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant ... Over himself, over his own body and mind, the individual is sovereign." 4

Modern students of medical ethics are very familiar with the fundamental principles of respect for autonomy and beneficence, elucidated in The Belmont Report⁵ and subsequently in the well-known text by Beauchamp and Childress. Respect for autonomy, or respect for persons, recognizes the patient's right to self-determination, literally self-rule, and our obligation as physicians to uphold that right. Beneficence refers to our obligation to act for the patient's welfare, or in the patient's best interest. One of the more fascinating dynamics of medical ethics, over the past century or more, has been a transition from beneficence to autonomy as the principle more often seen to trump, in settings where these two appear to conflict. In a famous trial involving consent for a surgical procedure in the early 20th century, Judge Benjamin Cardozo stated that "Every human being of adult years and sound mind has the right to determine what shall be done with his body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages."7

Just as Mill suggested that individual liberty trumped an individual's own good, we increasingly recognize the patient's right to refuse treatment that the physician believes best for that patient. In the wake of atrocities at the hands of Nazi physicians, the Code of Nuremberg in 1947 specifically stated that, with regard to clinical research, "The voluntary consent of the human subject is absolutely essential."8 Over the latter half of the 20th century and into the 21st, this notion increasingly took root, and extended into clinical medicine as well, in what is now commonly accepted dogma, such as the Doctrine of Informed Consent. Jehovah's Witnesses can refuse transfusion and Christian Scientists can refuse antibiotics or surgery, based on religious objection. Moreover, any adult of sound mind is generally seen as having the right to refuse any medical intervention, even life-saving intervention. The patient's "own good" is surely compelling to a caring physician, who may rightly work hard

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