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EDITORIAL

Professionally Responsible Counseling When a Fetal Anomaly is Diagnosed by Ultrasound

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Abstract

Ethics plays an essential role in the clinical management of pregnancies complicated by fetal anomalies diagnosed by ultrasound. Utilizing the *prima facie* ethical principles of beneficence and respect for autonomy, this paper first explicates the ethical concept of the fetus as a patient. This ethical concept provides the basis for a comprehensive approach to counseling pregnant women about the management of pregnancies complicated by fetal anomalies. Practical, ethically justified guidance is given for counseling about decisions both before and after viabilities.

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Introduction

This article provides an ethically justified, clinically practical guidance for counseling a pregnant woman when a fetal anomaly has been diagnosed by obstetric ultrasound. This guidance is based on professional ethics in obstetrics.[1] Professional ethics in obstetrics is based on ethical principles and professional virtues. Two ethical principles are pertinent to the topic of this article: the ethical principles of beneficence and the ethical principle of respect for patient autonomy. We therefore being with an explanation of these two ethical principles. We then deploy these ethical principles to explicate the ethical concept of the fetus as a patient. On the basis of this ethical concept, we address counseling a pregnant woman when a fetal anomaly has been diagnosed by obstetric ultrasound.

Ethical Principles of Beneficence and Respect for Patient Autonomy

Prima Facie Ethical Principles

The starting point for professional ethics in clinical practice is the ethical obligation to protect and promote the health-related interests of the patient. This commitment is quite general in its nature. In order to make it clinically applicable, it needs to be made more clinically specific. To do so, we interpret it in terms of two perspectives, that of the physician and that of the patient.[1]

Ethical principles convert each of these two perspectives into action guides in clinical practice. In professional ethics in obstetrics, ethical principles should be understood to have ethically justified limits, which are known as *prima facie* ethical principles.[1–3] *Prima facie* ethical principles generate *prima facie* ethical obligations, guides to what ought to be done unless ethical reasoning shows that another ethical obligation should guide clinical judgment, decision making, and behavior.

Ethical Principle of Beneficence

The ethical principle of beneficence translates this general commitment into clinical practice on the basis of a rigorous clinical perspective on the health-related interests of the patient. Beneficence creates the *prima facie* ethical obligation of the obstetrician to seek the greater balance of clinical benefits over clinical harms for the patient. On the basis of rigorous clinical judgment, informed by evidence-based medicine and a commitment to excellence in clinical practice, the obstetrician should identify clinical strategies that are reliably expected to result in the greater balance of clinical benefits, i.e., the protection and promotion of the patient's health-related interests, over clinical harms, i.e., impairments of those interests. The forms of clinical management supported in beneficence-based clinical judgment are known as medically reasonable.[1,3]

The ethical principle of beneficence has long and illustrious history in the global history of medical ethics. In Western medical ethics, for example, it dates back to at least the time of Hippocrates.[4,5] The Hippocratic Oath, for example, requires physicians to act in a manner that will "benefit the sick according to my ability and judgment".[4] One of earliest occurrence of the word "beneficence" is in the first book entitled "Medical Ethics" in the global history of medical ethics by the English physician-ethicist, Thomas Percival (1740–1804).[1]

The ethical principle of beneficence in obstetrics should not be confused with the principle of nonmaleficence, which is also known as *Primum non nocere* or "First, do no harm." Many think that *Primum non nocere* appears in the Hippocratic Oath nor in the texts that accompany the Oath. However, this is not the case.

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Beneficence was the primary consideration of the Hippocratic writers, which enjoins the physician to provide care that will benefit the patient. The Hippocratic text, *Epidemics*, is clear that beneficence has priority: "As to diseases, make a habit of two things—to help or to at least do no harm."[5]

This seemingly arcane commentary is not just historical but also conceptual and clinical: if *Primum non nocere* were to become the primary ethical principle of obstetrics, virtually all invasive aspects of obstetrics would be unethical because of the risks they involve for the pregnant woman. It might appear that, as an invasive form of clinical management, obstetric ultrasound would be ethically permissible. However, there are psychosocial risks of this physically noninvasive diagnostic tool. Every form of clinical management has the potential for some degree of biopsychosocial harm.[6] Given this clinical reality, making *Primum non nocere* the primary ethical principle in the professional ethics of obstetrics would result in clinical gridlock.

Ethical Principle of Respect for Patient Autonomy

A rigorous clinical perspective on the patient's health-related interests is not the only legitimate perspective. The patient's perspective on her own health-related, and other, interests must therefore also be taken account of by the physician.[1] Every adult pregnant woman has her own values and beliefs, according to which she is surely capable of making judgments about what will and will not protect and promote her health-related and other interests. All adult pregnant women should be assumed to possess the decision-making capacity to determine which clinical strategies are consistent with her interests and which are not, unless there is reliable evidence of clinical deficits in her decision-making processes. In making decisions about their medical care pregnant women may utilize values and beliefs that go far beyond health-related interests, e.g., religious beliefs or beliefs about how many children she wants to have. Since beneficence-based clinical judgment is limited by the competencies of medicine, it provides the physician no authority to assess the worth or meaning to the pregnant woman of her own nonhealth-related interests. Such are matters solely for the pregnant woman to determine for herself.

The patient's perspective is translated into clinical practice by the medical ethical principle of respect for autonomy. This principle creates the *prima facie* ethical obligation of the obstetrician to respect the integrity of the patient's values and beliefs, to respect her perspective on her interests, and to implement clinical strategies authorized by her as the result of the informed consent process. The informed process is typically understood to have three elements: (1) disclosure by the physician to the patient of adequate information about the patient's condition and the medically reasonable forms of clinical management for it; (2) adequate understanding of that information by the patient; and (3) a voluntary decision by the patient to authorize or refuse proposed management.[1,3] When a patient indicates that she would welcome support with understanding the information she has been provided, the obstetrician should ask her what questions she has and assure her that she should not hesitate to ask questions. These questions should be answered respectfully. A voluntary decision is a decision that is free of internal and external sources of controlling influence. The obstetrician should be alert to the presence of such influences and mitigate them.

Ethical Concept of the Fetus as a Patient

The obstetrician's clinical perspective on the pregnant woman's health-related interests and the commitment to protect and promote her health-related interests creates *prima facie* beneficence-based obligations to her. The pregnant woman's own perspective on her interests and the physician's commitment to respect her values and preferences creates *prima facie* autonomy-based obligations owed to her. The fetus, however, cannot meaningfully be said to possess values and beliefs, because of its insufficiently developed central nervous system. There is therefore no valid basis for claiming that a fetus has a perspective on its interests, which means that there can be no autonomy-based obligations to any fetus.[1] Nonetheless, the obstetrician has a perspective on the fetus's health-related interests and therefore can have *prima facie* beneficence-based obligations to the fetus, but only when the fetus is a patient. Because of its centrality for the ethical management of pregnancies complicated by fetal anomalies, the ethical concept of the fetus as a patient requires careful explication.

Prima facie beneficence-based ethical obligations to the fetus exist when the fetus can later, after birth, achieve independent moral status.[1] The fetus is a patient when two conditions are met: (1) the fetus is presented to the physician or other healthcare professional; and (2) there exist medical interventions, whether diagnostic or therapeutic, that reliably can be expected to result in a greater balance of clinical goods over clinical harms for the fetus in its future. The ethical concept of the fetus as a patient therefore depends on links to later becoming a child and, later still, achieving independent moral status.

One link to becoming a patient is viability, which should not be viewed as an exclusively biological property of the fetus. Instead, viability must be understood in terms of both biological and technological factors. It is only by virtue of both factors that a viable fetus can exist *ex utero* and subsequently become a child and later achieve independent moral status. In countries with different levels of technological capacity, viability is a close correlate of access to technological capacity. When access to technology is present, viability occurs at approximately 24 weeks of gestational age.[1,3]

The only possible link between the previable fetus and the child it can become is the pregnant woman's autonomy, because technological factors cannot result in the previable fetus becoming a child. When the fetus is previable, the link between a fetus and the child it can become can be established only by the pregnant woman's decision to confer the status of being a patient on her previable fetus. The previable fetus has no claim to the status of being a patient independently of the pregnant woman's autonomy. The pregnant woman is therefore free to withhold, confer, or, having once conferred, withdraw the status of being a patient on or from her previable fetus according to her own values and beliefs. The previable fetus is presented to the physician solely as a function of the pregnant woman's autonomy.

The ethical concept of the fetus as a patient has an important ethical and clinical implication: the divisive language of fetal rights has no meaning or clinical application to the fetus in obstetric practice. Current controversies about "right to life," especially its possible limited application to patients from non-Western cultures, can thus be avoided.

Management Options Before Viability for Pregnancies Complicated by Fetal Anomalies

Before viability, the management of a pregnancy complicated by fetal anomalies is ethically straightforward. The pregnant woman is free to withhold or withdraw the moral status of being a patient from any previable fetus, including the fetus newly diagnosed with anomalies. Respect for her autonomy in this matter creates the *prima facie* ethical obligation to be rigorously nondirective in counseling. The physician should offer the clinical alternatives of continuation or termination of pregnancy, but not make any recommendations for or against either alternative. For anomalies for which there is accepted third-trimester maternal-fetal medical or surgical intervention, e.g., spina bifida, these alternatives should also be offered and its nature and limitations explained. The physician's personal views about rearing a child with such an anomaly or about abortion should play no role in the counseling process.

If the woman elects an abortion, it should be performed unless the physician has moral objections to abortion in individual conscience, which should be respected by the patient and the physician's colleagues. As a matter of professional conscience, a physician unwilling to perform abortions should nonetheless make an appropriate referral. If the woman elects to continue her pregnancy, she should be apprised about decisions that will need to be made later so that she can begin to plan the rearing of her child.[1]

Respect for autonomy means that the obstetrician should not judge the reasons a woman has for terminating a previable pregnancy. Respect for autonomy also means that the obstetrician should be alert to substantially controlling or even coercive influences on her decisions about the clinical management of a pregnancy, such as from her husband, partner, or potential grandparents, and should advocate for her autonomous, informed decision, in order to protect her from such substantial control and coercion.[1]

An important subset of the option of termination of pregnancies is fetal reduction and selective termination of multiple pregnancies.[1] There are three ethically justifiable indications for reduction or selective termination of multiple pregnancies, related to three possible goals for a multiple pregnancy: (1) achieving a pregnancy that results in a live birth with one or more infants with minimal neonatal morbidity and mortality, (2) achieving a pregnancy that results in a live birth of one or more infants without anomalies detected antenatally, and (3) achieving a pregnancy that results in a singleton live birth.[1]

Management Options after Viability for Pregnancies Complicated by Fetal Anomalies

After viability, the obstetrician has the *prima facie* ethical obligation to recommend and provide usual obstetric management as the standard of care. The goal of this standard of care is to optimize perinatal outcome by implementing effective antepartum and intrapartum diagnostic and therapeutic modalities.[1]

There is an ethically justified exception to this beneficence-based, *prima facie* ethical obligation: termination of pregnancy after fetal viability when ethically justified criteria are satisfied. These are (1) certainty of diagnosis, and either (2a) certainty of death as an outcome of the anomaly diagnosed or (2b) in some cases of short-term survival, certainty of the absence of cognitive developmental capacity as an outcome of the anomaly diagnosed.[1] When these criteria are satisfied, recommending a choice between usual management and termination of pregnancy is ethically justified. Anencephaly is a classic example of a fetal anomaly that satisfies these criteria.[1]

A strong ethical argument can also be made that anomalies such as trisomy 13, renal agenesis, thanatophoric dysplasia, alobar holoprosencephaly, and hydranencephaly should also count as anomalies that satisfy the two criteria.[1] This is because, with these anomalies, either death is already a certain or a near-certain outcome or the certain or near-certain absence of cognitive developmental capacity is tantamount to death and so in beneficence-based clinical judgment causing death is an acceptable outcome.

For many anomalies, such as Down syndrome, spina bifida, isolated hydrocephalus, diaphragmatic hernia, achondroplasia, and most cardiac anomalies, neither death nor absence of cognitive developmental capacity is a certain or near-certain outcome. Although these anomalies involve incremental risks of mental and physical morbidity and mortality, they do not satisfy the two criteria for third-trimester abortion. Under no rigorous clinical evaluation can these conditions be regarded as tantamount to death or absence of cognitive developmental capacity. For such anomalies, the beneficence-based prohibition against terminating the life of a viable fetus remains robustly intact. Any clinical judgment that does not address and defeat this beneficence-based prohibition is defective on ethical grounds and therefore is inconsistent with the professional integrity.[1]

Many anomalies may involve burdens on patients, parents, society, communities, and social institutions. However, while those burdens may often be significant, they are concerns distinct from the obstetrician's beneficence-based, *prima facie* ethical obligation to protect and promote the fetal patient's interest just as they are distinct from what is in any patient's interests. Moreover, in theories of justice that emphasize equality of opportunity for human experience and development, the assumption of such burdens by society would be ethically obligatory.[7] Society has a justice-based obligation to look after its disabled and to maximize their developmental potential so that they can live fulfilling lives. Thus, in addition to violating the beneficence-based prohibition against killing, third-trimester abortion of fetal patients with Down syndrome and the other anomalies that do meet the two criteria enlists medicine to escape from the well-founded, justice-based obligations of parents, institutions, and society. We are hard-pressed, indeed, to see how this would be consistent with professional integrity and social justice.

Another exception to usual obstetric management is nonaggressive obstetric management. By this we mean that fetal monitoring and cesarean delivery are foregone because there is no beneficence-based, *prima facie* ethical obligation to provide them when two criteria are satisfied: there is (1) a very high probability, but sometimes less than complete certainty, about the diagnosis and, either (2a) a very high probability of death as an outcome of the anomaly diagnosed or (2b) survival with a very high probability of severe and irreversible deficit of cognitive developmental capacity as a result of the anomaly diagnosed.[1] When these two criteria apply, a choice between usual or nonaggressive obstetric management should be offered. Encephalocele is a classic example of a fetal anomaly that satisfies these criteria.

Conclusion

The diagnosis of a fetal anomaly with ultrasound is only the beginning of its professionally responsible management. Counseling of the pregnant woman is just as important, perhaps even more important. This counseling should be done professionally, using clinical standards generated by the *prima facie* ethical principles of beneficence and respect for autonomy.

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