REVIEW ARTICLE

Ethical Dimension of the Fetus with Malformation

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Abstract

The ethical dilemmas have an essential application in the clinical management of pregnancies complicated by fetal abnormalities with high respect for autonomy for both—mother and the fetus. Several options should be considered in the management of the pregnancy with a fetus which has either a structural or chromosomal defect.

Keywords: Chromosomal defects, Ethics, Fetal malformation, Management, Structural.

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Introduction

The ethical dilemmas in the field of prenatal diagnosis, management of fetal chromosomal, and structural abnormalities are highly controversial because of the contested status of the fetus and mother with additional potential conflict between mother and fetus. Ethical questions and dilemmas in the field of prenatal diagnosis include the nature and purpose of the diagnosis itself and the management of the information which is given to the woman and her partner. The ethical dilemmas have an essential application in the clinical management of pregnancies complicated by fetal abnormalities with high respect for the autonomy of both mother and the fetus, as the issues of termination of the pregnancy should be considered as an option in the management of the fetus with a structural or chromosomal defect.

In most countries around the world, termination of pregnancy remains a highly contentious moral dilemma and issue. Deep conflict arises from a battle between the women's right to have a choice and the fetus's right to life even for the fetus who is under enormous risk acquired by structural or chromosomal malformations. Despite enormous development in the field of medical technologies and genetic science which allows diagnosing fetal anomalies in the early stages of pregnancy, still, we are facing the fact that late-onset malformation can be detected only in the second and third trimesters. Losing hope for having a healthy child and making the decision to terminate an ongoing pregnancy is bringing up a moral dilemma with emotionally highly challenging issues. The relatively new field of prenatal diagnosis and development of the field of fetomaternal medicine which developed in the last 40 years, requires medical practitioners with extensive training and expensive, highly sophisticated technology.[1] Detection of congenital structural anomalies includes all procedures that lead to the diagnosis and detection of fetal anomalies. For a proper diagnosis—advanced and complex technology is required, as well as, dedicated and well-trained experts are needed to recognize and diagnose the congenital defect. The complexity of the issue is, even more, higher due to the ideological, religious, and social background that in underlying benefit the whole process. In the field of prenatal diagnosis, many ethical, social, and legal questions, conflicts

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and incompatible opinions are arising due to several factors. On one hand, we have a passionate opposition to abortion driven by a religious devoted motivation to protect the fetus even above the women's rights based on the idea that fetuses are living entities with interests of their own right from the beginning to remain alive. Therefore, with all rights, all humans have to protect these basic interests, including the right not to be killed.[2,3]

On another side, we have an ethical duty to provide information about the screening program. The development of new prenatal screening tests on the birth prevalence of many inherited diseases and ultrasound technological abilities is based in part on respect for the autonomy of pregnant women and their partners to obey the integrity of the patients.[2]

The discovery and ability to isolate fetal nucleic acid in maternal plasma have opened in the last decade, along with the possibilities for noninvasive, risk-free tests both for mother and fetus in the area of prenatal diagnosis. Although the development of these screening tests is providing safe, mass, and accurate screening, still, we have to keep in mind that these noninvasive prenatal tests and maternal blood tests are not providing the definitive diagnosis but they give the physicians and future parents a detection rate of 98–99% for the chromosomal anomaly. When the outcome of the cell-free deoxyribonucleic acid test is positive, it is usually followed by an invasive procedure for a decisive result. Invasive procedures such as chorion villus sampling or amniocentesis are the only tests which are accurate diagnostic tests with a procedure-related miscarriage of 0.5–1.0%. The introduction of ultrasound as a diagnostic tool in the field of prenatal medicine is considered safe for both mother and the fetus. The discovery of fetal abnormality is bringing up to society the question of freedom to terminate a pregnancy.[3]

We have to obey as well women's choice for reproductive freedom, as well as, freedom to procreate but at the same time, society has to respect someone's decision not to procreate, freedom not to gestate, as well as, autonomy to terminate a pregnancy. The autonomy of pregnant women and their partners is promoted when they are provided information relevant to decisions about whether to continue a current gestation which is affected by the congenital disease of malformation which has a great impact on the life quality and spans.[2–4] Facts about the health status of the fetus should be presented to future parents, the presence or absence of anomalies and the implications of anomalies for the child and the family if the future of the fetus is affected by genetic/chromosomal disorder which is causing health deprivation—both mental and physical resulting in suffering physical and emotional pain.[3,4] Medical facts about health conditions which are resulting in the life quality causing helplessness in all meaning, physical, and mental should be presented to pregnant patients clearly and objectively, providing all medical possible outcomes.[3,4] In providing information about screening, physicians not only promote the autonomy of future parents but also give the pregnant woman and her partner the opportunity to make their own decisions about what would be best to promote the well-being of their family. At the same time, physicians have a duty to provide emotional support and prevent and remove health-related harm to their patients. Pregnant patients who are experiencing emotional distress related to the idea that their fetus has an abnormality—physical or chromosomal, have a need for help in reducing and preventing such distress.[4,5] The physician is in a position to offer such help through follow-up meetings with the main idea to review the situation to discuss all possible options for pregnancy management and address the patient's emotional needs. Several options for the management of the ongoing pregnancy should be taken into consideration according to the legal options.[6]

- Abortion/termination of the pregnancy is one of the options legally available in most countries before fetal viability. Fetal viability is considered when "viability is reached when, in the judgment of the attending physician, there is a reasonable likelihood of the fetus sustained survival outside the womb, with or without artificial support."[6]
- Each country has different legal regulations for abortion. In some countries, termination of the pregnancy is restricted by law due to the limited access to abortion due to the lack of providers of abortion services.
- Nonaggressive approach: Continuing the pregnancy with management aimed at optimizing the well-being of the mother, conflicts between maternal and fetal well-being are resolved by giving priority to the mother's interests, this nonaggressive approach avoids procedures that increase maternal risks such as tocolysis and caesarean section for fetal indications.
- Aggressive approach: Continuing the pregnancy with management aimed at optimizing the well-being of the fetus. Conflicts between maternal and fetal well-being are resolved by giving priority to the fetus's interests. This aggressive approach uses medical and surgical procedures considered necessary to promote fetal well-being even though they involve increased risk to the mother.
- Intermediate approach: Continuing the pregnancy using an intermediate strategy that balances fetal and maternal interests. This balancing rational approach permits the mother to be exposed to risks for the sake of the fetus in some but not all situations. Before viability, there are usually no invasive therapeutic interventions that can be carried out for the sake of the fetus. The exception involves a small number of cases in which fetal therapy might be possible.
- Before viability, the main options are: To terminate the ongoing pregnancy, continue the pregnancy, or continue the pregnancy with the introduction of fetal therapy. Most fetal therapy is considered as experimental as all surgical therapy is considered a tentative procedure, and it is available only for a small number of fetal malformations

and only at a few research centers. Ethical dilemmas are rising up for medical procedures that are experimental and whose safety and effectiveness are still uncertain. Ethically acceptable to mention that such provided procedures are being carried out in a manner that meets rigorous ethical standards.

The decision about abortion is usually based on values and often on the religious beliefs of the patients and physicians.[7] Moral controversy and politicization of viewpoints can further increase the emotional distress of the woman. Presentation of the abortion should be done in a non-directive manner. Directive counseling in the form of termination of pregnancy should be done when continuing pregnancy involves serious risks to the life and health of the woman.[7]

Management for the fetuses with non-life-threatening anomalies is—the determination of viability is the same as for fetuses that lack anomalies-normal fetuses (range of 22–24 weeks). Management for life-threatening anomalies—are there any anomalies for which abortion >24 weeks is legal because fetuses having those anomalies are justifiably considered legally non-viable? The anomaly has to be one for which survival for more than a brief period after birth is impossible and can be diagnosed with a high degree of reliability. Abortion for serious fetal anomalies after 24 weeks is a legal option only infrequently except in the few states that allow abortions after viability for reasons other than maternal life and health.[8]

When pregnancy is carried beyond the point of viability, decisions need to be made—management up to and during delivery—aggressive versus nonaggressive approach. Recommendation for one over the other depends on the severity of the fetal anomaly. An aggressive approach is a choice when intervention would provide more than minimal benefit for the fetus.

- Promote fetal well-being, based on the principle of beneficence.
- If the fetus has an anomaly that is less serious.

Nonaggressive treatment is accepted when intervention would expose the mother to risks and would provide minimal or no benefit for the fetus. The fetal anomaly is diagnosed with a high degree of reliability and characterized by incompatibility with survival for an extended period and with severely diminished cognitive potential.

Gray Zone

In practice, we are facing "gray zone" when no strong argument to recommend.

- If the diagnosis is relatively reliable but there is uncertainty as to whether there will be a severely diminished cognitive potential.
- If the diagnosis carries a poor prognosis but there is uncertainty concerning the diagnosis.

Management Using Hospice Principles

Integrated support from the time of diagnosis through the birth and death of the infant and up to one year postpartum, addresses the emotional, spiritual, and medical needs of the family. After the prenatal diagnosis of a lethal condition, parents are presented with the option of an integrative program of ongoing supportive care. Therefore, the interdisciplinary team should be included—maternal-fetal medicine physicians, neonatology and anesthesia services, nurses, social workers, and religious counselors to provide all needed care and support for both parents and fetus.[9] Substantial support should be provided during labor and delivery. At birth, the attending neonatologist evaluates the infant, confirms the diagnosis and places the infant with the parents so they can share in their baby's life and death. Neonatologists should provide all comfort measures to keep infants warm, cuddled, fed, and given pain medications. Religious providers and social worker services should provide emotional and spiritual support to the mother and her partner and the care should be continued in the postpartum period by those providing grief support.

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