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End-of-life decision before and after birth: changing ethical considerations

Andrew B. Pinter*

Department of Paediatrics, University of Pécs, 7623 Pécs, Hungary

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Abstract Despite the dramatic improvement in the outcome of somatically handicapped neonates, vexing ethical issues remain. In which fetuses would termination be indicated? In which neonates are the malformations so serious that surgery and intensive care should not be initiated (withholding or not starting treatment)? Conversely, in which neonates should the initiated treatment be stopped (withdrawal of treatment)? These questions pose huge medical, legal, ethical, moral, and financial problems for doctors, lawyers, ethicists, and families.Fetuses and neonates with congenital anomalies can be divided into 6 groups: 1, those who have the potential for total recovery; 2, those with anomalies that would allow for a nearly normal life; 3, those with malformations requiring permanent supervision and/or medical care; 4, those with somatic rest defect and subnormal mental development; 5, those with serious somatic and mental damage; and 6, those with anomalies that are incompatible with life. The decision making should be tailored to each of these groups.The pediatric surgeon, besides taking into consideration the quantity and quality of the rescued life, should lower the anxiety of the parents, should follow the morals of a civilized society, should act according to the law, and finally, should convince himself to be a solution to a problem and not to be a cause of any.

In recent years, there has been an increase in the number of published articles addressing the ethical problems faced in the management of fetuses and neonates with serious malformations and/or chromosomal abnormalities. The purpose of this report is to provide pediatric surgeons and neonatologists with an ethical framework for the care of serious congenital malformations detected in the pre- and early postnatal period, and a practical guide for ethical decision making.

1. Historical background

Neonates born with congenital mental and somatic abnormalities have been in the spotlight for many centuries. Their deformities and mode of treatment have posed huge medical, legal, ethical, moral, and financial problems for doctors, lawyers, ethicists, and families.

Traditionally, there have been 2 schools of thought in dealing with such issues. One is the 2500-year-old Hippocratic oath "Above all, do no harm to the patient" (*salus aegroti suprema lex, primum nil nocere*), and the second one comes from Plato's idea, which states that people who have limited mental and physical capacity should not be allowed to live because they are burden on society [1]. This philosophy was fully accepted in Sparta, Greece, where the

* Tel.: +36 72 535 900; fax: +36 72 535 971.
E-mail address: andras.pinter@aok.pte.hu.

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malformed neonates were thrown down from the Greek Hill of Taigetos. This principle is also represented by the ancient rule of Norsemen, which states: "Every child which is born into this world shall be reared, baptized and carried to the church except that only which is born so deformed that the mother cannot give strength to it. It shall be carried to a beach and buried where neither men nor cattle go; that is the beach of the evil one" [2].

What has changed in the moral approach to treatment of congenitally deformed neonates over the past few centuries? The answer, unfortunately, is nothing. In prescribing treatment for such unfortunate fetuses and neonates, we try to lower the anxiety of the parents and follow the morals of a civilized society, although keeping in mind the implications of going against the law. Finally, we doctors must remind ourselves to solve problems, not to cause any.

2. Ethical dilemmas in the prenatal period

Currently, our situation has become even more complicated and cumbersome because we are required to make decisions not only for the neonates borne with abnormalities, but also for the probable malformations of the fetuses. The prenatal diagnosis of congenital anomalies has made counseling of the prospective parents a routine part of pediatric surgical practice and raises the issue of how best to advise and support a couple whose fetus has a significant birth defect [3]. In this situation, the pediatric surgeon should act as counselor and expert adviser to the pregnant woman, providing information about the specific malformation, the operative management, expected outcomes, and future quality of life. The problems in connection with fetuses are more complex because their interest and the interest of the mothers are often in conflict.

If there are medical indications to terminate a pregnancy, it is only justified if the anomaly has been proven. Termination of pregnancy is not acceptable based on the suspicion of a congenital anomaly.

3. Algorithm of decision making in the pre- and postnatal period

In the prenatal period, we may be required to decide on termination. However, if our decision is to maintain pregnancy, then delivery at term, whether induced, cesarean delivery, or vaginal delivery, pose only professional questions (Fig. 1).

After birth, we have to decide whether to initiate treatment or refuse it. If, for instance, we decide to withhold treatment, we are still able to subsequently change our

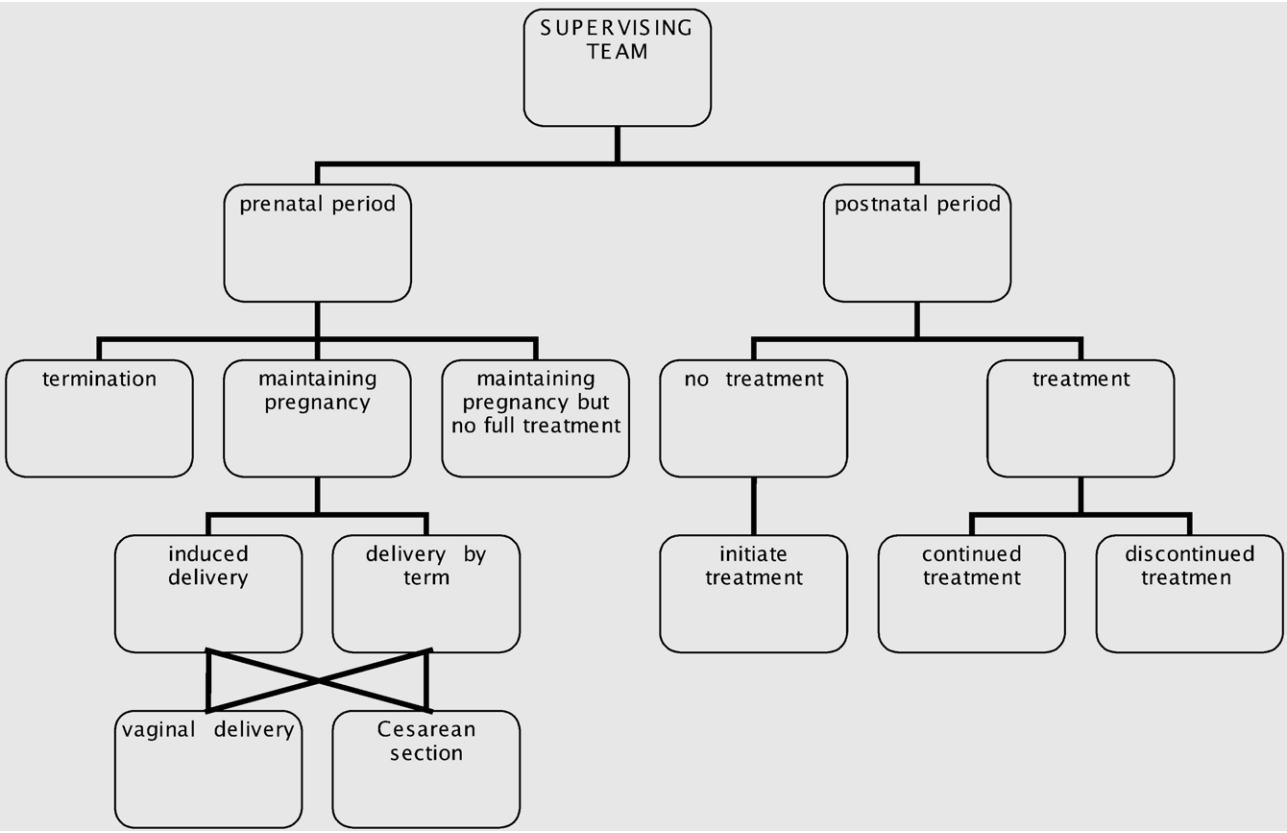

Fig. 1 Decision-making in the pre- and early postnatal period.