THE NCCB ON ANENCEPHALY

The Human Nature of the Anencephalic Infant

On September 20, 1996, the NCCB Committee on Doctrine issued a statement entitled “Moral Principles Concerning Infants with Anencephaly.” The statement provides helpful clarification on the ethics of caring for anencephalic infants. The condition of anencephaly, which can be diagnosed early and accurately by ultrasound imaging, is described in this way:

Anencephaly is a congenital anomaly characterized by failure of development of the cerebral hemispheres and overlying skull and scalp, exposing the brain stem. This condition exists in varying degrees of severity. Most infants who have anencephaly do not survive for more than a few days after birth. (Origins, vol. 26, no. 16, p. 276. All quotations herein, unless otherwise identified, have this same reference.)

The central ethical issues pertaining to anencephalic infants are: abortion, early induction of labor, postnatal care, and donation of organs for transplantation. Any evaluation of these issues is influenced by what is presupposed about the humanity of the infant. The NCCB statement addresses this question in the language of human dignity:

Doubts about the human dignity of the anencephalic infant, however, have no solid ground, and the benefit of any doubt must be in the child’s favor. As a general rule, conditions of the human body, regardless of severity, in no way compromise human dignity or human rights.

The combination of certain factors show that the anencephalic is a human being; the infant is generated from human parents, possesses the complete human genome, and functions as an integrated organism. Postnatally, the anencephalic exhibits typical newborn physical behaviors.

Given that the anencephalic infant is an innocent human being, the commonly recommended option of elective abortion is intrinsically evil and morally unacceptable under all circumstances. The statement points out that the right to life of the infant is equal to that of the mother:

According to the well-established teaching of the Catholic Church, the rights of a mother and her unborn child deserve equal protection because they are based on the dignity of the human person whatever the condition of that person.

The options of abortion and early induction of labor for these infants are sometimes defended simply by the claim that the anencephalic is not a being for whom the concept of “viability” properly applies. “Viability” is the gestational age at which a fetus can survive outside the womb with aggressive treatment (currently around 23 to 24 weeks). The moral significance of “viability” is that the direct destruction of a previable fetus or of a viable fetus is considered an abortion. If it can be shown that “viability” does not pertain to the anencephalic infant, then it is claimed that the prohibition against abortion cannot apply.

What is telling about this view is the basis on which it is concluded that “viability” has no moral significance for the anencephalic. The position bifurcates human existence into physiologic or organic existence and integrated or true human existence. Since the anencephalic achieves only a limited level of physiologic existence, “viability” as a human being is not possible. But this position is untenable. One and the same individual being cannot have two different types of existence. Human existence is one and unified: an individual is either fully human, or it is not a human being. To be fully human does not mean that all human functions must be actual, or that there must be actual physical capacities for human functions. Rather, it means that an individual by reason of being a member of the human species possesses a nature that includes the potential for actual operations, even though this potential may never be actualized due to some anomaly. Potential is a real aspect of an individual human being in addition to any actual functions and operations of the individual. It is on this unified view of the human being that the NCCB statement affirms that the anencephalic infant, despite its severely debilitated condition and brevity of postnatal life, is the subject of human rights and has a human dignity equal to all other human beings.

It can also be concluded from the NCCB statement that the mother’s womb cannot be regarded as a useless life support system that may be terminated because in general there is no moral obligation to provide useless treatment. Given the inestimable human dignity of the anencephalic child, the uterine environment in which he or she lives is not useless since it is supporting nothing other than a fully human individual.

Since abortion is unacceptable, are any other procedures permissible that result in the death of the child? The NCCB statement quotes the Ethical and Religious Directives for Catholic Health Care Services (hereafter, Directives) which pertains to the issue:

Operations, treatments and medications that have as their direct purpose the cure of a proportionately serious pathological condition of a pregnant woman are permitted when they cannot be safely postponed until the unborn child is viable, even if they will result in the death of the unborn child. (Directive 47)

The statement makes it clear that any morally acceptable procedure that indirectly results in the death of the anencephalic child must be a direct treatment of a life-threatening maternal pathology, which, it should also be mentioned, puts the life of the child at risk as well.

The Issue of Emotional Trauma

The attempt to prevent physical or psychological risks to the mother when no such risks exist by
terminating the life of the infant uses the death of the infant as the means for risk prevention:

Hence, it is clear that before "viability" it is never permitted to terminate the gestation of an anencephalic child as the means of avoiding psychological or physical risks to the mother. Nor is such termination permitted after "viability" if early delivery endangers the child's life due to complications of prematurity.

The NCCB statement provides an answer to the long-standing question of whether the alleviation of a mother's emotional anguish and trauma that is sometimes associated with this sort of pregnancy is itself a proportionate reason for terminating the life of an anencephalic infant. In particular, the statement addresses directive 49 of the Directives: "For a proportionate reason, labor may be induced after the fetus is viable." The NCCB statement shows that the psychological state of the mother does not qualify as a proportionate reason for terminating the life of the infant by inducing labor either before or after viability. The emotional trauma of the mother is in response to the condition of anencephaly, but the statement shows that the act of terminating the pregnancy is in itself directed at the infant, not the mother: "Anencephaly is not a pathology of the mother, but of the child, and terminating her pregnancy cannot be a treatment of a pathology she does not have."

If emotional suffering is the condition of the mother (and father), then direct treatment ought to be given for it. The statement acknowledges this problem and calls for appropriate care:

The profound and personal suffering of the parents of an anencephalic child gives us cause for concern and calls for compassionate pastoral and medical care as the parents prepare for the pain and emptiness that the certain death of their newborn child will bring. The mother who carries to term a child who will soon die deserves our every possible support.

Parents can benefit from bereavement programs or psychological counseling. Catholic health care institutions would do well to offer these services to parents of anencephalic children. Bringing the pregnancy to term, allowing optimal opportunity for baptism, and the opportunity for the mother and father to be with the child are all important steps toward bringing closure to the ordeal of the parents.

Postnatal Issues

The statement explains that the moral obligations regarding postnatal care for the anencephalic infant are the same as those for any patient whose death is imminent. First, the moral obligation to conserve human life must be fulfilled proportionate to the individual condition of the child:

The anencephalic child, during his or her probably brief life after birth, should be given the comfort and palliative care appropriate to all the dying. This failing life need not be further troubled by using extraordinary means to prolong it.

Second, the child must be certainly dead before any organs may be taken for transplantation. The shortage of viable pediatric organs for transplantation cannot justify their removal from a still living child. The NCCB statement addresses the issue in the following way:

It is most commendable for parents to wish to donate the organs of an anencephalic child for transplants that may assist other children, but this may never be permitted before the donor child is certainly dead.

This position is in stark contrast to the opinion held by the American Medical Association Council on Ethical and Judicial Affairs in 1995: "the value in the life of an anencephalic neonate is a value only for others" (Journal of the American Medical Association, 273:20:1615).

The NCCB Committee on Doctrine has provided important guidance on the ethics of treating anencephalic infants. The statement of the Committee should inform any effort to develop institutional policy and protocol concerning the treatment of anencephalic infants. In particular, the statement provides decisive guidance on the issue of whether emotional trauma is a proportionate reason for inducing labor.

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