

CATHOLIC ETHICS IN LIFE LIMITING PRENATAL DIAGNOSES

Written by

Tracy Winsor and Bridget Mora of Be Not Afraid Inc., in consultation with The National Catholic Bioethics Center (NCBC), and Robin L. Pierucci, MD, and Martin J. McCaffrey, MD.



One of the most difficult challenges for parents experiencing a prenatal diagnosis is the often-traumatizing attachment of lethal language to the baby alive in the womb. Parents should understand that phrases such as "fatal fetal anomaly," "lethal or terminal prenatal diagnosis," and "incompatible with life" are not clinical terms. More often than not, medical researchers and ethicists suggest these labels tend to reflect the judgment that a life lived with a significant disability is not worth living. At diagnosis, lethal language may be used to encourage the uptake of abortion. Once lethality is attached to a baby, it may also serve to steer the parents who do not abort into limiting their medical options during the pregnancy, and at labor and delivery, and to make decisions before birth regarding the care of their child.

It is important that parents have the best, most medically accurate information to make informed decisions for their unborn child with a prenatal diagnosis. Fatal terminology conveys a false impression that a prognosis can be made with certainty prenatally. Not only is that untrue, but studies have found that when offered the same medical care as other babies at birth, newborns with disabilities like Trisomy 13 and 18 exceed previously assumed lifespans and outcomes. "Life limiting" is a better term that more honestly states what can be known about babies with certain prenatal diagnoses before birth.

Prenatal referrals for palliative care and/or perinatal hospice care with the mindset of limiting medical options for a newborn at birth should not be made unless it is known with moral certainty that the prenatal diagnosis is (1) accurate and (2) that it will directly cause perinatal death with or without life-sustaining treatment and care routinely offered to newborns. The primary reason for this is that medical decisions, which are moral decisions, must be made with all available knowledge.

In the majority of cases, the most accurate information regarding the diagnosis, prognosis, and possible treatment options for a baby with a prenatal diagnosis can only be gained with a full medical evaluation of the child by appropriate medical specialists after he/she is born. Parents, who are charged with acting in their child's best interests, have both the right and the duty to gain such information in order to make medically informed and ethically appropriate decisions concerning their child's medical care.

The evaluation of the living newborn is so important that efforts should be made to stabilize the child at birth, including intubation when necessary, unless the intubation itself is burdensome because an airway is abnormal and tube placement is excessively difficult. In some cases, medical providers may suggest that parents may determine that intubation is unnecessarily burdensome if it appears probable that an infant's prognosis reduces the likelihood of future extubation, as may be the case if an infant has anencephaly. Even in such cases, parents should make the decision.

It should be noted that parents have the right to choose to forgo extraordinary treatment, but basic medical care is morally obligatory. An infant should not be denied basic care and proportionately beneficial life-sustaining treatments whose administration does not create an undue burden to the child. No infant should be allowed to die as a result of lack of nutrition and hydration or other basic care, such as the bandaging of exposed brain or organs, treatments like antibiotics, or other ordinary measures unless the benefits of any such measures are outweighed by the burdens, risks, or side effects from their administration. "Comfort care" protocols should meet this standard as well.

In addition, the assertion that feeding should be withdrawn because its administration creates disproportionate burdens to the baby should only be made following an appropriate medical evaluation. The typical infant who vomits following a feeding isn't then routinely denied any additional feedings.

To this extent, the living baby with a prenatal diagnosis (i.e., a significant disability) should be treated like any other infant. The rights of parents to provide for the basic needs of their child with a disability should be respected. Medical conditions that impact feeding should be discussed fully with parents, and all remaining options for the provision of hydration and nutrition should be explained to them.

Lethal language and the corresponding judgment against life-limiting conditions which may be characterized as uniformly "lethal" by medical providers, can impact the care of an infant in NICU. Medical providers may decide that the provision of supportive measures is futile in spite

of the wishes of parents. The placement of formal DNR (Do Not Resuscitate) orders in an infant's chart without parental consent violates the patient-doctor relationship in which the parent is presumed to speak on behalf of their child. A physician-initiated DNR denies parents informed consent and autonomy in decision-making regarding the care of their baby and may violate the parents' religious beliefs. It is also possible that an unofficial or verbal DNR order or not acting quickly if an infant is in crisis constitutes what some would term a "slow code." This is another means by which a medical team may disregard parental rights.

Relative to securing life-sustaining or restorative treatment, an understanding of the pediatric concurrent care provisions of the Affordable Care Act (ACA) may also be helpful for parents in advocating for their child. The ACA requires that all state Medicaid programs pay not only for hospice services for children under the age of 21 who qualify but also for treatment and care which is curative and therefore related to treatment of the child's condition. Section 2302 of the ACA provides a new standard of care wherein parents who accept pediatric hospice services can also pursue surgeries and other therapies for their child.

Finally, Be Not Afraid (BNA) offers links to medical journal articles related to prenatal diagnosis and the information shared in this newsletter. Visit the "Research" page at www.benotafraid.net. In addition, in cases in which there is any concern regarding morally appropriate care and treatment, BNA recommends that parents be referred to The National Catholic Bioethics Center (NCBC), which provides free consultations to individuals seeking guidance on the appropriate application of Catholic moral teachings regarding ethical issues arising in health care and life science. Visit the NCBC website at www.ncbcenter.org.