



ETHICS & MEDICS

A COMMENTARY OF THE NATIONAL CATHOLIC BIOETHICS CENTER ON
HEALTH CARE AND THE LIFE SCIENCES

DECEMBER 2024 † VOLUME 49, NUMBER 12

THE PROPER CATHOLIC AND PRO-LIFE RESPONSE TO LIFE LIMITING ANOMALIES: MOVING BEYOND PERINATAL HOSPICE

Martin J. McCaffrey, MD

The reversal of *Roe* had been the stated goal of many leading the pro-life movement, but there seems to have been no coordinated strategy for passage of meaningful abortion regulation at the state level. The ensuing abortion battles highlight the continued vulnerability of one group of infants. In seeking compromises to pass pro-life legislation in some states, infants prenatally diagnosed with “lethal anomalies” have been deemed exempt from abortion regulation. At this time in eleven states there are abortion exceptions for “fatal fetal anomalies.”¹ Another twenty-eight states allow for abortion of infants determined by medical providers not to be viable.

It would be a tragedy if this willingness to sacrifice a group of infants as collateral damage was only a feature of abortion debates. It is not. Since the 1990s, the pro-life community, including the Catholic community, has increasingly supported perinatal hospice as the compassionate alternative to abortion of infants with lethal anomalies who will die before or shortly after birth.²

While it may seem politically preferable to trade the harm done to women by abortion (and the violent end of an unborn child’s life) for the birth and peaceful passing of a child with a lethal anomaly in a mother’s arms, diagnosing an unborn infant with a lethal anomaly is challenging because there is no universally accepted definition of a *lethal* or *fatal* fetal anomaly. The conditions that are generally placed in this category include trisomy 13 and 18, severe brain malformations, conditions leading to lung underdevelopment, and absent or severely damaged kidneys. “Survival of at least six months has been described ... in all of the conditions frequently cited as lethal. Most strikingly, this includes both anencephaly (failure of the skull and parts of the brain to form) and bilateral renal agenesis (failure of kidneys to form).”³ Conditions that once were described as lethal, generally a result of our failure to provide any supportive medical care, have come to describe conditions which may be compatible with months, years, and decades of survival.

Since 2020, the American College of Obstetricians and Gynecologists has recommended all mothers be offered prenatal genetic screening.⁴ The standard prenatal genetic screen is the noninvasive prenatal test (NIPT) coupled with ultrasound. NIPT

analyzes a mother’s blood for fetal DNA. The current testing platforms target trisomy 21 (Down syndrome), trisomy 18, and trisomy 13. Down syndrome is not considered lethal, but trisomy 13 and 18 now constitute the largest category of lethal prenatal diagnoses.⁵ The medical literature demonstrates, however, that when standard, supportive medical care is offered infants with trisomy 13 and 18, 40–60 percent of infants are alive at one year and others may live for years, and even decades.⁶

Biases among Neonatologists and Obstetricians

Despite overwhelming evidence, it has been a challenge to have medical providers accept that the lethal language used to describe prenatal conditions for decades is inaccurate. Pediatric ethics expert Dr. John Lantos writing in 2013 stated, “Many clinicians object to life-sustaining treatment of infants with trisomy 13 and 18. These views are based on two ideas. First, that these trisomies are uniformly fatal. Second, that the burdens of treatment under these circumstances outweigh the benefits. These views are no longer tenable. Many infants with these trisomies survive for years. Many parents report infants with trisomies have an acceptable quality of life and are valued family members.”⁷

What these prolonged survivals for infants reveal is a self-fulfilling prophecy. If physicians say a condition is lethal, it becomes lethal. When parents are counseled that a prenatal diagnosis is fatal, and offered no hope for supportive medical interventions, they are left to choose between abortion or perinatal hospice. With a livebirth followed only by hospice care, a quick death is inevitable. There is a high likelihood it will occur within the first week of life. Thus, perinatal hospice is a major reason that survival for liveborn babies with trisomies 13 and 18 is reported as only 5–10 percent at one year.⁸ The decision not to provide any supportive medical care to infants prenatally diagnosed with trisomy 13 and 18 perpetuates the fallacy that these are lethal disorders. Lethality begets lethality.⁹

Despite the literature demonstrating that prolonged survival is possible for some infants with life-limiting conditions, medical providers persist in characterizing disorders with the potential for longer lives as fatal. Parents with prenatal trisomy diagnoses report being told by providers that their “child was incompatible with life (87%), if their child survived, they would live a life of suffering (57%), would be a vegetable (50%), would live a meaningless life (50%), would ruin their marriage (23%) or would ruin their family (23%).”¹⁰ Parents also report that not only were they offered abortion, 61 percent felt “pressured” to abort.¹¹

Why do biases persist in the face of irrefutable evidence demonstrating that the major life-limiting prenatal diagnoses are not predictably life-limited? The literature reveals that many providers understand that the common life-limiting genetic disorders are compatible with life, but when asked if they are compatible with a “meaningful life”, biases related to quality of life surface.

When surveyed, 55 percent and 46 percent of neonatologists and obstetricians respectively describe trisomy 18 as compatible with life. When asked, however, “Is trisomy 18 compatible with a meaningful life?” only 16 percent of neonatologists and 8 percent of obstetricians agreed.¹²

The unavoidable conclusion is that for many medical providers, the challenge with trisomy conditions is not survival but a life of significant disability. This reality is critical for Catholic, pro-life, and disability advocates. The USCCB identifies the dilemma: “We see defense of the right to life of persons with disabilities as a matter of urgency because the presence of disabilities is not infrequently used as a rationale for abortion. Moreover, those babies seriously disabled allowed to be born are often denied ordinary and usual medical procedures.”¹³

Views of Parents Insisting on Medical Support

The views of parents who have children with trisomy 13 and 18 have been studied and offer important insights for those counseling expectant parents.

In a survey of 187 parents whose children died, 89% reported the overall experience of their child’s life was positive. Of the 159 parents whose child lived longer than 3 months, half stated their child experienced more pain than other children and half recognized caring for a special needs child was more difficult than they anticipated. Yet, 98% reported their child enriched their life. Of the families who had other children, 82% felt that this child had a positive effect on siblings. Of all the parents, 3% report their marriage dissolved since the diagnosis of T13-18 while 68% stated this child had a positive effect on their relationship. When all parents were asked if they would continue a pregnancy if they discovered they were expecting another child with T13-18, 8% responded negatively, 9% were unsure, and 83% responded positively or stated that they would not have pursued prenatal testing initially.¹⁴

What a Difference a Prenatal Diagnosis Makes

Prenatal diagnosis increasingly identifies infants with trisomy 13 and 18, but some cases are not diagnosed until after birth. The stark difference in palliative care plans developed for these different scenarios is well described by Annie Janvier et al.¹⁵ In cases of prenatal diagnosis, infants born to parents choosing to continue the pregnancy mainly were offered and accepted perinatal hospice as palliative care. Not uncommonly, palliative care is the terminology used to refer to perinatal hospice. This is a confusing and inaccurate juxtaposition of terms. Palliative care, as defined by the American Academy of Pediatrics, is “an interdisciplinary care approach for children with life-limiting or life-threatening conditions that is focused on improving quality of life and supporting their physical and emotional needs. Pediatric palliative care is not hospice.”¹⁶ The expectation with perinatal hospice, however, is that the baby will die. Therefore, fetal monitoring and interventions for fetal distress, including cesarean section, are not offered. Infant care is limited to keeping the baby warm, the holding of the baby by the family, psychosocial support for the family, and administration of narcotics to reduce the baby’s distress. Generally, there is no plan for effective feeding. It should also be noted that medications used to comfort the baby also may suppress respiratory effort.

The factor in this study most highly associated with the likelihood that a baby with a trisomy diagnosis will die in the hospital after birth is a prenatal diagnosis. The authors state, “It seems palliative care for children with prenatal diagnosis is directed to a goal of having as short a survival as possible after delivery.”¹⁷ In contrast, infants diagnosed after birth have already received a range of interventions in the days before diagnosis. Their palliative care accurately reflects true palliative care. The child has a severe, life-limiting condition, but there are uncertainties, and treatments are employed that may prolong life while seeking to limit suffering that will not support a longer life.

Beyond Perinatal Hospice to Informed Consent

When medical interventions are offered to infants with trisomy 13 and 18, the evidence demonstrates survivals for these babies range from 40–60 percent at one year of life. Not all infants will survive their unique medical conditions, and infants surviving may require a range of medical interventions from simply supporting feedings with a feeding tube to more intensive procedures, including tracheostomy and cardiac surgery. These interventions, however, are always provided to babies with normal chromosomes and the same medical conditions. While babies with trisomy 13 and 18 have higher rates of complications from these procedures, these babies can thrive afterwards.¹⁸ Despite any success in overcoming the medical complications, a child with full trisomy 13 or 18 will have severe mental and motor impairments which medical care cannot change. This is a crucial reality which parents need to be informed about, and which also likely influences the views of physicians who are pessimistic about life with disability and the quality of life for surviving children.

When organizations emphasize perinatal hospice as the primary alternative to abortion for life-limiting anomalies, they are accepting the flawed premise that we can reliably predict the potential for an extended life. This is not the case. First, it is clear from the literature that prenatal diagnosis is not always correct. Prenatal ultrasound, especially as it relates to more complex cardiac defects, is challenging and dependent on the skill of the operators. The NIPT suffers from deficiencies in diagnosing trisomy 13 and 18 for a variety of reasons, but this is especially so for younger mothers. Second, as noted above, the literature demonstrates that infants with trisomy 13 and 18 receiving medical support can survive for years or decades. Third, a blanket perinatal hospice approach to such infants ignores these truths and leaves vulnerable infants subject to the prejudices of many maternal and newborn physicians which invariably influences their counseling.

In addressing exceptions for abortion for life-limiting anomalies, the proper pro-life response needs to move beyond perinatal hospice to informed consent. While there is absolutely a role for perinatal hospice for conditions in which an infant’s life expectancy will be predictably very short, providers also have a duty to disclose that conditions previously characterized as lethal are best described as life-limiting. In these cases physicians have a duty to assess a baby in the delivery room to confirm prenatal findings and to offer stabilization and further evaluation that will allow parents to make the most informed decisions about the life of their child. The perinatal hospice movement and faith in prenatal diagnosis has led some providers and parents to discount the need for provision

of basic medical assessment and confirmation of the initial prenatal findings. Ethically, perinatal hospice should offer parents the opportunity to confirm earlier findings. Some findings, such as anencephaly, may be obvious in the delivery room. In cases such as congenital heart disease, the findings may not be obvious without further study outside the delivery room.

When perinatal hospice care is pursued, Catholics need to be certain it is based on Catholic teaching. Hospice should never seek to expedite death. Narcotics should not be prescribed in doses with the intention to suppress breathing. A hospice care plan should always include adequate hydration and nutrition as the medical conditions allows. There is wide variability in perinatal hospice service adherence to these critical elements. The Catholic and pro-life community at large need to recognize that, though it may be based on a desire to reduce parental distress, some perinatal hospice practices may expedite death.¹⁹

A Catholic and Pro-life Response

While avoiding abortion harms and offering psychological benefits to families is important, it is clear that for some babies, perinatal hospice only postpones the day when the life of an infant, falsely labelled incompatible with life, will be ended. This occurs without offering the infant any standard measures to explore the potential of the baby to survive. The alternative is to offer parents of children with life-limiting disorders the opportunity to have their baby assessed in the delivery room, stabilized, and evaluated by a medical team using standard procedures for newborn resuscitation. This does not obligate a parent to further interventions, but if the parents desire further supportive interventions, they might opt for transfer to the neonatal intensive care unit for further evaluation. Following this evaluation, there would be discussion with parents regarding findings and the development of a care plan going forward. The discussion may determine that care will include continued medical support and interventions, or the discussion may conclude that there are significant life-limiting factors and a transition to perinatal hospice is the best recourse.

The Catholic and pro-life response to parents dealing with a challenging prenatal diagnosis should be to demand that physicians fulfill their duty to offer parents informed consent. Counseling delivered in cases of life-limiting prenatal diagnoses invariably includes abortion. Sometimes it also includes a discussion of perinatal hospice. It rarely spontaneously offers the option of assessment, standard resuscitation, stabilization, and evaluation. The parents have the right to the most accurate medical information as they make decisions for the care of a baby with a prenatal diagnosis. There has been a tendency for perinatal hospice services to characterize themselves as perinatal palliative care. Palliative care services are designed to assist parents as they consider all possible care paths. Proper palliative care services allow parents to explore their goals. They promote individualized decision-making with regard to obstetric management as well as postnatal care for the baby. Such services are agnostic regarding parental choices, but they should openly present all possible options.²⁰ Parents making the decision to seek life for their baby with a life-limiting disorder are often at odds with the biases of providers. There are case management services that are well established in assisting parents seeking life-affirming support through the pregnancy and for at least one year afterward.²¹

Catholic and pro-life communities bear the responsibility to be better educated and equipped to counsel others regarding prenatal diagnosis. It needs to be understood that not only is there no homogenous group of fetal anomalies that can be described as lethal, there is not even a homogenous group of life-limiting anomalies whose length of life can be reliably predicted when standard medical supports are available. Catholic teaching is clear: “Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate.”²² These are decisions, however, that should be made in conjunction with parents fully informed of any uncertainties regarding outcomes for their baby as well as the potential for benefit from medical interventions.

The English poet, John Donne, wrote, “No man is an island . . . any man’s death diminishes me, because I am involved in mankind, and therefore never send to know for whom the bell tolls; it tolls for thee.”²³ Whether death is expedited through abortion or denial of standard medical care, the plight of infants with life-limiting anomalies concerns every one of us. As Catholics we should believe that each one of these infants is here with special purpose, whether their lives be short or long. Our Lord felt the world was incomplete without each one of these children. The *Catechism* tells us, “Those whose lives are diminished or weakened deserve special respect.”²⁴ Our advocacy as Catholics and pro-life communities should be focused on being certain we honor the dignity of these infants, pursuing reasonable possibilities for life, not preoccupying ourselves with how best to end a life we decide is not worth living.

“The primary challenge we face as a society dealing with a prenatal diagnosis is not about the ‘end of the story’ or about the outcomes, disabilities, or even capabilities associated with any particular condition. Ultimately, our challenge is to continue to bear witness, by our words and actions, to the fact that a prenatal diagnosis does not affect the inherent dignity, the unique and unrepeatable human reality, of a baby.”²⁵

Martin J. McCaffrey, MD, is a professor of pediatrics and director of perinatal quality collaborative of North Carolina at University of North Carolina School of Medicine in Chapel Hill, North Carolina.

Notes

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ETHICS & MEDICS

DECEMBER 2024 † VOLUME 49, NUMBER 12

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Catholics and all people of good will effectively draw on the light and life of Jesus Christ and the Catholic moral tradition in addressing ethical challenges in health care and biomedical research; and the integral understanding of the human person underlying the teachings of the Catholic Church on respect for human life and dignity is better understood and more widely embraced in America and worldwide.

