Abstract. When the delivery of a baby at the edge of viability (twenty-two to twenty-five weeks) is imminent, gestational age is usually the primary indicator for resuscitation. However, four other variables—female sex, antenatal corticosteroid therapy, singleton birth, and increased birth weight—are also associated with better infant survival and neurologic outcome in intensive care, and the combination of all five variables provides a stronger prognostic tool. An ethical framework is provided here for use in determining whether proposed treatments are likely to defend the dignity and sanctity of a fragile periviable life. The framework is based on the principle of ordinary/proportionate and extraordinary/disproportionate medical treatment. The author recommends using the most recent outcome data and this ethical framework together to make perinatal resuscitation decisions. Use of gestational age alone is insufficient and ethically immoral. National Catholic Bioethics Quarterly 14.3 (Autumn 2014): 429–439.

The journey to parenthood technically begins with a nine-month anticipatory period, better known as pregnancy. Unfortunately, for many the journey is abbreviated by a preterm delivery and a subsequent domino effect of unanticipated decisions, stemming from the fact that premature infants are not merely small babies. Depending on the degree of prematurity, the baby’s physiology may be so immature that it is incompatible with life outside of the womb.

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Advances in neonatology have pushed back the limits of just how young and small a baby can be when we are able to successfully intervene, but sometimes—even if the infant survives—the cost of “success” remains extraordinarily high for both the infant and the entire family. Complicating this picture is our limited ability to predict survival or long-term outcome. Thus, at the edge of viability (twenty-two to twenty-five weeks), decision making about whether to resuscitate an infant is problematic.

For years this decision has been driven by the infant’s gestational age. However, the latest outcome data demonstrate that by using gestational age plus four additional variables, one can calculate a probability for survival and for survival with and without neurologic complications. This clinical evidence, combined with the ethical principle of ordinary/proportionate and extraordinary/disproportionate medical treatment, makes decision making for marginally viable infants based solely on their gestational age insufficient and ethically immoral.

In the course of a lifetime, a person is affected by millions of external experiences. Over this same span of years, we are affected internally by millions of physiologic changes. The changes begin when the mother’s single microscopic human egg and the father’s single sperm cell together inaugurate a nine-month embryologic dance of multiplication and division, cell migration and specialization, folding and twisting, and growth and maturation, all of which miraculously culminate in a physiologically separate, unique, and yet genetically related human being. Actually, all of a person’s organs continue to change throughout life, but as years advance, the process is called aging as opposed to developing. Human development is so extreme that although we live on land, breathe in air, and eat and digest food all our lives, we are unable to perform any of these activities during the prenatal period. Depending on the embryologic stage of development, lungs, a heart, bones, skin, and a digestive tract that is connected and patent from top to bottom may or may not be present and functional. Thus, early removal from the perfectly crafted intrauterine environment is potentially devastating.

Because pregnancy is supposed to last for nine months, not all preterm deliveries are equally at risk. In general, the more premature the infant, the greater the chances of subsequent problems. It is also possible for a term infant (defined as a child born at thirty-seven to forty weeks of gestation) to have an organ system that is still functionally immature—lungs are particularly known for this. The good news is that if there are no additional complicating factors, such as overwhelming infection or an absent essential organ system, we can now potentially rescue premature infants born as early as the pregnancy’s second trimester.

Interestingly, it is the abortion legislation of Roe v. Wade that established “a trimester framework for gestational age” and named twenty-eight weeks as the age of

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viability. This definition was upheld for years despite the medical reality that increasing numbers of premature infants born at less than twenty-eight weeks were being successfully resuscitated. Gestational age remained the legal definition of viability in the United States until 1992, when in “Planned Parenthood of Southeastern Pa v. Casey, the Courts abandoned Roe’s landmark trimester framework and adopted previability and postviability statutes.” Currently, individual states have their own legal definitions of viability, with the majority deferring this judgment to the attending physician. This leads back to the question, how does the doctor know if an infant is or is not viable?

The Gray Area of Periviability

The answer is complicated. Just as all patients with the same medical diagnosis remain individual patients with different nuances to their normal state as well as their pathological one, in addition to different abilities to live with the ramifications of what has gone wrong, the same is true for perivable infants. The gray zone of periviability is currently between twenty-two and twenty-five weeks’ gestation. Perivable, marginally viable, extremely premature, extremely low birth weight, and edge of viability are all phrases used to describe this population of infants who are so premature that the benefits of resuscitating them may be outweighed by the risks of doing so, specifically the risks of prolonging their death or enabling them to survive with overwhelming permanent problems.

In the United States, there has been a prevailing idea that at delivery, a neonatologist can look at a perivable infant and intuit if he or she will survive. This belief was tested by Dr. Jaideep Singh et al. and found to be false. They surveyed neonatologists in the United States to assess how they made resuscitation decisions in the delivery room for infants born at twenty-two to twenty-six weeks’ gestation, and found that how the infant looked at delivery, as demonstrated by their one and five minute Apgar scores and heart rates, was “neither sensitive nor predictive for death before discharge, survival with a neurologic abnormality, or intact neurologic survival.” This study indicated that waiting for an infant to “declare” itself vigorous enough to initiate intervention would seem problematic at best, and at worst a self-fulfilling prophesy for the already vulnerable. This remained true not only during the first minutes of life, but also extending into the hospitalization. As Singh et al. noted, “Nonsurviving infants seem to cloak themselves, not declare themselves, over days in the NICU [neonatal intensive care unit].”

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4 Ibid., 1051.
5 Ibid.
7 Ibid., 525.
The limited ability of neonatologists to predict how a periviable infant will respond is important, because the need for this assessment is often precisely why they are asked to attend a delivery where the gestational age or viability are unclear. Though gestational age does have a “strong association with outcome,” decision making based on it is problematic because it is an educated guess. Gestational age is based on the date of conception, and while some people are very aware of when they conceived, others have little or no idea. Today, ultrasounds obtained early in a pregnancy help establish or confirm a gestational date, but if this is not done early enough, the estimated gestational age may have an error as great as two weeks. At the edge of viability, this discrepancy has profound ramifications.

Other Neonatal Factors

In addition to gestational age, there are a number of other factors that influence neonatal outcome. In a landmark study done by the National Institute of Child Health and Human Development (NICHD) Neonatal Research Network, 4,446 infants born between twenty-two and twenty-five weeks’ gestation were studied specifically to determine what variables were relevant to morbidity and mortality. Gestational age was shown to have statistical relevance, but so did four additional variables. The study found that “of infants who received intensive care, exposure to antenatal corticosteroids, female sex, singleton birth, and higher birth weight (per each one hundred-gram increment)” were each associated with better outcomes.

In addition to identifying these five key variables, the authors also used this information to create an online “calculator.” The tool allows one to input a patient’s variables and obtain a prognostic percentage for survival, and for survival with and without neurologic impairment, based on the study’s outcome numbers. Since publication in 2008, the findings of this study have had such profound ramifications for care in these difficult pregnancies that, in 2013, a joint workshop between obstetricians, perinatologists, pediatricians, and neonatologists was convened. In the workshop’s published summary, periviable birth was defined “as delivery occurring from 20 0/7 through 25 6/7 weeks of gestation” and was noted to reflect “survival rates from 0% at twenty weeks to more than 50% at twenty-five weeks.” From the NICHD study, it is known that gestational age is just one of the statistically relevant variables that influence these outcome numbers.

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9 Ibid.
11 Ibid.
12 Tonse N. K. Raju et al., “Periviable Birth: Executive Summary of a Joint Workshop by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, Society for Maternal–Fetal Medicine, American Academy of Pediatrics, and American College of Obstetricians and Gynecologists,” Journal of Perinatology 34.5 (May 2014): 334. The notations 0/7 and 6/7 denote days 0 and 6 of the respective weeks.
As powerful as the information from the NICHD study is, its usefulness has some significant limitations. One of these limitations is the “calculator’s” inability to correct for additional relevant risk factors. As Katherine Griswold and Jonathan Fanaroff point out, the tool provides an ability “to make improved prognostic estimates for groups of infants but do[es] not address individual prognosis.” For example, a singleton female fetus at twenty-five weeks’ gestation, weighing seven hundred grams (an estimate determined by ultrasound), whose mother received prenatal steroids, has—according to the calculator—a survival rate of 82 percent. In reality, however, due to failure of the kidneys to develop, the chance of survival is currently zero. This is an extreme example, but it is also an unambiguous one. Prognosticating outcome quickly becomes much more complicated when either the diagnosis or its ramifications are less clear. Thus, in an increasingly complicated case, the prognostic ability of the NICHD calculator becomes increasingly limited. If basing the decision about whether or not to resuscitate a periviable infant is problematic when using the combined power of five statistically proven relevant variables, then using gestational age alone seems absurd.

Another concern about the outcomes found by the NICHD study is that the results are not necessarily applicable in other facilities. The hospitals participating in the study are academic level III or IV neonatal intensive care units, which does not describe where many periviable infants are born. Even those infants who are not necessarily at the edge of viability but have a birth weight of less than fifteen hundred grams or are under thirty-two weeks’ gestation have been shown to have worse outcomes if born outside a perinatal subspecialty center. Thus, for family counseling, the NICHD study data are important but not necessarily representative of an individual hospital’s outcomes. Knowing one’s own local statistics may be more important than the published study results.

Interestingly, there was a somewhat surprisingly wide variability in the outcomes among the participating NICHD centers. This was remarked on in both the NICHD study and the joint workshop report. At the workshop, modifiable and non-modifiable reasons for the outcome discrepancies were identified, and participants surmised that “local practices and protocols for withholding or withdrawing intensive care after birth” could also be affecting outcomes.

This is an ethically important point, as not having the capability to adequately resuscitate a periviable infant is one thing, but having the ability and not using it is another. Why is resuscitation not always offered? This could be because of years of only resuscitating infants above a certain gestational age. Such a scenario has happened before. More than one “seasoned” nurse has reminded me that, prior to

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13 Griswold and Fanaroff, “An Evidence-Based Overview of Prenatal Consultation,” e834.
16 Ibid.
the discovery of surfactant, if an infant needed to be placed on a ventilator, this was
the cue for the nurses to start filling out a death certificate. Rescuing progressively
smaller and gestationally younger infants has never been comfortable, and we are
again being challenged today in what we have become relatively comfortable doing.
That said, I also think that this issue is more complicated than breaking old habits.

At the joint workshop, there was consensus regarding the importance of prenatal
consultations for both conveying information to as well as hearing from families prior to
making decisions about periviable resuscitation. Before the workshop, both the Amer-
ican Academy of Pediatrics (AAP) and the Neonatal Resuscitation Program (NRP) had
created formal policies regarding perinatal consultations and what information should
be covered. However, despite these policies, there was no consensus about exactly
which periviable neonates to attempt to rescue or how this decision should be made.
Given that we do not agree on how to make this decision, it is not surprising that
there are differences in various institutions’ protocols regarding how aggressive to
be with this incredibly fragile population.

The lack of consensus about how to make the decision of whether or not to
resuscitate a marginally viable infant may be due in part to what Griswold and
Fanaroff call the “treatment dilemma”: “The risks of providing intensive care include
the prolongation of dying, infant pain and discomfort, and infant survival with a poor
quality of life. The other concern, however, is that noninitiation of treatment for an
infant who ultimately survives would result in increased morbidity and mortality for
that infant. . . . Faced with an uncertain outcome, there will always be risk that the
decision to resuscitate or not will end with an undesired result.”

Griswold and Fanaroff’s “treatment dilemma” puts a name to this inherent
ethical tension. Both perinatal and neonatal staffs strive to balance the use of medi-
cal technology with appropriate humility for what we can and cannot fix, knowing
that we risk genuinely harming an infant by doing either too much or too little. Add
to this tightrope walk parents who have been suddenly thrown into a crisis and then
asked to participate in a complex and emotionally crippling decision, and we have
the potential for significant confusion and frustration.

Ideally there would be time for everyone to discuss the situation, digest the
information, ask questions and discuss further, and then make a decision on the best
course of action. The reality is that there frequently is not the luxury of much time
before either the mother or the infant requires medical intervention. Depending on how
rapidly the situation is progressing, gestational age is sometimes the most expedient
piece of the larger puzzle to discuss. It is comparatively easy to determine, fairly easy
to explain, and relatively easy for a family in crisis to comprehend. Given the genuine
association of gestational age with outcome, comparative ease of communicating
what it is, and medical staff’s appropriate fear of damaging a baby, using gestational

17 Ibid., 332.
18 Griswold and Fanaroff, “An Evidence-Based Overview of Prenatal Consultation,”
e931.
19 Ibid., e934.
age as the primary aid in periviable decision making becomes understandable. But while gestational age may be the least complicated way of explaining what is happening, that does not mean it should be used as the sole indicator for resuscitation.

**The Dominance of Principlism**

Unfortunately, using gestational age alone for periviable decision making is not obviously immoral in the ethical framework commonly used in American medical policy. This framework is called “principlism,” and not only is it used by Griswold and Fanaroff to support the AAP/NRP policies, but it is also the predominant guideline for ethics in the American medical system. Principlism is based on the application of four principles: autonomy, beneficence, nonmaleficence, and justice. Without question, their application to medical situations can produce fair and compassionate evaluations, but problematically this is not automatically true since none of the four key principles inherently defends the intrinsic value of all human life. In their article “An Evidence-Based Overview of Prenatal Consultation with a Focus on Infants Born at the Edge of Viability,” Griswold and Fanaroff articulately illustrate how all four principles can be applied to periviable decision making. Much of what they write echoes the natural law wisdom of avoiding harm and only taking risks that have a reasonable chance of success. They clearly desire fairness and compassion for both the infant and the family, but there is no principle devoted to safeguarding the dignity and sacredness of all human life starting at conception. Thus, principlism can be appropriately applied yet still lead to an immoral conclusion.

For example, under principlism, parents can refuse the resuscitation of their twenty-five-week-old infant because they are not being guaranteed a perfect child. In a case I witnessed, as in most other pediatric ethical dilemmas, the parents were considered the “natural surrogates,” since no infant is autonomous. They believed that they were beneficent (doing good), nonmaleficent (avoiding harm), and just (providing fair treatment) by concluding that without a guarantee of a normal life, the life of their baby was not worth living and therefore no resuscitation should occur.

The neonatologists involved, who were neither overtly religious nor from the same religious background, all independently stated that if called to the delivery, they would resuscitate the baby. They discussed this with the family, including the fact that no newborn at any gestational age arrives with the guarantee of being “perfect.” Prenatal discussions also included the results of the NICHD tool, the specifics of their case, current standards of care, and the outcome statistics at that particular neonatal intensive care unit. Given this information, the infant could reasonably be expected

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20 Ibid., e931: “The ethical principles involved in neonatal resuscitation are similar to those in other areas of medicine: autonomy, beneficence, nonmaleficence, and justice.”


22 Griswold and Fanaroff, “An Evidence-Based Overview of Prenatal Consultation,” e932.
to survive and do well. Prior to the baby’s birth, the family left the hospital against medical advice, and the infant’s outcome remains unknown.

The family appeared to be reluctant to resuscitate their infant because the baby might not be perfect. A refusal to resuscitate an infant for this reason would be unethical, constituting euthanasia by omission. As stated in the *Ethical and Religious Directives*, “We have a duty to preserve our life and to use it for the glory of God, but the duty to preserve life is not absolute, for we may reject life-prolonging procedures that are insufficiently beneficial or excessively burdensome. Suicide and euthanasia are never morally acceptable options.”

Additionally, such a refusal would violate the principle of double effect. One criterion of this principle states that good ends cannot be procured through bad means. While the parents were attempting to achieve the good ends of beneficence and nonmaleficence, these must not be accomplished through the bad means of their child’s death due to intentional omission of medical intervention. Sadly, as shown above, the logic of principlism’s four tenets can be applied to defend a wrong decision by the parents, resulting in an unethical conclusion.

### Ordinary versus Extraordinary

To resolve the ethical problem of how to make decisions for resuscitating perivable infants, a system is needed that weds moral deliberation with medical ingenuity. This is what the principle of ordinary/proportionate and extraordinary/disproportionate medical care offers. It is a principle that is discussed in two documents which specifically address moral medical decision making: an address of Pope Pius XII to a congress of anesthesiologists, and the Congregation for the Doctrine of the Faith’s *Declaration on Euthanasia*. These documents explain what makes a medical treatment morally obligatory (“ordinary” or “proportionate” treatment) or morally optional (“extraordinary” or “disproportionate” treatment). As William May explains, ordinary medical treatment is “that kind of treatment which offers reasonable hope of benefiting the subject without imposing unacceptable burdens on the subject or others,” whereas extraordinary medical treatment is “treatment that imposes unacceptable burdens on the subject and/or others.”

May notes further that, with this idea of dividing medical intervention into ordinary and extraordinary treatments, Pius XII provides a “general approach” to medical decision making that is moral, without naming specific medical interventions. We thus have a framework for applying ethics to medical treatment that is

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24 Pius XII, Address to an International Congress of Anesthesiologists (November 24, 1957); and Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (May 5, 1980).


26 Ibid.
not beholden to a specific era or discovery. May explains that the second document, the *Declaration on Euthanasia*, strengthens this ethical framework by clarifying that “it is legitimate to consider the ‘quality’ of . . . life in relationship to specific kinds of treatments for a person in that condition,” but it is never morally appropriate to judge a life not worth living.\(^27\) This point is crucial. *Life* is never found too burdensome to continue, but a medical *treatment* can be.\(^28\)

To determine whether or not a treatment is ordinary/proportionate (and therefore obligatory) or extraordinary/disproportionate (and without moral obligation) depends on its degree of burdensomeness and uselessness.\(^29\) The burdensomeness of any treatment is a compilation of the riskiness of the treatment itself, plus its resulting physical, emotional, and psychological ramifications.\(^30\) So if the treatment options for an individual periviable infant are too burdensome, then it is morally appropriate not to resuscitate that baby. In the case described above, the neonatologists in essence stated that they would perform morally obligatory ordinary/proportionate care. Because of the inherent value of every human life at all stages of its existence, combined with the reasonableness of success, it would be immoral in this case not to attempt to resuscitate this baby. Neither gestational age alone nor the argument that the life saved is not worth living could morally justify abandoning this child.

This is completely different from concluding that medical treatment would be overly burdensome. Directive 57 of the *Ethical and Religious Directives* clarifies overly burdensome treatments as being “those that in the patient’s judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community.”\(^31\) The family in the case discussed here was financially secure and made it clear in so many words that they valued life with a guarantee of health. According to the United States Conference of Catholic Bishops, “the task of medicine is to care even when it cannot cure.”\(^32\) It is with humility for what we cannot fix that when treatment is indeed disproportionate, we change the goals of treatment and therefore the interventions too.

For example, oxygen and pain medication should be provided to keep a patient as comfortable as possible, but placement on a ventilator may not necessarily be indicated. In the neonatal intensive care unit, the urgency of keeping a baby in the family’s loving arms may be of greater value than the insertion of tubing that could prolong suffering and limit loved ones’ closeness. The magisterial principle of proportionate and disproportionate treatment demonstrates the commonsense wisdom that just because a technology exists, does not mean it has to be used. In principlism, autonomy is dominant and an autonomous patient or surrogate can, to varying degrees, determine what treatment they do or do not want. The ethics of the Catholic Church

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\(^{27}\) Ibid., 271.

\(^{28}\) Ibid., 273.

\(^{29}\) Ibid., 272.

\(^{30}\) Ibid.

\(^{31}\) USCCB, *Ethical and Religious Directives*, n. 57.

\(^{32}\) Ibid., part 5, introduction.
are dominated by the inherent obligation to first honor the dignity and sacredness of all human life, and then decide if the available medical treatment supports this duty.

The struggle over whether or not to resuscitate a periviable infant and the use of gestational age in making this decision is not a problem only in the United States. In Italy, a document called the *Carta di Firenze* outlined specific therapies to use (or not) during the individual weeks of twenty-two through twenty-five weeks’ gestation. Basically, the younger the gestational age, the less intervention was to be performed, and this was also true if the baby’s condition appeared to be poor at birth.\(^\text{33}\) In response to this document, the Italian National Bioethics Committee stated that the “presumption of identifying a temporal threshold below which to refuse, *a priori*, any attempt at resuscitation” is “‘ethically’ and scientifically unacceptable.”\(^\text{34}\) They also stated, “Like any other person needing assistance, extremely premature newborns have full right to the adoption of all the appropriate procedures to ensure their survival. The *Carta di Firenze* instead seems to invert this principle for newborns between twenty-two and twenty-three weeks, who appear to deserve resuscitation practices only exceptionally, when there is evidence of significant vital capacities or of the capacity to survive.”\(^\text{35}\)

Making infants (or anyone) prove their vitality first before offering help is ethically untenable. This is equivalent to saying that we should only rescue someone who is drowning if they are able to jump up and down and yell. The ethical principle behind the Catholic view is again the inherent dignity and sacredness of all human life. Care that is Catholic includes a particular obligation to the sick and vulnerable.\(^\text{36}\) When one is trying to decide whether or not to withhold, withdraw, or limit the care of a fragile periviable baby (who may or may not be vigorous at birth), it is not ethically defensible to make this decision based on the educated guess that defines gestational age.

**Inherent Goodness of Life**

There is a line of T-shirts that state, “Life is Good.” They got it right. Our secular world tolerates this idea with a shrug and perhaps a smile, but it is the nucleus of a much deeper concept. *Human* life in particular is good not because of anything I can do for myself, but because it is a gift from an all-good Creator. Because every life is a gift from God, there are no optional or worthless lives or periods of life that are worth less than others. Life never ceases to be valuable and sacred.

The ways in which today’s culture assigns value to certain periods of life are as intermittent as they are arbitrary. Using gestational age to determine which child to resuscitate or not is just another culturally consistent value assignment based on


\(^{34}\) Ibid., 2.

\(^{35}\) Ibid., 3.

\(^{36}\) USCCB, *Ethical and Religious Directives*, n. 3.
age. The side effect of this consistency is the unfortunate dulling of the alarm bells that should be ringing in our consciences. Yes, an infant’s gestational age should be accounted for in the larger discussion of whether or not our technology should be used; this is the grain of truth that makes it reasonable to consider. But gestational age does not define the value of the unborn child anymore than age defines our inherent value as we get older.

To ethically determine which if any medical treatments should or should not be applied to a periviable infant, there needs to be a presupposition that from conception to death all human life is inherently good. Then the treatment can be weighed as being either more or less likely to guard the dignity and sanctity of the human life. Conversations about periviable babies are never easy, nor should they be; a life is literally at stake. However, the principle of ordinary/proportionate and extraordinary/disproportionate treatments provides an ageless framework in which to judge the usefulness or burdensomeness of every medical technology—past, present, or future. In the face of what has been gleaned from clinical outcome data, as well as conceptually developed by Church doctrine, edge-of-viability decision making that is made solely by gestational age is both insufficient and morally unethical.