
Between Hope and Hard Choices: The Ethical Frontiers of Neonatal Care for Medically Complex Infants

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Abstract

Life-sustaining medical treatment decisions for critically ill newborns with medical complexity represent one of the most ethically complicated challenges in modern medicine. This multidisciplinary analysis examines the medical, legal, and ethical considerations surrounding withholding or withdrawing care from infants with congenital anomalies or extreme prematurity. A case study of 24-week preterm twins highlights the competing perspectives involved when quality of life predictions shape treatment limitations.

From the medical standpoint, data on survival rates given advancing medical therapies for preterm infants can provide context for guidelines for treatment, with treatment futility underpinning the benefit-burden analysis. We will overview key U.S. legislative actions and court cases outlines the evolving policies aimed at preventing discriminatory medical neglect of children with medical complexity (CMC), including the Rehabilitation Act, the Child Abuse Amendments of 1984, and the Americans with Disabilities Act. Finally, we will review the normative ethical framework proposed by Richard McCormick that introduces a "quality of life" criterion to determine the best interests of never-competent patients. Applying this model to the case study illustrates how parents and clinicians could approach treatment decisions through this ethical lens.

INTRODUCTION

The American Academy of Pediatrics defines children with medical complexity (CMC) as those who have "medical and/or behavioral conditions that impact two or more body systems, and have high utilization rates and needs for healthcare services, with technological assistance or dependence."¹ Life-sustaining medical treatment is routinely withheld or withdrawn from critically ill infants with medical complexity in neonatal intensive care units globally, comprising approximately 40%-60% of deaths in the pediatric intensive care unit.² Quality of life predictions shape 33-50% of decisions to limit treatment across Australia, Northern Europe, and the United States.³ Still, clear legislative protections are needed for medically complex infants equally entitled to live. Approximately 1 in 33 infants are born with a congenital anomaly annually in the United States alone,⁴ and with advancing medical capacity, this number continues rising.⁵ As CMC obviously lack competence to make their own medical decisions, this authority is granted typically to parents and physicians.⁶ Yet courts, legislators, and the public still grapple with outlining

consistent and non-discriminatory standards of care. Since the 1960s, state and federal statutes have evolved attempting to prevent medical neglect.⁵ But specific guidelines for treating medically complex neonates remain ambiguous and unevenly applied. The resulting variability in life and death decisions has prompted ethical debates over parental discretion, physicians' duties, and legislative responsibilities for protecting CMC. As intensive interventions increasingly save premature and medically complex infants, difficult questions arise regarding how much intervention is ethically appropriate based on judgments of quality of life and chances of survival. This paper examines dilemmas around guaranteeing non-discriminatory medical care for medically complex newborns through the context of a case study.

CASE STUDY

A 34-year-old primigravida pregnant with 24-week twins presented to obstetrics triage with severely elevated blood pressure. Laboratory results indicated preeclampsia with severe features. The patient underwent an emergency cesarean section. In the operating room, the neonatologist briefly met with the family to explain expected events over

the next hours and confirm their wish for neonatal resuscitation, which the parents affirmed. The twins were born one minute apart. Apgar scores were 8 and 9 at one minute for both twins, respectively. Over the subsequent few hours, both needed to be intubated, placed on mechanical ventilation, and given surfactant. In the NICU, head ultrasounds on day of life 3 showed no evidence of intraventricular hemorrhage in either neonate.

The attending neonatologist conducted a detailed discussion with the family regarding potential morbidity and mortality. The parents were told that at that gestational age, extremely preterm infants have an almost guaranteed risk of some degree of morbidity, ranging from corrective lenses to chronic conditions requiring assisted ventilation and tube feedings. On the fourth day of life, the parents requested a meeting with the neonatologist to have the infants removed from mechanical ventilation and transitioned to comfort care. They reported lacking the financial and social support to care for one or two children with intensive special needs. Both parents worked full-time and were living paycheck to paycheck. They stated that in retrospect, they would have declined resuscitation if they had known these outcomes. After being transitioned to comfort care, both twins passed away shortly thereafter.

MEDICAL ANALYSIS

Preeclampsia is a common hypertensive disorder of pregnancy affecting approximately 4% of pregnancies in the US.⁷ Preeclampsia is defined by new onset hypertension or worsening chronic hypertension, occurring after 20 weeks of gestation, combined with either new-onset proteinuria or other specific symptoms or laboratory abnormalities of end-organ damage. This disorder can be further categorized by the presence or absence of severe features based on predefined criteria.⁸ Progression from non-severe to severe can be gradual or rapid onset.

The pathogenesis of preeclampsia involves maternal and placental factors early in the pregnancy. Abnormal placental vasculature causes impaired uteroplacental blood flow leading to systemic endothelial dysfunction and clinical manifestations of disease. Risk factors for preeclampsia include personal and/or family history of preeclampsia, nulliparity, advanced maternal age (≥ 35 years old), obesity with a BMI > 30 kg/m², chronic hypertension, multifetal pregnancy, and preexisting chronic medical conditions (systemic lupus erythematosus, antiphospholipid syndrome, chronic kidney disease, sickle cell disease, diabetes

mellitus).^{8,9}

Delivery of the fetus and placenta is the definitive treatment of preeclampsia; however, timing and route of birth depends on standard obstetrics indications based on severity of preeclampsia, gestational age, and stability of pregnant woman and fetus. Expectant management (delivery timing ≥ 34 weeks) of preterm preeclampsia to prolong pregnancy to improve neonatal outcomes requires appropriate level care for both the mother and fetus for close monitoring and discussing maternal mortality risks. Delivery ≤ 34 weeks of gestation is indicated in preeclampsia with severe features with laboratory abnormalities, instability of pregnant woman and fetus.⁹

Preeclampsia can have unfavorable maternal and fetal health outcomes. Short-term complications on the fetus include oligohydramnios, fetal growth restriction, placental abruption, non-reassuring fetal status, increased risk of spontaneous or induced premature delivery and neonatal death.^{7,8,9} Extreme prematurity can be associated with significant morbidity and mortality.

Extremely Preterm Infant Outcomes

Although neonatal mortality rate has remained low since 1995, 65% of the deaths in the neonatal period in the United States still occur among preterm infants.^{10,11} Prematurity is defined as the infant born alive before 37 completed weeks of gestation, categorizing the degrees of prematurity as follows: Late Preterm (GA 34 to < 37 weeks), Moderate Preterm (GA 32 to < 34 weeks), Very Preterm (GA < 32 weeks), and Extremely Preterm (GA < 28 weeks).

Advances in care for mothers and extremely preterm infants have significantly changed in the past twenty years, with the development of new technologies and advanced therapies, which has contributed to the overall positive trend of improved survival rates in premature neonates since 2008, with the most benefit amongst infants born between 23 and 24 weeks of gestational age.^{12,13,14}

Neonates born preterm are more likely to require additional intervention at birth given their immaturity and are more vulnerable to injury from those interventions. Antenatal steroids are recommended to reduce the risk of bronchopulmonary dysplasia (BPD), a chronic lung disease of prematurity. In the delivery room, supportive neonatal care is the same as with term infants, however providing special attention to protective lung strategies.¹⁵ For infants with spontaneous breathing, positive pressure ventilation

should be initially considered as an alternative to routine intubation to avoid the risks of these invasive interventions. Infants who have poor respiratory effort or apnea, and/or a heart rate < 100 per minute, should be resuscitated with bag mask ventilation (BMV). If there is no response to BMV, intubation, surfactant administration and initiation of mechanical ventilation are indicated to provide respiratory support. Cardiopulmonary resuscitation increases the risk of germinal matrix hemorrhage and intraventricular hemorrhage which can negatively impact the neurodevelopmental outcomes of preterm infants, prompting sequential head ultrasounds during the first days of life for early detection and intervention.¹⁶

Despite the increase of survival for infants born ≤ 24 weeks, there is still 64% mortality and 43% survive with some neurodevelopmental impairment, including moderate to severe cerebral palsy, profound visual impairment, profound hearing loss or cognitive impairment.^{16,17,18} The development of bronchopulmonary dysplasia also impacts survival and long-term quality of life. The frequency of late death, severe respiratory morbidities, and neurodevelopmental impairments increases in a stepwise manner to over 80% corresponding with BPD severity.¹⁹ Predicting childhood survival and long-term morbidities in extremely preterm infants is challenging but data-driven discussions with a clear expression about our gaps and limitations in knowledge should guide counseling and decision making by clinicians and families.

LEGAL ANALYSIS

Baby Doe

In 1982, a baby boy known as “Baby Doe” was born in Indiana with Down Syndrome and a tracheoesophageal fistula. This condition required surgical intervention to connect the disconnected parts of the esophagus. However, influenced by their obstetrician’s narrow view of Down Syndrome, the parents chose not to authorize the surgery and withheld food and water for the child. The hospital nurses took legal action to challenge the parents’ decision, but the Indiana Supreme Court ruled in favor of the parents’ right to follow the obstetrician’s recommendation. “Baby Doe” unfortunately passed away at the age of six days before the case could be appealed to the United States Supreme Court.^{5,20,21}

The Reagan Administration argued that this case constituted “disability-based discrimination,” as infants without Down Syndrome would undoubtedly receive necessary treatment.

Subsequently, Reagan ordered the Department of Health and Human Services (HHS) to post notices in hospitals prohibiting failure to care for infants with disabilities. Any hospital doing so would be in violation of Section 504 of the Rehabilitation Act, which prohibits discrimination on the basis of disability in programs funded by the federal government and guarantees medically complex individuals will have meaningful access to health care and other services. It reads, “No otherwise qualified individual with a disability ... shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.” The Act defines “individual with a disability” as “any person who

1. has a physical or mental impairment which substantially limits one or more of such person’s major life activities;
2. has a record of such an impairment; or
3. is regarded as having such an impairment.” If the courts agreed, hospitals that refused to treat newborns with disabilities in the future could be denied federal funds.⁶

At the time, the courts invalidated the HHS’s regulation, finding that neither Section 504’s language nor its legislative history authorized providing heroic medical care to medically complex newborns. The court pointed to the Rehabilitation Act’s definition of “individual with a disability” and concluded that while some infants may fit this definition, there was no evidence of Congressional intent to apply § 504 so broadly as to eliminate consideration of treatment futility.⁶ The ruling stated that § 504 does not allow for government intervention when a parent makes the decision to withhold treatment, rather than a healthcare provider receiving federal funds.²⁰

Child Abuse Amendments of 1984

In response to the Baby Doe case and other similar issues in the ‘80s, Congress added a new clause to the Child Abuse Prevention and Treatment Act in the form of the Child Abuse Amendments of 1984. The amendments created a federal grant program to incentivize states to monitor and prevent medical neglect of infants with disabilities. The Amendments prohibited the “withholding of medically indicated treatment,” which means the failure to provide necessary treatment (including nutrition, hydration, and medication)—that the treating physician(s) believes will be most effective in improving or correcting all such conditions—to an infant with life-threatening conditions. The only exceptions to this are as follows:

1. The infant is chronically and irreversibly comatose;
2. The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or
3. the provision of such treatment would be “virtually futile” in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.²²

These Amendments were a strategic move by the Reagan administration to indirectly regulate behavior in treating infants with disabilities, given the resistance to direct federal regulation. The implications of these amendments and the precedent they set were significant. They set forth specific criteria and guidelines for the treatment of medically complex newborns in the United States, regardless of the wishes of the parents. This marked a major shift in the approach to medical ethics and law, particularly in cases involving infants with severe disabilities. The law underscored the importance of providing appropriate care based on professional medical judgment, and failure to do so could be considered a form of medical neglect.²¹

Baby K

In 1992, Baby K was born with anencephaly, a severe birth defect that left her permanently unconscious with only brain stem function. She was given ventilator treatment upon birth and during subsequent episodes of respiratory distress. Driven by her personal beliefs and Christian faith, Baby K's mother insisted on the continued use of a ventilator, despite the hospital staff's recommendation for a Do Not Resuscitate (DNR) order. The hospital argued that ventilator treatment was medically unnecessary and inappropriate, as it served no therapeutic or palliative purpose. They sought legal clarification and initiated a declaratory and injunctive proceeding to determine their obligations.²³

The case of *In re Baby K* set a significant legal precedent that interprets the Americans with Disabilities Act (ADA), the Emergency Medical Treatment and Active Labor Act (EMTALA), and the Rehabilitation Act in the context of medical treatment for medically complex infants. The court ruled that the ADA prohibits the denial of ventilator services to anencephalic infants, as this service would be available to a typically-developing infant at its parent's request. The hospital's refusal to provide ventilator services, despite the mother's request, was deemed a violation of § 504 because it was based solely on the infant's disability.⁶ The Fourth Circuit Court affirmed this decision, citing the EMTALA,

which requires the provision of “treatment necessary to prevent the material deterioration of the individual's condition” and contains no “standard of care” exception.²³ The District Court affirmed this decision, further ruling in 1994 that:

1. under EMTALA, the hospital was obligated to provide emergency stabilizing care for respiratory distress;²⁴
2. under the Rehabilitation Act, it would be discrimination to withhold ventilator treatment because of the anencephaly, as “handicapped” is statutorily defined to include a “congenital defect;”²⁵ and
3. under ADA, withholding of future ventilator treatment would be discrimination against a disabled person by denial of equal enjoyment of services, facilities, privileges, advantages, or accommodation of any place of public accommodations.²⁶

This case underscored the legal obligations of hospitals to provide necessary treatment to CMC and highlights the broad protections afforded to medically complex individuals under U.S. law. Unfortunately, Baby K died of cardiac arrest during her sixth visit to the emergency department of Fairfax Hospital.²³

GUIDELINES FROM THE AAP

The number of CMC discharged to home after birth or hospital admissions for acute conditions has dramatically increased, as long-term hospitalization of these children is no longer the preferred option. As a consequence, the complexity and severity of these conditions has also increased upon discharge, and CMC are now often required to continue medical interventions (e.g. oxygen, tracheostomies, dialysis, feeding tubes, etc.) at home that would have typically occurred in hospitals.²⁷ While discharging a child from the hospital can be complex, maintaining their care at home often poses a greater challenge, primarily due to a lack of community, lack of financial resources, and the family's emotional exhaustion. The numerous complex medical services required by CMC leads to families of CMC reporting the highest levels of unmet needs compared to all other children, with nearly 50% citing at least one unmet need (e.g. limited access to subspecialty medical care, dental care, or mental health care). More than half of CMC families have had to quit working for pay, and 57% report financial difficulties. 39.4% express strong dissatisfaction with the medical services received. Physicians also tend to underestimate the needs of families with CMC in terms of community referrals, care access, psychological support, and respite

care. Therefore, it is of utmost importance to establish a regular dialogue between the primary care provider (PCP) and early intervention teams in order to improve each child's health, development, and functionality.²⁸ Because of this, the American Academy of Pediatrics (AAP) has developed an extensive framework to address the medical, legal, and financial responsibilities associated with the care of CMC.

Before discharge, the AAP strongly encourages a shared decision-making (SDM) process between the PCP and patient/family. SDM is a collaborative process where patients, their families, and healthcare professionals participate equally in all decision-making phases to arrive at a treatment plan together. In discussion of treatment plans between a physician and their patient/family, many times it becomes evident that there lies a disconnect between the physician and the patient/family in terms of values and understanding of “best choices.” This can occur if the family does not understand the diagnosis and/or interventions, if financial stressors are not addressed, if cultural traditions are not acknowledged, or if the adequacy of the child/family's support systems is not explored. This can lead to a “stalling out” of the decision-making process. Therefore, the AAP advocates for the use of SDM, which allows for all voices to be heard to support the goals of both the child/family and the clinician. Elwyn et al. have outlined 3 types of “talks” that might help clinicians during SDM: “Choice Talk,” “Options Talk,” and “Decisions Talk” as frameworks for initiating the SDM process.²⁹

The PCP should play a central role in the discharge planning for CMC. The AAP has outlined the following 6 main issues to be addressed during before this process:²⁷

1. Establishing a partnership with the family and acute care staff to identify family and community resources that can support a successful transition to care at home.
2. Defining, locating, and connecting the child/family to a medical home.³⁰
3. Ensuring training is provided to family members and/or caregivers.³¹
4. Aiding in the process of selecting a home nursing agency and/or providers of medical supplies and equipment.
5. Identifying respite care providers.
6. Opening communication with the school district so that the Individualized Education Plan process for school services can be initiated.³²

An individualized family service plan developed with the family will determine the type and scope of services provided. Care staff should evaluate the desire and ability of families of CMC to provide care, assessing their needs,

resources, skills, time, and energy. The home and community should be evaluated to ensure that it can provide the resources and support necessary to care for the child at home and support the family. Not every child with medical complexity can be cared for at home. Instead, some families opt for care in foster homes, extended specialty hospitals (long-term acute care), or pediatric skilled nursing facilities.³³

Recognizing the importance in helping children with disabilities reach their full potential, Congress has taken steps to improve child developmental outcomes by mandating access to early intervention services. The Education of the Handicapped Amendments of 1986 supported these early intervention programs for infants from birth to 3 years with disabilities and mandated free public education for 3- to 5-year-olds by the 1990-1991 school year. The Individuals with Disabilities Education Act (IDEA) of 1990 further required states to develop community-based systems of care with early identification and services for infants with developmental delays. This includes access to services such as early screening and assessment services, social work services, assistive technology devices, transportation, interpretation services, and much more.³³ The AAP recommends CMC from birth to 3 years of age should be referred to local early intervention programs for developmental services. This may include adapted preschool programs, or medically-based habilitative therapies like physical, occupational, or speech therapy. Children with sensory deficits may require specialized referrals to programs that address visual and/or hearing impairments.²⁷

PCPs should also refer families with CMC to the Supplemental Security Income (SSI) program—established in 1972 by the Social Security Administration (SSA)—which provides financial assistance to low-income individuals with disabilities, including children. The SSA considers a child (birth to 18 years) disabled if they have a physical and/or mental impairment resulting in marked functional limitations, expected to last at least 1 year or result in death within 1 year.³⁴ Since its introduction, the number of child recipients has grown significantly, with over 1.1 million children under 18 eligible for SSI benefits as of 2019.³⁵ The SSI program remains crucial for children with special needs, offering monthly cash payments based on family income and resources, qualifying children for Medicaid in most states, and ensuring referral to state Title V programs. SSI payments vary by state, with the federal

benefit rate in 2009 being \$674 per month for an individual and \$1011 for a couple, and some states supplementing the federal rate with state funds. SSI also has an option of “presumptive disability,” which allows payments to begin quickly when there is a strong likelihood of the child being found disabled once all evidence is obtained, and children with certain conditions, such as prematurity and low birth weight, may meet the requirements for a presumptive disability decision at the local SSA office. Pediatricians treating children with these conditions should provide parents with a statement about the diagnosis and severity to support a presumptive disability decision request, allowing the child to receive SSI payments for up to 6 months during the formal eligibility evaluation.³⁴

Application to Case Study

From a legal perspective, the case with the 24-week-old twins touches on all three of these important pieces of legislation: the Rehabilitation Act, the ADA, and the Child Abuse Amendments. Simply put, both the ADA and the Rehabilitation Act prohibit discrimination on the basis of disability, requiring all individuals, regardless of their disabilities, to be given equal opportunities, including access to necessary medical treatments. The parents were informed that their babies had an almost guaranteed chance of having some level of morbidity. In the context of this case, the decision to deny life-sustaining treatment to the babies based on their potential disabilities is clearly discriminatory and a violation of both laws. As for the Child Abuse Amendments, these amendments were enacted to protect the rights of CMC and prevent the withholding of medically indicated treatment from infants with life-threatening conditions. Fulfilling the parents’ request to remove the babies from the ventilators is a form of medical neglect, as defined by these amendments. The law defines medical neglect as the withholding of treatment unless a baby is irreversibly comatose or the treatment for the newborn’s survival is “virtually futile.” The babies were born prematurely at 24 weeks due to preeclampsia, which is considered a life-threatening condition for both the mother and the babies.³⁶ However, they were stable and did not have any brain bleeding, which suggests that their condition was not “virtually futile” at the time. The twins met none of the exemptive criteria of the Amendments, meaning the decision to extubate them was also a violation of this law.

According to the AAP guidelines, the physicians should have engaged in a shared decision-making (SDM) process with the parents before discharge. This would have allowed

for a collaborative discussion where the parents’ concerns could have been addressed. The parents should have been better informed of the family and community resources that would have supported a successful transition to care at home. Especially because the parents seemed to have predominantly financial and social apprehensions, the care staff should have introduced them to the breadth of available early intervention services and referred the family to the SSI program, for which the twins might have been eligible. The twins met the disability criteria of being premature and underweight, and the PCP could have endorsed a presumptive disability decision request, which would have allowed the children to receive SSI payments for up to 6 months. By following these AAP guidelines, the physicians could have better supported the family in making informed decisions about their children’s care and ensured that the family had access to the necessary resources and support to care for their children at home.

ETHICAL ANALYSIS

Introduction

Dramatic advances in neonatal medical information and technology occur daily and these advances are being implemented almost immediately. Despite the dramatic technological advances, diagnostic and prognostic certainty for many neonatal conditions remains elusive. As a result, the appropriate decision-makers have to decide whether some medically complex newborns—such as those with congenital anomalies, low birth weights, and genetic defects—should be treated aggressively or not at all. This uncertainty has led to many newborns with serious congenital anomalies being treated aggressively. This treatment prolongs the lives of many newborns when in the past they would have been allowed to die. Such life-prolonging treatment decisions have far-reaching ramifications. One thing that is clear to serious observers in the field is that the implementation of medical advances and technology for some newborns is a mixed blessing at best. Despite proposed federal regulations (1984 Child Abuse Law)³⁷ and medical guidelines (American Academy of Pediatrics)^{38,39} that have helped to clarify treatment issues, there is still no consensus among responsible decision-makers on a moral criterion to assist parents and health care professionals on treatment decisions. There is general agreement within the medical, legal, and ethical professions that there are some medically complex newborns, in particular situations, whose lives need not be saved. Consensus ends, however, when an attempt is made to

determine which specific newborns should receive or not receive medical treatment. This diversity of opinions has brought to the forefront the urgent need for a normative moral criterion to assist decision-makers in their discernment of treatment decisions for these never-competent patients.⁴⁰

Today, parents and health care professionals are often forced to draw lines between newborns who will be treated and those who will not be. If these lines are being drawn, then ethicist Richard A. McCormick argues, “it is of public importance that we find out the criteria by which they are being drawn. My attempt is to search our tradition on the meaning of life and so forth and see if we couldn't develop criteria.”⁴¹ Realizing the magnitude of this problem, McCormick has established a moral criterion for treatment decisions regarding medically complex newborns as a “revised” natural-law ethicist in the Roman Catholic tradition.

McCormick's Criterion

McCormick will determine how treatment decisions are made for medically complex newborns by proposing his normative understanding of best interests which evolves gradually into his quality-of-life criterion. This is a patient-centered, teleological assessment, which is based on a normative understanding of what reasonable persons ought to choose in a particular situation for the never-competent patient.⁴² It appears that McCormick's quality-of-life criterion is nothing more than a further specification of his normative understanding of “best interests.”⁴³ McCormick has a normative understanding of “best interests” because, “as social beings, our good, our flourishing (therefore, our best interests) is inextricably bound up with the well-being of others.”⁴⁴ The “best interests” category is a composite category that involves quality-of-life considerations, benefit-burden considerations, and the use of proportionate reason as a tool for establishing what is promotive or destructive for the good of the person “integrally and adequately considered.”⁴⁵ McCormick understands “quality of life” to be an elusive term whose meaning varies according to context. However, at a more profound level, when the issue is preserving human life, the term assumes a more basic meaning. “Just as life itself is a condition for any other value or achievement, so certain characteristics of life are the conditions for the achievement of other values. We must distinguish between two sets of conditions: those that allow us to do things well, easily, comfortably, and efficiently, and those that allow us to do them at all.”⁴⁶ The quality-of-life

criterion is ethically significant for parents and health care professionals, because it represents not only the value of the whole person, but it affirms that respect for the human person entails considering all the relevant factors and circumstances that are involved in any situation.

There are real difficulties in trying to establish a perfectly rational criterion for making quality-of-life judgments. To make his quality-of-life criterion more concrete, McCormick will establish two guidelines and four norms that will further specify his criterion. The first guideline developed for dealing with never-competent patients focuses on the potential for human relationships associated with the infant's condition. By relational potential McCormick means “the hope that the infant will, in relative comfort, be able to experience our caring and love.”⁴⁷ Specifically, he proposes that “if a newborn baby had no potential for such relationships or if the potential would be totally submerged in the mere struggle to survive, then that baby had achieved its potential and further life-prolonging efforts were not mandatory, that is, would no longer be in the best interests of the baby.”⁴⁸ Therefore, according to this guideline, when a never-competent patient, even with treatment, will have no potential for human relationships, the appropriate decision-makers can decide to withhold treatment and allow the patient to die.⁴⁹ McCormick claims this quality-of-life approach has its foundation in the traditional ordinary-extraordinary means distinction that was later clarified by Pius XII.^{50,51} This is not an easy guideline to apply, especially in the case of never-competent patients. In essence, this guideline requires that the appropriate decision-makers must be able to determine if a minimally accepted “quality of life” can be expected. This determination ought to be made on the basis of the never-competent's “best interests” understood normatively. This guideline does not depreciate the value of the never-competent individual but affirms that a genuine respect for the person demands attention to the prospects held out by continued life.⁵²

This guideline of the potential for human relationships has been criticized for being too general and open to possible abuse.⁵³ McCormick himself stated when he advanced this guideline that it was “general and rather vague. But this is the way it is with all moral norms.”⁵⁴ Despite being convinced that this guideline is fundamentally sound, McCormick understood that he must further concretize it. Specifically, there are those circumstances when the never-competent patient has the potential for human relationships, but the underlying medical condition is critical and will

result in imminent death, or after treatment has been initiated it becomes apparent that the treatment is medically futile.⁵⁵ In these two situations it is clear that, besides the potential for human relationships, McCormick must incorporate an additional guideline that can weigh the benefits and burdens of certain treatments.

The second guideline of McCormick's quality-of-life criterion is the benefit-burden evaluation. "Where medical procedures are in question, it is generally admitted that the criterion to be used is a benefits-burden estimate... The question posed is: Will the burden of the treatment outweigh the benefits to the patient? The general answer: If the treatment is useless or futile, or it imposes burdens that outweigh the benefits, it may be omitted."⁵⁶ As is the case with his first guideline, McCormick claims the benefit-burden evaluation emerges from the "ordinary-extraordinary means" distinction.

McCormick believes that his notion of benefit-burden evaluation within his quality-of-life criterion is a logical development of the "ordinary-extraordinary means" distinction, or what he refers to as an extension of the tradition into new problem areas.⁵⁷ McCormick believes that the "ordinary-extraordinary means" distinction has an honorable history and an enduring validity. However, he argues that these terms "summarize and promulgate judgments drawn on other grounds. It is these other grounds that cry out for explication."⁵⁸

To further explain these "other grounds," McCormick reformulates the "ordinary-extraordinary means" distinction by advancing his benefit-burden evaluation. An extraordinary means is one that offers the patient no real benefit, or offers it at a disproportionate cost. For McCormick, one is called to make a moral judgment: Does the benefit of a proposed medical intervention really outweigh the harm it will inevitably produce? This is a quality-of-life judgment. The benefit-burden interpretation is not a departure from the Catholic tradition. It is a reformulation of the tradition in order to deal with contemporary bioethical problem areas.⁵⁹

The reason for this reformulation of the tradition is that over the centuries the "ordinary-extraordinary means" distinction has become less objective and more relative because medicine and technology have become more sophisticated. The medical profession is committed to curing disease and preserving life. Today, we have the medical technology to make this commitment a reality. However, McCormick

argues that "this commitment must be implemented within a healthy and realistic acknowledgment that we are mortal."⁶⁰ Therefore, there is a need to reformulate the basic value of human life under new circumstances. For many contemporary ethicists the traditional terminology of ordinary-extraordinary means has outlived its usefulness and could take us only so far, especially in the case of medically complex newborns.⁶¹ Focusing on the value of human life, McCormick sought to reformulate the "ordinary-extraordinary means" distinction without abandoning the tradition. Contemporary medical problems no longer only concern newborns for whom biological death is imminent. Modern medicine and technology have the ability to keep almost anyone biologically alive. Therefore, a gradual shift has occurred from the means to reverse the dying process to the quality of life sustained and preserved as the result of the application of medical technology.⁶² Today, because of the advancements in medicine and technology, the focus is on the quality of life thus saved that establishes a means as extraordinary.

To address this shift in the problem from means to quality of life preserved, McCormick has reformulated the "ordinary-extraordinary means" distinction to mean the "benefit-burden evaluation."^{63,64} For McCormick, "it is clear that the judgments of burden and benefit are value judgments, moral choices. They are judgments in which, all things considered, the continuance of life is either called for or not worthwhile to the patient."⁶⁵ In making these moral judgments one can see how proportionate reason is used as a tool for determining whether a particular life-sustaining treatment is a benefit or a burden, that is, in the "best interests" of the never-competent patient and those involved in the decision-making process.

The benefit-burden evaluation was also proposed by the Sacred Congregation for the Doctrine of the Faith in its Declaration on Euthanasia and by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in its Deciding to Forego Life-Sustaining Treatment.⁶⁶ The issuance of the Declaration on Euthanasia in 1980 by the Magisterium gave McCormick further justification for incorporating the benefit-burden evaluation into his quality-of-life criterion.⁶⁷ It also gave him further proof to anchor his guideline and thus his criterion for treatment decisions in the benefit-burden evaluation. Medical treatments are not morally mandatory if they are either gravely burdensome or useless for the patient.^{68,69,70,71,72} McCormick has a normative

understanding of medical futility, which considers whether the agreed on potential effect is of any value and benefit to the newborn, that is, in the newborn's "best interests" normatively understood. For McCormick, a medical treatment might be successful in achieving an effect (physiologically effective), but the effect might not be beneficial to the patient (qualitatively effective). Since the goal of medical treatment is to benefit the patient, it follows that nonbeneficial treatment is medically futile. This entails making a value judgment and the evaluation of whether a treatment is a benefit or a burden can be open to personal interpretation. That means these evaluations can be "borderline and controversial."⁷³

The two guidelines of McCormick's quality-of-life criterion, even though he argued they were both reformulations of the "ordinary-extraordinary means" distinction, continued to be criticized by ethicists Leonard Weber, John Connery and Warren Reich for being too relative, subjective, and consequential in nature. To address this criticism McCormick, along with ethicist John Paris, S.J., proposed the following norms that would further specify the capacity for human relationships and the benefit-burden evaluation in 1983:

1. Life-saving intervention ought not to be omitted for institutional or managerial reasons. Included in this specification is the ability of this particular family to cope with a badly disabled baby.
2. Life-sustaining interventions may not be omitted simply because the baby is retarded. There may be further complications associated with retardation that justify withholding life-sustaining treatment.
3. Life-sustaining intervention may be omitted or withdrawn when there is excessive hardship on the patient, especially when this combines with poor prognosis.
4. Life-sustaining interventions may be omitted or withdrawn at a point when it becomes clear that expected life can be had only for a relatively brief time and only with continued use of artificial feeding.⁷⁴

These norms or rules do not mandate certain decisions, nor do they replace the role of prudence and eliminate conflicts and decisions. They are simply attempting to provide outlines of the areas in which prudence should operate.⁷⁵

McCormick further specified his quality-of-life criterion to help enlighten medical situations for the appropriate decision-makers. However, guidelines, even specified by concrete norms, cannot cover all circumstances and every possible situation. McCormick's quality-of-life criterion assists the appropriate decision-makers by giving them a range of choices. As rational persons, it is up to the

appropriate decision-makers to examine each situation using proportionate reason, and the guidelines advanced by McCormick in his quality-of-life criterion, to determine what is in the "best interests" of the never-competent patient and those involved in the decision-making process. McCormick makes clear that no criterion can cover every instance where human discretion must intervene to decide. There is always the possibility of human error because we are finite and sinful people. For McCormick, "the margin of error tolerable should reflect not only the utter finality of the decision (which tends to narrow it), but also the unavoidable uncertainty and doubt (which tends to broaden it)."⁷⁶ With the assistance of these guidelines and norms, McCormick believes that the appropriate decision-makers will be given the necessary guidance to act responsibly.

To assist parents and health care professionals further in medical decision-making for medically complex newborns, five specific diagnostic treatment categories have been established. These categories attempt to encompass, as far as possible, the entire spectrum of medically complex newborns. They are based on McCormick's moral criterion of the potential for human relationships.

McCormick has plotted the two extreme positions on this spectrum of medically complex newborns, but has left the "conflictual middle," to be filled in by healthcare professionals and bioethicists.⁷⁷ These diagnostic categories will attempt to complete the "conflictual middle." The "conflictual middle" pertains to those neonatal anomalies that fall into the "gray area" of treatment decisions.⁷⁸ These diagnostic treatment categories have been arranged in a way that demonstrates the application of McCormick's "best interests" category. There is a logical progression on the spectrum from the newborn who does not warrant medical treatment to the newborn who does warrant medical treatment.

The five diagnostic treatment categories are:

1. The handicapped newborns whose potential for human relationships is completely nonexistent.
2. The handicapped newborn who has a potential for human relationships but whose potential is utterly submerged in the mere struggle for survival.
3. The handicapped newborn who has a potential for human relationships but the underlying medical condition will result in imminent death.
4. The handicapped newborn who has the potential for human relationships but after medical treatment has been initiated, it becomes apparent that the treatment may be medically futile.
5. The handicapped newborn who has the potential for human relationships and has a correctable or

treatable condition.⁷⁹

Establishing a full set of diagnostic treatment categories is not a panacea for determining treatment decisions for medically complex newborns. Not all medical conditions can be placed in specific categories; there is a marked difference in the severity of conditions within each category. Not all health care professionals or even bioethicists could or would agree to these specific categories. Nevertheless, as McCormick argues, “we ought to attempt, as far as possible, to approach neonatal medical complexities through diagnostic categories, always realizing that such categories cannot deflate important differences and that there will always remain gray areas.”⁸⁰ The establishment of these five diagnostic treatment categories is an attempt to meet the challenge set before health care professionals and bioethicists to assist parents and medical professionals in making treatment decisions for medically complex newborns.

Ethical Evaluation

As discussed in the Case Study section, the neonatologist explained that babies born extremely premature had a high chance of having some level of morbidity, which could range from the need for glasses to the need for long term chronic medical care requiring assisted ventilation and feeding tubes. But at this point these determinations could not be made with any certainty. The question is did the neonatologist give the parents all the medical, legal and social viable options to obtain informed consent?

It would appear that the twins would fit under category four of McCormick’s Diagnostic Categories. In this fourth diagnostic treatment category, since the potential for human relationships is present, McCormick’s second guideline of his quality-of-life criterion—the benefit-burden evaluation—would be applied to determine whether the boys should continue to be treated aggressively. What is to be determined is whether the benefit of the treatment will outweigh the burden to the newborns. If the parents in consultation with the health care professionals determine that further medical treatment would not improve the newborn’s prognosis, or benefit the overall well-being of the newborns, then, all things considered, parents should decide that further treatment would not be in the “best interests” of the newborns. However, if more time is needed to determine the prognosis of the boys, and if the boys are stable and appear to be benefiting from the aggressive treatment, then the benefits outweigh the burdens. These twins, at this point

in time, are benefiting from the treatment. Their respiration is being assisted by the surfactant, there is no apparent bleeding on the brains, and they are stable. To support this position McCormick’s first norm, that further specifies the burden-benefit evaluation, can be applied. “Life-saving intervention ought not to be omitted for institutional or managerial reasons. Included in this specification is the ability of this particular family to cope with a badly disabled baby.” The parents state that “they did not have the support financially or physically to potentially have two special needs children.” Even though they may not have the means the state will take care of these twins medically, and financially. Therefore, it appears that further treatment for these boys is morally obligatory, because it is a proportionate means. It can also be argued that the parents could not give informed consent, because they did not truly understand the medical and legal issues surrounding this case.

The notion of a normative understanding of “best interests” considers not only the relevant medical facts but also the relevant social and familial factors. Financial and emotional costs ought to be considered. That means, if the social factors are excessive, then the newborn should not and would not want to be treated, because it would place excessive burdens on those who must care for the newborn’s existence. What the newborn “ought” to want should encompass the needs of those who will care for this child. These children, at this point in time, do not have a firm prognosis. They are stable and seem to be progressing medically. If the parents do not have the means to take care of these children, then the state will provide the necessary means. Both social and familial factors ought to play a proportionate role in determining the benefit/burden evaluation.⁸¹

When a medically complex newborn has the potential for human relationships and after initiating treatment, it becomes apparent that the treatment is medically effective, even though there is no firm prognosis, then parents in consultation with health care professionals are morally obliged to continue medical treatment. This is a value judgment that is based on McCormick’s guidelines of relational potential and benefit/burden evaluation. McCormick’s moral criterion sets basic parameters and enlightens the particular medical situation. Ultimately, the parents will use prudence to examine the medical facts and to weigh, all things considered, whether the benefits of treatment outweigh the burdens to the newborn. In this

diagnostic treatment category, the burdens and benefits need to be weighed carefully. Until there is a firm prognosis and all viable options are considered, these boys should continue to be aggressively treated. Once there is a firm prognosis, and if that prognosis indicates that further treatment is medically futile, then McCormick's criteria can be reapplied to the situation.

McCormick argues that his moral criterion is appropriate for decision-makers because it considers not only the relevant medical facts and the pertinent circumstances of the situation, but also familial and social factors, such as, religious, cultural, emotional, and financial factors. Parents in consultation with health care professionals can best determine what the newborn ought to want and protect his or her "best interests" by using McCormick's quality-of-life moral criterion. As reasonable people, parents are most knowledgeable about the family situation into which the newborn is born. This includes knowing the financial, emotional, and social factors. Parents can also weigh and balance the religious and cultural values that inform their decision-making. Health care professionals have the specialized medical knowledge and clinical expertise that can assist parents in the decision-making process. They also have a level of objectivity that parents may lack because of the overwhelming emotional stress of the situation. Clinicians also are well aware of the laws that protect medically complex children. Together, parents and health care professionals are able to determine what are the appropriate needs of this newborn, to assess these needs, and to determine whether medical treatment is in the "best interests" of the newborn "integrally and adequately considered."

Conclusion

McCormick's moral criterion is appropriate for decision-makers because it emphasizes "the reasonable." It stresses the need for decision-makers to examine the medical facts, the circumstances of the situation, foreseeable consequences, social and familial factors, and other pertinent data before deciding on an appropriate course of action. McCormick's moral criterion also stresses that these facts are to be considered always within the context of the Christian story, so that the "best interests" of the medically complex newborn are always promoted and protected. Treatment decisions for medically complex newborns are value judgments that must be based on the appropriate needs of the newborn. These value judgments can possibly become

distorted by self-interested perspectives and technological considerations. Decision-makers who use McCormick's moral criterion are not immune from making mistakes. We are a finite and sinful people. What is being said is that because the content of this moral criterion is reasonable, and because these decisions are made within the context of the Christian story, less chance exists that such treatment decisions will be pushed to the extremes. McCormick's moral criterion is appropriate for all decision-makers because it protects the "best interests" of the handicapped newborns by promoting value judgments that are grounded in reason.

CONCLUSION

Over 40 years after the Infant Doe cases brought public scrutiny to treatment limitations for medically complex newborns, the landscape remains uncertain. In 1985, few parents knew if their children would be born with severe disabilities. Today, prenatal testing can identify many serious conditions before birth, enabling specialized medical planning.²⁰ However, some hospitals still limit or discourage intensive treatment of extremely premature infants based on subjective survival or quality judgments, despite evidence showing active care improves outcomes.⁸²

Medical advances also raise ethical questions about non-discriminatory standards of care. While lifesaving technologies promote survival, they also enable more subjective valuations of lives deemed unworthy or overly-burdensome. Judgments about predicted quality of life are subjective yet central to decisions to limit treatment. Meanwhile, the moral rights and protections of vulnerable infants are weighed unevenly against assumptions about the burden of their disabilities. Legislative guidance still fails to guarantee equity in life-saving measures. Parental discretion continues receiving high priority status, though not absolute. Physicians must follow professional obligations over just the parents' wishes, but the definition of "futile" care allows room for debate depending on disability tolerability and rising NICU costs. Any infant born alive warrants non-discriminatory access to non-futile, life-saving interventions. Achieving standardized practices upholding rights protections remains challenging but vital.

The complex balance between quality considerations and preserving sanctity of life continues evolving across ethics debates and legislative approaches surrounding medically complex newborns. Further tools are required to foster compassionate and legal care focused on the best interests of

each vulnerable infant as an individual.

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and acts as a central point for a child's medical and non-medical care. It aims to provide comprehensive care that is accessible, family-centered, and culturally effective.

31. Caregivers must receive training in caring for feeding tubes, tracheostomies, respiratory treatments (e.g. nebulizers, ventilators), wound care, intravenous lines, and medication administration. Cardiopulmonary resuscitation (CPR) training is also typically recommended.

32. An Individualized Education Plan (IEP) is a written plan for the provision of services for the education of students who are disabled. For more information, see Price-Ellingstad, D., Reynolds, J., Ringer, L., Ryder, R., & Sheridan, S. (2000). *A Guide to the Individualized Education Program*. U.S. Department of Education. <https://www2.ed.gov/parents/needs/speced/iepguide/index.html>

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40. There is an ethical distinction regarding competent, non-competent, and never-competent patients. A competent patient is one who can make decisions regarding health care for him or herself. A non-competent patient is one who was once competent, but now lacks that decision-making capacity. A never-competent patient is one who never had this decision-making capacity and never will have it in the future.

41. Castelli, James. "Richard A. McCormick, S.J., and Life/Death Decisions." *St. Anthony Messenger* 83 (August 1975): 34. Interview with Richard A. McCormick.

42. The structure and individual components that make up McCormick's moral criterion for decision-making are normative; they center on what "ought" to be the case, not what "is" the case. By normative McCormick means what the never-competent patient would want because he or she "ought" to want it. The never-competent patient "ought" to make this choice because it is in his/her "best interests." For a more detailed analysis of McCormick's position on a normative understanding of his patient-centered approach, see McCormick, Richard A. "The Rights of the Voiceless." In *How Brave a New World?: Dilemmas in Bioethics*, 99–113. Garden City, NY: Doubleday, 1981.

43. Ethicist Robert Weir disagrees with McCormick on this point. Weir argues that the quality-of-life criterion and best interests' criterion are distinct and separate. McCormick responds to Weir by stating: "I believe Weir is wrong when he asserts that for those who use quality-of-life assessment,

'it is not necessary to consider the best interest of the neonate.' It is precisely because one is focused on best interests that qualitative considerations cannot be ignored but indeed are central. Weir is clearly afraid that quality-of-life considerations will be unfair. But they need not be. It all depends on where the line is drawn. I am all the more convinced of the inseparable unity and general overlap of best interests and quality-of-life considerations when I study Weir's clinical applications of his ethical criteria."

McCormick, Richard A. Review of *Selective Nontreatment of Handicapped Newborns*, by Robert Weir. *Perspectives in Biology and Medicine* 29, no. 1 (Winter 1986): 328.

44. McCormick, Richard A. "The Rights of the Voiceless." In *How Brave a New World?: Dilemmas in Bioethics*, 101. Garden City, NY: Doubleday, 1981. It should be noted that McCormick's understanding of "best interests" is grounded in his "revised" natural law position. "I believe we do have reasons for assuming we know in many cases what an incompetent would want. We may assume that most people are reasonable, and that being such they would choose what is in their best interest. At least this is a safe and protective guideline to follow in structuring our conduct toward them when they cannot speak. The assumption may be factually and per accidens incorrect. But I am convinced that it will not often be... I believe most of us want to act reasonably within parameters that are objective in character, even though we do not always do so. Or at least I think it is a good protective policy to assume this." *Ibid*, 104–105.

45. It should be noted that when McCormick refers to benefits in his "best interests" category it is not restricted to medical benefits. Benefits also apply to social and familial benefits. This notion of "benefit" originates in Pellegrino's four components of "best interests" that McCormick has incorporated into his "best interests" category. For a more detailed analysis of Pellegrino's position, see Pellegrino, Edmund, M.D. "Moral Choice, The Good of The Patient and The Patient's Good." In *Ethics and Critical Care Medicine*, edited by J. C. Moskop and L. Kopelman, 117–138. Dordrecht, Netherlands: D. Reidel, 1985.

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47. McCormick, R. A. (1974). "To Save or Let Die: The Dilemma of Modern Medicine." *JAMA* 229, no. 2: 172–176.

48. McCormick, R. A. (1986). "Focus on the NICU: The Best Interests of the Baby." *Second Opinion* (Park Ridge, Ill.), no. 2: 23.

49. This does not mean that once a decision has been made to forego or discontinue treatment, that the dying person is not treated with dignity and respect. For McCormick, even though a person has reached his or her potential and no treatment is recommended, as members of society we still have a moral obligation to give comfort to the person while he or she is in the dying process. That comfort would consist in palliative care. Palliative care is aimed at controlling pain, relieving discomfort, and aiding dysfunction of various sorts.

50. McCormick quotes Pius XII as saying that an obligation to use any means possible "would be too burdensome for most men and would render the attainment of the higher, more important good too difficult." Pius XII. "The Prolongation of Life." *Acta Apostolicae Sedis* 49 (1957): 1031–1032.

51. McCormick understands Pius XII to say that certain treatments may be refused because it would lead to a life that lacks the proper quality. Weber, Leonard J. *Who Shall Live?: The Dilemma of Severely Handicapped Children and Its Meaning for Other Moral Questions*. New York: Paulist Press, 1976.

52. Cahill, Lisa Sowle. "On Richard McCormick: Reason and Faith in Post-Vatican II Catholic Ethics." In *Theological Voices in Medical Ethics*, edited by Allen Verhey and Stephen Lammers, 91. Grand Rapids, MI: William B. Eerdmans Publishing Co., 1993. The potential for human relationships is based in the Catholic tradition. McCormick bases this potential for human relationships in the Catholic tradition. The Christian story does not yield concrete answers and fixed rules, but it does yield various perspectives and insights that inform human reasoning. One such insight is that human life is a basic good but not an absolute good. Since human life is a relative good, and the duty to preserve it is a limited one, then it is not always morally obligatory to use all means to preserve human life if a person cannot attain the higher, more important good. For McCormick, the "higher" more important good is the capacity for relationships of love. The core of this guideline is developed from the love commandment found in the New Testament.
53. Both Leonard Weber and John Connery have criticized McCormick's quality-of-life criterion. For a more detailed analysis, see Weber, Leonard J. *Who Shall Live?: The Dilemma of Severely Handicapped Children and Its Meaning for Other Moral Questions*. New York: Paulist Press, 1976 and Connery, John. "Quality of Life." *Linacre Quarterly* 53 (February 1986): 26-33.
54. "They really root in general assertions that must be fleshed out by experience, modified by discussion and consultation, propped up and strengthened by cautions and qualifications. It is in the process of their application that moral norms take on added concreteness." McCormick, Richard A. "To Save Or Let Die: State Of The Questions." *America* 131 (October 5, 1974): 171.
55. It should be noted that the term "medically futile" is an elusive and ambiguous term. There are four major types of medical futility. First, physiological futility—an intervention cannot lead to the intended physiological effect. Second, imminent demise futility—an intervention may be futile if despite that intervention the patient will die in the very near future (this is sometimes expressed as the patient will not survive to discharge, although that is not really equivalent to dying in the near future). Third, lethal condition futility—an intervention may be futile if the patient has an underlying lethal condition which the intervention does not affect and which will result in death in the not too far future (weeks, perhaps months, but not in years) even if the intervention is employed. Fourth, qualitative futility—an intervention may be futile if it fails to lead to an acceptable quality of life. For a more detailed analysis of medical futility, see Brody, Baruch A., and Amir Halevy. "Is Futility A Futile Concept?" *Journal of Medicine and Philosophy* 20, no. 2 (April 1995): 126-129.
56. McCormick, Richard A. "Technology and Morality: The Example of Medicine." *New Theology Review* 2 (November 1989): 26.
57. McCormick writes: "A basic human value is challenged by new circumstances, and these circumstances demand that imagination and creativity be employed to devise new formulations, a new understanding of this value in light of these new circumstances while retaining a basic grasp upon the value. For example, in-vitro fertilization poses questions about the meaning of sexuality, parenthood, and the family because it challenges their very biological roots." McCormick, R. A. "A Proposal for 'Quality of Life' Criteria for Sustaining Life." *Hospital Progress* 56, no. 9 (1975): 76-79.
58. McCormick, R. A. (1986). "Focus on the NICU: The Best Interests of the Baby." *Second Opinion* (Park Ridge, Ill.), no. 2: 19. McCormick further states: "We must admit that the terms 'ordinary' and 'extraordinary' are but code words. That is, they summarize and are vehicles for other judgments. They do not solve problems automatically. Rather they are emotional and mental preparations for very personal and circumstantial judgments that must take into account the patient's attitudes and value perspectives, or what the patient would have wanted. 'Ordinary' and 'extraordinary' merely summarize other underlying judgments. They say very little in and of themselves." McCormick, R. A. "A Proposal for 'Quality of Life' Criteria for Sustaining Life." *Hospital Progress* 56, no. 9 (1975): 77.
59. McCormick further states that: "It must be remembered that the abiding substance of the Church's teaching, its rock bottom so to speak, is not found in the ordinary means-extraordinary means terminology. It is found in a basic value judgment about the meaning of life and death, one that refuses to absolutize either. It is that judgment that we must carry with us as we face the medical decisions that technology casts upon us." McCormick, Richard A. "Technology and Morality: The Example of Medicine." *New Theology Review* 2 (November 1989): 29. Emphasis in the original.
60. Richard McCormick, *The Critical Calling: Moral Dilemmas Since Vatican II* (Washington, D.C.: Georgetown University Press, 1989), 365.
61. McCormick argues there are two reasons for this: First, the terminology too easily hides the nature of the judgment being made. The major reference point in factoring out what is "reasonable" (benefit) and "excessive" (burden) is the patient—his or her condition, biography, prognosis, and values. The terminology, however, suggests that attention should fall on the means in an all too mechanical way. Second, many people misinterpret the terms to refer to "what physicians ordinarily do, what is customary." This is not what the term means. In their ethical sense, they encompass many more dimensions of the situation. Richard McCormick, *Health and Medicine in The Catholic Tradition* (New York: Crossroad Press, 1987), 145.
62. McCormick, Richard A. "To save or let die: the dilemma of modern medicine." *Jama* 229, no. 2 (1974): 172-176.
63. Besides McCormick's benefit-burden evaluation, other ethicists have suggested various terms to reformulate the ordinary-extraordinary means distinction. Paul Ramsey suggests that the morally significant meaning of ordinary and extraordinary medical means can be reduced almost without remainder to two components—a comparison of treatments to determine if they are "medically indicated" and a patient's right to refuse treatment. See Ramsey, Paul. *Ethics at the Edges of Life: Medical and Legal Intersections*. Yale University Press, 1978.
64. Robert Veatch maintains that the terms "ordinary" and "extraordinary" are "extremely vague and are used inconsistently in the literature." Beneath this confusion he finds three overlapping but fundamentally different uses of the terms: usual versus unusual, useful versus useless, imperative versus elective. See Veatch, Robert M. *Death, Dying, and the Biological Revolution: Our Last Quest for Responsibility*. Yale University Press, 1976. For further examples, see McCormick, Richard A. "The Quality of Life, The Sanctity of Life." *The Hastings Center Report* 8, no. 1 (1978): 30-36. <https://doi.org/10.2307/3560325>.
65. Paris, John, and Richard McCormick. "Saving Defective Infants: Options for Life or Death." *America* 148 (May 1, 1983): 313-17.
66. See President's Commission for The Study Of Ethical Problems In Medicine And Biomedical And Behavioral Research, Nathan T. Sidley. "Deciding to Forego Life-

Sustaining Treatment: Ethical Medical, and Legal Issues in Treatment Decisions.” *Journal of the American Academy of Psychiatry and the Law Online* 12, no. 4 (December 1, 1984): 411.

67. The Congregation concludes that, “it will be possible to make a correct judgment as to the means by studying the type of treatment being used, its degree of complexity or risk, its cost and possibilities of using it, and comparing these elements with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources.” Congregation for the Doctrine of the Faith, “Declaration On Euthanasia,” *Origins* 10 (August 1980): 263.

68. Ethicists Warren Reich, John Connery, S.J., Leonard Weber, and Donald McCarthy disagree with McCormick’s interpretation of the tradition on the benefit-burden distinction. Ethicist Richard Sparks writes: “For Reich, Weber, Connery, and McCarthy the limiting factor is the quality of life, which, if judged to be excessively burdensome, can make the presumably beneficial treatment extraordinary and optional, [sic] must be caused by or directly related to the use of the means contemplated. In other words, ‘the burden must be the burden of medical treatment, not the burden of handicapped existence.’” Sparks, Richard C. *To Treat Or Not to Treat: Bioethics and the Handicapped Newborn*, 1988, 110.

69. McCarthy, Donald G. “Treating defective newborns: who judges extraordinary means?” *Hospital Progress* 62, no. 12 (1981): 45-50.

70. John Connery, S.J., “Prolongation Of Life: A Duty And Its Limits,” *Linacre Quarterly* 47 (May 1980): 151-165

71. Weber, L.J. *Who Shall Live?: The Dilemma of Severely Handicapped Children and Its Meaning for Other Moral Questions*. An Exploration Book. Paulist Press, 1976, 88-98.

72. Reich, Warren T. “Quality of life and defective newborn children: An ethical analysis.” *Quality of Life: The New Medical Dilemma* (1990): 161.

73. Paris, John, and Richard McCormick. “Saving Defective Infants: Options for Life or Death.” *America* 148 (May 1, 1983): 313–17.

74. *Ibid*, 358-359.

75. *Ibid*, 359.

76. *Ibid*, 360.

77. McCormick writes: “It is the task of physicians to

provide some more concrete categories or presumptive biological symptoms for this human judgment. For instance, nearly all would likely agree that the anencephalic infant is without relational potential. On the other hand, the same cannot be said for the mongoloid infant. The task ahead is to attach relational potential to presumptive biological symptoms for the gray areas between such extremes.”

McCormick, R. A. (1974). “To Save or Let Die: The Dilemma of Modern Medicine.” *JAMA* 229, no. 2: 172-176.

78. This would include anomalies in which the newborn has the potential for human relationships, but the potential is utterly submerged in the mere struggle for survival, or the medical condition will result in imminent death, or it has been determined that further treatment is medically futile. Certain anomalies that would fall within this category would be spina bifida, hypoplastic left heart syndrome, trisomy 13, trisomy 18, Lesch-Nyhan syndrome, etc.

79. For a more complete analysis of these five diagnostic categories see Clark, P.A. *To Treat Or Not to Treat: The Ethical Methodology of Richard A. McCormick, S.J., as Applied to Treatment Decisions for Handicapped Newborns*. Creighton University Press, 2003.

80. McCormick, R. A. (1986). “Focus on the NICU: The Best Interests of the Baby.” *Second Opinion* (Park Ridge, Ill.), no. 2: 24.

81. It should be noted that McCormick’s position on social and familial factors has been criticized for being too restrictive and deviating from both the Catholic tradition and from his own normative understanding of “best interests.” McCormick claims that his restrictive notion of social and familial factors, as they pertain to treatment decisions for medically complex newborns, is due to the fact that a broader interpretation could lead to social utilitarianism. This caution is certainly relevant because the possibility of potential abuse is always present. However, the safeguards McCormick has built into his quality-of-life criterion—guidelines and norms—should help to alleviate the possibility of such abuse. In addition, health care professionals serve as a safeguard in that they can act as the newborn’s advocate should they suspect abuse.

82. Executive Office of the President. (2020). *Protecting vulnerable newborn and infant children*. Federal Register. <https://www.federalregister.gov/documents/2020/10/02/2020-21960/protecting-vulnerable-newborn-and-infant-children>

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