Parental Decisions and Physician Responsibilities

Stefan C. Weiss

Advances in technology have created unforeseen ethical dilemmas that medical students will routinely confront. Thus, the teaching of bioethics continues to assume a more central role in medical education. Indeed, California now requires course work in ethics as a prerequisite to medical licensure.

One specific ethical dilemma concerns the use of neonatal technology to sustain life. The benefit of prolonging life must sometimes be weighed against considerations about quality of life. For nearly half a century, neonatal intensive care units have been a locus for this debate. In 1974, many prominent physicians gave supportive testimony to the Senate Subcommittee on Health regarding the practice of passive euthanasia for infants born with birth defects.1

The euthanasia debate becomes polarized between the sanctity and quality of life. Further complicating the debate is that the imperiled newborn lacks decision-making capacity and thus requires a proxy. Although some contend for the absolute role of the parent in this situation, others argue that parents in these initial moments are not suited to serve as surrogate decision makers.

United States legal tradition accords parents presumptive authority to make decisions for their children on the assumption that parents will always act in accordance with the child’s best interest.2 Furthermore, because parents play an ongoing role in the lives of their children, decisions regarding the welfare of a child also affect the parents. However, the choice of parents to withhold treatment because they believe themselves incapable of caring for an impaired child is considered by some to be insufficient grounds to ignore the at best poorly defined interests of the child. If society is to impose itself upon the family, it must bear some responsibility for the consequences of its interfeence.

Others conclude that in situations involving the life or death of a child, the parent is not capable of making medical decisions for that child. Competing claims on a parent’s resources can lead to inappropriate decisions based on a weakly justified utilitarian standard. The initial disappointment that a parent experiences at the birth of a child who fails to meet a socially defined construct of perfection can result in a parent’s choosing, at least temporarily, to ignore the child’s best interest. In these situations, society must stand in loco parentis. Third-party intervention, however, may not always support prolonging life. The state often must intercede when parents subject newborns to futile overtreatment because of their understandable inability to say good-bye.2

In this issue of MSJAMA, the winners of the 2000 John Conley Ethics Contest for Medical Students address the ethical obligations of the physician who is asked by the parents of a neonate with trisomy 21 to withhold treatment for a lethal, but surgically repairable, medical condition. Joel Frader, MD, introduces the debate by addressing the responsibilities of both the physician and society to imperiled newborns.

REFERENCES
THE STUDENT ESSAYS THAT MADE UP THE ENTRIES FOR THE JOHN Conley Ethics Contest this year prompt another set of reflections on the so-called Baby Doe controversy. Almost 20 years after unprecedented federal action to determine the bounds of medical decision-making, fundamental conflict remains.

In April 1982, the Reagan administration and, subsequently, Congress limited medical and parental discretion regarding treatment of infants with disabilities. The index case involved a newborn with Down syndrome and a tracheoesophageal fistula with esophageal atresia who died because the parties withheld surgical intervention; the child became known as the Indiana Baby Doe.1 The federal action reflected both the recognition of the need to counter discrimination against persons with disabilities and the growing power of religious conservatives in US politics. The debate about how to respond to persons with disabilities continues, perhaps even more strenuously than before, now augmented by outspoken advocates for individuals with disabling conditions.

In the debate about how to respond to persons with disabilities, we seem to have lost sight of several important points. First, by the time of the Baby Doe regulations and subsequent federal legislation, US pediatricians and parents had already begun a major change in attitudes and practices regarding infants born with Down syndrome and neural tube defects, among the most common congenital conditions that had previously prompted nontreatment. The withholding of surgery for the Indiana baby with trisomy 21 that prompted the ruling by the then Department of Health, Education, and Welfare (now Health and Human Services) was probably exceptional. The heavily-handed federal approach likely had more political significance than production of meaningful changes in the care of infants with Down syndrome or meningomyelocele.

Second, the concern for infants with life-affecting disorders identifiable at birth has diverted attention from the more than 400,000 infants born prematurely each year in the United States. This represents approximately 11% of US births.2 Many of these infants acquire long-lasting disabilities because of their early birth and the measures used to sustain their lives. What stands out about this latter group, statistically and economically, is the relatively small amount of effort our society invests in preventing premature birth compared to the huge allocations for the purpose of rescuing tiny infants who would have benefited from continued intrauterine growth and development. According to the March of Dimes (MOD), caring for these “complicated births” costs from $20,000 to $40,000 per infant, compared to $400 for uncomplicated deliveries.3

Approximately 12.4% of US mothers received inadequate prenatal care in 1996.4 Assuming that improved prenatal care can reduce the rate of preterm births, a relatively small investment in prenatal care could reap substantial human and monetary gains. We seem to prefer to split medical and philosophical hairs about who should receive what arcane and expensive postnatal intervention, rather than take on the social, economic, and ethnic discrimination that contributes to a US infant mortality rate in 1994 of 8.0 per 1000 live births, nearly twice as high as Japan with a rate of 4.3.5

Finally, we should examine the overplayed discussion of the “rights” of infants (or children, or adults) with disabilities. Rights involve claims by individuals or classes against the larger society. By implication, rights invoke the notion of special entitlements that outweigh other considerations, such as fairness or justice. As with many debates in our society, invoking rights seems to limit, rather than open, useful dialogue. Rights language seems to preclude close examination of real, though sometimes subtle, differences between those assigned specific entitlements. However, because of limited resources, life requires choices that often stand in opposition to traditional claims of rights. In 1996, our nation spent more than 13% of the Gross Domestic Product (GDP) on health care, compared to approximately 9% in Canada or 7% in Great Britain, countries with equivalent or better health outcomes, as measured by standard morbidity and mortality measures.6 Many now question whether we in the United States are maximizing dollars spent. Perhaps we need to choose more carefully among the many different interventions on which we spend the health care dollar. Despite our distaste for the word, we already employ rationing of care in the United States although often based on ability to pay, rather than some notion of the utility or degree of benefit realized from the medical care. Not all individuals actually benefit from all possible (or legally mandated) interventions. We would be better served to focus on what we can do to benefit individuals with specific needs, rather than spend health dollars inefficiently simply to concede to certain rights claims.

The Baby Doe debate indeed rages on, though more as symbol than substance. It is time to talk about how to ensure that infants come into the world at the right time, having received appropriate prenatal care. If we accomplish that, perhaps the rationing discussions can take on a more civil and productive tone.

REFERENCES

©2000 American Medical Association. All rights reserved.
WE ARE SYMBOLIC CREATURES LIMITED IN KNOWLEDGE AND action by the language we share. Words are the primary symbols we use to construct a picture of reality and to communicate the meaning of our existence. Thus, language shapes our reality and compels us to act accordingly. However, words can be frustrating and language confusing. Perhaps this is why so many of the great philosophers chose to tell stories. Stories transcend language and convey their essential truths even when isolated words are not understood. Stories serve as guiding stars for individuals living in complex societies. Plato used dialogues; Shakespeare produced plays; Jesus taught in parables; C. S. Lewis wrote children's stories. Faced with the complex task of making ethical decisions in the midst of modern medicine, I offer a story.

We ducked out of the blazing sun and into the darkness of Doña Rita's thatch-roof house. Little Enrique let go of my hand and threw himself on the floor alongside his brothers and sisters, sending a hen squawking and flapping from beneath the cornhusks. The turbulence flared the kitchen fire and sent smoke swirling around the silhouette crouched beside the hammock. The hammock held a little bundle causing it to scrape the dirt floor with each gentle pass. I knelt beside Doña Rita and peered down at Baby José. How could I explain? Baby José was dying.

I had spent hours listening to his little heart gurgle. A university education and 3 years of medical school and all I could do was play with my stethoscope. Doña Rita took Baby José into her arms and pushed him into my chest. This was Doña Rita's 11th time giving birth, and it will be the fourth time for her and Don Martin to watch one of their children die. Doña Rita put her face to the floor and began to cry; her children scooted closer. Enrique unwrapped a burlap package revealing the only book his family owned. Thanks to a few lessons under the mango tree, Enrique was the most educated member of the family; when he read he felt his mother's joy. He began sounding out words, "El amor . . ."

I adjusted my stethoscope and listened—"always protects, always trusts, always hopes, always perseveres. Love never fails." Enrique had been practicing and the words flowed smoothly. Baby José's brown flat eyes gazed into mine; he had the characteristic moon face of Down syndrome, but lacked the happy drool and sparkling eyes. A confident pediatric heart surgeon back home would have fixed Baby José and had him smiling again in no time. But in this country, where young lives were taken by malaria, dehydration, respiratory disease, and infection, Baby José was beyond medical hope. Three years of medical school, and I could only listen with a stethoscope. "Where there is knowledge, it will pass away . . . now these three remain: faith, hope, and love. But the greatest of these, es el amor." I removed the stethoscope and looked over at Enrique; a boy of 10 years, who had never been to school, had just taught me one of life's greatest lessons.

After morning rounds my attending sent me to room 4312. I took a deep breath, knocked, then entered. A proud new father jumped to his feet and bravely reached for his wife's hand. "Your baby is going to be fine," I announced. The parents exhaled. "We know why your son has problems eating. Food cannot pass from his stomach to the intestines because he has duodenal atresia."

"Can anything be done?" the father interjected.

"Yes, the problem is correctable with surgery." The parents were visibly relieved.

"Why don't we sit down," I offered. "Anatomical defects like the one your son has are often associated with chromosomal abnormalities." I paused. "After our initial exam it appears that your son has a genetic condition known as Down syndrome."

"Down syndrome?" the father interrupted. The new mother squeezed her husband's hand.

"Yes, your little boy likely has an extra chromosome 21. Children with this genetic condition have special medical and educational needs. With the advances of modern medicine we are able to manage this condition quite successfully. Many people with trisomy 21 live to reach age 40. They hold jobs and enjoy good relationships with family and friends."

"My son has Down syndrome!" The father was flushed with anger, and the tremor in his voice evoked a rush of tears from his wife.

"I know this comes as a shock to you and that the adjustment will be difficult. I brought you some literature that you might want to read to help you understand your son's condition. In addition, I have included the names of a few parents who also have children with trisomy 21. They would love to share their parenting experiences. Please give them a call if you wish. The most important thing for us to do now is that which is best for your baby. I will give you some time to read this material, and then I will return to answer questions. Study the consent forms for your baby's surgery. The surgery is very important; he may die without it. We will talk more about the procedure and the consent forms when I return."

Later that day, as I prepared for evening rounds, I overheard the nurses talking: the parents did not want to sign the consent forms for surgery. I sat down heavily. I understood. The parents, like my parents, had expectations—career, home, investments, and finally a family. The birth of a disabled child shattered the dream of the perfect family. I stood up to join my team on rounds.

"Student Dr Clark," my attending focused her attention on me. "The parents of Baby Joe feel that they are not pre-
pared to raise a child whose quality of life they believe will be impaired. They have requested that no further medical intervention take place. What ethical principles should we apply to this situation?"

"Autonomy, beneficence, nonmaleficence, justice, double effect." I started to recite the standard answers that allow most medical students to score a passing grade in ethics.

She queried, "Have you ever heard of Baby Doe?"

"Yes, Baby Doe was born in the 1980s with Down syndrome and esophageal atresia. Baby Doe’s parents declined surgical intervention and allowed their child to starve to death. As a result, the definition of child abuse expanded to include the failure to provide necessary medical treatment. In addition, the Baby Doe regulations state that the prospect of a disability should play no role in treatment decisions."

"Student Dr Clark, how should we then handle this situation?"

"If this was a television drama, we would send a memo to the ethics committee, threaten the parents with a maximum sentence of 10 years, and make the child a ward of the state. In a court of law, a judge would then rule that being born with Down syndrome is not a reason to condemn Baby Joe to die. We would then perform the surgery and save the life of Baby Joe."

My attending asked, "Why do we not respect the autonomy of the parents and their right to decide what is best for Baby Joe?"

"We do. Even the presidential commission that was convened to address the case of Baby Doe recognized that there is no absolute obligation to sustain life. It was found that no individual is entitled to all of a family’s resources nor those of society. However, this is not a case of a severely ill and malformed infant who requires heroic efforts and enormous resources for a chance at a limited life filled with pain and isolation. With minimal medical attention, Baby Joe will have what those born without an extra chromosome have: the chance to experience all of the joys and sorrows of life. By agreeing to not treat Baby Joe, we concede that imperfection is grounds to deny a person of fundamental rights. We should not condemn a child to die only because he falls short of parental expectations."

"Should we thus act like they would on television?"

"No, a court order does not provide Baby Joe with a loving family. Surgery is needed, but the parents have their needs too. The parents have suffered a tremendous loss, they were denied the son that they expected. We should give the parents a chance to be good parents, to love and enjoy their baby. Even without the duodenal repair, we can keep Baby Joe healthy for a few days. We will use that time to give the parents space to grieve, and then introduce them to the other parents in the community who are raising children with Down syndrome."

The next morning with my stethoscope around my neck I carried Baby Joe to room 4312. I arranged the chairs so that mom and dad had to sit close to Baby Joe and me. From my coat pocket I pulled out a picture of Baby Jose´ swinging in his little hammock and I told a story about a baby named Jose´ who lacked the opportunities for medical care afforded to babies born in the United States.

"If you are real quiet and listen real hard, you can hear Enrique slowly read about faith, hope, and love." I handed my stethoscope to the new father. "Listen," I said softly.

The new father pulled the baby to his chest and adjusted the stethoscope over his son’s heart. The mother squeezed close to her husband and stared into Baby Joe’s eyes. "I can hear it!" exclaimed the dad with joyful tears. Mom kissed her husband and reached for her son. I looked at Baby Jose´s picture and said softly, “but the greatest ethical principle of all, es el amor.”

**2001 John Conley Ethics Essay Contest for Medical Students**

In light of the recent report on medical errors by the Institute of Medicine (IOM), this year’s topic focuses on the ethics of disclosing medical errors to patients. We ask that you consider the following scenario: During your surgical clerkship, you observe a medical mistake during a procedure in the operating room. The error does not result in the patient’s death, but requires the patient to extend his stay in the hospital several days. In addition, the postoperative pain experienced by the patient is more significant than it would have been otherwise. The attending physician informs the patient that there was a complication during the procedure, but does not specify that it was secondary to his error. Later, the patient asks you the explain what happened. How do you respond?

The judges for the 2000 John Conley Ethics Contest were Joel Frader, MD, Northwestern University of Medicine; Benjamin Wilfond, MD, National Institutes of Health; Audiey Kao, MD, PhD, AMA Institute for Ethics.

**REFERENCES**

Making Mortal Decisions at the Beginning of Life: 
The Case of Impaired and Imperiled Infants

Jason Morrow, University of Texas Medical Branch, Galveston

Nearly 20 years have passed since the Reagan administration first drafted the “Baby Doe rules” that mandated treating impaired newborns unless (1) they are permanently comatose, (2) any treatment would merely prolong their death, or (3) treatment would not be effective. These rules were largely inspired by clinical encounters during the late 1970s and early 1980s, when infants born with multiple congenital abnormalities, such as Down syndrome and duodenal atresia, were allowed to die. The Baby Doe rules represent the first US legislative attempt to regulate the treatment decisions of physicians regarding intervention at the beginning of life. Since then, policymakers and jurists have contemplated the proper role of federal policy in this area. Some have supported these rules, insofar as they aim to prevent discrimination against disabled children as well as certain forms of child abuse and neglect. The rules have been criticized as being too distant from the reality of clinical decision-making, inconsistent with regulations regarding incompetent adults, or ineffective in light of other, less protective policies concerning the medical care of children.

The controversy regarding Baby Doe continues unabated, with the debate generally between those defending the absolute value of life and those who believe in the absolute priority of liberty. The extreme polarity may be a natural consequence of rhetoric in public debate, which, in the case of religiously and politically divisive issues such as euthanasia, abortion, cloning, in vitro fertilization, and stem-cell research, is often emotionally charged and laden with canonical commitments. However, controversy implies complexity. For behind the veil of rhetoric and polarization lies the insuperable plurality of moral understandings, the intrinsic uncertainty of medical prognoses, and the inherent ambiguity of quality-of-life assessments.

Recent controversies surrounding the proper care of imperiled newborns have emerged from the explosion of medical technologies. Technological developments in the treatment of infectious disease and of the complications of premature and low birth-weight infants have reduced infant mortality rates, increased survival rates, and virtually eliminated severe forms of certain diseases. Yet the ability to save lives places parents and physicians in a morally precarious position: they must determine when the costs of expensive interventions outweigh the benefits. These decisions are especially troublesome because they usually require immediate and irreversible action, though they are invariably speculative and shrouded in uncertainty.

The controversies involving treatment at the beginning of life have been long debated. Plato wrestled with the legitimacy of infanticide. He articulated a widely accepted but clandestine approach that aimed to improve the hereditary qualities of the Greek population: “...the offspring of the inferior, and any of those of the other sort who are born defective, [physicians] will properly dispose of in secret, so that no one will know what has become of them.”

The usefulness of allowing certain infants to die remains an important aspect of the moral justification for refusing to treat impaired newborns. This justification derives largely from the questionable ontological status of these infants. While all newborns are human, they generally lack the characteristics of personhood, such as the intrinsic cognitive capacities that confer moral culpability upon mature individuals. Newborns lack a meaningful concept of self, they cannot foresee the consequences of their actions, and they cannot deliberate rationally. Moreover, they are not established extrinsically as productive members of society. Religious traditions suggest that the incipient relationships of newborns to society may be deemed less worthy of emotional and moral investment than the more mature relationships of older children and adults to society.

Peter Singer argues that parents and physicians can justify infanticide on the basis of total utility: “When the death of a disabled infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the disabled infant is killed.” This argument relies on a “replaceability” thesis. It stipulates that since newborns lack the rationality, autonomy, and self-consciousness of persons, they can be selectively killed and replaced with healthier ones in the same way that early prenatal diagnosis affords selective abortion of severely deformed fetuses.

The logical force of this argument is compelling since it potentially provides society with more useful citizens (as Plato would argue) and families with healthier infants, but it involves an impoverished understanding of interpersonal and deontological relationships. First, the legal determination of citizenship and full protection under the law occurs at, or near, birth, so caregivers have a prima facie obligation to treat newborns as if they are more like persons than mere masses of flesh. Second, the birth of a child, healthy or impaired, represents a significant moment in the life of a family. The replaceability thesis grossly underestimates the bonding families can experience during the course of conception and pregnancy. Therefore, it neglects the uniqueness and value of gestation and being born. Third, though newborns possess few “person-making characteristics,” their potential for becoming a person, even if they require tech-
nological intervention to survive, generates an interest in remaining alive. Perhaps the future interests and abilities of an infant secure for that infant a claim to the custody and care necessary to achieve personhood. Finally, replaceability undermines the value of diversity in human form. While it may not maximize total utility to live with disfigurement or impairment, living a life with suboptimal prospects can still be full of joy and value.

Physicians rarely engage in theoretical excursions such as the replaceability thesis. However, by virtue of their unique role in society physicians regularly participate in decisions that demand quality of life assessments. In the neonatal intensive care unit (NICU), these assessments are complicated by the preferences of parents who frequently interpret multiple congenital abnormalities as a sign that a reasonable quality-of-life will be impossible. The role of the physician should be to educate parents against these prejudices.

For centuries, the medical profession has endowed its members with the knowledge and skills required to treat disease and deformity. Physicians have often been the vanguard of technological mastery, increasingly charged with the onerous responsibility of determining when intervention is appropriate. Underlying this responsibility is a foundation of core principles, including beneficence, nonmaleficence, and compassion. Unfortunately, conscious use of these principles is not often helpful when the best interests of patients are varied and apply to many relevant but competing parties. The challenge of applying core principles to complex cases at the beginning of life can hopefully engage the morality and empathy of the modern medical enterprise.

Neonatologists spend their careers in the NICU, but it is a foreign world to most people. Clinical encounters for parents are often novel and jarring experiences, where hopes and expectations of health and happiness can be threatened by the birth of even a mildly deformed or impaired child. Parents are almost always unprepared for premature or hazardous delivery. They often feel victimized, shocked, angry, and guilty. They may feel unworthy or unable to assume the role of caregiver. In negotiating the details of intensive care, neonatologists may confuse parents and thereby distort the balance of power. They may feel unworthy or unable to assume the role of caregiver. In negotiating the details of intensive care, neonatologists may confuse parents and thereby distort the balance of power. Thus, empathy is paramount when they render clinical decisions. Neonatologists must anticipate the vulnerability of parents, collaborate with them, and gently guide them through their decision, especially when parents are hostile or recalcitrant.

All physicians should discuss the standards of care appropriate to similar clinical situations. For instance, failure to treat an infant with a mild case of Down syndrome and correctable intestinal atresia is inconsistent with best medical practice and thus neglectful. Useful and comforting measures a physician can initiate include introducing parents to families who have encountered similar dilemmas, and connecting them with outreach organizations that help parents raise children with special needs. Similarly, searching for adoptive parents may reveal an abundance of families willing to raise such a child, which in turn would seem to undermine the moral acceptability of hastily engaging in selective infanticide.

The moral complexities of Baby Doe have forced physicians to deliberate the most responsible ways to implement new technologies. Federal regulations have met with significant resistance, especially by physicians who feel that the medical profession can meet the moral challenges of medicine without coercion. Such optimism is warranted if physicians fulfill their duty to explain to the public the ineradicable presence of disease, disability, and less-than-maximum utility in our society. At that point, they retain the right to advocate for the judicious and compassionate use of life-saving interventions. When physicians engage in collective moral discourse they can forge successful therapeutic alliances with their patients and their patients’ families. Then, with collaborative and empathetic decision-making, they will make an increasingly crowded NICU a good place to live.

REFERENCES