

Medical Futility in Pediatric Care

Felipe E. Vizcarrondo, MD

Abstract. The transition from the paternalistic paradigm of the Hippocratic tradition to the present model of shared decision making has altered the patient–doctor relationship. This change has engendered conflicts between patients and physicians, especially in pediatric medicine, where the patients are dependent on their parents because of their inability to consent to an intervention independently. Navigating this complex relationship can become particularly fraught when medical futility is invoked. This situation is complicated further by the divergent approaches to shared decision making among physicians and the ethical perspectives these positions reflect. Catholic doctrine on the role of parents in medical-ethical decision making provides insight into navigating these difficult clinical issues and ideologies. *National Catholic Bioethics Quarterly* (Spring 2019): 000–000.

The Hippocratic tradition enjoined the physician to do no harm, to do good to the patient, and even to hold the patient’s interest above self. The traditional image of the physician was that of a benign father figure who had both moral and technical authority over the patient. This model of the physician was accepted by society for many years. There was little participation of the patient in medical decision making.

By the mid-twentieth century, as the world became aware of the atrocities perpetrated by German physicians during the Nazi regime, the international medical community became very concerned with the rights of patients, especially the right to give informed consent to medical intervention. The Nuremberg Code in 1947 and the

Felipe E. Vizcarrondo MD, MA, is an associate professor in the Miller School of Medicine and an affiliate faculty member in the Institute of Bioethics and Health Policy at the University of Miami, in Florida. He is the president of the Miami Guild of the Catholic Medical Association.

The views expressed in the *NCBQ* do not necessarily represent those of the editor, the editorial board, the ethicists, or the staff of The National Catholic Bioethics Center.

Declaration of Helsinki in 1964 grounded the principle of respect for the autonomy of human subjects in biomedical research.¹ In the United States, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research issued the Belmont Report in 1979 in response to the Tuskegee Study of Untreated Syphilis in the Negro Male conducted by the United States Public Health Service.² The Belmont Report recognized three basic principles: respect for persons, beneficence, and justice.³ Clinicians were enjoined to observe these principles in medical decision making in human subject research and in clinical practice.

Philosophers Thomas Beauchamp and James Childress followed with their proposal for the “four principles approach,” which is the most frequently applied ethical framework in medical decision making. The philosophers proposed the following four principles: (1) respect for autonomy (a norm of respecting the decision-making capacity of autonomous persons), (2) nonmaleficence (a norm of avoiding the causation of harm), (3) beneficence (a group of norms for providing benefits and balancing benefits against risks and costs), and (4) justice (a group of norms for distributing benefits, risks, and costs fairly).⁴ The development of this new approach fundamentally changed the paternalistic Hippocratic paradigm of medical decision making that had been the rule for centuries. The traditional image of the physician as an authoritative expert was replaced by the physician as an advocate for the self-determination of the patient. Respect for patient autonomy became the most prominent consideration of the physician in the doctor–patient encounter.

The first principle of Beauchamp and Childress is so critical to modern medical ethics that it deserves special discussion. *Respect for autonomy* may be defined as respect for the individual’s right to self-determination. Self-determination requires two conditions: the opportunity to exercise free will, and the capacity for moral agency.⁵ It is the principle that recognizes that human beings can make reasonable choices of their own that differ from the choices of others. Autonomy refers to the right of the patient to reasonably choose or refuse a proposed treatment. Respect for the patient’s self-determination is essential for a healthy doctor–patient encounter. Physicians exercise their own autonomy as they make recommendations and propose choices based on their knowledge and experience in the practice of medicine.

Obtaining informed consent, currently an ethical and legal standard in medicine, is a practical manifestation of respect for the patient’s autonomy. The physician makes a diagnosis, recommends treatment, and explains benefits and risks to the patient,

1. John M. Luce and Douglas B. White, “A History of Ethics and Law in the Intensive Care Unit,” *Critical Care Clinics* 1.25 (January 2009): 223, doi: 10.1016/j.ccc.2008.10.002.

2. Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 5th ed. (New York: Oxford University Press, 2001), 94–96.

3. The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, Department of Health, Education, and Welfare, *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research* (Washington, DC: US Government Printing Office, 1975), available at <https://www.hhs.gov/>.

4. Beauchamp and Childress, *Principles of Biomedical Ethics*, 12.

5. *Ibid.*, 57.

who understands the information and accepts the proposed therapy.⁶ The encounter is characterized by good communication, mutual respect, and shared decision making. Application of these norms presumes that the patient is an adult with the competency to make his own decisions.

Unique Aspects of Pediatric Medical-Ethical Decision Making

The principles of beneficence, justice, and respect for self-determination ground certain basic considerations that should inform all ethical decision making in medicine: medical indications, patient preferences, quality of life, and socioeconomic factors. Although these basic considerations are universal, their application often differs between children and adults.⁷

Medical Indications

Indications for medical intervention are derived from the medical facts. After careful clinical assessment, the physician will make the judgment that an intervention would benefit the patient. Once the decision to treat is made, the physician will consider different courses of therapy and assess the effectiveness and risk of each before deciding which to choose. In the doctor–patient encounter, several appropriate medical goals may be pursued: restoration of health or function, relief of symptoms, preservation or prolongation of life, education, and counseling. Although medical indications can differ in adults and children, this consideration is largely the same in both populations.

Patient Preferences

The ability to express preferences and have others respect them is crucial to a sense of personal worth. Patient preferences are recognized by the legal system as a fundamental right: each person has a right to control his or her own body and the right to be protected from unwanted intrusions.⁸ An adult patient has the capacity to consent to or refuse medical care. Refusal of care by a competent and informed adult should be respected even if this leads to serious harm to the individual. For example, courts have upheld the legal right of adult Jehovah’s Witnesses to refuse lifesaving blood transfusions.⁹ Another practical manifestation of self-determination is reflected in the statements of individual choice that patients are encouraged to make in advance of serious disease or disability. Through a durable power of attorney for health care, the patient can designate a family member or friend to be his surrogate decision maker. The patient also can use a written advance directive to document

6. Albert R. Jonsen, Mark Siegler, and William J. Winslade, *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, 6th ed. (New York: McGraw-Hill, 2006), 54–55.

7. *Ibid.*, 11.

8. *Ibid.*, 60.

9. *Ibid.*, 65.

his wishes in case he is incapacitated and cannot actively participate in the decision-making process.¹⁰

Patient preferences in pediatric medicine are influenced by the child's age, maturity, and dependence on adults. Children are often too immature to formulate preferences or make judgments about personal interests; the child is at the beginning of life, and it is difficult to predict his values and preferences. Moreover, the child is under the care of adults whose authority is extensive. These features of pediatric medicine modify the way in which the pediatrician exercises his basic responsibilities.

The doctor–patient relationship is a social interaction. The extent to which the child can fill the social role of patient determines the extent to which the responsible adult participates in the clinical encounter. The child–parent dyad is recognized by the pediatrician as the fundamental unit in the relationship. Of note, the physician owes his obligation to the child, not the parent.

Self-determination is one of the goals of the child's growth and development, and it depends on a set of cognitive, psychological, and social skills that develop gradually. The parent and the pediatrician should promote the development of these skills to enable the child to reach independence and autonomy. During infancy and early childhood, the paternalistic approach is not only acceptable but mandatory. In order to benefit and protect the child, the parent and the pediatrician make the medical decision for the child, acting in his best interests. As the child grows and matures, he will show signs of independence and commence to make choices. These choices should be respected and discussed, and the child gradually should be made part of the decision-making process. An older child may be able to assent to an intervention. In some cases, a child in his mid-teens may be able to understand medical indications for intervention, comprehend the benefits and risks of treatment, and express a preference.

Quality of Life

There is tension between the much-debated concepts of human dignity and personhood. Both greatly influence the idea of the quality of life of the individual patient. Human dignity is an attribute of all human beings and linked to their spiritual dimension. It is God-given, not earned, and it cannot be taken away. It follows that every human being is an inherently valuable member of the human community. Human dignity is the foundation for human rights, which are rooted in the natural law. For this reason, human rights are inalienable and morally inviolable. Personhood, in contrast, is defined by characteristics such as the ability to reason, self-determination, and the capacity to communicate; expressions of functionality; and social utility.¹¹ An individual's personhood can be gravely affected by disease or disability; an individual's human dignity cannot.

10. *Ibid.*, 84–85.

11. J. Daryl Charles, *Retrieving the Natural Law: A Return to Moral First Things* (Grand Rapids, MI: Eerdmans, 2008), 56, 200–208.

The competent practice of medicine aspires to improve the quality of the life of patients by improving their health and well-being without taking action that compromises their human dignity. A person's quality of life is considered good if the person is satisfied with his physical and psychological situation in life. Quality-of-life judgments are not entirely subjective; they consider behavior, performance, and function. But as the concept expresses a value judgment, there is opportunity for ambiguity and bias. An objection to the use of moral quality-of-life judgements when making treatment decisions is that a shift in focus could occur from "will treatment benefit the patient?" to "is the patient's life of benefit to him?" Quality-of-life judgments are influenced by the values and beliefs of the patient, physician caregiver, and surrogate if applicable. Quality of life is a poor criterion to follow and ought not to predominate in the decision-making process.

Quality of life discussions often arise when considering whether to discontinue life support. Important differences distinguish between moral judgments of quality of life in adults and children. When an adult is incapable of expressing preferences, the history of that person's preferences and lifestyle often enables others to estimate how to value and adapt to future states. A child's life is almost entirely in the future; with little or no past history, substituted judgment is not possible. Consequently, parents and physicians often use a best-interest standard, which considers whether a procedure or course of treatment relieves suffering, preserves or restores function, and sustains the quality as well as the extent of life.

When addressing the question of withholding life-prolonging treatments from infants and children, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research specifically was concerned with the responsibility of the surrogate, who must justify a life-or-death decision for a person who cannot speak for himself. The President's Commission concluded that if the medical intervention is clearly beneficial, the treatment should continue. If the treatment merely prolongs the dying process, it is more burdensome than beneficial for the patient and therefore not beneficent. In this case, treatment may be discontinued. In ambiguous cases, the President's Commission recommended that physicians accept parental judgment, recognizing parental authority and autonomy.¹²

Socioeconomic Factors

Medicine has traditionally concentrated on the needs of individual persons seeking medical care. But the one-on-one encounter between patient and physician is not isolated from the influence of family, friends, cultural values, and economic conditions. Some socioeconomic factors are the role of family and friends, the cost of medical care, and the allocation of medical resources. It is tempting but simplistic to say that socioeconomic factors should never be allowed to influence a decision about

12. President's Commission for the Study of Ethical Problems in Medicine and Biomedical Behavioral Research, *Decision to Forego Life-Sustaining Treatment: A Report of the Ethical, Medical, and Legal Issues in Treatment Decisions*, March 1983, available at https://repository.library.georgetown.edu/bitstream/handle/10822/559344/deciding_to_forego_tx.pdf?sequence=1&isAllowed=y.

a patient. However, as a general rule, socioeconomic factors should not supersede other considerations.

Today, the doctor–patient encounter occurs in a different, more complex environment than in the past. The physician is connected to organizations and governmental agencies that require attention and at times appear to conflict with the primary concern of caring for the patient. The present-day physician also has responsibilities and obligations toward the common good of society.¹³

The family, parents, and siblings—who are essential to the care of the child patient—are a focal point of pediatric care. The parents of an ill child are often equally responsible for the well-being of other children. Often, parents will devote almost exclusive attention to the sick child, and they may ask themselves whether this is unfair to them and their other children.

The cost of medical care, formerly the responsibility of the patient, is increasingly subsidized by insurance companies or government agencies. The equitable allocation of resources is greatly debated, with little consensus on how to go about it. Rationing may be needed when resources are scarce. In some situations, this is essential to the common good, such as during battlefield triage or natural disasters. Even in ordinary clinical situations, the claims of one patient may override the claims of another.¹⁴

Medical Futility

The concept of futility is part of ordinary language and has been applied throughout history to many different situations. Futility applied to a medical intervention is of more recent vintage. Albert Jonsen claims the concept of medical futility “entered the vocabulary of bioethics” in the 1980s during the AIDS epidemic.¹⁵

Different ethicists have used the term in varying ways. In *Principles of Biomedical Ethics*, Beauchamp and Childress define a *futile* or *pointless* intervention as one that offers no benefit to the patient. They add that in practice, “the term futility is now used to cover many situations of predicted improbable outcomes, improbable success, and unacceptable benefit burden ratios.” Because of this lack of specificity, the authors recommend avoiding the use of the term *futility* altogether in favor of more precise language.¹⁶ However, we should acknowledge that the concept of medical futility is part of the current language of bioethics, and the term will continue to be used.

Catholic bioethicist William E. May defines *futility* in terms of withholding or withdrawing treatment that is extraordinary or disproportionate. These criteria are based on what he calls burdensomeness and uselessness: either the burden is unacceptable

13. Jonsen et al., *Clinical Ethics*, 159–161. The Hippocratic tradition focused on the physician’s responsibilities to his patients and pupils; duties to society were not addressed by the Hippocratic Oath.

14. *Ibid.*, 192.

15. Albert R. Jonsen, *The Birth of Bioethics*, 2nd ed. (New York: Oxford University Press, 2003), 409.

16. Beauchamp and Childress, *Principles of Biomedical Ethics*, 134.

or the treatment will not improve the patient's condition. May clarifies that it is the treatment that is burdensome or useless, not the patient or his life.¹⁷

Is there a difference between withholding and withdrawing treatment? Some claim that withdrawing treatment could be the direct cause of death, while withholding treatment would not be. There is no ethical difference between withholding an intervention and discontinuing an existing therapy course once the treatment has been deemed futile. Clinicians routinely do trials of therapy; if they start patients on a treatment course that proves ineffective, they may switch to a different intervention or discontinue the therapy entirely. A careful evaluation of the benefits and burdens posed by the decision is essential to the determination.¹⁸ Importantly, withholding or withdrawing treatment cannot be intended to cause the death of the patient.¹⁹

In 1990, bioethicist Lawrence Schneiderman based his definition of medical futility on quantitative outcome data. He proposed that if an intervention was not successful in more than 1 percent of cases, it would be considered futile.²⁰ Of interest, Ezra Gabbay and colleagues conducted a meta-analysis of relevant articles that supported or refuted claims of futility between 1980 (when the concept of medical futility was introduced) and 2008: "Forty-seven studies supporting a claim of futility and 45 refuting were reviewed. . . . Our findings imply that in most circumstances physicians cannot confidently rely on published outcome data to make determinations of medical futility."²¹

When Is a Medical Intervention Futile?

Cardiopulmonary resuscitation (CPR) was introduced in the 1960s and originally applied to patients who arrested during anesthesia. This new technique was felt to help and not to harm, and it was applied to most patients who suffered cardiac arrest. Shortly, it became evident that even though many improved initially, the clinical course and expected time of death of the patients were not affected. Was CPR merely interfering with the dying process and not really sustaining life? In 1974, the American Heart Association recommended that CPR not be used when there is irreversible illness and impending death.²²

A ventilator is routinely applied in cases where CPR results in a patient who cannot sustain respiration. In the 1976 case of Karen Ann Quinlan, the Supreme Court of New Jersey established that the surrogate could refuse mechanical ventilation

17. William E. May, *Catholic Bioethics and the Gift of Human Life* (Huntington, IN: Our Sunday Visitor, 2000), 262.

18. Beauchamp and Childress, *Principles of Biomedical Ethics*, 120–123.

19. *Catechism*, 2278.

20. Lawrence J. Schneiderman, Nancy S. Jecker, and Albert R Jonsen, "Medical Futility: Its Meaning and Ethical Implications," *Annals of Internal Medicine* 112.12 (June 15, 1990): 945–954, doi: 10.7326/0003-4819-112-12-949.

21. Ezra Gabbay et al., "The Empirical Basis for Determinations of Medical Futility," *Journal of General Internal Medicine* 25.10 (October 2010): 1083, 1088, doi: 10.1007/s11606-010-1445-3.

22. Luce and White, "History of Ethics," 225.

for an incompetent person. In the 1990 case of Nancy Cruzan, also an incompetent patient, the United States Supreme Court ruled that life-sustaining treatment could be removed at the surrogate's request.²³ In both cases, medical futility was invoked as the basis for the decision to withdraw life-sustaining treatment.

In 1982, Baby Doe was born with Down syndrome, a tracheoesophageal fistula, and esophageal atresia. The parents declined surgery as well as the provision of nutrition and fluids, and the child died as a result. In 1983, Baby Jane Doe was born with spina bifida. She was treated not surgically but simply with antibiotics and wound dressings. She survived with many fewer disabilities than expected. In 1985, these cases led to the Baby Doe amendment to the Child Abuse Law, or the Baby Doe rules, which extended the definition of child abuse and neglect to include withholding medically indicated treatment from children with disabilities. The rules stated that decisions made on the basis of the infant's future quality of life were not valid and advocated mechanisms for reporting such practices.²⁴ The Baby Doe rules have been rarely enforced in the years since 1985. At the same time, newborn medicine has evolved dramatically. Many more neonates who are born prematurely and present with complex conditions are treated successfully.

In 1997, the Society of Critical Medicine issued a statement: "Treatments should be defined as futile only when they will not accomplish their intended (physiologic) goal. Treatments that are extremely unlikely to be beneficial, are extremely costly, or are of uncertain benefit may be considered inappropriate and hence inadvisable, but should not be labeled futile."²⁵ The American Medical Association concurs with this interpretation in its *Code of Medical Ethics*.²⁶

The concept of medical futility was introduced in bioethics and medical decision making, in part because patients allegedly were subjected to excessive interventions by their physicians or at their own or their surrogates' demand. Respect for patient autonomy required that the patient's request be obeyed, creating tension between patient autonomy and the integrity of the physician. Physicians were also concerned about overtreating the patient. As there are two parties involved, both with inherent dignity, there must be a balance between patient's rights and physician's rights. The medical decision ought not to be unilateral; it must be a joint decision.

Another factor in the debate over medical futility is the concern that while the driving force of a decision to withhold or withdraw life-sustaining treatment is usually a poor prognosis, the reality of limited resources can be an underlying consideration.

23. *Ibid.*, 226; *In re Quinlan*, 70 N.J. 10 (1976); and *Cruzan v. Director, Missouri Dept. of Health*, 197 U.S. 261 (1990).

24. Council on Developmental Disabilities, Minnesota Department of Administration, "Baby Does and the Right to Lifesaving Treatment," 1–9, accessed April 16, 2019, https://mn.gov/mnddc/honoring-choices/cnnReports/Moral_and_Ethical_Issues4-Baby-Doe-Kappel.pdf.

25. Ethics Committee of the Society of Critical Care Medicine, cited in Luce and White, "History of Ethics," 231.

26. American Medical Association, "Medically Ineffective interventions," opinion 5.5, *Code of Medical Ethics* (June 2016), <http://www.ama-assn.org/>.

Bioethicists Michael Rubin and Robert Truog describe rationing as the best way to distribute limited resources to patients on the basis of their needs when the intervention could be of value to all. They affirm that bedside rationing occurs frequently in the clinical setting. This decision may consider societal perspectives on cost and the allocation of limited resources. The authors recommend that patients and their families not participate in the deliberation process.²⁷ The discussion and subsequent development of policy ought to occur in the conference room, not at the bedside.

Clinician ethicist Edmund Pellegrino affirms that in order to understand futility, one must recognize that there can be a significant moral dimension to clinical decision making.²⁸ He proposed three criteria to help decision makers, physicians, and patients decide together when a treatment plan would not be of benefit: effectiveness, benefits, and burdens. He defines effectiveness as an estimate by the physician, based on clinical facts, of the ability of the treatment intervention to improve the condition of the patient. The determination of effectiveness is objective. Benefit is understood as perceived by the patient. Clinical questions frequently arise; these ought to be answered. But the physician ought not to influence the patient in this deliberation. The determination of benefit is subjective. Burden refers to the physical, psychological, and financial cost imposed by the treatment. The patient and physician partner in this deliberation. The determination of burden is both objective and subjective. These criteria would help the clinician determine if the intervention is beneficial to the patient or not. The careful examination of the three criteria would enable the physician and patient *together* to decide if the intervention would be beneficial; the intervention would be futile if it conveyed no benefit.

Medical Futility in the Pediatric Setting

Medical futility is often debated in the neonatal nursery, particularly the neonatal intensive care unit (NICU), and the pediatric intensive care unit (PICU). Intensivists and neonatologists are frequently faced with medical-ethical decisions that require wisdom and discernment. The experience of this group of clinicians has helped to develop an understanding of the concept of futility as it is uniquely applied to pediatric medicine.

What should be done when parents demand an intervention the physician deems inappropriate for or not beneficial to the patient? In the United States, there is consensus that shared decision making is the best way to approach the conflict between the parents and the physician in pediatric care. Unilateral physician decision making is “not the default for pediatric intensivists.”²⁹ How can conflicts between the two parties be resolved?

27. Michael A. Rubin and Robert D. Truog, “What to Do When There Aren’t Enough Beds in the PICU,” *AMA Journal of Ethics* 19.2 (February 2017): 162, doi: 10.1001/journalofethics.2017.19.2.ecas3-1702.

28. Peter A. Clark, “Medical Futility in Pediatrics: Is It Time for a Public Policy?,” *Journal of Public Health Policy* 23.1 (Spring 2002): 70–71.

29. Kavita Morparia, Mindy Dickerman, and Sarah Hoehn, “Futility: Unilateral Decision Making Is Not the Default for Pediatric Intensivists,” *Pediatric Critical Care Medicine* 13.5 (September 2012): e311–e315, doi: 10.1097/PCC.0b013e31824ea12c.

The initial considerations do not vary greatly from what occurs in adult medicine. To reach the decision that an intervention is futile, the physician considers outcome data, his own experience as well as that of others, and most importantly, the goal of the therapy. A source of conflict in pediatric health care is that the physician's goal of therapy may not coincide with that of the parent. Parents must be fully informed and given enough time to fully understand the clinical situation, deliberate, and propose a course of action. Free and honest discussion with the physician must follow. For example, parents might request mechanical ventilation for their child with severe brain injury. In this case, the physician may justify withholding the intervention on the basis of an unfavorable assessment of burdens and benefits. But the parents may consider survival even with severe neurological sequelae a reasonable goal.

The parent is the primary and principal caretaker of the child. This concept is supported by Catholic teaching and both natural and civil law.³⁰ The right to life is the most basic human right based on the natural law. Preservation of life ought to be the first concern of both parent and physician unless the intervention is obviously futile and of no benefit to the child. In a situation where the parents are undecided or uncertain, the decision ought to be made to preserve the life of the child. In an emergency situation where the intervention could be successful, albeit unlikely but not futile, the correct approach is to follow the wishes of the parent.

In many cases, a joint decision can be made which benefits the child while imposing the least burden on him. In the NICU, for example, the physician may be confronted with the birth of a very immature child. Before calling an attempt at resuscitation futile, it is best to consider a therapy course and the goal of the intervention. If the goal is survival, and the outcome data show no survivors among patients in the infant's condition, the intervention would be justifiably declared futile. The situation can be clearly explained to the parents. Because this is a straightforward case, a joint decision to withhold intervention is likely to be agreed on as in the best interests of the child.

Many situations are not this clear. Sometimes the intervention's futility is based on a quality-of-life judgment. This situation introduces the danger of bias, of imposing the physician's values on the decision-making process. The physician may not share the same values as the parent. The physician's values are moral judgments and must be clearly identified as such to the parent, not presented as medical facts. In general, parents are reasonable people who want to act in their child's best interests. In most cases, shared decision making between fully informed parents and the physician will result in a decision acceptable to both sides. In some particularly difficult cases, the hospital ethics team and the palliative care team can help provide additional insight and support.³¹

30. Natural Family Planning Program, US Conference of Catholic Bishops, "Rights and Duties of Parents," accessed April 17, 2019, <http://www.usccb.org/>.

31. Mark R. Mercurio and John H. Seashore, "Futility in the Newborn and Pediatric Setting," in *What's the Point? Clinical Reflections on Care That Seems Futile*, ed. David H. Smith et al., available at <https://bioethics.yale.edu/>.

When death is imminent, most parents agree with the health care team to limit interventions that result in pain and discomfort but provide little benefit to their child. Parents may be reluctant to decide to withdraw or withhold an intervention and may prefer the burden of the decision to be placed on the physician. Sometimes this occurs after a protracted illness when parents are emotionally and physically exhausted. Pediatric intensivist Alexander Kon proposes an approach of “informed non-dissent.” The physician would be the decision maker, although the parent would be able to reverse the decision at any time. Kon claims this is a compassionate, non-paternalistic ethical alternative that accommodates the wishes of the parents.³² Recent events in the United Kingdom have shown the degree of conflict that can occur when the right of the parent to be the final arbiter is not respected.

Dissenting Parents

Charlie Gard

Charlie Gard had a severe neurological disease and required intensive care and mechanical ventilation. He was hospitalized at the Great Ormond Street Hospital (GOSH), a leading children’s hospital in the United Kingdom, from the age of three months until he died at nearly twelve months of age. The child’s disease was considered incurable by his physicians, but experimental treatment was available in the United States. Initially, physicians in both countries agreed to try the experimental treatment. However, his transfer was delayed by ethical and legal deliberations. Three months after his hospitalization began, Charlie’s condition had deteriorated, and the GOSH physicians were of the opinion that the experimental therapy was futile and not in his best interests.

At the heart of these deliberations was the question, Was Charlie suffering in his current state, and would prolonging his life through experimental therapy therefore constitute excessive burden for potentially minimal gain? A legal battle ensued, with Charlie’s parents and others pressing for his transfer, which the GOSH physicians refused. The next month GOSH asked the court to override the parents’ decision. When this request was granted, discussion to withdraw life support was started. The parents continued to pursue transfer. During this time, Charlie remained at GOSH receiving intensive care, including mechanical ventilation. Many appeals to higher courts were all in favor of withdrawing life support. Life support was discontinued approximately six months later, and Charlie died in hospice.³³

Alfie Evans

At approximately the same time, a similar clinical scenario developed, also in the United Kingdom. When he was six months old, Alfie Evans was admitted to Alder Hey Children’s Hospital (AHCH) with a seizure disorder that eventually was

32. Alexander A. Kon, “Informed Non-Dissent: A Better Option Than Slow Codes When Families Cannot Bear to Say ‘Let Her Die,’” *American Journal of Bioethics* 11.11 (November 2011): 22–23, doi: 10.1080/15265161.2011.603796.

33. “Charlie Gard: A Family’s Real Life Story in the Spotlight,” *Featureworld*, accessed May 7, 2019, <https://www.featureworld.co.uk/>.

identified as a neurodegenerative disorder. He required intensive care and mechanical ventilation. The parents requested transfer to Bambino Gesù Hospital in Rome, which had agreed to accept Alfie. Transfer was denied because AHCH argued that Alfie's condition would not tolerate transport. The hospital requested the court to approve the withdrawal of life support. Alfie's parents accused AHCH of giving up. He remained at the hospital in intensive care on ventilator support for nearly a year. After twelve months in the hospital, Alfie's condition remained unchanged. At that time AHCH requested the court to withdraw parental rights from Alfie's parents and to withdraw mechanical ventilation. The legal battle continued, life support was discontinued several months later, and Alfie died at almost two years of age.³⁴

Both clinical scenarios are examples of parents dissenting from the recommendation of the physician caregivers. Both cases involve a very sick infant with a low probability of recovery. Both sets of parents appear to be loving and caring, well informed, and acting in what they perceive to be the child's best interests. Legal consultation early in the process attempted to resolve the conflict between the parents' rights and the physician's authority as decision maker. And yet the relationship between both sets of parents and their children's health care teams became adversarial, creating enormous emotional hardship and attracting significant media attention.

Parental Rights and Authority

Law in the United States

There is consensus in the United States regarding the role of parents in the care of their child. It is recognized that parents ought to be able to direct the upbringing, education, and care of their children, including medical care, without intervention from the state. Parents bear the responsibility for the well-being of their children; they have wide discretion when determining what that consists of. Catholic teaching supports these rights and duties of parents.³⁵ At the same time, parental discretion is not absolute. Children are considered human beings in their own right, with interests that must be acknowledged regardless of their parents' preferences. Also, society has an interest in the welfare of children and accepts the obligation of protecting them from harm, even at the hands of their parents. As competent decision makers, parents are morally and legally required to meet certain standards when making decisions for their child. Parents may refuse standard medical care for themselves, but they are not free to make the same decision for their children.

In the United States, it is generally believed that shared decision making is the most equitable way to resolve cases in which parents dissent from the physician's judgment that an intervention is futile. Unilaterally withdrawing or withholding an intervention without involving the parent is considered not to be in the best interests of the child or the family. Parents, particularly those without a medical background, may be unable to understand the medical nuances that make a specific situation futile,

34. "Alfie Evans: Legal Battle Toddler Dies," BBC News, April 28, 2018, <https://www.bbc.com/>.

35. Natural Family Planning Program, "Rights and Duties of Parents."

or they may be emotionally unable to make a choice that they equate to “giving up” on their child.

Faced with these scenarios, clinicians in Texas worked to establish a specific protocol for the interaction between the physician and the patient after medical futility has been invoked. The Texas Advance Directives Act was enacted in 1999 to promote shared decision making between patient and physician. Under the law, the attending physician can withhold or withdraw a treatment he considers inappropriate or futile based on the irreversible nature of the patient’s condition, overruling the patient’s decision to continue treatment.³⁶ This law protects physicians against legal action. The fear of litigation has led physicians to continue treatment they considered futile when demanded by the patient.

When the physician refuses to comply with the patient’s request to continue treatment, the ethics committee is consulted, and the patient is invited to participate in the ethics consultation process. If the conflict persists after consultation, the patient is given the option of transferring to another institution that will accept him and comply with the request. A decision must be made no more than ten days after the ethics consultation recommendation. The patient may ask for a court order to extend the period. During this time, treatment must continue. If transfer to another institution does not occur within ten days, the treatment is discontinued. The legislation provides a “legal safe harbor” for the physician and the institution. This was the first such law in the country.³⁷ Similar legislation was enacted in California in 2009.³⁸

This practical guideline provides some structure to the decision-making process in difficult cases; it allows the parent and the physician to have an active voice in the process. This approach is in line with Catholic teaching, as the rights of the parents are respected, and the best interests of the child predominate.

Law in the United Kingdom

In the United Kingdom, one can sense a different conception of what defines parental authority and its limitations. The cases of Charlie Gard and Alfie Evans suggest a legal environment that is much more willing to override parental authority in complex medical cases. The European legal system is based on human-rights standards set by the United Nations Convention on the Rights of the Child and the European Convention on Human Rights.³⁹ During disputes, limitations on parental

36. Regina Okhuysen-Cawley, Mona L. McPherson, and Larry S. Jefferson “Institutional Policies on Determination of Medically Inappropriate Interventions: Use in Five Pediatric Patients,” *Pediatric Critical Care Medicine* 8.3 (May 2007): 226, doi: 0.1097/01.PCC.0000264317.83788.ED.

37. Robert L. Fine, et al., “Medical Futility in the Neonatal Intensive Care Unit: Hope for a Resolution,” *Pediatrics* 116.5 (November 2005): 1220, doi: 10.1542/peds.2004-2790.

38. Alexander A. Kon, “The Shared Decision-Making Continuum,” *JAMA* 304.8 (August 25, 2010): 903, doi: 10.1001/jama.2010.1208.

39. United Nations International Children’s Emergency Fund, “A Summary of the Rights under the Convention on the Rights of the Child,” fact sheet, accessed April 16, 2019, https://www.unicef.org/crc/files/Rights_overview.pdf; and Council of Europe, European Convention on Human Rights, November 4, 1950, available at <http://www.hri.org/docs/ECHR50.html>.

authority often are justified by appealing to the child's rights and best interests. The legal system is commonly consulted to settle disputes between patient and physician. It appears that immediately resorting to the law is the prevailing strategy to resolve conflict.

Despite the appearance of a tendency toward limiting parental authority, attorney and ethicist Eliana Close asserts that the legal system in the United Kingdom supports shared decision making, which is based on the following precepts. First, the parents must act in the child's best interests, not their own. Second, doctors independently can withhold or withdraw treatment they consider futile, which they have no obligation to provide.⁴⁰ There is obviously the potential for great conflict here.

Critics of the law in the United Kingdom state that the current law is based on a value-laden best-interests norm, the legal process and appeals take too long, and courts are deciding on medical matters which are outside their expertise. Close and colleagues respond that the best-interests standard is adequate, although it should be stated more clearly and ought to be limited by policies of resource allocation. They affirm the courts are the best source of justice for the patient in these difficult situations. They admit the current system could be improved by removing the physician's authority to unilaterally withdraw or withhold treatment and allowing the parents a voice in this decision. The final decision would still, however, be made by the court.⁴¹

Indeed, the best-interests standard is value laden; the parent and the physician may have very different perceptions of the child's best interests. This potential for conflict is a limitation of the standard and can be allayed only by the active participation of the parent in decision making. Close and colleagues still consider referral to legal action to be the best way to resolve the conflict. This view may be changing, however. The model in Europe, which is currently weighted more heavily toward paternalism, is slowly shifting to an approach that allows the patient to have a greater voice in decision making. Even European critical care specialists are beginning to accept the paradigm of shared decision making as the most appropriate.

Ethical Differences

Different ethical cultures among European and American physicians may help explain this difference in their legal systems. A survey of cultural and ethical perspectives among American and European physicians revealed that European doctors showed an attitude of paternalism, while the American attitude tended toward respect for patient autonomy.⁴² A German pulmonologist commented, "Most patients aren't educated or responsible enough to decide all by themselves; they need advice." Physicians were asked if they would provide life-sustaining therapy to a patient if

40. Eliana Close, Lindy Willmott, and Benjamin P. White, "Charlie Gard: In Defence of the Law," *Journal of Medical Ethics* 44.7 (July 2018): 477, doi: 10.1136/medethics-2017-104721.

41. *Ibid.*, 478, 479.

42. Leslie Kane, "US vs European Physicians: Their Ethical Differences, Medscape Ethics Report 2014," slide show presentation, Medscape, February 2, 2015, <https://www.medscape.com/>.

they considered the intervention futile. The majority of both American and European doctors answered in the negative. The answers also were very similar when physicians were asked if they would provide intensive care to a newborn who was likely to die or would have a “terrible” quality of life if it survived: about two-thirds of physicians in both groups would not provide care. In their comments, however, American doctors were more willing to share decision making with the parents; European physicians were more likely to claim allocation of resources as a justification not to treat.

Giles Birchley, a British bioethicist with a background in ICU nursing, believes that parental rights are based on ownership of the child (“the child being parental property”) and the child’s lack of self-determination (the child is a nonperson because of lack of self-determination). These are the characteristics that define “intrinsic” parental rights, and based on these rights, he affirms competent parents are entitled to demand experimental treatment.⁴³ The child is recognized as the property of the parents, not as a human being in his own right, a separate individual from the parents. This analysis clearly differs from the prevailing cultural and legal climate in the United States and from the Catholic Church’s understanding of the rights and responsibilities of parents. Interestingly, they and Birchley arrive at similar conclusions regarding the primacy of parental rights when making decisions about their child’s care.

Writing about the Charlie Gard case, ethicists Dominic Wilkinson and Julian Savulescu claim that contrary to popular belief, most conflicts between patient and physician are handled by shared decision making in the United Kingdom. The authors make three recommendations. First, there should be a low threshold for using experimental treatment in patients who have been through conventional therapies without success and would otherwise die. If the patient requests, he should be transferred as soon as possible to an institution that has agreed to accept him and provide the experimental treatment. Second, experimental treatment should be started without delay. Third, the treatment should be applied on a trial basis and withdrawn if the side effects appear greater than the benefits. The authors are critical of the lengthy legal process in the Charlie Gard case. They recommend arbitration by an independent ethics review panel, which in many cases could avoid referral to the legal system. They recommend that if there is reasonable disagreement, the parents ought to make the final decision.⁴⁴ The arbitration panel recommended by Wilkinson and Savulescu is reminiscent of the bioethics committee called for in the Texas Advance Directives Act.

In response to Alfie Evans’s case, there has been a popular movement in the United Kingdom to modify the law so parents have a greater voice in medical decision making, especially in disputed cases. There seems to be support from some members of Parliament. The parents of Charlie Gard are active leaders in the movement to

43. Giles Birchley, “Charlie Gard and the Weight of Parental Rights to Seek Experimental Treatment,” *Journal of Medical Ethics* 44.7 (July 2018): 449, 451, doi: 10.1136/medethics-2017-104718.

44. Dominic Wilkinson and Julian Savulescu, “Hard Lessons: Learning from the Charlie Gard Case,” *Journal of Medical Ethics* 44.7 (July 2018): 432–442, doi: 10.1136/medethics-2017-104492.

alter the law; they want to address problems with the best-interests test and allow ethical discussion before the court intervenes.⁴⁵

Medical-ethical decision making occurs in clinical practice on a regular basis. For example, when the pediatrician decides to prescribe an inexpensive limited-spectrum antibiotic rather than an expensive broad-spectrum antibiotic, he considers medical indications, patient preferences, cost, and resources. These basic considerations are part of the deliberation, all within the context of doing the best for the patient with the least of burden resulting in a just action. The physician should heed the basic considerations and consult with the parents, and all parties involved should jointly arrive at a decision that is just when (1) medical futility has been invoked; (2) the decision is made to withdraw or withhold therapy, especially in end-of-life situations; or (3) the action may result in the patient's death.

Ethical deliberations in pediatrics are more complex because of the dependence of the child on the parent. The pediatrician and the parent decide together on the basis of the best interests of the child as perceived by the parent. The cases of Charlie Gard and Alfie Evans are examples of what can happen when parents dissent from the recommendations of the physician caregivers when medical futility has been invoked.

The different outlooks on decision making and parental rights between physicians in the United States and the United Kingdom call attention to the need for dialogue. The dependence of UK physicians on the legal system in the ethical deliberation may contribute to the conflict between parent and caregiver. Shared decision making between parent and pediatrician is essential to making a beneficent, just decision. The teachings of the Catholic Church can enhance this dialogue by providing a framework through which to consider the rights and responsibilities of parents and by contributing guidance on respecting human life when making difficult end-of-life decisions.

45. Clare Dyer, "Alfie Evans Case: Proposed Law Aims to Prevent Conflicts between Parents and Doctors," *British Medical Journal* 361.8151 (May 5, 2018): k1895, doi: 10.1136/bmj.k1895.