

The Catholic Tradition on the Due Use of Medical Remedies: The Charlie Gard Case

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Abstract

The widely publicized British case of Charlie Gard became an international *cause célèbre* when the treating physicians petitioned the British courts to prevent the parents from taking their dying child to America where a physician held out promise of an unproven experimental therapy. The case became more sensationalized when the press reported that Pope Francis had intervened in the case against the position of the Vatican's Academy for Life on the appropriate response to a patient with a lethal genetic disorder for which there was no known treatment. A review of the centuries-long teaching of Catholic moral theology on care of the dying demonstrates that the pastoral concern of Pope Francis for the grieving parents did not signal a change in church teaching on the care of the dying patient or reveal a disagreement between Pope Francis and the Academy for Life's position on the appropriate care of Charlie Gard.

Keywords

Catholic moral tradition, experimental therapy, Pope Francis, Charlie Gard, medical decision-making, parental authority

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The high-profile British case of Charlie Gard, an infant who was born with an extremely rare genetic disorder called encephalomyopathic mitochondrial DNA depletion syndrome (MDDS) ended with the death of young Charlie on July 29, 2017, a week shy of his first birthday.¹ Charlie's physicians at London's Great Ormond Street Hospital (GOSH), and multiple external consultants, were unanimous that there is no known treatment for Charlie's form (RRM2B) of the genetic disorder.² His treating physicians believed Charlie could probably experience pain and that there was nothing further medicine could do to alter his condition or benefit him. His physicians proposed withdrawing mechanical ventilation and allowing him "to die with dignity." Charlie's parents disagreed with his doctors' assessment. They desperately wanted to try an experimental treatment (nucleoside therapy) that had been proposed by a physician in the United States, called "Dr. I" in the court records. He was identified in subsequent court proceedings as Dr. Michio Hirano of New York's Columbia Medical Center.³

The dispute between the family and the physicians became a legal issue when the hospital petitioned the British courts to protect Charlie from additional suffering that might occur by moving him to the United States for the experimental therapy without any expectation, in the views of his treating physicians, of any medical benefit to the infant. The case was heard in the Family Division of the High Court by Justice Nicholas Francis.⁴ After a hearing in which Justice Francis took evidence from all parties in the case, the judge, with what he commented was "the heaviest of hearts, but with complete conviction for Charlie's best interests," ruled in favor of the petition submitted by the physicians. His decision was upheld as a matter of British law by the Appeals Court,⁵ the UK Supreme Court,⁶ and the European Court of Human Rights,⁷ each of which noted its great empathy for the difficult plight of the parents.

1. Debra Goldschmidt and Hilary Clark, "Baby Charlie Gard Dies after Life Support Withdrawn," *CNN*, July 29, 2017, <http://edition.cnn.com/2017/07/28/health/charlie-gard-death/index.html>.

2. *Great Ormond Street Hospital v. Yates* [2017] EWHC 972 (Fam) (England and Wales High Court Family Division), April 11, 2017, <http://www.bailii.org/ew/cases/EWHC/Fam/2017/972.html>.

3. Sahah Bosley, "US Doctor's Intervention in Charlie Gard Case 'Raises Ethical Questions,'" *The Guardian*, July 25, 2017, <https://www.theguardian.com/uk-news/2017/jul/25/michio-hirano-us-doctor-intervention-charlie-gard-case-raises-ethical-questions>.

4. *Great Ormond Street Hospital v. Yates* [2017] EWHC 1909 (Fam) 24 July, 2017 Case No: FD17P00103. <https://www.judiciary.gov.uk/judgments/great-ormond-street-hospital-v-yates-and-gard-24-july-2017/>.

5. *Yates & Anor v. Great Ormond Street Hospital for Children NHS Foundation Trust* 2017 WLR(D) 391 [2017] EWCA Civ 410 Court of Appeal Civil Division. <http://www.bailii.org/ew/cases/EWCA/Civ/2017/410.html>.

6. UK Supreme Court, "In the Matter of Charlie Gard—Determination of Permission to Appeal Application," June 8, 2017, <https://www.youtube.com/watch?v=P6rPmvGINhA>.

7. *Gard and Others v. The United Kingdom*, European Court of Human Rights July 3, 2017, [https://hudoc.echr.coe.int/eng#{"itemid":\["001-175359"\]}](https://hudoc.echr.coe.int/eng#{). See also Owen Bowcott, "Charlie Gard: European Court Rejects Plea to Intervene in Life-Support Fight," *The*

Press Responses to the Case

The case quickly became an issue in the international press and social media. Then it emerged as an apparent public dispute between the views of Archbishop Vincenzo Paglia,⁸ the President of the Vatican's Pontifical Academy for Life, and Pope Francis on the Catholic Church's position on the use of medical interventions to prolong life.⁹

The purported dispute has been sensationalized by accusations of “euthanasia, a Kafkaesque hostage-like situation,” and “a failure to accept people with disabilities.” A university-based bioethicist wrote in *CRUX* that “Little Charles Gard has been sentenced to die by those who hold power over him in the United Kingdom.”¹⁰ The author noted in his article that Catholic moral theology generally lets those closest to the good in question decide how to weigh such choices. In his view, in the Gard case, “that is obviously the parents.” The presumption of parental authority, however, is not absolute. Child protective service agencies exist to prevent situations in which a vulnerable minor is placed at risk by a parental decision. Furthermore, the Committee for the Protection of Human Subjects of Biomedical and Behavioral Research was created by the US Congress in 1978 to establish standards and guidelines for research on vulnerable classes of patients such as such as African Americans, pregnant women, fetuses, children, the mentally handicapped, residents of nursing homes, the terminally ill, and “volunteers” in third world countries, each of which within recent history had been exploited by medical researchers.¹¹

Guardian, June 27, 2017, p. 1, <https://www.theguardian.com/law/2017/jun/27/charlie-gard-european-court-rejects-plea-to-intervene-in-life-support-fight>.

8. Philippa Hitchins, “Vatican’s Academy for Life Issues Statement on Baby Charlie Gard,” Vatican Radio, Vatican City, June 28, 2017, <http://www.news.va/en/news/vaticans-academy-for-life-issues-statement-on-baby>.
9. Dan Bilefsky and Sewell Chan, “Dispute Over British Baby’s Fate Draws in Pope and US President,” *The New York Times*, July 3, 2017, <https://www.nytimes.com/2017/07/03/world/europe/uk-trump-pope-francis-charlie-gard.html>.
10. Charlie Camosy, “On the Charlie Gard Case, The Church Needs to be Clear,” *CRUX*, July 3, 2017, <https://cruxnow.com/commentary/2017/07/03/charlie-gard-case-church-needs-clear-prophetic/>.
11. Henry K. Beecher, “Ethics and Clinical Research,” *The New England Journal of Medicine* 274 (1966): 1354–60, <https://doi.org/10.1056/nejm196606162742405>; General Assembly of the World Medical Association, “Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects,” *Journal of the American Medical Association* 310 (2013): 2191–94, <https://doi.org/10.1001/jama.284.23.3043> (the *Helsinki Declaration* makes clear that in the dual role of physician-researcher, the role of leader takes precedence over that of the scientist); Robert V. Carlson, Kenneth M. Boyd, Daniel J. Webb, “The Revision of the Declaration of Helsinki: Past, Present and Future,” *British Journal of Clinical Pharmacology* 57 (2004): 695–713, <https://dx.doi.org/10.1111%2Fj.1365-2125.2004.02103.x>; Mike Stobbe, “Ugly Past of U.S. Human Experiments Uncovered,” *NBC News*, February 27, 2011, www.nbcnews.com/id/41811750/ns/health-health_care/t/ugly-past-us-human-experiments-uncovered/#.Wa1AoYvorjz8.html; Marcia Angell, “The Ethics of Clinical Research in the Third World,” *The New England Journal of Medicine* 337 (1997): 847–49, <https://doi.org/10.1056/nejm199709183371209>.

An even more sensationalized statement was published in the *National Review* by a writer who described Charlie and his parents as being held in a “Kafkaesque” situation.¹² The author maintained that the parents alone should have final say over whether Charlie could be brought to America to receive treatment. He also insisted that the state “get out of the way” of the parents trying to act in the best interests of the child and allow the parents and other doctors “*who reasonably believe* [italics added] this other treatment could help.” “Here was a moment,” he wrote, “for the Vatican to stand up and announce what the Catholic faith teaches about human life and our duties to one another and the God-given authority of parents over their children.”

While the author observed that it may be the case that Charlie Gard’s parents would be adding to the suffering of their son by traveling to America with him while he is mortally ill, and conceded that such a choice “may be the wrong decision,” in his view, it should still be “their decision.” To reinforce his arguments, the author added—without any documentation—that “other parents whose children suffered from a similar condition and were deemed to have no hope have seen recovery through this therapy.”

Another university bioethicist published an article in a Catholic journal denouncing the High Court’s ruling as “A Story of Disability Bias.”¹³ Although the author did cite John Paul II’s distinction in *Evangelium Vitae* that “to forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia,”¹⁴ she argued, “Yet there is another story here.” What was significant for her was the High Court’s repeated and consistent allusion to Charlie’s mental disability and brain damage as a key reason for not attempting the experimental treatment, a treatment that, as she noted, “*a doctor in the United States is willing to attempt and that people have supported with their funding*” (italics added). The fact that a physician in the United States “was willing to attempt an experimental treatment” on a seriously compromised infant or that “people have supported that proposal with funding,” does not address, let alone resolve, the ethical or legal issues raised in the *Gard* case.

Perhaps the most egregious distortion in the press was an item published in *Breitbart*, the alt-right outlet of former White House chief policy advisor Steve Bannon.¹⁵ Under a headline proclaiming, “Pope Francis Reverses Vatican Judgement on Charlie Gard Case, Siding with Parents,” the author of the article, a frequent critic of Pope Francis, wrote, “In a rare display of ecclesiastical cross-purposes, Pope Francis

12. Michael Brendan Dougherty, “The Vatican’s Statement on the Charlie Gard Case Is a Disgrace,” *The National Review*, June 30, 2017, <http://www.nationalreview.com/article/449159/vaticans-charlie-gard-statement-sides-state-over-family>.

13. Jana Bennett, “Charlie Gard: A Story of Disability Bias,” *America*, July 7, 2017, <https://www.americamagazine.org/politics-society/2017/07/07/charlie-gard-story-disability-bias>.

14. John Paul II, *Evangelium Vitae* (March 25, 1995), 65, http://w2.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae.html.

15. Thomas D. Williams, “Pope Francis Reverses Vatican Judgment on Charlie Gard Case, Siding with Parents,” *Breitbart News*, July 3, 2017, <http://www.breitbart.com/london/2017/07/03/pope-francis-reverses-vatican-judgment-charlie-gard-siding-parents>.

has reversed the statement from his newly appointed head of the Academy for Life regarding care for a British baby suffering from a debilitating genetic condition.” The story continued, “On Sunday Francis expressed his support for the parents of ten-month old Charlie Gard, suggesting they be allowed to do everything possible to treat their son.”

That far-reaching reading of the pope’s comments was the writers’ interpretation of an official Vatican statement that the pope had been following the parents’ case “with affection and sadness,” praying “that their desire to accompany and care for their own child to the end is not ignored.”

The pope’s statement was one of pastoral concern, not a detailed analysis of the appropriate use of medical treatments in this case. A further reading of the *Breitbart* article reveals the focus of the essay was not a papal assessment of the appropriate medical care of Charlie Gard, but the ongoing hostility of certain pro-life groups in the Vatican to the leadership of Archbishop Paglia and Pope Francis. The story took on a broader context when the *New York Times* republished comments of the pope under the headline “Dispute Over British Baby’s Fate Draws in Pope and U.S. President.”¹⁶ Neither the *Breitbart* account nor the *New York Times* article provided a detailed analysis of the Gard case let alone a theological explanation of any purported change in Catholic teaching on the care of profoundly ill patients.

High-Court Opinion in Case

In his earlier opinion Justice Francis noted that “No one in the world ever treated this form of MDDS (RRB2B) with nucleoside therapy.”¹⁷ The therapy had been utilized with a different mutation (TK2) from that which affects Charlie Gard with some success (a 4 percent survival rate in a study on mice). The judge also noted in his opinion for the court, “There is no evidence that nucleoside therapy can cross the blood/brain barrier which it must do to treat RRM2B.”¹⁸ Furthermore, the American researcher who had proposed using the experimental therapy acknowledged in telephone testimony to the High Court that the proposed therapy has never been tested, even in animal studies, for the mutation that afflicted Charlie Gard. The researcher also opined, without physically examining Charlie Gard or reviewing his medical records, that the damage to Charlie’s brain is likely to be “irreversible.” Justice Francis, in his finding of facts, concluded that the proposed therapy “is unlikely to result in any improvement in the infant’s medical condition.”¹⁹

16. Dan Bilefsky and Sewell Chan, “Dispute Over British Baby’s Fate Draws in Pope and U.S. President,” *The New York Times*, July 3, 2017, <https://www.nytimes.com/2017/07/03/world/europe/uk-trump-pope-francis-charlie-gard.html>.

17. *Great Ormand Street Hospital v. Yates* [2017] EWHC 1909 (Fam) April 11, 2017 Case No: FD17P00103, para. 20, <https://www.judiciary.gov.uk/wp-content/uploads/2017/05/gosh-v-yates-and-gard-20170411-1.pdf>.

18. *Ibid.*

19. *Ibid.*

Limits to Parental Authority in Medical Decision Making

The paradigmatic American bioethics case on the right of parents to make medical decisions for a sick child occurred in 1971 at Baltimore's Johns Hopkins Hospital. It involved the refusal by the parents of an infant born with Down syndrome and duodenal atresia to authorize a readily available surgical procedure that had an extremely high likelihood of success in alleviating the duodenal atresia.²⁰ That case dramatically changed the prevailing public attitude on the right of parents to determine the medical treatment for such a child. In an influential essay on the *Hopkins* case, William G. Bartholome, a pediatric resident who witnessed what happened at Johns Hopkins Hospital—the infant was put in a back room of the hospital, left unfed for 15 days, and allowed to starve to death—forcefully argued that “children are not chattel.”²¹ He maintained that an infant is not the property of the parents, but a person who possesses human dignity and thus a moral claim to medical treatment that holds a realistic promise of benefit. Multiple classic bioethics cases in the US and UK from *Karen Ann Quinlan*²² and Tony Bland²³ to *Jahi McMath*²⁴ highlight the limits on what medical treatments must be provided to patients for whom there is no realistic medical expectation of benefit. There is also a substantial literature on the limits of parental authority in medical decision-making.²⁵

20. James M. Gustafson, “Mongolism, Parental Desires, and the Right to Life,” *Perspectives in Biology and Medicine* 16 (1973): 529–57, <https://doi.org/10.1353/pbm.1973.0049>.
21. William G. Bartholome, “The Child-Patient: Do Parents Have the Right to Decide?” in *The Law–Medicine Relation: A Philosophical Explanation*, ed. S. F. Spicker, J. M. Healey Jr., and H. Tristan Englehardt (Dordrecht, Netherlands: Reidel 1982), 126–32.
22. *In re Quinlan*, 355 A.2d 647 (NJ 1976).
23. *Airdale N.H.S. Trust v. Bland* [1993] A.C. 789 House of Lords; Luke Traynor, “Hillsborough Inquests: 96th Victim Tony Bland 18, Died Four Years After 1989 Tragedy,” *The Mirror*, April 29, 2014, <http://www.mirror.co.uk/news/uk-news/hillsborough-inquests-96th-victim-tony-3472171>.
24. John M. Luce, “The Uncommon Case of Jahi McMath,” *Chest* 147 (2015): 1144–51, <https://doi.org/10.1378/chest.14-2227>; John J. Paris, Brian M. Cummings, Michael Patrick Moore, “‘Brain Death’, ‘Dead’ and Parental Denial: The Case of Jahi McMath,” *Cambridge Quarterly of Healthcare Ethics* 23 (2014): 371–82, <https://doi.org/10.1017/s0963180114000048>.
25. John J. Paris, Michael D. Schreiber, “Physicians’ Refusal to Provide Life-Prolonging Medical Interventions,” *Clinics in Perinatology* 23, no. 3 (1996): 563–71; John J. Paris, Michael D. Schreiber, “Parental Discretion in Refusal of Treatment for Newborns,” *Clinics in Perinatology* 23 (1996): 573–81; John J. Paris, Michael D. Schreiber, Michael P. Moreland, “Parental Refusal of Medical Treatment for a Newborn,” *Theoretical Medicine and Bioethics* 28 (2007): 427–41, <https://doi.org/10.1007/s11017-007-9046-9>; Paul Helft, John M. Lantos, Mark Sigler, “The Rise and Fall of the Futility Movement,” *The New England Journal of Medicine* 343 (2000): 293–96, <https://doi.org/10.1056/nejm20001123432116>; Ferdinand Schoeman, “Parental Discretion and Children’s Rights: Background and Implications for Medical Decision-Making,” *The Journal of Medicine and Philosophy* 10 (1985): 45–62, <https://doi.org/10.1093/jmp/10.1.45>; Douglas S. Diekema, “Parental Decision Making,” *Ethics in Medicine*, University of Washington School of Medicine, <https://depts.washington.edu/bioethx/topics/parent.html>.

Perhaps the most dramatic rejection of the thesis that parents alone have the right to make decisions for profoundly compromised children is the case at California's Oakland Children's Hospital of Jahi McMath, an eleven-year-old girl who, following an extremely complicated surgical procedure, hemorrhaged so much blood that her neurologists diagnosed her as "brain dead."²⁶ Despite statutory standards in California and all but one of the fifty states in the United States—as well as 79 foreign countries—that a clinical finding of "brain death" means "legally dead,"²⁷ Jahi McMath's mother insisted that "in this country a parent has the right to make decisions concerning the existence of their child."²⁸ Even after an independent court-appointed pediatric neurologist from Stanford University Medical Center conducted extensive tests that confirmed the patient's medical status, and a Superior Court judge ruled the girl was "legally dead," the mother insisted that she wanted a tracheostomy performed and a feeding tube inserted so that the family could transfer the girl to another facility for further medical treatment.

The Role of Courts in the Gard Case

Commentators have questioned why the decision in the Gard case was not left in the hands of the parents. Justice Francis addressed that issue in his opinion for the High Court. He noted that "While a child's parents have the power to give consent for their child to undergo treatment, in the UK overriding control is vested in the court exercising its independent and objective judgement in the child's best interests." This principle, he reminded the public, has been enunciated over the years in numerous cases. Sarah Woolley has noted that in the United Kingdom "medical decision-making is one area of the law where both [competent] children and the state can intercede and limit parental decision making."²⁹ As she observed, in the UK "the state can interfere if parental decisions are not seemingly in the child's 'best interests'." This exception, designed to protect infants and children, was introduced in the parliamentary Children's Act of 1989 to replace an outdated notion of parental rights that regarded children as parental possessions.³⁰ The act authorized the courts to guarantee that the child's best

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26. *Winkfield v. Children's Hospital Oakland*, Case No. R613-07508 (CA Super. Ct. Dec 20, 2013), <http://thaddeuspope.com/jahimcmath.html>; Lisa Fernandez, "Judge Declares Oakland Teen Legally Dead," *NBC Bay Area*, December 24, 2013, <http://www.nbcbayarea.com/news/local/Third-Doctor-Declares-Jahi-McMath-of-Oakland-Legally-Dead-237179681.html>.
 27. Ajay Kumar Goila, Mridula Pawar, "The Diagnosis of Brain Death," *Indian Journal of Critical Care Medicine* 13 (2009): 7–11, <https://doi.org/10.4103/0972-5229.53108>.
 28. Catherine E. Shoicket, "Jahi McMath's Family Searches for Options as Life-Support Cutoff Looms," *CNN*, December 30, 2013, <http://www.cnn.com/2013/12/29/health/jahimcmath-girl-brain-dead/index.html>.
 29. Sarah L. Woolley, "The Limits of Parental Responsibility regarding Medical Treatment Decisions," *Archives of Diseases in Childhood* 96 (2011): 1060–65 at 1063, <https://doi.org/10.1136/adc.2010.198432>.
 30. UK Parliament, *The Children's Act 1989*. Granted Royal Assent on November 16, 1989 and became an Act House of Commons, Tuesday November 16, 1989. Parliamentary

interest was, in fact, the motive of the parents with regard to medical decision-making. This change was, in part, a recognition that even good, caring, loving parents can and sometimes do make a medical decision antithetical to the best interests of the child—not necessarily out of malice or the desire to end the child’s life—but from a lack of understanding of the limits of medicine, or more likely anxiety, fear, or unrealistic hopes and expectations.

Adhering to the policy articulated in The Children’s Act of 1989, Justice Francis stressed that under British law once a conflict between a family and the treating physicians is brought to court, the court itself must make an independent assessment of the patient’s best interests. In his graphic phrasing, “the wishes of the parents, however understandable in human terms, are wholly irrelevant to consideration of the objective ‘best interests’ of the child.” In his argument Justice Francis quoted Lord Donaldson’s landmark ruling in the 1991 case of *Re J* that while there is a strong presumption in favor of prolonging life “in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to a treatment that will cause increased suffering and produce no commensurate benefit.”³¹

Finally Mr. Justice Francis highlighted the United Kingdom’s Supreme Court position in *Airdale NHS Trust v. Bland* (1993)³² that “decision makers must look at [the patient’s] welfare in the widest sense, not just medical, but social and psychological, they must consider the nature of the medical treatment in question, what it involves and its prospects for success, they must consider what the outcomes of that treatment for the patient is likely to be, and they must try and put themselves in the place of the individual patient.”

Church Teaching on Use of Medical Interventions

While the British High Court did not cite the Vatican’s authoritative statement on care of the dying, the 1980 *Declaration on Euthanasia*,³³ it is instructive to read section 4 of the declaration on “Due Proportion on the Use of Remedies”:

For such a decision to be made, account will have to be taken of the *reasonable* wishes of the patient and the patient’s family, *as also the advice of the doctors who are specially competent in the matter* [italics added]. The latter may in particular judge that the investment in instruments and personnel is disproportionate to the results foreseen; they may also judge that techniques applied impose on the patient strain or suffering out of proportion with the benefits which he or she may gain from such techniques.

Debates (Hansard). House of Commons. November 16, 1989, col 457, <https://publications.parliament.uk/pa/cm/198889/cmhansrd/1989-11-16/Debate-1.html>.

31. *In re J* (A Minor) (Wardship: Medical Treatment) [1991] Fam 33 at 46, <https://www.ncbi.nlm.nih.gov/pubmed/11648249>.

32. *Airdale NHS Trust v. Bland* [1993] 2 WLR 316.

33. Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (May 5, 1980), http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19800505_euthanasia_en.html.

This is not a new Church doctrine. The 1980 *Vatican Declaration*, issued in the pontificate of St. John Paul II and cited extensively in his 1995 encyclical *Evangelium Vitae*, is a summary of centuries of consistent Catholic moral analysis on the care of the sick and dying. As one of us wrote in an earlier essay entitled “The Hour of Our Death: Contemporary Approaches to End-of-Life Care,”³⁴ the Catholic understanding of life and death is not shared in the contemporary American approach on the “due use” of medical interventions. Daniel Callahan, the noted commentator on American approaches to health care, has observed that Americans tend to believe that “death is an option.”³⁵ Americans also anticipate there is a technological fix for every medical problem. They believe that if doctors tried hard enough they could not only delay, but conquer death itself. We have, as it were, adopted the utopian vision of Francis Bacon in *New Atlantis* of a technological society that seemingly knows neither death nor disorder.³⁶ We share in Bacon’s expectation of salvation through science and immortality through medicine.

Insights of Richard McCormick

The late Richard A. McCormick, SJ, among the preeminent Catholic moral theologians of the late twentieth century, addressed that issue in a *JAMA* article entitled, “To Save or Let Die.”³⁷ Although his article was published in a medical journal, it was more a theological discourse on the meaning and purpose of creation than a medically centered analysis. We are, he writes, created not merely for physical existence, but for a higher goal, eternal union with God. For McCormick, human or physical life is thus “a relative good, and the duty to preserve it a limited one.” These limits are defined by the *means* required to sustain life.

To support his analysis McCormick cites Pope Pius XII’s address to an International Congress of Anesthesiologists on “The Duty to Prolong Life.”³⁸ In that talk Pius XII noted that “We are normally obliged to use only ordinary means to preserve life.” The Pope went on to state that “A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good [eternal life] too difficult.” McCormick explained that this teaching implied that life and death, as well as all temporal activities, are subordinated to spiritual ends. This means that to

34. John J. Paris, “The Hour of Our Death: Contemporary Approaches to End-of-Life Care,” *America*, September 22, 2015, <https://www.americamagazine.org/issue/hour-our-death>.

35. Daniel Callahan, *The Troubled Dream of Life* (Washington, DC: Georgetown University Press, 2000), 163.

36. Francis Bacon, *New Atlantis*, ed. Brian Vickers (1627; repr., Oxford: Oxford University Press, 2008).

37. Richard McCormick, “To Save or Let Die: The Dilemma of Modern Medicine,” *JAMA* 228 (1974): 172–76, <https://doi.org/10.1001/jama.1974.03230400034027>.

38. Pius XII, “On the Duty to Prolong Life” (address, International Congress of Anesthesiologists, Rome, November 24, 1957), http://www.lifeissues.net/writers/doc/doc_31resuscitation.html.

concentrate all one's efforts on clinging to physical life not only distorts one's view of life, but destroys the pursuit of the relational goals that define the goal and end of Creation. As McCormick summarized the issue, "The very Christian meaning of life is seriously jeopardized when undue and unending effort must go into its maintenance." From this he concluded that "It is neither inhuman nor un-Christian to say that there comes a point where an individual's condition itself represents the negation of any truly human—that is, relational—potential." When that point is reached, he rhetorically asks, "Is not the best treatment, no treatment?" His response was, "I believe that the *implications* of the traditional distinction between ordinary and extraordinary means point in this direction."

McCormick is not dismissing a life irrevocably trapped in medical machinery as a life "not worth living." Rather, he writes, "When in human judgment this potentiality [for relationships] is totally absent or would be, because of the condition of the individual, totally subordinated to the mere effort for survival, that life can be said to have achieved its potential."

That judgment is rather readily accepted by most people for the comatose 93-year-old patient with metastatic cancer and multi-system organ failure. It is not as readily accepted for a newborn infant with a rare genetic malformation for which there is no known treatment. From a theological perspective, McCormick notes, there is no significant difference. Each life regardless of age has achieved its maximum potential.

McCormick concluded his *JAMA* article with the reminder that "allowing to die" is not the same as "euthanasia." Nor, he emphasized, does it imply that there is such a thing as "a life not worth living." Every human being, regardless of age or condition is of incalculable value. The issue, he writes, is not whether this or that individual has value. In his words, "Of course he has, or rather, *is* a value." The point for McCormick is whether this individual has any potential in maintaining physical survival—other than by clinging to biological existence by aggressive medical measures.

Historical Background on the Catholic Tradition on Limits of Medicine

The 1980 *Vatican Declaration* is a summary of constant teaching going back to the fourth-century writings of St. Basil the Great. Basil, after noting that the art of medicine was a divine gift that permits us to heal the sick, nevertheless condemned "whatever requires an undue amount of thought or trouble or involves a large expenditure of effort and causes our whole life to revolve, as it were, around the solicitude of the flesh."³⁹

That quotation, which invites theological reflection on the limits of the moral duty to preserve physical life, became, in the thirteenth century, the basis of Thomas Aquinas's reflections on suicide and mutilation found in questions 64 and 65 in the

39. Basil, *The Long Rules*, in *The Ascetical Works*, trans. M. Monica Wagner, The Fathers of the Church (Washington, DC: Catholic University of American Press, 1962), 330–31.

Secundae Secundae.⁴⁰ It, subsequently, was the basis of the sixteenth-century Catholic moral theologians' responses to questions on the obligation to preserve health and life by means of the scientific advances developed during the Renaissance in anatomy, physiology, and surgery. Among the questions raised was the moral duty of undergoing surgery at a time before sepsis and anesthesia were known or available.

Such well-known sixteenth-century commentators as Francisco de Vitoria (1483–1546), Domingo de Soto (1494–1560), and Domingo Báñez (1528–1604) developed the doctrine on the use of “ordinary and extraordinary” measures to preserve health and prolong life. Paulina Taboada, a physician and director of the Center for Bioethics at the Pontifical Catholic University of Chile, noted in an address to the Fourteenth General Assembly of the Pontifical Academy for Life that a historical review of the tradition does not need to be analyzed *de novo*.⁴¹ We already have excellent historical studies of the issue published by Daniel Cronin, Gerald Kelly, and Kevin Wildes as well as analysis of the tradition by James McCartney, Maurizio Calipari, and John Paris.⁴²

For the sixteenth-century Catholic moralists, “ordinary” and “extraordinary” referred not to technique or hardware, but to moral obligation. Failure to adhere to one's moral duties was sinful. So the question for confessors and thus for the moralists—who served as guides on moral issues for the confessors—was the degree of culpability and more importantly the question of “what excused” the individual from the duty to utilize an intervention that was available and which might restore health or prolong life, but at an extremely high cost to the patient in terms of suffering.

Beginning with the teachings of the Dominican Domingo de Soto that religious superiors could only require their subjects to use medicine that could be taken without too much difficulty through the Vatican's 1980 *Declaration on Euthanasia* there have been clear limits set on what one is obliged to undergo to preserve life. The most famous formula for that limitation was first proposed in 1595 by another Dominican

40. Thomas Aquinas, *Summa Theologiae* 2–2, q. 64, a. 5; q. 65, a.1.

41. Paulina Taboada, “Ordinary and Extraordinary Means of the Preservation of Life: The Teaching of Moral Traditions” (address, Fourteenth General Assembly of the Pontifical Academy for Life, Vatican City, February 25–26, 2008), <https://www.catholicculture.org/culture/library/view.cfm?recnum=8772>.

42. Daniel Cronin, *Ordinary and Extraordinary Means of Conserving Life* (Rome: Gregorian Press, 1985); Gerald Kelly, “The Duty of Using Artificial Means of Preserving Life,” *Theological Studies* 11 (1950): 203–20, <https://doi.org/10.1177/004056395001100202>; Kevin Wilde, “Ordinary and Extraordinary Means and the Quality of Life,” *Theological Studies* 57 (1996): 500–12, <https://doi.org/10.1177/004056399605700306>; James J. McCartney, “The Development of the Doctrine of Ordinary and Extraordinary Means of Preserving Life in Catholic Moral Theology Before the Karen Ann Quinlan Case,” *Linacre Quarterly* 47 (1980): 215–24, <http://epublications.marquette.edu/cgi/viewcontent.cgi?article=2510&context=lnq>; Maurizio Calipari, “The Principle of Proportionality in Therapy: Foundation and Applications Criteria,” *Neurorehabilitation* 19 (2004): 391–97; John J. Paris, “The Catholic Tradition on the Use of Nutrition and Fluids,” in *Birth, Suffering and Death*, ed. Kevin Wildes (Netherlands: Kluwer, 1992), 189–208.

theologian, Domingo Báñez, on what he labeled a distinction between “extraordinary” and “ordinary” means, by which was meant measures proportionate to one’s condition or state in life. Thus, if something were very costly, extremely painful, excessively burdensome—or if it did not offer substantial benefit to the patient—there was no moral obligation to use it. That standard applied even to life-saving measures.

That the doctrine has continued unchanged to the present day is seen in the Vatican’s 1980 *Declaration on Euthanasia*, which states, “It is permitted, with the patient’s consent, to interrupt those means where the results fall short of expectation.” Withdrawing treatment, in the words of the Vatican’s Sacred Congregation for the Doctrine of the Faith, “is not the equivalent of suicide [or euthanasia]; on the contrary, it should be considered as an acceptance of the human condition, or a wish to avoid the application of a medical procedure disproportionate to the results that can be expected, or a desire not to impose excessive expenses on the family or community.”

The clearest statement of that teaching is found in the *Relecciones Theologiae* by another sixteenth-century Dominican theologian, Francisco de Vitoria.⁴³ In a commentary on the obligation to use food to preserve life, Vitoria asks, “Would a sick person who does not eat because of some disgust for food be guilty of a sin equivalent to suicide?” His reply: “If the patient is so depressed or has lost his appetite so that it is only with the greatest effort that he can eat food, this right away ought to be reckoned as creating a kind of impossibility, and the patient is excused, at least from mortal sin, especially if there is little or no hope of life.”

Vitoria provides an everyday example of the type of “delicate treatment” that would be beyond what one is obliged to employ to preserve life: chickens and partridges. Even if prescribed by the doctor, Vitoria held, these special foods need not be chosen over eggs and other common items. This was true, Vitoria noted, even when the individual knew for certain that he could live another twenty years by eating such special foods. If this was true of chickens and partridges in Vitoria’s time, how much the more so for total parenteral nutrition, ventilators, or proposed but unproven experimental therapies?

That Vitoria’s views were neither unique nor subsequently abandoned is best seen in a 1950 essay entitled “The Duty of Using Artificial Means of Preserving Life” published in *Theological Studies* by the widely respected Jesuit moralist Gerald Kelly.⁴⁴ Kelly was concerned with the same question that confronted the British courts in the Bland and then the Gard case: Is there a moral obligation to continue medical interventions for an irreversibly comatose patient? After a thorough survey of the prior teachings on the subject, Kelly finds that the authors hold that “no remedy is obligatory unless it offers a reasonable hope of checking or curing a medical condition (*Nemo ad inutile tenetur*).” From this Kelly concluded that no one is obliged to use any means if it does not offer a reasonable hope of success in overcoming that person’s condition.

43. Francisco de Vitoria, *Relecciones Theologiae*, trans. Ernest Nys (New York: Wiley & Sons, 1964).

44. Kelly, “The Duty of Using Artificial Means of Preserving Life.”

When asked if oxygen and intravenous feeding must be used to extend the life of a patient in a terminal coma (the term “terminal coma” as used by Kelly in 1950 implied not death but irreversibility of the comatose state), Kelly replied,

I see no reason why even the most delicate professional standard should call for their use. In fact, it seems to me that, apart from very special circumstances, the artificial means not only need but should not be used, once the coma is reasonably diagnosed as terminal [irreversible]. Their use creates expense and nervous strain without conferring any real benefit.

(The somewhat inapt phrase “persistent vegetative state” was coined in 1972 by an American neurologist, Dr. Fred Plum and a Glasgow surgeon, Bryan Jennet, to replace the phrase “terminal coma” in describing the medical condition of irreversible coma.⁴⁵)

A 1958 doctoral dissertation written at the Gregorian University in Rome, “The Moral Law in Regard to the Ordinary and Extraordinary Means of Preserving Life,” by the late Daniel A. Cronin (bishop of Fall River, MA, 1970–1991; archbishop of Hartford, CT, 1991–2003) provides the most authoritative historical study of this topic.⁴⁶ After a review of over fifty moral theologians—from Aquinas to those writing in the early 1950s—Cronin concluded that the Church’s teaching is consistent in its view: “Even natural means can become optional if taking them requires great effort or if the hope of beneficial results (*spes salutis*) is not present.” For the patient whose condition is irreversible, Cronin writes, “even ordinary means, according to the *general norm*, have become extraordinary [morally dispensable] for the patient.”

Cronin’s retrospective analysis of the tradition established that the Catholic moralists held that no medical interventions are absolutely obligatory regardless of the patient’s status. How then did the idea that some medical measures (such as artificial nutrition and hydration) must always be provided the patient gain currency? Perhaps it arose from the hesitancy expressed by Kelly to advise physicians that it is morally permissible to discontinue intravenous feeding lest such action be misinterpreted as a form of Catholic euthanasia.

That reluctance was intensified in Charles McFadden’s widely circulated 1949 edition of *Medical Ethics*.⁴⁷ McFadden wrote that while the long-term use of artificial feedings could constitute a grave and nonobligatory burden, as a matter of practical medical advice, he would never propose the removal of intravenous feeding once it had been instituted. The danger is that of scandal, or guilt on the part of the family, or misuse by insensitive or unscrupulous physicians. Those not familiar with nuanced distinctions, he argued, might believe that the patient had been deliberately killed to alleviate his suffering. Opposition to the applications of the traditional doctrine to medical practice soon led to the notion that what was theoretically correct was not only

45. Lawrence K. Altman, “Fred Plum, Neurologist who Helped Coin ‘Persistent Vegetative State,’ Dies at 86,” *The New York Times*, June 12, 2010, <http://www.nytimes.com/2010/06/13/health/13plum.html>.

46. Later published as Daniel Cronin, *Ordinary and Extraordinary Means of Conserving Life*.

47. Charles McFadden, *Medical Ethics* (Philadelphia: F.A. Davis, 1956).

rash; it was wrong. From there it was an easy step to the position that it was wrong because it violated fundamental principles such as, “One must always use ‘ordinary’ means to preserve life.”

The issue of the due use of medical interventions mostly dropped from the moral theology literature until the 1970s. Paul Ramsey adopted and updated Kelly’s formulation in a 1970 essay “On (Only) Caring for the Dying” that has yet to be surpassed for insight and beauty in describing the Christian’s responsibility toward the dying.⁴⁸ Ramsey’s version reads, “Never abandon care.” For the dying, Ramsey maintains that care is not recourse to pretended remedies; it is comfort and company. For those, such as the highly publicized Karen Ann Quinlan, who were in an irreversible comatose condition, and thus beyond both, Ramsey held there is no objection to withholding or withdrawing what he labeled “pretended remedies.” The application of the theory in the Quinlan case occurred when Ramsey equated the respirator and the intravenous treatment as equally aimless means of prolonging the life of someone in an irreversible coma.

Ramsey’s perspective on the Quinlan case was subsequently endorsed by Richard McCormick, when, during a hearing of the President’s Commission on Ethical Problems in Medicine, the question was raised on whether there was any moral difference between removing a respirator, antibiotics, or artificial feeding from Karen Ann Quinlan. McCormick’s reply from the Catholic tradition was an unequivocal, “No.”⁴⁹ If, for example, Quinlan were to contract pneumonia, McCormick testified, there would be no need to use antibiotics because she would stand to gain nothing from such an intervention. A similar argument could likewise be made with regard to the continued use of feeding through the nasogastric tube. (Quinlan’s parents never asked to have her feeding tube removed. The only issue they raised in the courts was the withdrawal of the ventilator.⁵⁰)

Until such highly emotionally charged cases as Quinlan, Schiavo,⁵¹ or Gard, there was little ambiguity or hesitancy about ending medical measure to prolong life. For example, in his frequently anthologized 1976 discourse to the Massachusetts Medical Society, Dr. J. Englebert Dunphy admonished physicians, “There is no need to prolong a useless and tragic life [of a patient racked with cancer] *by force feeding* or giving antibiotics . . . to drag it out for a few more

48. Paul Ramsey, “On (Only) Caring for the Dying,” in *The Patient as Person* (New Haven: Yale University Press, 1970), 113–65.

49. Richard A. McCormick, “Testimony Before the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical Behavioral Research” (unpublished address, Washington, DC, June 25–26, 1982), obtained through personal correspondence.

50. Julia Quinlan and Joseph D. Quinlan, *Karen Ann* (New York: Bantam, 1977), 165.

51. Timothy E. Quill, “Terri Schiavo—A Tragedy Compounded,” *The New England Journal of Medicine* 352 (2005): 1630–33, <https://doi.org/10.1056/nejmp058062>; John J. Paris, “Terri Schiavo and the Use of Artificial Nutrition and Fluids: Insights from the Catholic Tradition on End-of-Life-Care,” *Palliative Supportive Care* 4 (2006): 117–20, <https://doi.org/10.1017/s1478951506060160>.

agonizing days or weeks.”⁵² In his sharply stated summary, “That is the science without the humanity of medicine.”

In an essay published in 1977 in *America* magazine entitled “A Quiet Death, with Dignity,” Cornelia Holbert wrote about her mother, an 86-year-old victim of multiple strokes whose newly contracted pneumonia was being treated by intravenous fluids and antibiotics.⁵³ At her own request, the mother was disconnected from those (simple, ordinary, and customary) treatments. She was kept comfortable by a fingertip dipped in ice water and smoothed over her tongue. During this time, her beloved rosary was placed in her hand. In Holbert’s moving words, “Love flowed now, not merely love of compassion, but the love of adoration for the glory of a soul stripped down to its pure white essence.”

Holbert’s essay published in a leading Catholic journal of opinion evoked no charges of euthanasia, it conjured up no horrors of death by starvation and dehydration, and it provoked no episcopal warnings of denigration of “life.” Rather, it was received as an exposition in simple story form of the fervent Catholic prayer for the profoundly ill: “For a speedy recovery or a happy death.”

That understanding of life, death, and the role of medicine continues to predominate in the thinking and writing of contemporary Catholic theologians. It is most recently seen in the statement of the Conference of Catholic Bishops of England and Wales on the Gard case: “We should never act with the deliberate intention to end a human life . . . We do, sometimes, however, have to recognize the limitations of what can be done.”⁵⁴ That policy was repeated in the official statement on the Gard case issued by Archbishop Paglia for the Vatican’s Academy for Life.⁵⁵ In addition, the statement noted,

The proper question to be raised in this and in any other unfortunate similar case is this: what are the best interests of the patient? We must do what advances the health of the patient, but we

52. J. Englebert Dunphy, “On Caring for the Patient with Cancer,” *The New England Journal of Medicine* 295 (1976): 313–19, <https://doi.org/10.3322/canjclin.27.2.109>.

53. Cornelia Holbert, “A Quiet Death with Dignity,” *America*, March 12, 1977, 214–16.

54. Peter Smith, “Regarding the Medical Treatment of Baby Charlie Gard,” *The Catholic Church in England and Wales*, June 28, 2017, <http://www.catholic-ew.org.uk/Home/News/Baby-Charlie-Gard-Final-Ruling>.

55. The Academy for Life Statement on Charlie Gard can be found in “Vatican’s Academy for Life Issues Statement on Baby Charlie Gard,” *Vatican Radio*, June 29, 2017, http://en.radiovaticana.va/news/2017/06/29/vaticans_academy_for_life_issues_statement_on_charlie_gard/1322138. A more recent statement of the traditional Catholic teaching on the limits of medicine is Pope Francis’ address on what he labeled the dangers of “overzealous treatment.” The brief discourse on end-of-life care was a reaffirmation of Archbishop Pagalia and the Pontifical Academy for Life’s position on the Charlie Gard Case. Francis, “Message of His Holiness Pope Francis to the Participants in the European Regional Meeting of the World Medical Association”(address, Vatican City, November 7, 2017), http://w2.vatican.va/content/francesco/en/messages/pont-messages/2017/documents/papa-francesco_20171107_messaggio-monspaglia.html.

must also accept the limits of medicine and . . . avoid aggressive medical procedures that are disproportionate to any accepted results or excessively burdensome to the patient or family.

The statement ended with an unusual personal coda by Archbishop Paglia:

Dear Charlie, dear parents, Chris Gard and Connie Yates, we are praying for you and with you.

+ Vincenzo Paglia

President, Pontifical Academy for Life

That pastoral expression of compassion and prayers for the suffering parents by Archbishop Paglia, much like the expression of pastoral concern in Pope Francis's public comments on the Gard case, was not a redirection of the Church's traditional teaching on the appropriate medical care of the dying or irreversibly comatose patient, but a prayer for those who at the hour of death are in need of God's compassionate mercy. Prayers for the suffering ought not be confused with doctrinal teaching.

The Relation of Physiological Concerns and Spiritual Needs of Patients

The subordination of physiological concerns to the patient's spiritual needs is the hallmark of authentic Catholic thinking. It is based on a clear and careful reiteration of the classical theological assumptions upon which medicine and the efforts to treat people have been based—"to prolong living in order to pursue the purpose of life." The burden a person would experience in striving to obtain the purpose of life, not the burden associated with the means to prolong it, is, and traditionally has been, the focus of Catholic moral concern.

It is this bedrock teaching of theology on the meaning of life and death, neither of which in the Christian framework ought to be made absolute, and not a misplaced debate on the potential efficacy of unproven experimental therapies that should guide our judgements on the difficult and sometimes trying decisions cast up by modern medical science. As McCormick reminded us, to do otherwise, to count mere biological existence as a patient-benefit, is to let slip one's grasp on the heart of the Catholic moral tradition on these matters. It is that tradition, developed over centuries of living out the gospel message on the meaning of life and death—and not some immediate personal agenda—that is and continues to be the source of the Catholic Church's teaching on the duty to preserve health and life.

Conclusion

The Catholic theological perspective on care of the sick and dying and the reasoning of the British High Court share the same foundational principle: a patient-centered

approach. Both the church's teaching and the British courts concur that such a decision for a profoundly compromised infant requires input from *both the parents and the doctors*. While it remains true that decisions regarding the treatment of profoundly sick children belongs first of all to the parents, there remains a vital public interest in and responsibility for the welfare of the most vulnerable among us. If, as proved true in the Gard case, there is an irreconcilable conflict between the views of the parents and that of the treating physicians on the patient's "best interests," under long-standing British legal standards the dispute is to be resolved not by the tabloids, social media, or the number of signatures on a public petition, but by an independent assessment of the court. Both the British legal tradition and the Church centuries-long moral reflection on the care of the sick and dying concur on the factors to be taken into consideration for a decision in the patient's "best interests."

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