The Forgoing of Life-Sustaining Treatment for Children

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In antiquity, sick or disabled children were often left to die in the open, and even infanticide was not unusual up until the 20th century. These morally questionable practices were at least partly informed by the heritage of our Greek ancestors, who obligated physicians to not provide treatment of no perceived benefit. Hippocrates wrote:

Whenever therefore a man suffers from an ill which is too strong for the means at the disposal of medicine he surely must not even expect that it be overcome by medicine. [Treatment in such a situation was] ... allied to madness.

And Plato in *The Republic* advised the physician:

For those whose bodies were always in a state of inner sickness he did not attempt to prescribe a regime ... to make their life a prolonged misery ... medicine was not intended for them and they should not be treated even if they were richer than Midas.

Following along with our rapid advancement in the biological understanding of human health and disease and our vastly improved ability to effectively treat “inner sickness,” our normative ideas about benefit, harm, and misery have evolved. Nowadays, because of an abundance of resources available in the most economically developed countries, it is often medicine’s first instinct to try to save the seriously ill or disabled before we start to worry about contributing to unacceptable suffering or prolonging misery.

As the Greeks accurately perceived, questions about which human lives are worth extending through medical efforts and which are better off being let go are inescapable; theirs was a first attempt at ethically answering an enduring dilemma for the medical profession. In this chapter, we will focus on issues raised when we consider forgoing life-sustaining treatment for a child, a matter complicated by the fact that children are often unable to intelligibly and reliably speak for themselves. We note from the
outset a variety of sources that have come to inform this kind of a discussion, including some that are more conceptual, like religious doctrine and moral philosophy, and some that are more pragmatic, like law and professional and institutional guidelines. Not surprisingly, these sources are prone to occasional disagreement, and in canvassing them, we do not pretend to definitively reconcile all controversy. Still, we argue that some operational consensus is required to effectively manage the real decisions that must be taken at the clinical bedside. This requires basic agreement with respect to moral and legal boundaries. And while law and ethics are not coincident with each other, they often share similar goals: preventing harm and promoting good.

We also think it vital from the outset to stake an independent claim to the moral importance of virtue in medicine. We need not unconditionally adopt a “virtue-based” ethic or philosophy, but the argument in this chapter is informed by a professional commitment to the values of truth and trust. Aristotle described truth as “the proverbial door which no one can fail to hit.” By this, he meant to emphasize that almost every belief formed from human experience possesses an element of truth. We agree that there is an irreducible empirical quality to truth, even while acknowledging that some kinds of understanding are superior to others. Few question the importance and value of trust in medicine as an essential ingredient in any moral relationship between physicians and patients. In pediatrics, this trust, which extends to parents, must also exist between parent and child and, because of the unique vulnerability of the child, between state and child, and physician and state.

As we address the ethical issues related to the consideration of forgoing life-sustaining treatment in children, a number of questions immediately surface: What pathological conditions could potentially qualify for the cessation or noninstigation of life-sustaining treatment? When should this occur? How should it occur? Perhaps most importantly (if not pragmatically), who should decide these things? With respect to the last question, we have long granted parents the authority to make medical decisions for their children. Indeed, as a moral matter, we oblige them to do this because of their special relationship; we presume that, as naturally affectionate caregivers, they will attempt to do right by their children. This deference is also partly justified on practical grounds; as preadolescent children are assumed to be cognitively incapable of making acceptably informed decisions about their lives, a reliable and dependable surrogate is needed, and few are better positioned to fill this role than parents. However, experience shows that not all parents are deserving of a grant of decision-making authority. That thematic concern runs throughout this book.

Decisions to not provide medical care for children that result in their death are usually uncontroversial if all parties involved in the decision agree. Empirically, we typically see a lack of ethical controversy (or
conversely, general agreement) when any of the following clinical conditions manifest: terminal illness (or alternatively, unpreventable death); unmanageable pain and suffering; and the so-called permanent vegetative state. We observe here, as an important aside, that very few pediatric disease states can immediately and confidently be classified as resulting in unmanageable pain and suffering. When such states of existence do manifest, it is typically only after much effort has been made over extended periods of time to treat the condition or conditions. We also note the difficulty of diagnosing a permanent vegetative state in an infant or young child who has any cortical brain that is capable of ongoing development.

Regarding the more resolute classification of terminal illness, we note that most ethical controversy here revolves around the characterization of the inevitability of death. While there is rarely anything like true certainty in medical prognosis, we consider a pathological condition to be properly regarded as terminal when that determination is based on the best available knowledge at hand, and expert medical opinion is such that no treatment can be offered that will prevent the condition from causing biological death in some predictable time period (days, months, years). Here, it is worth spending a little time distancing this term from a close cousin, "futility," whose use has fallen out of favor (though we believe it still does some inappropriate dirty work at the bedside). The essential problem with the word "futility" is its multiplicity of intended meanings. One can speak of physiological futility, which comes closest to resembling terminality, as an inability to produce a desired physiological response by a proposed intervention. One can speak of quantitative futility as the probabilistic failure of any intervention derived from previous knowledge, experience, and/or available statistical data. Finally, one can speak of qualitative futility as applying to an intervention whose outcome is deemed not worthwhile for a host of considerations, most frequently quality-of-life concerns. Significantly, the use of the term "futility," even so narrowly defined and qualified, does not automatically prescribe the next therapeutic moves, nor does it lead to consensus decision making. Its qualified use does, however, provide a basis for removing misunderstanding. For example, when the forgoing of life-sustaining treatment is considered, providing further intervention may be classified as futile in terms of the chance of short-term survival or in terms of its leading to a worthwhile life. Such a key qualification sets the stage for a better discussion of the empirically derived physiological facts and the moral arguments that might justify a particular action, assuming the veracity of those facts.

We note discouragingly that futility is often unintentionally interpreted in a pejorative manner at the bedside. If parents resist the withdrawal of medical care but are told that treatment is futile, what they sometimes hear is that treatment is not worthwhile or that it is a waste of time, which may quickly be refashioned into a bothersome waste of time. Such
misunderstanding might only serve to entrench differences of opinion regardless of their ultimate validity. As such, without clear qualifiers in place, we argue that the word is best avoided in negotiations with families about end-of-life care. Professionals can find alternative language to argue why they are not obliged to provide treatment they consider useless or harmful. Invoking an easily misconstrued word like "futility" threatens to change the debate from one focused on when it is right to forgo life-sustaining treatment to one concerning power and influence, that is, the right of parents to control what is happening to their child over a perceived professional or institutional authority.

On this note, we argue that the use of tactful language is as much a part of the practice of medicine as it is of political diplomacy. That physicians, in practice, have a determining role in recognizing when it may be appropriate to forgo life-sustaining treatment does not constitute the final step in the process. The next step is one of counseling, which is a complex, sociological exercise that critically depends on the skill of the provider. We all are familiar with model counselors and those who should have never been granted the privilege. We argue that professional skill in the counseling process is ethically obligatory. In addition to constituting a virtue, conscientious negotiating more often than not leads to a lessening of harm to all vested parties, a lessening of conflict and misunderstanding, and the promotion of good ends based on justifiable principles.

For this reason, we are wary of the recent enthusiasm of many providers to promote futility legislation across the country, much like the ongoing experiment in Texas. We are especially wary of its potential effect in pediatrics. The desire to expeditiously circumvent the hard moral work involved in ending seriously compromised early human life is quite understandable, but it risks undercutting trust by creating time-insensitive bypasses. We argue that there is independent moral value for the profession in avoiding actions that have the appearance of coercion, subtle or otherwise, in order to affect a desired nontreatment outcome. The exercise of professional virtues such as patience, prudence, and empathic counseling more often than not resolves the situation, even if the time frame for doing so is exasperating and longer than most physicians would prefer.

Having touched on "easy" cases, like terminal conditions, we now turn to what we perceive to be the most enduring moral problem faced in end-of-life decision making for children: the issue of when it may be appropriate to forgo life-sustaining treatment when the prospects for a child's physical and mental flourishing are seriously jeopardized. Many thoughtful providers, parents, and child advocates have attempted to forge an acceptable ethical path that appropriately weights the "inherent value" of a child's life with, as Walter writes, "a life that, on balance, does not warrant aggressive treatment." Not surprisingly, considerable disagreement remains the norm, and actual decisions often depend on the attitudes and inclinations
of the case-specific players. A hallmark conceptual difficulty lies in our inability to sensibly weigh the binary outcomes faced. At least in secular terms, death is ineffable and cannot be compared with a life of profound disability, as the two outcomes are incommensurable.

Recognizing this, we often turn to a seemingly more amenable calculus and attempt to weigh the perceived benefits of life extension accruing to a severely disabled child as compared with its burdens. But here we run into a deep problem of perspective, so provocatively identified by Robertson:

[The essence of a quality of life judgment is a proxy's judgment that no reasonable person can prefer pain, suffering, and the loneliness of, for example, life in a crib with an IQ level of 20, to an immediate painless death. ... [A] standard based on healthy normal development may be entirely inappropriate to this situation. One who has never known the pleasure of mental operation, ambulation, and social interaction surely does not suffer from their loss as much as one who has. ... [L]ife and life alone, whatever its limitations, might be of sufficient worth. ... [O]ne should always be hesitant to accept proxy assessments of quality of life because the margin of error in such predictions may be very great. ... [E]ven if the judgment occasionally may be defensible, the potential danger of quality of life assessments may be a compelling reason for rejecting this rationale for withholding treatment.]

Children incapable of expressing their own interests must rely on another's assessment. We follow Robertson in worrying about the ability of any surrogate to adopt the proper perspective. We acknowledge the ethical importance of honoring what appear to be reasonable parental wishes in cases of ambiguity and uncertainty, and also recognize the practical impossibility of policing parental motivations for their decisions. Nevertheless, we are reluctant to wholeheartedly endorse such deference.

We are also seriously concerned about the quality of information transactions between parents and providers. In medicine, health professionals determine facts, frame arguments, and present choices, especially where life-sustaining treatment is concerned. As Meyers writes:

[Autonomy undercutting power asymmetries prevail and decision making in routine care relies much more on assent than on consent. ... health care in general, and critical care in particular, represent profoundly difficult contexts for genuinely autonomous choices.]

Of course, to counteract the inevitable, and in some sense insurmountable, knowledge asymmetry between physicians and parents, the former have a duty to recognize those misunderstandings that significantly increase the risk of medical decisions that are, all things considered, uninformed. Some physicians take this responsibility more seriously than others. In addition, physicians have a duty to recognize when their own understanding and knowledge are incomplete. Nowhere is this more critical than in
the forecasting of another's quality of life, a quintessential value judgment, which if we are honest, no physician has expertise in solely by virtue of his or her medical training.

We argue that it is easy to conflate value judgment with medical or physiological fact. In doing so, we do not deny physicians, parents, or others the right to opine about another's quality of life, but it is another step to equate this interpretation of another's posited human existence with something like authoritative truth. Most physicians, by virtue of their professional attainment in life, cannot claim personal, subjective understanding of the seriously cognitively impaired life of a disabled child; we are readily capable of genuine sympathy, but rarely true empathy. As such, prognostications informed by our view from "normalcy" are fraught with ethical risk and can lead to inappropriate recommendations. Parents, who are not in a position to know differently and are often unexpectedly thrown into an emotional crisis by life-or-death circumstances, are vulnerable to persuasion, even if unintentionally.

As an example, consider a recent study by Laureys and colleagues. The investigators asked 17 individuals who were in a chronic locked-in state (mean six years) and could communicate only by eye movement or blink, but otherwise could not move, their views on the quality of their lives. For many of us, such a state of existence might, without the vantage of authentic experience, appear to be a condition worse than death. However, the patients interviewed typically reported a meaningful quality of life, and they seldom demanded euthanasia. Measures of mental well-being and psychological distress were not significantly lower than those of age-matched controls. The researchers concluded that "to judge a book by its cover is unfair."

Such empirical data, which suggest a possible disconnect between our perception of profound disability and the actual experience of it, fundamentally challenge physicians involved in end-of-life decision making for children: Are we really capable of adequately distinguishing for parents the physiological facts that we rightly bear expertise on from the moral meaning of those facts? If not, how can we improve our counseling with respect to end-of-life care, when the decision involves choosing between a predicted "poor" quality of life and death? Such provocation is not meant to deny that most, if not all, of us agree that our rational preference is to avoid lives filled with disability, mental incapacity, chronic pain, and the like. Furthermore, we ought not prefer such a life for our children as well. This is not prejudice, nor is it discriminatory. However, even as we can and should maintain such preferences, we should not presume the easy and simple transposition of this preference to an incompetent who has never experienced life as we do.

Having set forth some of our ethical concerns about forgoing lifesustaining treatment for children, we now turn to describe how expert
professional panels in pediatrics and bioethics have approached the issues in three English-speaking countries (the United States, Canada, and the United Kingdom). Not surprisingly, there are numerous thematic similarities among these national-level organizational pronouncements, but there are also areas of distinctiveness. At the outset, we note that almost all professional- or institutional-level guidelines are by necessity the product of compromise, as the end goal is to achieve a reasonably broad consensus across a diversity of opinion. While admirable in aim, the diplomatic aspiration to achieve consensus predictably forces a conceptual concession to provide less specificity, so that the language itself contained within recommendations can remain open to individual interpretations.

Starting in the United States, in 1994 the Bioethics Committee of the American Academy of Pediatrics (AAP) published guidelines on the forgoing of life-sustaining treatment. They prominently rely on the best-interests standard (which animates much discussion throughout this book) to provide a principled means to direct ethically minded decision making by surrogates. In essence, the best-interests standard has pragmatically come to act as a balancing test measuring perceived benefits and burdens, weighing them against each other in some reasoned fashion, and on the basis of that metric, providing a decision about treatment. We hope that the reader will recognize that, morally, everything depends on our first accepting the commensurability of the proposed comparative variables.

In fact, many do agree with the list of considerations that ought to be included in the calculus. For example, the AAP Bioethics Committee’s list of benefits includes prolongation of life with the proviso that “continuation of biological existence without consciousness may not be a benefit”; a reduction in pain and disability; and an increase in physical pleasure, emotional enjoyment, and intellectual satisfaction. Why there needs to be an increase in these pleasures is not explained, and we note it does not follow ipso facto that, because something is not a benefit, it must constitute a burden. Strictly speaking, if a human being happens to be nonsentient, it makes little sense to speak of burden to that individual, in the absence of demonstrable physiological pain. The burdens include (on cue) intractable pain, irremediable disability or helplessness, emotional suffering, and invasive and inhumane interventions or other activities that severely detract from the patient’s quality of life. Again, we pause here to question the acceptability of irremediable disability or helplessness, without further elaboration by the AAP. Regardless, it should be apparent that each of these assessments is somewhat wooly, that is, to some extent they are invariably subjective determinations, and as such provide ample opportunity for personal preferences and value judgments to slip into the calculus. To be fair, the committee emphasizes that quality of life should
be interpreted from the patient’s point of view and rejects its use to reflect social worth.

In 1996, the committee updated its published position by acknowledging that different people may interpret, value, and weigh benefits and burdens differently:

[Physicians should recommend the provision or forgoing of critical care services based on the projected benefits and burdens of treatment, recognizing that parents may perceive and value these benefits and burdens differently from medical professionals.]

This is an important concession insofar as it parallels a general normative trend in medicine away from the long-prevalent paternalistic model of doctors knowing what is best for their patients. Nevertheless, as a pragmatic matter, heightened recognition that there is room for reasonable disagreement in the net benefit–burden calculus has largely complicated decision making, as it has provided surrogates with conceptual footing to stake more controversial claims; so-called vitalists can now argue that it may be in the best interests of an irreversibly nonsentient child to remain alive so long as there is no overwhelming pain or suffering, and the problem becomes, how are we to convincingly refute this position? As such, a few physicians have openly lamented and criticized the steady march away from a more physician-centered model for defining best interests, though this is hardly a predominant sentiment in the 21st century.

In 2000, the AAP published its recommendations for forgoing life-sustaining treatment in abused children. Not surprisingly, these guidelines mirrored the aforementioned benefits–burdens–best interests calculus, but also included that decisions to forgo treatment in cases of severe brain injury need not be limited to children in a vegetative state. This publication offered no further elucidation. The AAP also recommended, following legal precedent, the appointment of a guardian ad litem in all cases of child abuse requiring life-sustaining treatment in which a parent or guardian may have a conflict of interest. Finally, in 2004, the AAP published guidelines for “do not resuscitate” (DNR) orders for children who require anesthesia and surgery. These state that DNR orders are ethically appropriate “when the burdens of resuscitation exceed the expected benefit.” Such orders do not have implications for other therapeutic interventions that might be appropriate for the patient. DNR orders may be written for children when “in the judgment of the treating physician an attempt to resuscitate the child would not benefit the child and the parent or surrogate decision maker ... expresses his or her preference that CPR be withheld in the event that the child suffers a cardiopulmonary arrest, as long as this is in accordance with the child’s best interests.”
The Canadian Paediatric Society is more specific in its recommendations. At the outset, a strikingly different tone is noticeable:

[All] children, regardless of handicap either actual or potential, have a justified claim to life and therefore to such medical treatment as is necessary to either improve or prolong life.

Not surprisingly, this high-minded language is qualified by a statement that the decision to use life-sustaining treatment must be guided by the best interests of the child, which are defined as the balance of potential harm or distress resulting from the pursuit of a given treatment. Like the U.S. guidelines, these state that the interests of the infant should override those of the community, health profession, or family but, in notable addition, that the best interests of the child will usually favor the provision of life-sustaining treatment even when a chronic physical or mental handicap will continue to be present.

The Canadian emphasis on children's rights and surrogates' obligations is further seen in its setting forth specific exceptions to "the general duty of providing life sustaining or life prolonging treatment" as follows:

1. irreversible progression to imminent death,
2. treatment which is clearly ineffective or harmful,
3. instances where life will be severely shortened regardless of treatment, and where non-treatment will allow a greater degree of caring and comfort than treatment,
4. lives filled with intolerable pain and intractable pain and suffering.

The guidelines continue:

[If] the child's condition is incompatible with survival or where there is broad consensus that the condition is so severe that treatment would not provide a benefit in terms of being able to restore or maintain the patient's health, intervention may be unjustified. Similarly, where treatment would involve suffering and distress to the child, these and other burdens must be weighed against anticipated benefit, even if life cannot be prolonged without treatment.

Finally, our brief survey takes us to the United Kingdom, where, in 1997, the Royal College of Paediatrics and Child Health issued guidelines on foregoing life-sustaining treatment for children. Five situations were given in which the forgoing of life-sustaining treatment might be considered:

1. Brain death
2. Permanent vegetative state
3. The "no chance" situation. The child has such severe disease that life sustaining treatment simply delays death without significant alleviation of suffering. Medical treatment in this situation may thus be deemed inappropriate.
4. The "no purpose" situation. Although the patient may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect them to bear it. The child in this situation
will never be capable of taking part in decisions regarding treatment or its withdrawal.

5. The "unbearable" situation. The child and/or family feel that in the face of progressive and irreversible illness further treatment is more than can be borne. They wish to have a particular treatment withdrawn or to refuse further treatment irrespective of the medical opinion on its potential benefits.

In reviewing all of these professional guidelines, we observe, with admitted cynicism, that some question begging always follows the persistent reliance on fuzzy terms, like "best interests," "benefits," and "burdens," and that seems hardly diminished by attempts at further clarity with terms like "no purpose" or "unbearable." For example, just how much mental impairment need there be before we can conclude that it is unreasonable for a child to bear life? We hope it is not too difficult for the reader to see how such well-intended guidance can easily be manipulated by the craftier among us.

Recalling our earlier discussion regarding futility, we conclude by noting that any chosen language is only so helpful in solving these moral puzzles. These words describe situations that are unavoidably filled with value judgments about the moral meaning of human existence. With even modest introspection, we are bound to see their limitations and deficiencies. Indeed, nice-sounding words that "justify" our decisions cannot completely extinguish underlying intractable tension, regardless of their strategic value in making us feel psychologically better. Furthermore, there is a danger worth stressing: by seeking refuge in the safe-appearing meanings of such words and concepts, we always risk the possibility of collusive provider–parent agreement without adequate attention to the incompetent child. Anecdotally, we note that a recent official inquiry in Britain found that individuals with cognitive disability were abused, neglected, and discriminated against in the health care system.28 As such, we should always feel obligated to closely scrutinize how specific biological details inform our rendering of the proposed benefit–burden analysis in each instance; in fully dispensing with our ethical professional duty, following Hume, we should be transparently prepared to defend how the "is" of life's biological details produce the "ought" in end-of-life decision making.

To complete this chapter's discussion of the issues related to ending life-sustaining treatment for infants and children, we now turn to a sampling of laws and legal decisions from several English-speaking jurisdictions. We do not attempt to provide an exhaustive legal history of the subject. All English-speaking democracies recognize a parens patriae function for the governmental authority, which is in its most generic form a sovereign power to protect the most vulnerable in society. However, modern states typically view their relationship to parents and children primarily in passive custodial
terms, being prepared to intercede in family life only as a last resort when there is a compelling basis to question natural surrogates' child-rearing conduct. Pragmatically, governmental review of parental medical decision making nowadays almost never arises unless there is an intractable conflict between parents and providers about the ethically correct course of action or, in more operational terms, if there is fundamental disagreement about the best interests of the child.

Two classic sorts of cases present themselves to courts of law for ultimate disposition. The first pits parents who want to end potentially lifesaving treatment against providers who feel that such intervention is warranted, and the second pits parents who want to extend potentially lifesaving treatment against providers who feel that such intervention is inappropriate. Here we note an important mechanistic distinction between the two kinds of cases, particularly in the United States. The final move for U.S. health care providers in cases of the former type is to initiate formal involvement by the state's child protection services. This decision amounts to a conclusion by providers that the parents or guardians have taken a position that substantially threatens the child, and that at least temporary custody by the state is warranted. In cases of the latter type, the child neglect construct is far less often a suitable conceptual fit for analyzing the conflict. Parents who are committed to preserving a child's biological life and who insist on continuing medical care that others find objectionable are rarely appropriately characterized as neglectful or abusive (though we can imagine such a case when the pain and suffering of the child are incontrovertible). Thus, legal resolution in these kinds of cases does not necessarily imply a role for the state's child protective services.

Two factually similar cases recently adjudicated in the United Kingdom serve to illustrate the kinds of typical controversies just described. The British have largely eschewed legislative means, and instead follow a common law approach, to resolving disputes surrounding life-sustaining support for infants and children. Judges tend to rely heavily on the best-interests standard to evaluate the legal propriety of surrogate decisions. The two cases occurred about a decade apart and dealt with life-sustaining treatment for children with severe spinal muscular atrophy (SMA). In the more recent case, M.B. was an 18-month-old infant with SMA who was totally paralyzed apart from some eyebrow and eye movement. Some providers assessed the child's condition as intolerable and therefore argued that life-extending treatment would be an unacceptable burden based on their perception of ongoing overwhelming discomfort, pain, and distress. The hospital sought a declaration from the court to allow the withdrawal of life-sustaining treatment over the objections of the parents, who believed that their child was cognitively intact, able to enjoy the company and social interaction of others, and not excessively burdened by pain and suffering.
In deciding that it was in the child's best interests to continue medical treatment, Justice Holman stated he was unaware of a U.K. court ever being asked before to approve, against the will of the parents, that life support may be withdrawn or discontinued, with the predictable, inevitable, and immediate death of a conscious child with sensory awareness and assumed normal cognition and no reliable evidence of any significant brain damage.

He also questioned the utility of "intolerability" as a meaningful measure when weighing the benefits and burdens for a disabled child:

I avoid reference to the concept "intolerability." It seems to me that it all depends on what one means by "intolerable" and the use of that word really expresses a conclusion rather than provides a test. If it is correct to say ... that life is literally "intolerable," then it is hard to see in what circumstances it should be artificially prolonged. If conversely it is "tolerable" then it is hard to see in what circumstances it should be permitted, avoidably, to end. ... the concept of "intolerable to the child" should not be seen as gloss on, much less a supplementary test to, best interests.

Consistent with his desire to avoid rendering terms laden with subjective value judgment, the justice finally argued that his role was not to be concerned with ethical issues, only legal ones:

I myself am not concerned with any ethical issues which may surround this case. My task ... is to decide, and only to decide, where the objective balance of the best interests of M lies. If I decide that it is not in his overall best interests to continue with a given form of treatment ... then I must say so; and it will follow as a matter of law (and I will declare) that it is lawful to withdraw or withhold that form of treatment. The ethical decision whether actually to withdraw or withhold it must be made by the doctors concerned. Judges are neither qualified to make, nor required, nor entitled to make ethical judgments or decisions.

Whatever the merits of his substantive choice to decide for life extension for the child, we find Justice Holman's claim to neutrality under the guise of legal objectivity rather naive. To argue that his decision has no ethical bearing on how doctors should ultimately act is not only disingenuous (should they now risk liability for not following the command of the court?), it falsely dichotomizes an inherent task for the law when it is forced to resolve disputes involving the appropriateness of medically dependent life extension. His legal judgment, couched in the language of best interests rather than intolerability, still cannot escape expressing moral value; it represents a deliberate decision to put more weight on the "worth" of a gravely incapacitated human life over other presumably important considerations. We argue that it is a mistake to try to hide behind a purported legal neutrality in cases such as this; law and ethics cannot so easily be divorced when it comes to life-and-death matters.
The MB ruling stands in contrast to Re C (1998), which also involved a child with severe SMA. The judge in this case ruled on whether objecting physicians would be legally required to initiate life-sustaining treatment if requested to do so by parents in the future. C was a 16-month-old child with severe SMA, who was placed on a ventilator following a respiratory arrest. Providers judged that life-sustaining treatment was simply a means of postponing death without significant alleviation of suffering and, therefore, sought declaratory relief so that they could avoid further intervention once the child was removed from the artificial respiratory support. The parents agreed that their child could be taken off the ventilator, but insisted on reintubation and mechanical ventilation should a further respiratory arrest occur. Independent medical expert opinion sided with the treating physicians, and the hospital sought leave from the court to manage the child as had been advised, that is, to extubate and not reintubate should there be further respiratory distress.

Justice Brown delivered the judicial opinion, referring to the disease as dreadful and the case as tragic. He found that the baby was in a “no chance” situation, using the term from the aforementioned Royal College of Paediatrics report concerning life-sustaining treatment for children. He ruled that

[t]here be leave to treat the minor C, as advised by Dr H, such treatment to include the withdrawal of artificial ventilation and non-resuscitation in the event of a respiratory arrest and palliative care to ease her suffering and permit her life to end peacefully and with dignity, such treatment being in C’s best interests. ... [W]hile the sanctity of life is vitally important, it is not the paramount consideration. The paramount consideration here is the best interests of little C.

Further substantive clarification of how the interests of C are definitively surmised by the court is lacking. Much as in the MB case, it is obvious that a core value judgment prioritizing certain factors over others underpins Justice Brown’s opinion. Notably, the opinion draws some of its justification from overt policy considerations. Justice Brown argues that forcing providers to treat would be

[t]antamount to requiring the doctors to undertake a course of treatment which they are unwilling to do. The court could not consider making an order which would require them to do so.

Of course, judges and legal theorists across many jurisdictions have long found safe harbor in the act–omission distinction, even while ethicists and philosophers have criticized the distinction. We only identify the issue here for the reader and note the many nuanced problems in determining intention and causality in both moral and legal terms.

The contrasting judgments in MB and C decided only a few years apart in the United Kingdom serve our purpose of emphasizing to the reader the flexibility or fickleness of judicial interpretation of common law, depending
on one's point of view. To be fair, the different decisions may also reflect changing social mores, attitudes, or awareness in Britain about aggressive life-sustaining treatment for a disabled child, which may be partly spurred by the increasing availability of improved technology and long-term care options. A decade ago, parents of a child with severe SMA type 1 would most likely never have been offered the option of long-term ventilation at a nursing facility, as that choice was not as economically or technically viable as it is now.

Turning now to U.S. law, as articulated by judges, legislators, and regulators, we see a tradition of the state favoring life-preserving outcomes rather than life-ending ones. This moral tilt is articulated by the majority United States Supreme Court opinion in the *Cruzan* case:

The choice between life and death is a deeply personal decision of obvious and overwhelming finality. We believe [a State] may legitimately seek to safeguard the personal element of this choice through the imposition of heightened evidentiary requirements. It cannot be disputed that the Due Process Clause [of the Constitution] protects an interest in life as well as an interest in refusing life-sustaining medical treatment. ... We think a State may properly decline to make judgments about the "quality" of life that a particular individual may enjoy, and simply assert an unqualified interest in the preservation of human life to be weighed against the constitutionally protected interests of the individual.56

*Cruzan* is an important U.S. decision on the life-sustaining treatment issue, and its legal meaning is complex. We note it here but will not attempt further elaboration, particularly given its unclear effect on end-of-life decision making for children.

The United States has both statutory and common law sources to guide decision making that involves life-sustaining medical treatment for infants and children. The common law tradition flows from the *parens patriae* doctrine and, quite predictably, operationalizes in the form of a legal best-interests standard. Judges rely on a similar set of considerations that inform ethical analysis of when it may be permissible or obligatory to withhold or withdraw life-sustaining treatment from a child. Thus, in disposing of a contested case, judges usually rely on evidence about perceived benefits and burdens of treatment to the child. A comprehensive but inexhaustive list of factors to be considered includes the following: (1) the child's present level of physical, sensory, emotional, and cognitive functioning; (2) the quality of life, life expectancy, and prognosis for recovery with and without treatment; (3) the various treatment options and their risks, benefits, and side effects; (4) the nature and degree of physical pain, suffering, or serious complications resulting from the medical condition, from treatment, and resulting if treatment is withdrawn; (5) whether treatment would on balance be more beneficial than burdensome to the child; (6) whether pain and suffering resulting from removal of treatment could be minimized; (7) the degree of humiliation, dependence, and loss of dignity resulting
from the condition and treatment; (8) the opinion of the family and their reasons and motivations for holding those opinions regarding treatment; and (9) the child’s preference, if it can be ascertained.

As we have argued before, an inescapable set of value judgments must enter into this legal decision-making calculus. Numerous cases can be canvassed in order to demonstrate how state courts at various levels have mapped specific facts onto the benefit–burden analysis. Suffice it to say that despite relative consensus about animating principles for life-or-death medical treatment decision making, there is hardly uniform application across U.S. jurisdictions. This inconsistency simply reflects an ongoing thematic point: judges are human beings who bring their own predispositions, cultural commitments, and moral attachments to the task of legal interpretation. Cases often turn on the relative weight that individual legal decision makers choose to place on certain facts.

We do think it important here to emphasize a theme frequently evidenced in U.S. case and statutory law. As a child begins to mature and demonstrate the capacity to speak for him- or herself, courts will begin to seriously incorporate any such informed opinions into their final calculus. This is consistent with the robust moral and legal tradition in American society to prioritize individual autonomous choices in the absence of other compelling considerations. A paradigmatic illustration of judicial deference to an adolescent’s expression of autonomy comes from Illinois, In re E.G.\textsuperscript{31} The case involved a 17-year-old teenager diagnosed with leukemia who refused to consent to blood transfusions as a part of therapy due to her religious faith as a Jehovah’s Witness. Her mother and she had consented to all other treatments and had signed a waiver of provider liability for failure to administer blood products. The treating physician testified that he was “impressed with her maturity” and felt the patient “competent to understand the consequences of accepting or rejecting treatment.” Nevertheless, under advice from hospital counsel, child neglect proceedings were initiated and eventually resulted in the appointment of a temporary guardian who consented to transfusions, which the patient received.

The case continued and eventually the patient herself was allowed to testify; she “indicated that her decision was not based on any wish to die, but instead was grounded in her religious convictions.” The trial court disposition of the case ended with the judge ruling that the patient was medically neglected, and a guardian was appointed to consent to further treatment. The patient and her mother appealed the decision, and before the state Supreme Court, the issue was “whether [an allegedly mature] minor like E.G. has a right to refuse medical treatment.” In a divided decision, the court reversed the finding of neglect and held:

The State’s parens patriae power pertaining to minors is strongest when the minor is immature and thus incompetent (lacking in capacity) to make decisions on her own. [It] fades, however, as the minor gets older and disappears upon her reaching
adulthood. The State interest in protecting a mature minor in these situations will vary depending upon the nature of the medical treatment involved. Where the health care issues are potentially life-threatening, the State’s ... interest is greater than if the health care matter is less controversial.

In deciding in favor of E.G. in terms of her medical decision, the court emphasized that, while the statutory age of majority in the state was 18, “that age is not an impenetrable barrier that magically precludes a minor from possessing and exercising certain rights normally associated with adulthood.” The court detailed a list of circumstances in which both the legislature and common law had granted minors authority to make medical treatment decisions for themselves (e.g., sexually transmitted diseases, pregnancy) and stated that the chief role of the trial court in this case was to determine whether the minor was mature enough to make health care choices on her own. Notably, the court did not find the First Amendment issue of free religious exercise relevant to its disposition of the case.

However, the dissenting judge picked up on a not-so-subtle inconsistency in the majority’s opinion:

The safeguarding of health and the preservation of life are obviously different conditions. ... I am sure that in a host of matters of far less importance it would not be held that a minor however mature could satisfy a requirement of being of legal age. It would not be held that a minor was eligible to vote, to obtain a driver’s or a pilot’s license.

Indeed, it is striking that the majority chose to respect the adolescent’s “mature” choice when the stakes were highest and the consequences to her so final, despite the state legislature’s having failed to grant the opportunity to find such maturity in less critical situations. This disconnect suggests that, at least under the circumstances of this case, the court has a distaste for an efficiency-driven argument that justifies a partly arbitrarily defined legal age of majority. We know that the age of 18 is merely an imperfect approximation; it necessarily includes some who shouldn’t be included and excludes some who shouldn’t be excluded. But from a policy standpoint, we cannot imagine society making individual maturity assessments on all teenagers from time to time to determine which decision-making capacities they possess and which they still need time to develop. Why the majority in the E.G. opinion felt obliged to grant individual evaluation under the circumstances presented remains a core legal controversy. We note that in a different state with a different set of judges’ eyes, it is quite conceivable that this case might have been decided in the opposite manner (affirming the trial court’s finding of neglect).

If deference to emerging autonomy is an important ethical and legal consideration in life-ending medical treatment choices for minors on the brink of attaining majority, it is important to contrast this construct with how life-ending decisions for infants have been viewed legally in the United
States for the past two to three decades. Heightened state and governmental scrutiny has been the norm and flows from the national politicization of common practices first publicized in the 1970s. Public reports from that time documented that some nonterminal infants died each year in U.S. hospitals as a result of the withdrawal or withholding of treatment, and surveys demonstrated that a large percentage of physicians were willing to forgo life-sustaining treatment for disabled infants. In one study it was revealed that 85% of pediatric surgeons and 65% of pediatricians surveyed were willing to honor parental wishes not to perform necessary surgery on an infant with Down syndrome, but less than 6% would deny similar treatment for a child without the disability.

Some physicians made such life-ending decisions regardless of parental preference, even though such unilateral action generally was considered unlawful. At the time these practices were gaining national attention, law professor John Robertson wrote:

In the case of a defective infant the withholding of essential care would appear to present a possible cause of homicide by omission on the part of parents, physicians, and nurses, with the degree of homicide depending on the extent of premeditation. Following a live birth the law generally presumes that personhood exists and that there is entitlement to the usual protections, whatever the specific physical or mental characteristics of the infant maybe. Every state imposes on parents a legal duty to provide necessary medical assistance to a helpless minor child. If they withhold such care, and the child dies, they may be prosecuted for manslaughter or murder. ... likewise physicians and nurses may face criminal liability ... even when all Parties, including the parents, are in agreement.

Partly out of reaction to these events and rather infamous individual cases in Indiana, New York, and Maryland, the U.S. Congress amended the Child Abuse Prevention and Treatment Act (CAPTA) in 1984 (PL 98-457). These amendments and their administrative interpretation (often collectively termed the “Baby Doe rules”) make conditional the receipt of certain federal funds for state child protective agencies dependent on the local adoption of federal reference criteria for defining medical neglect for children under a year of age (42 USC 5106 (b) (2) (B)).

Medical neglect was defined as the “withholding of medically indicated treatment” from disabled infants with “life threatening conditions.” Medically indicated treatment was then defined as that which, in the treating physician’s reasonable medical judgment, will be most likely effective in ameliorating or correcting all [of the infant’s life threatening] conditions, except that the term does not include the failure to provide treatment ... to an infant when, in the treating physician’s reasonable medical judgment,

(A) the infant is chronically and irreversibly comatose;
(B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant’s life
threatening condition, or (iii) otherwise be futile in terms of the survival of the infant; or
(C) the provision of such treatment would be virtually futile in terms of the survival of the infant and treatment itself under such circumstances would be inhumane.

These amendments were subsequently interpreted by the federal administration (through the Department of Health and Human Services). “Virtually futile” was interpreted as “highly unlikely to prevent death in the near future” on the basis of reasonable medical judgment (45 CFR pt 1340 app at 306). And a treatment was inhumane if

the treatment itself involves significant medical contraindications or significant pain and suffering for the infant that clearly outweigh the very slight potential benefit of the treatment for an infant highly unlikely to survive. ... the balance is clearly to be between the very slight chance that treatment will allow the infant to survive and the negative factors relating to the process of the treatment.

In the commentary to the amendments, the primary role of parents is made clear: “[E]xcept in highly unusual circumstances, [decisions to provide or withhold medically indicated treatment] should be made by the parents or legal guardian” (50 Fed. Reg. 14, 878 14, 880 (1985)). However, the legislative history also qualifies that “the parents’ role as decision maker must be respected and supported unless they choose a course of action inconsistent with applicable standards established by law” (50 Fed. Reg. 14, 880).

We note that the CAPTA amendments and the Baby Doe rules are fundamentally passive legal instruments and do not compel state courts to any specific action. For states that desire federal funding as support for their local child protective agencies, there is an obvious attraction to adopting the federal language for defining medically indicated treatment for infants under a year of age. Thus, not surprisingly, almost all states immediately followed suit. But actual enforcement of these federal legal standards is strictly the business of state child protective agencies and interpreting state courts. CAPTA merely stipulates that local child protective services have the authority to pursue any legal remedies that may be necessary to prevent the forgoing of life-sustaining treatment from an unqualified infant. The almost theatrical history of these notorious regulations, their minimal on-the-ground enforcement after an initial wave of conservative enthusiasm, and their mixed but enduring impact on clinical care from the 1980s until today is well documented. The reader is referred to a voluminous literature on the subject matter; almost needless to say, the Baby Doe rules remain highly controversial in the United States.

As the states were writing and modifying their statutes dealing with end-of-life issues, a number of landmark cases were heard that influenced these statutes and the action of health professionals. They have in common the
drama of the law courts, intensive care units caring for the most fragile and moribund infants, and the actions and anguish of distraught parents. For example, in Illinois in 1991, the Health Care Surrogate Act was signed into law. It followed a well-publicized case that occurred at the Presbyterian-St. Luke’s Center in Chicago. In August 1988, Sammy Linares, an infant aged 6 months, had become asphyxiated by inhaling a rubber balloon and suffered a cardiac arrest. He was maintained on life support in a persistent vegetative state. In April 1989, following a refusal by the hospital and attending physicians to discontinue life support in the absence of a court order, the father, Rudy Linares, performed this act while keeping hospital workers at bay with a handgun. This followed an incident the previous December when the father had disconnected the baby from the ventilator but was physically restrained by security guards while the ventilator was reconnected. Despite the manner in which the father acted, there clearly was much sympathy for him. A coroner found that asphyxiation from a balloon was the primary cause of death, and a grand jury declined to issue an indictment for homicide. Mr. Linares did receive a suspended sentence for a misdemeanor arising from a weapons charge. The statutory law that followed made it clear that life-sustaining treatment could be withdrawn, without judicial involvement, from a patient without decisional capacity. The conditions that would allow this were that a surrogate could request withdrawal if two physicians certified one of the following:

a). imminent death; that is, when death is inevitable within a short time, “even if life sustaining treatment would be initiated or continued”;

b). permanent unconsciousness, for which initiating or continuing life support, in light of the patient’s medical condition, provides only minimal medical benefit;

c). incurable or irreversible condition that imposes severe pain or an inhumane burden that will ultimately cause the patient’s death and for which initiating or continuing life-sustaining treatment provides only minimal medical benefit.

The Act protects the parties involved provided they follow the legislation “with due care.” Similar legislation exists in all the other states and they appear to eschew a best interests approach and quality of life judgments.

Finally, we turn to Australia, which also has a mixed approach. Somewhat like the U.S. CAPTA amendments, there is statutory law that supports physician’s when an infant is terminal or in a persistent vegetative state; for example, the South Australia Consent to Medical Treatment and Palliative Care Act states that a physician who is responsible for the management of a terminally ill patient is under no duty to use, or to continue to use, life sustaining measures in treating the patient if the effect of doing so would be merely to prolong life in a moribund state without any real prospect of recovery or in a persistent vegetative state.
The *parens patriae* doctrine also animates common law and, as articulated by Justice Brennan in *Marion’s Case,* underlies and informs the law: each person has a unique dignity which the law respects and which it will protect. Human dignity is a value common to our municipal law and to international instruments related to human rights. The law will protect equally the dignity of the hale and hearty and the dignity of the weak and lame; of the frail baby and of the frail aged; of the intellectually able and the intellectually disabled. ... our law admits of no discrimination against the weak and disadvantaged in their human dignity.⁸⁷

Much as in the United States and the United Kingdom, this state power is manifested through courts adopting a best-interests standard. Here again, we see an inherent tilt toward life preservation in case law and some evidence to suggest that quality-of-life decisions will generally be frowned upon judicially: "The law does not permit decisions to be made concerning the quality of life nor any assessment of the value of any human life."³⁸ (*F v. F* [unreported, 2 July Supreme Court of Victoria]).³⁹ This case involved a proposal to stop feeding an infant with spina bifida. Similar language is seen in a later judgment from the High Court of Australia involving a wrongful birth suit (which the court rejected):

[I]n the eyes of the law, the life of a troublesome child is as valuable as that of any other; and a sick child is of no less worth than one who is healthy and strong. The value of human life, which is universal and beyond measurement, is not to be confused with the joys of parenthood, which are distributed unevenly.⁴⁰

**CONCLUSION**

In this chapter, we have attempted to survey a variety of arguments and sources to improve the reader’s understanding not only of the issues involved in decisions to withdraw or withhold life-sustaining treatment taken on behalf of children, but also of the core moral tensions that resist resolution regardless of whether one looks to ethical reasoning, professional consensus, or law for answers. It is necessarily an incomplete treatment. Nevertheless, we believe a good accounting of the controversies should not shy away from a critical assessment of the inadequacies of any singular approach, however high-minded.

Moral value judgment is inescapable in this arena, and one must ultimately come to recognize one’s own final commitments in any given case. The authors differ in this regard, as one (G.M.) is drawn much more to deontological, rights- and virtue-based arguments, while the other (S.S.) is an admitted mixed consequentialist who is comfortable living with some internal contradictions. Rather than try to settle our disputes, together we believe that it is more important for our readers to begin to appreciate the implications of adopting any moral rationale. We both agree that wisdom can be gained only when we start with a humble predisposition.
References


