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CHALLENGING PARENTAL DECISIONS TO OVERTREAT CHILDREN

Dale L. Moore†

MUCH OF THE DIALOGUE ABOUT medical treatment decisions involving children, particularly infants, has been dominated by illustrations and discussions of undertreatment. Examples include the several “Baby Doe” cases, in which parents of handicapped newborns withheld consent for life-saving treatment, prompting efforts by the federal government to define undertreatment as tantamount to child abuse or neglect.¹ Raised more recently, and in need of examination, is the question whether overtreatment should be similarly classified as child abuse,² and accordingly constitute grounds for displacing physician or parental authority over medical decisions. This Article will explore some of the issues raised by cases of overtreatment and the implications of superseding parental control.

I. THE “BABY L” CASE

A case study that may be used as a starting point for discussion of overtreatment issues is that of “Baby L.”³ The case

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1. See President’s Comm’n for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions*, 224-26 & n.95 (Mar. 1983) [hereinafter President’s Commission] (discussing the Infant Doe case and the regulations issued in its wake, creating *inter alia* a “hot-line” 800 telephone number to report instances of undertreatment).

2. See Rasa Gustaitis, *Right to Refuse Life-Sustaining Treatment*, 81 PEDIATRICS 317, 321 (1988) (arguing that child abuse and neglect laws could be used to prevent futile life-supporting treatment).

3. See John J. Paris et al., *Physicians’ Refusal of Requested Treatment: The Case of Baby L*, 322 NEW ENG. J. MED. 1012, 1012-13 (1990) (discussing the facts of the “Baby L” case in its first reported form). See also Gina Kolata, *Battle Over a Baby’s Future Raises Hard Ethical Issues*, N.Y. TIMES, Dec. 27, 1994, at A1, A12 (discussing the similar case involving Ryan Nguyen in Oregon).

raises substantive questions about defining medical care as “futile” or “inhumane,” as well as procedural questions concerning the appropriate party to apply the definitions.

Baby L was two years old at the time her case went to court. Baby L was born after thirty-six weeks of gestation, weighing 1970 grams. Numerous problems manifested themselves prior to, during, and after her delivery. For example, during gestation she developed an obstructed kidney, and during labor she experienced heart-rate decreases and showed other signs of significant fetal distress.⁴ Her Apgar scores (a measure of physical condition immediately after delivery)⁵ were poor. She required resuscitation and mechanical ventilation, suffered seizures, and was unresponsive except to painful stimuli. At one month of age Baby L underwent surgery for the insertion of a feeding tube. A tracheostomy was performed when she was seven months old. When she finally was discharged from the hospital, at fourteen months of age, she required around-the-clock nursing care. Only two weeks after discharge, she was readmitted to the hospital. Baby L was in and out of the hospital for the next several months for various illnesses, including pneumonia and septic shock. At twenty-three months of age, she entered the hospital, needing both mechanical ventilation and intravenous medication to support her cardiac function. Baby L’s mother insisted throughout this time that “everything possible be done to ensure [her] child’s survival.”⁶

The substantive issues raised by the case were identified by Baby L’s caregivers, who, after much discussion,⁷ eventually reached the conclusion that “further medical intervention was not in the best interests of the patient [because it] would subject the child to additional pain without affecting the underlying

4. Paris et al., *supra* note 3, at 1012 (discussing the baby’s problems during pregnancy and delivery, including the presence of meconium below her vocal cords).

5. See THE MERCK MANUAL OF DIAGNOSIS AND THERAPY 1979 (Robert Berkow ed., 16th ed. 1992) (explaining that the Apgar scoring system measures an infant’s color, heart rate, respiration, reflexes, and muscle tone, with low scores often associated with residual neurological damage).

6. Paris et al., *supra* note 3, at 1013 (discussing the mother’s desire to keep the child alive).

7. Parties to the discussions included the chiefs of the services involved in Baby L’s care, primary care physicians, nurses, the hospital’s attorney, and the chair of the institutional ethics committee.

ing condition or ultimate outcome."⁸ As those who reported this case further explained, "unless a reversal or amelioration of the underlying condition could be expected, painful interventions would be futile and inhumane."⁹

The procedural question regarding the appropriate decisionmaker in such a case is answered by the authors' of the Baby L case study in discussing the relative responsibilities of caregivers and patients or their families:

It is the physician, not the patient, who must sort out the possibilities, weigh the pros and cons, and recommend a course of action. That responsibility should not be shifted onto the shoulders of the patient in a misguided attempt to respect autonomy. The patient or family can of course accept or reject the physician's recommendation. They are not free, however, to design their own treatment; nor is the physician bound to provide it.¹⁰

Baby L's mother, however, apparently disagreed with both the substantive and procedural conclusions of the caregivers. She sought legal counsel who initiated a court proceeding seeking an order to force physicians to continue treatment.¹¹ In the meantime, Baby L's condition stabilized somewhat and she was able to breathe without the assistance of a ventilator. Her mother, however, continued to press the demand that mechanical ventilation be employed in the event of a relapse. Accordingly, a court hearing was held. A hypothetical question from the judge elicited a response from the physicians' attorney stating that if the judge were to issue an order requiring mechanical ventilation, the physicians would decline to comply because obeying it would violate their ethical obligations to the patient.¹²

Failure to comply with such an order would be risky business, as courts take contempt of their orders quite seriously. That point of contempt was never reached, however. As is typical in legal cases involving patients who are unable to speak for themselves, the judge in this case had appointed a guardian ad litem to represent Baby L. A guardian ad litem's responsibility

8. Paris et al., *supra* note 3, at 1013 (discussing opinions of Baby L's caregivers).

9. *Id.* (discussing the medical team's actions in the Baby L case).

10. *Id.* (discussing the patient-physician relationship).

11. *Id.* (discussing events leading to the litigation of the Baby L case).

12. *Id.* (discussing response by caretakers' attorney if the court had issued an order for mechanical ventilation).

is to inquire about the facts of a case and to outline for the judge a resolution that is in the best interests of the party who is unable to speak for herself. Guardians ad litem are especially needed in cases like Baby L's, since the attorneys before the court are championing the views of their own clients, in this case the mother and the physicians, rather than acting as an advocate for the patient.

The guardian ad litem contacted a pediatric neurologist who was willing to acquiesce in the wishes of Baby L's mother and assume the child's care.¹³ As of 1990, when the case study was published, Baby L was still alive, retaining the mental status of a three-month old child, in a blind, deaf, and quadriplegic state.

The authors who reported the Baby L case study emphasized two points: that the physician's obligation is to his or her patient rather than others, including families; and that it is important to protect the physician's right to follow his or her conscience, even when to do so means rejecting the demand of a patient or surrogate.¹⁴ They also admonished caregivers to observe substantive and procedural safeguards in such cases. The substantive focus of any decision must be the patient's best interests; the presumption is that those interests will be served by respecting the family's wishes in favor of continuing treatment. Minimal procedural requirements for reversing that presumption include "agreement among health care workers, the concurrence of an ethics committee, openness to a second opinion, and a comprehensive note in the patient's chart detailing all the factors considered in the decision."¹⁵

II. SOME RESPONSES TO THE BABY L CASE

After this account of the Baby L case appeared in the *New England Journal of Medicine*, the *Journal of Perinatology* solicited and published commentary from several

13. Cf. Robert M. Veatch & Carol M. Spicer, *Medically Futile Care: The Role of the Physician in Setting Limits*, 18 AM. J. L. & MED. 15, 34 (1992) (asserting that even if another colleague is willing to prolong care, the former physician's concern for the infant should not end).

14. Paris et al., *supra* note 3, at 1014 (discussing a physician's right to follow his or her medical judgment even if contrary to the pleas of patients' families).

15. *Id.* at 1014 (discussing the minimal requirements for reversing the presumption of respecting the family's wishes).

members of its editorial board.¹⁶ Although the views of some respondents are difficult to characterize, all of them seemed sympathetic to the plight of the physicians involved in caring for Baby L. More respondents than not either agreed with, or at least defended, the approach taken by Baby L's physicians. Others, however, forewent the opportunity to take a position. One commentator expressed concern about defining ventilatory treatment as "futile" in Baby L's case and stressed the importance of not "misus[ing] the language of futility to mask quality of life judgments."¹⁷ Another, however, focused on the occasional inability of parents "to appreciate that their decisions . . . may not serve the best interests of the child, and indeed may prolong pain, suffering, and the act of dying."¹⁸ These statements, while highlighting different aspects of the case, are consistent with each other. The concept of futility should not be used to hide value judgments or to displace as decisionmakers parents who are attentive to the best interests of their children. On the other hand, when appropriate, demands for overtreatment that disregard a child's best interests should be challenged and resisted.

III. FUTILE AND INHUMANE: SUBSTANTIVE ISSUES IN THE BABY L CASE

Were mechanical ventilation and other rescue-oriented interventions for Baby L "futile?" After all, it is not obligatory, legally or morally, to offer futile treatment. The difficulty, of course, is not in stating the principle, which is well-accepted, but with the identification of those treatments that fall into the category of "futile." Certainly a treatment that will not work, because it "will not produce the effect being envisioned,"¹⁹ is futile by even the most restrictive definition. This concept, sometimes referred to as "physiological futility,"²⁰ may be illustrated by an example drawn from my experience caring for

16. See *Point-Counterpoint: Physicians' Refusal of Requested Treatment*, 10 J. PERINATOLOGY 407, 407-15 (1990).

17. *Id.* at 407 (for the views of Alan R. Fleischman).

18. *Id.* at 414 (for the views of Gerald Nathenson).

19. Veatch & Spicer, *supra* note 13, at 18 (arguing that providers and insurers are not obligated to provide care with no relevant effect).

20. Stuart J. Youngner, *Who Defines Futility?*, 260 JAMA 2094, 2094 (1988) (discussing the circumstances under which life-sustaining interventions may be limited without the informed consent of the patient or family).

a patient with permanent renal failure. This particular patient had been receiving hemodialysis several times each week when he suffered from a ruptured cerebral aneurysm and was rendered comatose. This incident occurred prior to the Medicare program's funding of hemodialysis, when dialysis was still being rationed because the machines were in a shorter supply than could adequately meet the demand. Because of this patient's dismal neurological status, he was no longer considered a candidate for receiving hemodialysis. Accordingly, he remained in the intensive care unit (ICU), comatose, and attached to a ventilator, but he was not receiving hemodialysis. Without dialysis, the potassium level in his blood would inexorably rise to the point where cardiac arrest would be inevitable. His attending physician, however, refused to issue a "do not resuscitate" directive. Rather, he expressly ordered resuscitation in the event of a cardiac arrest, perhaps because he feared that in the absence of such a command, the ICU nurses and house staff would not initiate such undoubtedly futile activity. The patient sustained a cardiac arrest during my shift on duty, and the ensuing resuscitation attempt was a clear example of treatment that is "futile" in the "physiologically futile" sense: it simply did not (and was not destined to) work.

The concept of physiological futility, however, does not adequately explain the Baby L case. Neither mechanical ventilation, nor other rescue measures, when administered to her during crises, could be characterized as futile in that narrow sense. Whether these treatments should be regarded as "inhumane," however, is a closer question. After all, Baby L apparently remained capable of experiencing pain despite her compromised condition.²¹ That aspect distinguishes this case from that of *Baby K*,²² whose mother also has insisted that caregivers continue to provide aggressive rescue measures for her child. Baby K is anencephalic, which means that she has no conscious experience of pain and suffering. Thus, while resuscitative measures

21. Paris et al., *supra* note 3, at 1013 (discussing the extent of Baby L's neurological defects resulting in her ability to experience only pain).

22. *In re Baby K*, 16 F.3d 590, 598 (4th Cir. 1994), *cert. denied*, 115 S. Ct. 91 (1994) (holding that the Emergency Medical Treatment and Active Labor Act obligates hospitals to provide treatment to an anencephalic infant brought to the hospital in respiratory distress).

arguably provide her with no benefit, it is harder to describe such measures as "inhumane."

IV. WHO SHOULD APPLY THE DEFINITIONS: THE PROCEDURAL ISSUE

The procedural question, of course, is who should be assigned the responsibility of deciding whether the treatment is futile or inhumane and whether it should be withheld or withdrawn? As in many other cases, the answer to the procedural question in the case of Baby L controls the substantive outcome. Certainly her caregivers would decide one way, and her mother the other. Some would argue that the determination whether treatment is "futile" is solely a medical responsibility.²³ Provided that the definition of "futile" is limited strictly to treatments that simply *will not work*, this assignment of responsibility is probably not controversial. If, however, the substantive concept of futility is expanded to encompass treatment that cannot *cure* an underlying condition or illness yet remains *effective* in maintaining a "diminished" quality of life, responding to the procedural question becomes much more problematic. One reason is that "[m]edical diagnoses, prognoses, and judgments regarding the efficacy of interventions are inherently uncertain and appeals to futility mask poor communication with patients, providing a subterfuge for supplanting patient values with caregiver values and hiding a power struggle between patients and their physicians."²⁴

V. FEDERAL REGULATORY MODEL

The Department of Health and Human Services (HHS), in promulgating various versions of the "Baby Doe" regulations, has responded to some of the substantive and procedural questions raised by controversial treatment decisions. The present version of these regulations, issued pursuant to the federal

23. See Lance K. Stell, *Stopping Treatment on Grounds of Futility: A Role for Institutional Policy*, 11 ST. LOUIS U. PUB. L. REV. 481, 492 (1992) (asserting that the medical responsibility for determining futility is well-founded in legal and medical principles). See also *Barber v. Superior Court*, 195 Cal. Rptr. 484, 491 (1983) (holding that a doctor's refusal to continue treatment, though intentional and with knowledge the patient would die, does not violate any legal obligation to the patient).

24. Stell, *supra* note 23, at 492-93 (asserting objections to the premise that physicians should be able to withhold treatment solely on the grounds of futility).

Child Abuse and Neglect Prevention and Treatment Act,²⁵ is procedurally and substantively much less intrusive than the original version, issued in 1982 pursuant to the federal Rehabilitation Act.²⁶ The same rationale, however, appears to underlie both versions of regulations: that the presumption in favor of parental decisionmaking for children cannot always be honored. Deference to parental decisionmaking is based on the belief that, in general, parents will make their children's medical decisions on the basis of the children's best interests. In the case of newborns who are seriously ill due to prematurity, or who are born with handicapping conditions, however, parental choices in favor of nontreatment (or "conservative" treatment) are suspect and perhaps unworthy of the deference traditionally accorded to parental decisions. The reason seems to lie in a concern that such nontreatment decisions may be tainted by considerations other than the best interests of the child, for example the economic or emotional well-being of the rest of the family.

Since "medical neglect" of an infant triggers intervention, the substantive component of the federal regulations attempts to delineate that concept.²⁷ In large part, this delineation is accomplished by defining what falls outside the scope of "medical neglect." According to the regulations, "medical neglect" does not include failing to provide treatment²⁸ to an infant on the basis of a "reasonable medical judgment" that (1) the infant is "chronically and irreversibly comatose," or (2) treatment "would merely prolong dying, [would] not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or [would] otherwise be futile in terms of the survival of the infant," or (3) "treatment would be virtually futile in terms

25. See, e.g., 45 C.F.R. §§ 1340.1-.20 (1994) (implementing the Child Abuse Prevention and Treatment Act).

26. See President's Commission, *supra* note 1 (noting that § 504 of the Rehabilitation Act of 1973 treats Down Syndrome as a handicap, although that section had been used only once for newborns with congenital anomalies prior to the Indiana Infant Doe case). *But see* Bowen v. American Hosp. Ass'n, 476 U.S. 610, 647 (1986) (holding that the regulations issued under § 504 of the Rehabilitation Act of 1973 were invalid because they exceeded the authority conferred by Congress under § 504).

27. 45 C.F.R. § 1340.15(b)(1) (1993) (stating that withholding "medically indicated treatment from a disabled infant with a life-threatening condition" constitutes medical neglect).

28. *Id.* § 1340.15(b)(2) (excluding "appropriate nutrition, hydration, or medication" from the term treatment in this context).

of the survival of the infant and the treatment itself under such circumstances would be inhumane.”²⁹ The procedural component of the regulations calls for an enforcement mechanism to be created by each state’s child protective services system.³⁰

These regulations shed little additional light on the murky concept of futility. The interpretative guidelines accompanying the regulations, however, explain “inhumane” treatment as involving significant medical contraindications and/or significant pain and suffering that clearly outweigh the very slight potential benefit for an infant highly unlikely to survive.³¹ This definition is helpful in that it provides the criterion for distinguishing “inhumane” treatment from “futile” treatment — significant pain and suffering disproportionate to any potential benefit. In a case such as Baby L’s, for example, the concern about inflicting pain may provide an independent reason for challenging the continuation of treatment.

Two additional significant features of the substantive aspects of these regulations should be noted. One is their heavy reliance on “reasonable medical judgment[s]”³² in determining that certain conditions, such as the futility or inhumaneness of a particular treatment, have been satisfied. The other significant feature, which is more critical to the present discussion, is that the withholding or withdrawal of treatment under these conditions is permissive, not mandatory. This feature is no doubt a reflection of the regulators’ and legislators’ predominant concern with *undertreatment* and medical neglect, and not with *overtreatment* and affirmative abuse. Nonetheless, cases like that of Baby L force our attention to a question that parallels the one addressed by the regulations: When does overtreatment become abusive, constituting justification for displacing parental and/or physician authority over medical decisions?³³

29. *Id.* See also John M. Freeman & Peggy C. Ferry, *New Brain Death Guidelines in Children: Further Confusion*, 81 PEDIATRICS 301, 301 (1988) (offering a somewhat different articulation of the regulations).

30. 45 C.F.R. § 1340.15(c) (1994) (requiring mechanisms within a state’s child protective service system to facilitate responses to the reporting of medical neglect).

31. *Id.* § 1340 app. ¶ 9 (noting this determination is an appropriate factor for a physician to consider in selecting among possible treatments).

32. See *id.* (emphasizing the importance of “reasonable medical judgment”).

33. See Gustaitis, *supra* note 2, at 320 (arguing that physicians should be permitted to act on behalf of an infant and advocate nontreatment even if the parents desire prolonged treatment if the physician determines that the treatment would be futile and cause unjustifiable suffering).

VI. OVERTREATMENT AS CHILD ABUSE

"If parents insist on continuing treatment and physicians know it to be futile and a cause of unjustifiable suffering, the Do No Harm principle will oblige physicians to act in the baby's behalf, despite parental opposition."³⁴ It seems that the case of Baby L may be just such a case. And it also seems that serious consideration should be given to other such cases under the rubric of prevention or cessation of child abuse.

One might wonder who is ready to take such a step, however. Consider, for example, an article published in 1990, which reports the experience of a neonatal ethics committee in a tertiary care hospital.³⁵ The committee deliberated about the treatment of infants suffering from congenital anomalies. The authors report that "[g]enerally, in the experience of our group, when the infant's condition appears hopeless but the parents wish to continue care for their infant, treatment is continued for a period of time to allow the parents to come to terms with the hopelessness of their infant's condition."³⁶ But if overtreatment is, at least in some cases, abusive, then how long should parents be permitted to use their infant as a means to their own ends of "coming to terms with the hopelessness" of the situation? After all, during the time it takes them to "come to terms," their child may well experience pain caused by the continued treatment. Moreover, the parents ultimately may be unable to "come to terms" with that reality of hopelessness. At some point, most likely sooner rather than later, the infant's interests should absolutely supersede those of his or her parents. The remaining questions, then, are how and by what standards should the decision to supplant parental authority proceed?

34. *Id.* (noting it is usually the parents who advocate a less aggressive treatment).

35. Myra J. Edens et al., *Neonatal Ethics: Development of a Consultative Group*, 86 PEDIATRICS 944, 944-47 (1990) (noting the advisory group was created in response to several court cases and proposed federal regulations concerning treatment of potentially handicapped infants).

36. *Id.* at 947 (noting there are a few exceptions to this general observation). See also Gustaitis, *supra* note 2, at 319 (reporting that it is not uncommon to maintain life-support equipment on a child until the parents are better able to cope with the concept of death).

VII. AN APPROACH TO CASES OF OVERTREATMENT

It is assumed that cases involving overtreatment indeed occur and are undesirable. They may in fact be more common than not, simply because federal regulations on infant care have bolstered the already existing instinct of physicians to rescue rather than abandon their patients. In addition, the national climate of concern about protecting rights of the disabled would make even the appearance of a discriminatory treatment decision highly unattractive.

A second assumption underlying this discussion is that where uncertainty about a diagnosis or prognosis exists, treatment should be provided while the uncertainties are being resolved. Physicians should not be reluctant to initiate treatment for fear that once initiated it cannot be withdrawn. The more appealing plan is to decide doubtful cases in favor of treatment, at least until the diagnosis and prognosis have been clarified.³⁷

VIII. SUBSTANTIVE ASPECTS OF THE APPROACH TO OVERTREATMENT

Medical treatment is sometimes painful and often poses risks. A parent may nonetheless choose to expose a child to such medical treatment, despite its dangers, because a decision favoring treatment serves the best interests of the child. The pain experienced by the child may even be bearable to contemplate, if the potential for rescuing the child and restoring health is present. In some cases, however, the potential for restoring health is absent. In those cases, should a parent's demand for continued treatment be resisted on the basis that such treatment disserves the child's interests? To answer this question, it is useful to outline the factors that should be considered in evaluating a child's best interests.

As with adults, the assessment of the child's best interests should include consideration of the *uniqueness and dignity of every person*; the possibility and extent of preserving the patient's life; preservation, improvement, or restoration of the patient's health or functioning; *relief of the patient's suf-*

37. Pieter J.J. Sauer, *Ethical Decisions in Neonatal Intensive Care Units: The Dutch Experience*, 90 PEDIATRICS 729, 730 (1992) (noting that moral obligations require further treatment when the effect of the treatment is unclear).

fering; and such other factors that a reasonable person in the patient's medical and personal circumstances would want considered. Decisions for an adult often reflect upon the adult's life style to determine the values or views that should inform decisionmaking. In contrast, *a judgment for a child is more forward-looking: it focuses on the child's potential and the opportunity for future development.*³⁸

Valuing the "uniqueness and dignity of every person" would suggest, at the very least, that a child should not be used as the means to achieve even the worthwhile end of allowing his or her parents to "come to terms" with a hopeless prognosis. The desire to provide "relief of the patient's suffering" would call for an end to inhumane treatment, that is, treatment causing pain and suffering disproportionate to any potential benefit.³⁹ This analysis would support the action of the caregivers in challenging continued treatment for Baby L. Standing alone, however, this analysis would not support the action of the caregivers who challenged continued treatment for Baby K, given the absence of any suggestion that continued treatment was inhumane.

IX. CONCLUSION: PROCEDURAL APPROACHES TO OVERTREATMENT

By what means should a challenge to overtreatment be made, and should such a challenge be mandatory or permissive? If inhumane overtreatment is indeed abusive, it would seem that a challenge should be mandatory. It should not be made lightly, of course; safeguards of the sort stressed in the reports on Baby L are critical.⁴⁰ Added to those safeguards should be a requirement that vigorous efforts at persuasion show themselves to be of no avail before a more open challenge is made.⁴¹ The vehicle for such a challenge could parallel that

38. New York State Task Force on Life and the Law, *When Others Must Choose* 121 (1992) (emphasis added).

39. See *supra* note 31 and accompanying text (indicating it is solely the effect upon the pain and suffering of the child that should concern the physician in assessing whether to administer treatment).

40. See *supra* note 15 and accompanying text (discussing safeguards for the prevention of overtreatment).

41. Personal experience with a bioethics committee and consultation service leads me to believe that most, though not all, apparently irreconcilable differences can be resolved without coercive measures.

which already exists for undertreatment cases; that is, through a report to the state's child protective services agency made mandatory rather than permissive, by amending the federal regulations regarding inhumane treatment. Finally, although I am loath to suggest a judicial forum for such a challenge, it should be available as a matter of last resort.

