

Ethics and the Care of Critically Ill Infants and Children

Committee on Bioethics

ABSTRACT. The ability to provide life support to ill children who, not long ago, would have died despite medicine's best efforts challenges pediatricians and families to address profound moral questions. Our society has been divided about extending the life of some patients, especially newborns and older infants with severe disabilities. The American Academy of Pediatrics (AAP) supports individualized decision making about life-sustaining medical treatment for all children, regardless of age. These decisions should be jointly made by physicians and parents, unless good reasons require invoking established child protective services to contravene parental authority. At this time, resource allocation (rationing) decisions about which children should receive intensive care resources should be made clear and explicit in public policy, rather than be made at the bedside.

Since the advent of means for supporting newborns with respiratory distress, neonatal and pediatric intensive care has helped tens of thousands of children survive life-threatening illness and the rigors of major surgical intervention. For more than a decade, however, many responsible for the health care of children have debated the appropriateness of applying life-sustaining medical technology (LSMT) to all critically ill children. (The term LSMT here applies to methods of supporting life typically applied in intensive care units, such as the use of ventilators and mechanical or pharmacologic support of circulation. The term critically ill here refers to disorders requiring such LSMT. Both terms defy precise definition.) As a recent AAP policy statement¹ on forgoing LSMT notes, the value of such therapy may be uncertain, especially when first considered. Good medical practice may favor initiation of LSMT until clarification of the clinical situation and relevant ethical values can occur. Much discussion has focused on highly visible "selective nontreatment of handicapped infants"² and the responses of the federal government, now known colloquially as the "Baby Doe" rules.^{3,4} In the last few years, clinicians and the public also have become increasingly concerned about the high costs, in terms of money, time, and psychosocial consequences, of neonatal and pediatric intensive care.

NEWBORNS AND INFANTS

Much controversy has surrounded the treatment of newborns and older infants with readily identifi-

able medical problems, including genetic disorders, malformations and deformations, and, to some extent, extreme prematurity and/or low birth weight. Scientific understanding and improved technology have permitted reductions in mortality for infants affected by an enlarging list of conditions. A better appreciation of what can be done to help many infants with disabilities and social considerations of fairness have led to the application of life-saving medical interventions to critically ill newborns and infants who, not long ago, physicians might not have treated vigorously. Concern that some infants, eg, those with Down syndrome and gastrointestinal obstruction, received insufficient treatment led to the federal legislation (the 1984 Child Abuse Amendments) and regulations that sought to ensure appropriate medical therapy for all disabled infants.

Looking back, the measures to prevent undue discrimination against disabled infants seem to have produced at least two unintended consequences. First, it seems that many persons in the health care and child advocacy professions, along with the general public, misunderstand the various federal and other legal requirements regarding treatment decisions for infants with critical illnesses.⁵⁻⁷ Thus, misconceptions about the Baby Doe rules may have become de facto benchmarks for treatment decisions about critically ill newborns and older infants. Second, attention concentrated on saving the lives of infants, some with permanent, severe disabilities or neurodegenerative disorders, has hampered sufficient attention to the possible overuse of LSMT.

With regard to the first point, the actual language of the 1984 Child Abuse Amendments may permit more physician discretion than some realize. Although the law mandates provision of LSMT to most seriously ill infants, it does provide for exceptions in the case of permanent unconsciousness, "futile" treatment, and "virtually futile" therapy that imposes excessive burdens on the infant. Physicians, with parental agreement, may even forgo giving hydration and nutrition when they think these measures are not "appropriate." (Quoted words and phrases come directly from the law.³)

With regard to the second point, possible overuse of LSMT, several book-length studies,⁸⁻¹¹ one personal account from parents,¹² and recent essays by pioneering neonatologists^{13,14} have suggested that modern newborn care may, at times, constitute over-treatment. Articles for the general public have communicated the same message.¹⁵⁻¹⁷ As previously noted, after the Child Abuse Amendments of 1984, two reports of a survey of neonatologists^{5,6} indicated

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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that many who specialize in the care of sick newborns believe they are legally constrained to provide LSMT to infants, even when their medical judgments and the views of the parents concur that withholding treatment is preferable.

Although many would like to have simply interpreted and easily applied substantive standards for clinical decisions about critically ill infants, medical and moral complexity make such rules imprudent. Scientific uncertainty regarding outcome continues in the neonatal intensive care unit. Some very tiny infants with documented brain insults, such as those that may occur with periventricular hemorrhage, defy expectations and survive with no apparent clinical deficits. Available evidence, however, continues to indicate that the decreased mortality brought about by neonatal intensive care has been accompanied by increased morbidity, ie, serious mental and physical limitations among survivors that impose burdens on affected children and their families.^{18,19} These factors also play legitimate roles in decision making.^{20,21}

A few well-publicized cases in the early 1980s led some to conclude that physicians and parents commonly denied beneficial treatment to imperiled newborns. However, no reliable evidence that decisions endangering children have been widespread exists. Most cases of lethal nontreatment seem to have involved infants with trisomy 21 and myelomeningocele.²²⁻²⁴ However, by the early 1980s professional and public views about infants with Down syndrome and spina bifida had generally shifted to favor treatment.²⁵ This view is supported by results from a survey of pediatricians done in Massachusetts in the mid-1980s.²⁴

The AAP supports parental involvement in decisions about imperiled infants from the earliest possible moment. Obstetricians and pediatricians need to inform and counsel parents about available options when prenatal diagnostic procedures identify disorders in fetuses. Women may legitimately decide about the treatment they and their fetuses receive.^{26,27} Once parturition occurs, parents continue to have a vital role in decision making under the presumption that they accept responsibility for nurturing the infant and providing reasonable care.²⁸

The AAP believes that parents and physicians should make reasoned decisions together about critically ill infants using the principles of informed parental permission recently articulated by the AAP.²⁹ Such decisions should consider the benefits and burdens of treatment alternatives. Physicians should remember that many parents want a strong role in these decisions³⁰ and that parents may bring values to the process that differ sharply from those of the physician. In rare instances, as required by law and sound ethical standards, it may be necessary to invoke established child protective mechanisms if parents wish to forgo LSMT, physicians disagree, and the parties cannot resolve their differences with help from subspecialists, ethics consultants, or ethics committees.

CHILDREN BEYOND INFANCY

As with infants, two basic questions arise in the care of children beyond the first year: Which values and whose authority ought to govern in medical treatment decisions about the critically ill? Published court cases indicate that parents have been permitted to exercise broad discretion when acting on their children's behalf,³¹⁻³⁶ even when court-appointed guardians ad litem or other counsel opposed the parental choice.³⁷⁻³⁹ Laws in some states permit parents to execute advance directives on behalf of minors (Choice and Dying. State laws regarding end-of-life decision making for minors. New York, NY: Choice and Dying; September 1995:1-2).⁴⁰ In addition to according due respect to the beliefs, feelings, and needs of the family as expressed by parents, as children get older and acquire cognitive skill, experience, and emotional maturity, their individual views deserve careful consideration. Sensitive clinicians and parents acknowledged this in the professional literature as long as 20 years ago.⁴¹

In the realm of pediatric critical care, the North American literature provides sparse evidence of systematic approaches to limiting LSMT.^{42,43} The pediatric intensive care unit, however, unlike the neonatal intensive care unit, has not been the focus of bureaucratic or political debate and action. Pediatric intensivists and their colleagues and consultants in ethics have tended to make decisions about discontinuing LSMT similar to the way clinicians, loved ones, ethicists, and the courts make such decisions for incompetent adult patients.^{44,45}

RESOURCE ALLOCATION AND DECISIONS TO LIMIT LSMT

Recently, concerns about the high cost of critical care have led to attempts to manage critical care resources through the use of quantitative indicators of prognosis.⁴⁶⁻⁵¹ Some physicians, administrators, and planners would like to use increasingly accurate statistical predictors of outcome to exclude patients from receiving intensive care services. Indeed, population-based mathematical tools may prove helpful in evaluating the effectiveness of various interventions, in comparing outcomes of similar treatments used at different sites, and in informing parents of the probability of the outcome of treatment. Such studies, however, have an important inherent limitation—their results apply to groups of patients, not individuals. In the absence of perfect outcome prediction (100% survival or death, based on experience with large numbers of patients), statistical indicators cannot tell clinicians which particular patient will die or live (and with what residual problems). Moreover, even overwhelming odds of success or failure of treatment cannot take into account the complex values that individuals, including patients, family members, physicians, and other health care providers, bring to a treatment decision. Therefore, the AAP opposes the use of these formulas as the principal determinants of whether individual patients receive intensive care.

The controversy over the usefulness of critical care

resources has been most poignantly highlighted by public debates about futile medical treatment.⁵²⁻⁵⁶ In these discussions, physicians and other care givers have demonstrated concern that medical resources are being used inappropriately and that continued treatment violates deeply held beliefs about what properly constitutes professional activities. Others feel that professional objections to so-called futile treatment masks prejudices about those who are disabled, who come from disadvantaged social groups, or who are dying.

The AAP thinks that judgments about which diagnostic categories of patients should receive or be denied intensive care based on considerations of resource use are social policy deliberations and should be made after considerable public discussion, not ad hoc at the bedside.

CONCLUSIONS

Our society has reached a consensus that some critically ill infants previously denied treatment should receive advanced medical and surgical care. A large majority of physicians and other persons agree that most infants with Down syndrome with gastrointestinal obstruction and most infants with myelomeningocele should have surgery and other treatment they need.

There is less agreement, however, about how much treatment to provide other critically ill infants and children. Medical and public controversy still rages about the appropriate limits, if any, to place on the treatment of extremely low birth weight and premature infants, about infants with hypoplastic left heart syndrome,⁵⁷ about children with chromosomal abnormalities with known very limited life spans, about infants with complex congenital abnormalities, and about children in the final stages of terminal cancer or other fatal chronic disorders. Many think that laws, regulations, and government policies have unduly constrained parents and physicians from exercising reasonable judgments about whether to forgo LSMT.

A judicial and legislative consensus has developed that the values of patients, rather than those of physicians or policy makers, should determine the extent of the application of LSMT.⁵⁸ As noted, some states have empowered proxy decision makers to execute advance directives regarding LSMT on behalf of minors. Legislation and regulation about disabled infants conflict with the legal trends governing all other patients. In the absence of compelling evidence that infants require special legal protection, the AAP thinks that parents of newborns should have the same decision-making authority they have with older children.

Limited resources may require equitable limits on medical treatment. Such restrictions require careful consideration of their social, cultural, and economic consequences and deserve to be made at a public policy level, not at the bedside.

RECOMMENDATIONS

1. Decisions about critical care for newborns, infants, and children should be made similarly and with informed parental permission.
2. 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.
3. Decisions to forgo critical care services on the grounds of resource limitations, generally speaking, are not clinical decisions, and physicians should avoid such "bedside rationing."

However, because many in the American public think that our health care system spends excessively on critical care services, society should engage in a thoroughgoing debate about the economic, cultural, religious, social, and moral consequences of imposing limits on which patients should receive intensive care.

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REFERENCES

1. American Academy of Pediatrics, Committee on Bioethics. Guidelines on forgoing life-sustaining medical treatment. *Pediatrics*. 1994;93:532-536
2. Weir RF. *Selective Nontreatment of Handicapped Newborns: Moral Dilemmas in Neonatal Medicine*. New York: Oxford University Press; 1992
3. US Child Abuse Protection and Treatment Amendments of 1984. Pub L No. 98-457
4. Child abuse and neglect prevention and treatment program: final rule. 50 *Federal Register* 14878-14901
5. Kopelman LM, Irons TG, Kopelman AE. Neonatologists judge the "Baby Doe" regulations. *N Engl J Med*. 1988;318:677-683
6. Kopelman LM, Kopelman AE, Irons TG. Neonatologists, pediatricians, and the Supreme Court criticize the "Baby Doe" regulations. In: Caplan AL, Blank RH, Merrick JC, eds. *Compelled Compassion: Government Intervention in the Treatment of Critically Ill Newborns*. Totowa, NJ: Humana Press; 1992:237-266
7. Frader J. Review of compelled compassion. *N Engl J Med*. 1992;327:824
8. Guillemin JH, Holmstrom LL. *Mixed Blessings: Intensive Care for Newborns*. New York: Oxford University Press; 1986
9. Frohock FM. *Special Care: Medical Decisions at the Beginning of Life*. Chicago, IL: University of Chicago Press; 1986
10. Bosk CL. *All God's Mistakes: Genetic Counseling in a Pediatric Hospital*. Chicago, IL: University of Chicago Press; 1992
11. Anspach RR. *Deciding Who Lives: Fateful Choices in the Intensive-Care Nursery*. Berkeley, CA: University of California Press; 1993

12. Stinson R, Stinson P. *The Long Dying of Baby Andrew*. Boston, MA: Little, Brown & Co; 1992
13. Silverman A. Overtreatment of neonates? A personal retrospective. *Pediatrics*. 1992;90:971-976
14. Stahlman MT. Ethical issues in the nursery: priorities versus limits. *J Pediatr*. 1990;116:167-170
15. Kolata G. Parents of tiny infants find care choices are not theirs. *New York Times*. September 30, 1991:A1
16. Brody JE. A quality of life determined by a baby's size. *New York Times*. October 1, 1991:A1
17. Quindlen A. Crimes against the smallest of children. *New York Times*. January 29, 1992:A21
18. Paneth N, Stark RI. Cerebral palsy and mental retardation in relation to indicators of perinatal asphyxia. *Am J Obstet Gynecol*. 1983;147:960-966
19. Blank RH. Rationing medicine in the neonatal intensive care unit (NICU). In: Caplan AL, Blank RH, Merrick JC, eds. *Compelled Compassion: Government Intervention in the Treatment of Critically Ill Newborns*. Totowa, NJ: Humana Press; 1992:97-103
20. Strong C. The neonatologist's duty to patient and parents. *Hastings Cent Rep*. 1984;14:10-16
21. Hardwig J. What about the family? *Hastings Cent Rep*. 1990;20:5-10
22. Lantos J. Baby Doe five years later: implications for child health. *N Engl J Med*. 1987;317:444-447
23. Todres ID, Krane D, Howell MC, Shannon DC. Pediatricians' attitudes affecting decision making in defective newborns. *Pediatrics*. 1977;60:197-201
24. Todres ID, Guilleman J, Grodin MA, Batten D. Life-saving therapy for newborns: a questionnaire survey in the state of Massachusetts. *Pediatrics*. 1988;81:643-649
25. Caplan AL. Hard cases make bad law: the legacy of the Baby Doe controversy. In: Caplan AL, Blank RH, Merrick JC, eds. *Compelled Compassion: Government Intervention in the Treatment of Critically Ill Newborns*. Totowa, NJ: Humana Press; 1992:105-122
26. Board of Trustees, American Medical Association. Legal interventions during pregnancy. *JAMA*. 1990;264:2663-2670
27. Committee on Ethics, American College of Obstetricians and Gynecologists. *Patient Choice: Maternal-Fetal Conflict*. Washington, DC: American College of Obstetricians and Gynecologists; 1987. ACOG Committee opinion 55
28. *Bowen v American Hospital Association*, 106 S Ct 2101 (1986)
29. Committee on Bioethics, American Academy of Pediatrics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*. 1995;95:314-317
30. Harrison H. The principles for family-centered neonatal care. *Pediatrics*. 1993;92:643-650
31. *In re PVW*, 424 S2d 1015 (La 1982)
32. *In re Crum*, 580 NE2d 876 (Ohio Probate Ct 1991)
33. *In re Lawrence*, 579 NE 2d 633 (Ind 1991)
34. *Newmark v Williams*, 588 A2d 1108 (Del 1991)
35. *In re Rosebush*, 491 NW2d 633 (Mich App 1992)
36. *In re "Baby K"*, 16 F3d 590 (4th Cir 1994)
37. *In re CA*, 603 NE2d 1171 (Ill App 1992)
38. *Guardianship of Doe*, 583 NE2d 1263 (Mass 1992)
39. *Care and Protection of Beth*, 587 NE2d 1377 (Mass 1992)
40. Jefferson LS, White BC, Louis PT, Brody BA, King DD, Roberts CE. Use of the Natural Death Act in pediatric patients. *Crit Care Med*. 1991;19:901-905
41. Schowalter J, Ferholt J, Mann N. The adolescent patient's decision to die. *Pediatrics*. 1973;51:97-103
42. Lantos JD, Berger AC, Zucker AR. Do-not-resuscitate orders in a children's hospital. *Crit Care Med*. 1993;21:52-55
43. Leikin S. A proposal concerning decisions to forgo life-sustaining treatment for young people. *J Pediatr*. 1989;115:17-22
44. Frader J. Ethics in pediatric intensive care. In: Fuhrman BP, Zimmerman JJ, eds. *Pediatric Critical Care*. St Louis, MO: Mosby-Year Book, Inc; 1992:7-15
45. Glover JJ, Holbrook PR. Ethical considerations. In: Holbrook PR, ed. *Textbook of Pediatric Critical Care*. Philadelphia, PA: WB Saunders Co; 1993:1124-1130
46. Knaus WA, Wagner DP, Lynn J. Short-term mortality predictions for critically ill hospitalized adults: science and ethics. *Science*. 1991;254:389-394
47. Knaus WA, Wagner DP, Draper EA, et al. The APACHE III prognostic system: risk prediction of hospital mortality for critically ill hospitalized adults. *Chest*. 1991;100:1619-1636
48. Pollack MM, Ruttiman UE, Getson PR. Pediatric risk of mortality (PRISM) score. *Crit Care Med*. 1988;16:1110-1116
49. Pollack MM, Getson PR. Pediatric critical care cost containment: combined actuarial and clinical program. *Crit Care Med*. 1991;19:12-20
50. Tyson J, Wright E, Malloy M, Wright L. How predictable is the outcome and care of ventilated extreme low birth weight (ELBW <1000 g) infants? *Pediatr Res*. 1991;29:237A
51. Horbar JD, Onstad L, Wright E, NIH Child Health and Human Development Neonatal Research Network. Predicting mortality risk for infants 501-1500 grams at birth: a national institutes of health neonatal research network report. *Crit Care Med*. 1993;21:12-18
52. Paris JJ, Crone RK, Reardon F. Physicians' refusal of treatment: the case of Baby L. *N Engl J Med*. 1990;322:1012-1015
53. Twedt S. Should comatose boy live? Hospital, dad differ. *Pittsburgh Press*. June 3, 1991:1
54. Smothers R. Atlanta court bars efforts to end life support for stricken girl, 13. *New York Times*. October 18, 1991:A10
55. Nelson LJ, Nelson RM. Ethics and the provision of futile, harmful, or burdensome treatment to children. *Crit Care Med*. 1992;20:427-433
56. Truog RD, Brett AS, Frader J. The problem with futility. *N Engl J Med*. 1992;326:1560-1564
57. Storch TG. Passive euthanasia for hypoplastic left heart syndrome. *Am J Dis Child*. 1992;146:1426
58. Armstrong CJ. Judicial involvement in treatment decisions: the emerging consensus. In: Civetta J, Taylor RW, Karby RR, eds. *Critical Care*. Philadelphia, PA: JB Lippincott Co; 1988