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Life and Death Decisions in the Nursery: Standards and Criteria for Withholding Lifesaving Treatment from Infants

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LIFE AND DEATH DECISIONS IN THE NURSERY:
STANDARDS AND PROCEDURES FOR WITHHOLDING
LIFESAVING TREATMENT FROM INFANTS

STEVEN R. SMITH*

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INTRODUCTION

That the conduct of human affairs does not always conform to the requirements of the law is a surprise to no one. But in few areas of critical life and death decisions is there such a disparity between commonly recognized principles of law and developing medical practice as exists in the area of withholding lifesaving medical care from infants, notably defective infants. The law is said to restrict physicians and parents from withholding lifesaving treatment from infants for the

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purpose of causing their deaths.¹ Yet it is reported that it is not uncommon for lifesaving treatment to be denied severely defective infants, and that thousands of infant deaths result each year from this lack of treatment.²

1. The legal principles and existing laws regarding withholding medical care from infants are carefully reviewed and analyzed in Ellis, *Letting Defective Babies Die: Who Decides?* 7 AM. J. LIT. MED. 393, 402-13 (1982) [hereinafter cited as Ellis]; Horan, *Euthanasia, Medical Treatment and the Mongoloid Child: Death as a Treatment of Choice?*, 27 BAYLOR L. REV. 76, 78-85 (1975) [hereinafter cited as Horan]; Mueller & Phoenix, *A Dilemma for the Legal and Medical Professions—Euthanasia and the Defective Newborn*, 22 ST. LOUIS U. L. REV. 501, 504-17 (1978) [hereinafter cited as Mueller & Phoenix]; Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 217-43 (1975) [hereinafter cited as Robertson]; Robertson, *Legal Aspects of Withholding Medical Treatment from Handicapped Children*, in LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS 213, 214-22 (A.E. Doudera & J.D. Peters eds. 1982) [hereinafter cited as Robertson, Legal Aspects]; Sharp & Crofts, *Death with Dignity, the Physician's Civil Liability*, 27 BAYLOR L. REV. 86 (1975); Survey, *Euthanasia: Criminal, Tort, Constitutional and Legislative Considerations*, 48 NOTRE DAME L.J. 1202, 1203-27 (1973); Note, *Birth Defective Infants: A Standard for Nontreatment Decisions*, 30 STAN. L. REV. 599, 613-19 (1978) [hereinafter cited as *A Standard for Nontreatment*]. See also Foreman, *The Physician's Criminal Liability for the Practice of Euthanasia*, 27 BAYLOR L. REV. 54 (1975) [hereinafter cited as Foreman]; Levin & Levin, *DNR: An Objectionable Form of Euthanasia*, 49 U. CIN. L. REV. 567 (1980) [hereinafter cited as Levin & Levin]. According to these commentators, those who withhold lifesaving treatment from infants might be guilty of murder, involuntary manslaughter, conspiracy, child abuse and neglect, and violating the child abuse reporting laws. See, e.g., Foreman, *supra*. It is also suggested that civil liability might be imposed for wrongful death, negligence, abandonment, and violations of federal civil rights. See generally Mueller & Phoenix, *supra*. The Department of Health and Human Services has suggested that hospitals receiving federal financial assistance violate federal law if they withhold treatment, or permit treatment to be withheld because an infant is handicapped. See notes 222-36 and accompanying text *infra*.

The consensus of the commentators is that withholding lifesaving treatment from infants violates current legal standards. At least one commentator believes that an alternative "medical-feasibility standard" is permitted under current laws. See *A Standard for Nontreatment, supra*, at 623-32. This, however, is only a slight variation in the interpretation of current legal standards.

Under certain conditions, parents have been found guilty of homicide for failing to provide adequate medical care for their children. See, e.g., *Stehr v. State*, 92 Neb. 755, 139 N.W. 676, *aff'd on reh'g*, 94 Neb. 151, 142 N.W. 676 (1913); *State v. House*, 260 Or. 138, 489 P.2d 381 (1971); *State v. Williams*, 4 Wash. App. 908, 484 P.2d 1167 (1971). The history of parental obligation to provide medical care is reviewed in *State v. Clark*, 5 Conn. Cir. Ct. 699, 261 A.2d 294 (1969). See generally Katz, Howe & McGrath, *Child Neglect Laws in America*, 9 FAM. L.Q. 1 (1975).

2. Estimates given before a congressional subcommittee of the number of infant deaths resulting from the withdrawal of lifesaving treatment ranged from a few thousand to several thousand each year. *Medical Ethics: The Right to Survival, 1974: Hearings Before the Subcommittee on Health of the Senate Committee on Labor and Public Welfare*, 92d Cong., 2d Sess. [14, 26 (1974)] (testimony of Dr. Robert E. Cooke and Dr. Raymond S. Duff) [hereinafter cited as *Medical Ethics Hearings*]. See also Duff & Campbell, *Moral and Ethical Dilemmas in a Special Care Nursery*, 289 NEW ENG. J.

This disparity between the law and practice may result from confusion in the medical community about the legal standards for non-treatment decisions,³ or from the absence of any effective mechanism to enforce the law.⁴ The purpose of this article is to clarify important issues regarding the legal standards which should be used in making treatment decisions, and to suggest ways that such legal standards might be enforced.

Much of the discussion of withholding lifesaving treatment has been of an unusually high quality.⁵ There remains some confusion,

MED. 890 (1973) [hereinafter cited as Duff & Campbell]. In this article the authors estimated that 14% of all infant deaths which occurred in the hospital were a result of withdrawing or withholding medical treatment. *Id.*

3. Both those physicians who specialize in the treatment of neonates and those who do not, have indicated to the author uncertainty about their legal position in withholding treatment from infants. Some expressed doubts that their own conduct conformed to the requirements of the law. These physicians uniformly appeared deeply concerned about the effects of these decisions upon the infants and their families, and most expressed a desire to have a clear understanding of their legal responsibilities.

Any legal standards which are applied must be clear so as to avoid continuing the confusion in the medical community on this issue. In their effort to eliminate the confusion regarding the withholding of treatment through the discontinuance of life-support systems, the Los Angeles bar and medical associations agreed upon certain guidelines. According to these standards, treatment may be withheld if brain death criteria are met (see note 15 *infra*), if the provisions of the Natural Death Act are met (see note 36 *infra*), or if the patient is in an irreversible coma and had not expressed a desire to have life-support systems in such circumstances and the family or guardian agrees to the termination. See Middletown, *Bar Joins in Issuing Life-Support Guidelines*, 7 BAR LEADER 27 (July-Aug. 1981). While efforts to clarify the legal obligations of the physicians should be made, some doubts must be expressed as to the wisdom, and even the propriety, of medical and bar associations determining such standards through joint statements. It would seem more appropriate for these groups to submit such proposals to the legislatures or to file amicus briefs for judicial evaluation in pending court actions.

4. In many instances, the decision to withhold lifesaving medical treatment is not authoritatively reviewed by anyone. See notes 209-46 and accompanying text *infra*.

5. For a few of the excellent articles and discussions on this subject see P. RAMSEY, *ETHICS AT THE EDGES OF LIFE* 189-267 (1978) [hereinafter cited as RAMSEY]; WHO SHALL LIVE? (K. VAUX ed. 1970); Bennett, *Allocation of Child Medical Care Decision-Making Authority: A Suggested Interest Analysis*, 62 VA. L. REV. 285 (1976) [hereinafter cited as Bennett]; Coburn, *Morality and the Defective Newborn*, J. MED. PHILOS. 340 (1980); Duff & Campbell, *supra* note 2; Ellis, *supra* note 1; Fletcher, *Attitudes Toward Defective Newborns*, 2 HASTINGS CENTER REP. 21 (1974) [hereinafter cited as Fletcher]; Freeman, *Is There a Right to Die—Quickly?*, 80 J. PEDIATRICS 904 (1972); Mueller & Phoenix, *supra* note 1; Robertson, *supra* note 1; Smith, *On Letting Some Babies Die*, 2 HASTINGS CENTER REP. 37 (1974); Shatten & Chabon, *Decision-Making and the Right to Refuse Lifesaving Treatment for Defective Newborns*, 3 J. LEGAL MED. 59 (1982); Trinkaus, *Decision Making for Newborns in LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS* (A. Douders & J. Peters eds. (1982)); *A Standard for Nontreatment*, *supra* note 1. *But see* Sherlock, *For Everything There is a Season: The Right to Die in the United States*, 1982 B.Y.U. L. REV. 545, 561 (claiming that the discussion of euthanasia has been of low quality).

however, about several central issues. Areas of confusion which will be examined in this article are the autonomy privacy interests of children which can be exercised by parents,⁶ the distinction between "ordinary" and "extraordinary treatment,"⁷ and the proper factors to be considered in making nontreatment decisions.⁸ The full complexity, extent, and implications of these decisions have not been recognized. The complexity of nontreatment decisions is demonstrated by a Decision Matrix,⁹ which also aids in the identification of the factors which may play a role in nontreatment decisions. It is postulated that parents cannot exercise a *child's* autonomy rights, that the distinction between extraordinary and ordinary treatment is confusing and dangerous and that generally the perceived quality of life of an infant or the effect of its life on its family or others are not legally sufficient bases for withholding treatment. The circumstances under which parents may properly be permitted to withhold treatment are identified.

"Infants," as used in this article, refers to minors not old enough or competent to participate in any way in making medical decisions. Competent adults, and children with the degree of maturity which permits them to understand and appreciate medical alternatives and consequences,¹⁰ and even adults who were once competent, present significantly different issues.¹¹ They can participate in a determination of

6. See notes 49-92 and accompanying text *infra*.

7. See notes 117-46 and accompanying text *infra*.

8. See notes 147-206 and accompanying text *infra*.

9. See notes 96-118 and accompanying text *infra*.

10. Competent adults are generally thought to have a right, at least partially based in their right to privacy, to refuse medical treatment for themselves even though this refusal might seriously endanger their lives. See, e.g., *Holmes v. Silver Cross Hospital*, 340 F. Supp. 125 (N.D. Ill. 1972); *Satz v. Perlmutter*, 379 So. 2d 359 (Fla. 1980); *Suenram v. Society of Valley Hosp.*, 155 N.J. Super. 593, 383 A.2d 143 (1977). However, in many instances the courts have found reasons to compel the treatment.

Courts commonly identify the protection of the rights of innocent third parties as their reason for ordering medical treatment. See, e.g., *Application of President and Directors of Georgetown College*, 331 F.2d 1000, *reh'g denied*, 331 F.2d 1010 (D.C. Cir.), *cert. denied*, 377 U.S. 978 (1964); *Unites States v. George*, 239 F. Supp. 752 (D. Conn. 1965); *Hamilton v. McAuliffe*, 277 Md. 336, 353 A.2d 634 (1976); *Raleigh Fitkin-Paul Morgan Memorial Hosp. v. Anderson*, 42 N.J. 421, 201 A.2d 537, *cert. denied*, 377 U.S. 985 (1964). In many of these cases it would appear that the courts' reason for ordering treatment is their reluctance to permit even a competent adult to die for the lack of relatively risk-free treatment when this treatment is refused for what the courts view as insignificant reasons. See generally Byrn, *Compulsory Lifesaving Treatment for the Competent Adult*, 44 *FORDHAM L. REV.* 1 (1975); Cantor, *A Patient's Decision to Decline Life-Saving Treatment: Bodily Integrity versus The Preservation of Life*, 26 *RUTGERS L. REV.* 228 (1973); Paris, *Compulsory Medical Treatment and Religious Freedom: Whose Law Should Prevail?*, 10 *U.S.F.L. REV.* 1 (1975); Note, *Compulsory Medical Treatment and Constitutional Guarantees: A Conflict?*, 33 *U. PITT. L. REV.* 628 (1972).

11. Adults who were once competent have had an opportunity to participate in treatment decisions before becoming incompetent. See, e.g., *In re Quinlan*, 70 N.J. 10, 355

whether or not to undertake treatment and, therefore, exercise their rights of privacy directly. Lifesaving treatment is broadly defined as medical activity which will have a nontrivial impact on the survival of the infant in the foreseeable future; medical treatment which is not lifesaving is not considered.¹² Although there are circumstances involving nonlifesaving treatment in which there is an important state interest, the state interest in such situations is less profound, immediate, and clear than it is in life and death decisions.¹³ This article does not deal with the distribution of a scarce medical resource as between two infants when only one may have it, e.g., two infants need a special neonate incubator and only one is available.¹⁴ Nor does it deal directly

A.2d 647, *cert. denied*, 429 U.S. 922 (1976) (court noted that Karen Ann Quinlan previously advised parents she would not want to be maintained in a vegetative condition); *In re Storar* (Eichner), 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (1981) (court permitted discontinuance of patient's respirator after noting that prior to incompetency he had consistently requested he not be maintained by artificial means in the event of an irreversible coma).

There are dangers inherent in relying exclusively on statements concerning one's wishes for treatment in the event that he should become nonsapient. Such statements may not have been carefully considered and may be only the cavalier or heroic comments made when not facing life and death decisions. The "living will" or "natural death" legislation is an effort to deal with this issue. See notes 36-38 and accompanying text *infra*.

12. Courts have been reluctant to overturn parental decisions to withhold nonlifesaving treatment from infants even when the treatment has been recommended by medical authorities. The courts have ordered such treatment when there is a need, for example, to protect third parties from the harm of infectious diseases. These decisions generally have upheld legislatively mandated treatment such as compulsory smallpox vaccinations. See note 30 *infra*. Courts have, on rare occasions, ordered nonlifesaving treatment when the lack of such treatment would have serious nonfatal effects on the child. See, e.g., *People v. Labrenz*, 411 Ill. 618, 104 N.E.2d 769, *cert. denied*, 344 U.S. 824 (1952); *In re Sampson*, 65 Misc. 2d 658, 317 N.Y.S.2d 641 (N.Y. Fam. Ct. 1970), *aff'd*, 27 N.Y.2d 900, 278 N.E.2d 913, 328 N.Y.S.2d 686 (1972).

There are also instances when the parents' decision to consent to treatment has been questioned. Parental decisions to have a child sterilized have been scrutinized by the courts even though the parental decision is, *arguendo*, based on the fact that the difficulty in rearing the child will be eased by the treatment when the child's mental condition makes it impossible for him to understand the consequences of sexuality. For a review of the attitude of the courts toward these parental decisions see Bennett, *supra* note 5.

13. *Roe v. Wade*, 410 U.S. 113, 163 (1973) (the state has an interest in protecting the health of a pregnant woman and may to some extent regulate abortions to protect the health of the woman during the first two trimesters of pregnancy). There are limited circumstances where the state interest in requiring treatment, which is not clearly lifesaving, may be as strong as the ordinary lifesaving treatment case. Compulsory inoculation against contagious disease or examination for contagious diseases may protect others from potentially fatal disease. See, e.g., *People v. Strautz*, 386 Ill. 360, 54 N.E. 360 (1944) (state may compel examination for venereal disease of those charged with sex related offenses). See also note 12 *supra* & note 30 *infra*.

14. The distribution of scarce lifesaving medical facilities presents special problems which are different from the issues presented when the resources are currently available

with the definition of infant death.¹⁵ We are generally dealing with infants with at least some level of higher brain activity (so that they are not dead by any recognized standard)¹⁶ although the special problems

for everyone immediately needing them. Even when scarce medical resources must be distributed to only a limited number of those who require them, there is no agreement whether, or to the extent to which, the "value" of the lives of those involved should be considered in making treatment decisions. See Annas, *Allocation of Artificial Hearts in the Year 2002: Minerva v. National Health Agency*, 3 AM. J.L. & MED. 59 (1977); Katz, *Selection of Hemodialysis and Organ Transplant Recipients*, 22 BUFFALO L. REV. 373 (1973); Note, *Due Process in the Allocation of Scarce Life Saving Medical Resources*, 84 YALE L.J. 1734 (1975).

Scarcity of medical resources often results from the allocation of society's total resources. The indirect effects on other patients of treating one patient with scarce medical resources are extremely uncertain and impossible to calculate. See generally Kramer, *Ethical Issues in Neonatal Intensive Care: An Economic Perspective*, in ETHICS OF NEWBORN INTENSIVE CARE 75 (1976).

15. The permanent cessation of all brain activity is now commonly considered to be the definition of death. Many states have adopted brain death by statute, e.g., ALASKA STAT. § 09.65.120 (Supp. 1981); KAN. STAT. ANN. § 77-202 (1977 & Supp. 1980); MD. ANN. CODE art. 43 § 54f (1980 Repl. Vol.). See Biörck, *When is Death?*, 1968 WIS. L. REV. 484; Brant, *Last Rights: An Analysis of Refusal and Withholding of Treatment Cases*, 46 MO. L. REV. 337, 338-40 (1981) [hereinafter cited as Brant]; Capron & Kass, *A Statutory Definition of Standards for Determining Human Death: An Appraisal and a Proposal*, 121 U. PA. L. REV. 87 (1972) [hereinafter cited as Capron & Kass]; Charron, *Death: A Philosophical Perspective on the Legal Definitions*, 1975 WASH. U. L.Q. 979; Compton, *Telling the Time of Human Death by Statute: An Essential and Progressive Trend*, 31 WASH. & LEE L. REV. 521 (1974); Hirsh, *Brain Death: Medico-Legal Fact, or Fiction*, 3 N. KY. L.F. 16 (1975); Price, *Defining Death and Dying: A Bibliographic Overview*, 71 L. LIB. J. 49 (1978); Schneck, *Brain Death and Prolonged States of Impaired Responsiveness*, 58 DEN. L.J. 609 (1981). There are, however, some jurisdictions in which it is not clear that brain death has been completely accepted. Commonwealth v. Golston, 373 Mass. 249, 255, 366 N.E.2d 744, 749 (1977), cert. denied, 434 U.S. 1039 (1978).

16. It has been suggested that the definition of death should be based on higher brain function. Buchanan, *The Limits of Proxy Decisionmaking for Incompetents*, 29 U.C.L.A. L. REV. 386, 404-06 (1981); Kluge, *The Euthanasia of Radically Defective Neonates: Some Statutory Considerations*, 6 DALHOUSIE L.J. 229, 244-54 (1980) [hereinafter cited as Kluge]. See R. VEATCH, *DEATH, DYING AND THE BIOLOGICAL REVOLUTION* 68 (1976); Capron & Kass, *supra* note 15; Olinger, *Medical Death*, 27 BAYLOR L. REV. 22 (1975) [hereinafter cited as Olinger]. Louisiana at least appears to implicitly accept a higher brain death standard for infants by prohibiting parents from withholding lifesaving treatment from defective infants, but permitting the treatment to be withheld from permanently comatose infants. La. Rev. Stat. Ann. § 1299.36.1 (West Supp. 1983). See *In re P.V.W.*, No. 82-CA-2637 (La. Dec. 10, 1982) (available Feb. 20, 1983, on LEXIS, States library).

Definitions of "human person" have been proposed, although not generally seriously considered or approved, which would further narrow the group of beings given the full protections of the law. One such suggestion is for a "delayed personhood policy" under which the state would delay recognizing the child's personhood until its potential for development and growth is established. MARKS & SALKOVITZ, *The Defective Newborn: An Analytic Framework for a Policy Dialogue* in ETHICS OF NEWBORN INTENSIVE CARE 110-11 (1976) [hereinafter cited as MARKS & SALKOVITZ]. At the other extreme, legisla-

of the infant with anencephaly¹⁷ are noted. We assume that we are dealing with postnatal, or at least postviable, infants so that abortion issues are not relevant.¹⁸ In short, we are dealing with human persons to the extent that there is a current common or constitutional understanding of that concept.¹⁹

I. LIFESAVING TREATMENT, PARENTAL AUTHORITY AND THE RIGHT OF PRIVACY

A. Parental Authority and Medical Decisions

Parents generally are empowered to make medical decisions concerning their infant children.²⁰ This authority, as the more general

tion has been introduced to define human life as beginning at conception. See note 19 *infra*.

17. Complete anencephalics are normally stillborn, although some live for 4 and even 16 days in extreme cases. J. WARKANY, *CONGENITAL MALFORMATIONS* 199 (1971). Of greater concern here are partial anencephalics. Such infants have no forebrains and may or may not have midbrains. They are limited to primitive functions necessary to life and will live, with motor actions comparable to those of a normal human fetus after 3 or 4 months gestation. *Id.*

18. It may be that a state could define human life so as not to include all viable fetuses, although its authority to do so is not entirely clear. The Supreme Court has suggested (without clearly saying so) that a state could not define a fetus as fully human prior to viability. *Colautti v. Franklin*, 439 U.S. 379 (1975); *Roe v. Wade*, 410 U.S. 113 (1973); Special Project, *Perspectives on Viability*, 1980 ARIZ. ST. L.J. 128. See generally, Note, *Artificial Gestation: New Meaning for the Right to Terminate Pregnancy*, 21 ARIZ. L. REV. 755 (1979). The strict limitation on withholding treatment from infants is fully consistent with a general right to abortion. By understanding viability as the beginning of human life, for example, one can argue for abortion rights (the destruction of something not yet human) and for severe limits on withholding treatment from infants (destroying something that is human).

19. For discussions regarding the definition of human life which would deny "personhood" status to defective infants see McCormick, *To Save or Let Die—The Dilemma of Modern Medicine*, J. A.M.A. 172 (1974) [hereinafter cited as McCormick]; Note, *Withholding Treatment from Defective Newborns: Substituted Judgment, Informed Consent, and the Quinlan Decision*, 13 GONZ. L. REV. 781, 787-89 (1978) [hereinafter cited as *Substituted Judgment*].

Legislative proposals have been made to define human life as beginning prior to viability notwithstanding the decisions of the Supreme Court. S. 1741, 97th Cong., 1st Sess., 127 CONG. REC. S11514 (daily ed. Oct. 14, 1981); H.R. 900, 97th Cong., 1st Sess., 127 CONG. REC. H128 (daily ed. Jan. 19, 1981); see Hyde, *The Human Life Bill: Some Issues and Answers*, 27 N.Y.L. SCH. L. REV. 1077 (1982) [hereinafter cited as Hyde].

20. In *Bonner v. Moran*, 126 F.2d 121 (D.C. Cir. 1941), a leading child treatment consent case, the court noted that:

[i]n deference to common experience there is general recognition of the fact that many persons by reason of their youth are incapable of intelligent decision. . . . Hence, it is not at all surprising that, generally speaking, the rule has been considered to be that a surgeon has no legal right to operate upon a child without the consent of his parents or guardian.

Id. at 122. See, e.g., *Parham v. J.R.*, 442 U.S. 584 (1979); *Friedrichsen v. Niemotka*, 71

right of parents to make decisions for their children, rests on the right of privacy of parents in child rearing²¹ and on the common law assumption that parents have the greatest possible interest in the physical and emotional well-being of their children.²² Theoretically this strong interest in promoting the best interests of their children will lead parents to make careful medical decisions which advance the health of the child at the least risk to the child.²³ In practice, of course, parents' medical decisions may, in some instances, be influenced by factors which are not consistent with the best interests of the child. The cost of care,²⁴ the effects of the child on the family,²⁵ the fact that

N.J. Super. 398, 177 A.2d 58 (1962); *Lacey v. Laird*, 166 Ohio St. 12, 139 N.E.2d 25 (1956). See Arleen, *Intervention Between Parent and Child: A Reappraisal of the State's Role in Child Neglect and Abuse Cases*, 63 GEO. L.J. 887 (1975); Bennet, *Allocation of Child Medical Care Decision-Making Authority: A Suggested Interest Analysis*, 62 VA. L. REV. 285 (1976); Ewald, *Medical Decision Making for Children: An Analysis of Competing Interests*, 25 ST. LOUIS U. L.J. 689 (1982); Shaw, *Dilemmas of "Informed Consent" in Children*, 289 NEW ENG. J. MED. 885 (1973); Note, *State Intrusion into Family Affairs: Justifications and Limitations*, 26 STAN. L. REV. 1383 (1974). See also note 22 *infra*.

21. The interest in family life and the rights of parents to make important decisions for their children, based on constitutional privacy, and its antecedent constitutional concepts, have been recognized for some time. See *H.L. v. Matheson*, 450 U.S. 398 (1981) (parents have an interest in knowing about immature minors' decisions even when the minors are exercising a constitutionally protected right of privacy, *i.e.*, to obtain an abortion); *Bellotti v. Baird*, 443 U.S. 622 (1979) (legal restrictions on minors which support the parental role aid the child's growth into a mature citizen); *United States v. Orito*, 413 U.S. 139 (1973) (privacy protects marriage, motherhood, child rearing and education); *Roe v. Wade*, 410 U.S. 113 (1973) (privacy protects procreation decisions and includes child rearing); *Wisconsin v. Yoder*, 406 U.S. 205 (1972) (American tradition supports the parents' primary role in their children's upbringing); *Ginsberg v. New York*, 390 U.S. 629 (1968) (the constitution supports the parents' claim to control the upbringing of their children); *Pierce v. Society of Sisters*, 268 U.S. 510 (1925) (parents have a constitutional right to direct the education of their children).

22. See *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1980), *cert. denied*, 445 U.S. 959 (1980); *Zoski v. Gaines*, 271 Mich. 1, 260 N.W. 99 (1935); *Friedrichsen v. Niemoetka*, 71 N.J. Super. 398, 177 A.2d 58 (1962); *In re Hofbaure*, 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979); *Rogers v. Sells*, 178 Okla. 103, 61 P.2d 1018 (1936); *In re Green*, 220 Pa. Super. 191, 286 A.2d 681 (1971); *Weston's Adm. v. Hospital of St. Vincent of Paul*, 131 Va. 587, 107 S.E. 785 (1921); *In re Hudson*, 13 Wash. 2d 673, 126 P.2d 765 (1942). See also RESTATEMENT (SECOND) OF TORTS § 892A (1979); W. PROSSER, LAW OF TORTS § 9 (4th Ed. 1971).

The common law right for parents to make medical decisions for their children, of course, also rested on the property interests of the parents in the children. See Note, *Unequal and Inadequate Protection Under the Law: State Child Abuse Statutes*, 50 GEO. WASH. L. REV. 243 (1982), citing D. BAKAN, *SLAUGHTER OF THE INNOCENTS* 26-32 (1971).

23. Ordinarily, of course, the interests of the child and parents are similar, or the differences in their interests are not significant.

24. See Kindregam, *The Court as a Forum for Life and Death Decisions: Reflections on Procedures for Substitute Consent*, 11 SUFFOLK U.L. REV. 919, 933 (1977) [hereinafter cited as Kindregam].

the child is unplanned and "unwanted" by the parents,²⁶ the parents' religious beliefs (e.g., which proscribe the use of medical care),²⁷ a failure of the parents to fully understand medical treatment issues, or emotional problems of the parents²⁸ may all affect the parents' medical decision concerning the child.

Because parent's interests may conflict with the best interests of their children, the right of parents to make medical decisions for infants is not unlimited. Decisions by parents to withhold necessary blood transfusions for religious reasons,²⁹ to refuse consent for their children to receive vaccinations against dangerous childhood diseases,³⁰ and to voluntarily commit their children to mental institutions³¹ are illustrative of the range of medical determinations by parents which are subject to some review and potential reversal. The general trend seems to be to provide increased review of the critical medical decisions of parents.³²

25. *Id.*

26. *Id.*

27. See note 29 *infra*.

28. Child abuse may be representative of the extreme difference between the interests of the child and the interests of the parents. The frequency of child abuse suggests that parents' emotional problems and the like may often interfere with the best interests of the children. See *In re Clark*, 185 N.E.2d 128 (Ohio 1962).

29. See *Jehovah's Witnesses v. Kings County Hosp.*, 278 F. Supp. 488 (W.D. Wash. 1967), *aff'd per curiam*, 390 U.S. 598 (1968); *In re Ivey*, 319 So. 2d 53 (Fla. Dist. Ct. App. 1975); *Wallace v. Labrenz*, 411 Ill. 618, 104 N.E.2d 769, *cert. denied*, 344 U.S. 824 (1952); *Morrison v. State*, 252 S.W.2d 97 (Mo. App. 1952); *State v. Perricone*, 37 N.J. 463, 181 A.2d 751, *cert. denied*, 371 U.S. 890 (1962); *Application of Brooklyn Hosp.*, 45 Misc. 2d 914, 258 N.Y.S.2d 612 (1965); *In re Clark*, 185 N.E.2d 128 (Ohio 1962).

Courts have been willing to order blood transfusions for unborn children or even for mothers of unborn children. *Raleigh Fitkin-Paul Morgan Mem. Hosp. v. Anderson*, 42 N.J. 421, 201 A.2d 537, *cert. denied*, 377 U.S. 985 (1964). Cf. *Jefferson v. Griffin Spalding County Hosp.*, 247 Ga. 86, 274 S.E.2d 457 (1981) (woman was ordered to submit to a caesarean section if necessary to save the life of an unborn child).

30. *Zucht v. King*, 260 U.S. 174 (1922); *Wright v. DeWitt School Dist.*, 238 Ark. 906, 385 S.W.2d 644 (1965); *Auten v. School Bd.*, 83 Ark. 431, 104 S.W. 130 (1907); *Board of Educ. v. Maas*, 56 N.J. 245, 152 A.2d 394 (N.J. Super. Ct. 1959), *aff'd* 31 N.J. 537, 158 A.2d 330, *cert. denied*, 363 U.S. 843 (1960); *In re Mursh*, 140 Pa. Super. Ct. 472, 14 A.2d 368 (1940). Cf. *Jacobson v. Massachusetts*, 197 U.S. 11 (1905) (upholding statute requiring smallpox vaccinations for residents).

31. *Parham v. J.R.*, 442 U.S. 584 (1979) (parental decision to voluntarily commit minor to a mental institution must be reviewed by an independent professional at the institution).

32. Recent discussions of court intervention in lifesaving treatment for infants include Bennett, *supra* note 5; Goldstein, *Medical Care for the Child at Risk: On State Supervision of Parental Autonomy*, 86 YALE L.J. 645 (1977) [hereinafter cited as Goldstein]; Horan, *supra* note 16; Mueller & Phoenix, *supra* note 1; Robertson, *supra* note 1; Sokolosky, *The Sick Child and the Reluctant Parent—A Framework for Judicial Intervention*, 20 J. FAM. L. 69 (1981) [hereinafter cited as Sokolosky]; Note, *Protecting Chil-*

Particularly when the decision of the parents would put the infant's life in unnecessary jeopardy, a strong state interest in reviewing the decision exists. This, of course, is consistent with the strong state interest in the protection of human life.³³ Some courts have been even reluctant to permit competent adults to refuse lifesaving treatment for themselves.³⁴ There has been particular concern when the refusal of lifesaving treatment is not being made currently by the patient himself.³⁵ "Natural death"³⁶ and other legislation to provide for "living wills,"³⁷ for example, routinely contain procedural and substantive

dren from Parents Who Provide Insufficient Care—Temporary and Permanent Statutory Limits on Parental Custody, 1980 ARIZ. ST. L.J. 953 [hereinafter cited as *Protecting Children From Parents*]; Note, *Judicial Limitations on Parental Autonomy in the Medical Treatment of Minors*, 59 NEB. L. REV. 1093 (1980) [hereinafter cited as *Judicial Limitations*].

33. Although the interest in preserving life is one of the strongest interests the state has, it is generally not thought to be strong enough to prevent an adult from refusing treatment for himself. *In re Osborne*, 294 A.2d 372 (D.C. Ct. App. 1972). See generally, Brankt, *Last Rights: An Analysis of Refusal and Withholding of Treatment Cases*, 46 MO. L. REV. 337 (1981); Richards, *Constitutional Privacy, the Right to Die and the Meaning of Life: A Moral Analysis*, 22 WM. & MARY L. REV. 327 (1981); Ward, *Euthanasia: Medical and Legal Overview*, J. KAN. B.A. 317 (1980); Note, *Right to Refuse Treatment: Under What Circumstances Does It Exist?*, 18 DUQ. L. REV. 607 (1980). But see note 10 *supra*.

34. See note 10 *supra*.

35. Even when courts have permitted treatment to be withheld from incompetent patients they have noted the need to provide some method of assuring that these decisions are appropriate or within legal standards. See, e.g., *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977); *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976); *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S. 2d 266 (1976).

36. CAL. HEALTH & SAFETY CODE §§ 7185-7195 (West Supp. 1981); TEX. REV. CIV. STAT. ANN. art. 459h, §§ 1-11 (Vernon 1982).

See Kaplan, *Euthanasia Legislation: A Survey and a Model Act*, 2 AM. J.L. & MED. 41 (1976); Note, *The California Natural Death Act: An Empirical Study of Physicians' Practices*, 31 STAN. L. REV. 913 (1979); Note, *The Right to Die: A Proposal for Natural Death Legislation*, 49 U. CINN. L. REV. 228 (1980).

37. One proposed model "living will" provides in part:

B. If, due to injury or illness, sudden or gradual, I become incompetent, and my condition becomes such that:

- (1) I am in irreversible coma, in the opinion of the treating physician; or
- (2) I have been continuously unconscious for a period of one week and, in the opinion of my treating physician, I have suffered severe irreversible brain damage which will permanently render me incompetent; (or that even partial physical recovery would be accompanied by severe, irreversible brain damage rendering me incompetent); or
- (3) My condition is terminal and hopeless and death is imminent;

then, as of that time, I withdraw my actual or implied consent to, and substitute this REFUSAL of, all further treatment of me by artificial means and devices (such as the use of a respirator) and all further therapeutic or emergency care; and I direct that all further treatment of me or my condition by such artificial

safeguards to protect against the wrongful withholding of lifesaving treatment by guardians or physicians.³⁸

Despite the strong state interest in protecting the lives of infants, and therefore its interest in reviewing decisions to withhold treatment from infants, only a small percentage of such decisions are reviewed or brought to the attention of the state.³⁹ It is estimated that there are thousands of cases each year in which physicians, with or without the participation and consent of parents, decide to withhold lifesaving treatment from infants.⁴⁰ Yet there are relatively few appellate deci-

means and devices or the rendition of such further therapeutic or emergency care shall cease.

Clarke, *The Choice to Refuse or Withhold Medical Treatment: The Emerging Technology and Medical-Ethical Consensus*, 13 CREIGHTON L. REV. 795, 839 (1980). For another model "living will" see Note, *The Living Will: Already a Practical Alternative*, 55 TEX. L. REV. 665 (1977). See Kutner, *The Living Will: Coping With the Historical Event of Death*, 27 BAYLOR L. REV. 39 (1975); Roth & Wild, *When the Patient Refuses Treatment: Some Observations and Proposals for Handling the Difficult Case*, 23 ST. LOUIS U.L.J. 429 (1979); Comment, *Rejection of Extraordinary Medical Care by a Terminal Patient: A Proposed Living Will Statute*, 64 LA. L. REV. 573 (1979).

38. The California Natural Death Act, for example, requires that the directive to withhold treatment be signed in the presence of two witnesses who are not related to or beneficiaries of the estate of the declarant. Such a declaration is effective for only five years. The form of the directive to withhold treatment is set out in the statute. CAL. HEALTH & SAFETY CODE §§ 7178-7189.5 (West Supp. 1981).

39. It is, of course, impossible to know the percentage of decisions to withhold lifesaving treatment from infants which come to the attention of the legal system. There is currently no enforced requirement that such decisions be reviewed by the state, or even reported to the state. See notes 217-23 and accompanying text *infra*.

Arguably, the failure to provide lifesaving treatment to infants could be required to be reported to the state under state child abuse and neglect reporting statutes. See, e.g., KY. REV. STAT. § 199.335(7)(2) (Supp. 1980) which provides:

Any physician, osteopathic physician, nurse, teacher, school personnel, social worker, coroner, medical examiner, child caring personnel, resident, intern, chiropractor, dentist, optometrist, health professional, peace officer, mental health professional or other person who knows or has reasonable cause to believe that a child is an abused or neglected child, shall report or cause a report to be made in accordance with the provisions of this section. When any of the above specified persons is attending a child as part of his professional duties, he shall report or cause a report to be made in accordance with the provisions of this section.

Id. All the states now have reporting statutes. Brown, *Child Abuse: Attempts to Solve the Problem by Reporting Laws*, 60 WOMEN LAW. J. 73 (1974); Sussman, *Reporting Child Abuse: A Review of the Literature*, 8 FAM. L.Q. 245 (1974).

Courts have apparently not been called upon to determine whether state reporting statutes require such reports when physicians know that medical treatment is being withheld from defective infants.

40. See, e.g., *Medical Ethics Hearings*, *supra* note 2, at 26, where the following discussion is recorded:

Senator Kennedy. . . .

May I ask you about the magnitude of the problem. What are the numbers

sions dealing with these issues and no reason to believe that lower courts are being presented with substantial numbers of these cases.⁴¹

of the children that are being not treated? What numbers are we really talking about?

Dr. Duff. I do not think anyone knows the answer to that question. I guess that our report is the first one that put a figure on the percentages of deaths that occurred as a result of withdrawing or withholding treatment. Our figure is 14 percent.

Senator Kennedy. Fourteen percent of what?

Dr. Duff. Of deaths that occur in our unit. Fourteen percent of 299 deaths occurring there in the period of 2-½ years.

Senator Kennedy. Were what?

Dr. Duff. Were as a result of withdrawing or withholding treatment.

Senator Kennedy. So, can you extrapolate nationally on these figures and reach any approximation?

Dr. Duff. Dr. Cooke did that one time. I am not sure exactly what sort of figure he came up with. I am sure it was several thousand a year.

Senator Kennedy. What would you say, Dr. Cooke?

Dr. Cooke. I tried to figure out that if you took the number of babies you take care of in your intensive care nursery, and multiply it by the number of intensive care nurseries around the country, you would end up with probably several thousand.

Senator Kennedy. Several thousand.

Dr. Cooke. Infants which have had treatment withdrawn, and that withdrawal has been the cause of their deaths.

I think it is fair to point out that physicians tend toward a feeling of omnipotence, and whether all of those infants would have survived or not is another story. Some of them may well have died with treatment.

Senator Kennedy. Can you give us any idea of that?

Dr. Cooke. It would depend very much on the individual cases as to whether or not they would make it through a long period of treatment, but I would think that one could make a rough guess that possibly half might succumb to complications and the like along the line of usual treatment; so we are talking about a couple of thousand infants a year who would have survived if treatment had not been withdrawn. It is not a small problem by any means.

Id.

41. A number of instances in which withholding lifesaving treatment has been brought to the attention of courts involve either petitions for court orders for treatment or criminal charges if withholding medical services leads to the death of the infant. See notes 1 *supra*, 70, 121, 148 & 206 *infra*; *Medical Ethics Hearings*, *supra* note 2, at 9-10 (statement of Dr. Raymond Duff).

Infrequently a case involving withholding treatment comes to the attention of the public. During the 1970's two cases at Johns Hopkins received attention. In both cases simple surgery was refused for infants with Down's syndrome resulting in the death of the infants. In 1972 the New York Times Magazine reported a similar case. Ellis, *Letting Defective Babies Die: Who Decides?*, 7 AM. J.L. & MED. 393, 399-400 (1982). More recently the decision of a Bloomington, Indiana couple to refuse surgery on their infant child (Baby Doe) received wide publicity in the spring of 1982. The parents of the child refused to consent to surgery to connect the child's esophagus and stomach. The child died six days after birth while legal proceedings were underway. The county prosecutor attempted to have treatment ordered for the child. The county court refused to order the treatment and the Indiana Supreme Court did not overturn that decision, although the

Nor is it customary for other governmental agencies to review decisions to withhold lifesaving treatment. While Professional Service Review Organizations⁴² and other hospital review committees may review patient hospital records, these reviews often are concerned primarily with level and cost of treatment (overtreatment) issues. The committees generally do not review the legality of decisions to withhold treatment.⁴³ Even if these committees were inclined to review decisions to deny treatment, they would be at best *post hoc*, functioning only after the death of the infant. Moreover, such committees lack clear criteria on which to make judgments about when withholding treatment is appropriate and legal.

Life and death infant nontreatment medical decisions are gener-

case did not come before the Indiana court as an appeal. The prosecutors considered filing criminal charges but ultimately decided not to do so. *Indiana Baby's Brief Life Provokes Far-Reaching Questions*, The Courier-Journal, April 17, 1982, at A1 col. 1; *No Charges to be Filed in Death of Baby*, The Courier-Journal, April 20, 1982, at C12 col. 1. See also *Born to Die?*, The Louisville Times, May 26, 1982, at C1, col. 5. The Indiana courts have continued to refuse to reconsider the case because it is moot. See The Courier-Journal, Feb. 4, 1983 at B4 col. 5. Additional details concerning the case are difficult to obtain because the Indiana Supreme Court sealed the records of the case. The assistant administrator to the court, Karl Mulvaney, however, indicated that the infant had multiple serious heart defects, that a guardian ad litem had been appointed who declined to join in an effort to overturn the decision to withhold treatment, and that a six person task force reviewed the decision not to treat and concurred with it. Personal conversation with Karl Mulvaney in Indianapolis, Indiana.

Because so little is known about the details of the Baby Doe case, it is virtually impossible to know what standards were applied in the case. If, for example, the child had serious heart defects in addition to the esophageal defect the surgery required may have been contraindicated. The fact that a guardian ad litem was appointed and that a six person committee considered and approved the decision to withhold treatment suggests that a significant review process was employed by the physicians, hospital or courts.

42. P.L. 92-603 (1973) (amended P.L. 95-142 (1977)) established the Professional Service Review Organizations (PSROs) process. PSROs are charged to determine whether services are "medically necessary," the quality of services necessary to meet professionally recognized standards, and whether services could be provided on an outpatient basis. P.L. 92-603 § 1155(a)(1). See J. BLUM, P. GERTMAN & J. RABINOW, *PSROs AND THE LAW* (1977) and a review of the book, Ball, *Review of PSROs and the Law*, 22 St. Louis U.L.J. 534 (1978); Ball, *PSRO: An Alternative to the Medical Malpractice System as a Quality Assurance Mechanism*, 36 Md. L. Rev. 566 (1977); Halvinghurst & Blumstein, *Coping with Quality/Cost Trade-Offs in Medical Care: The Role of PSROs*, 70 Nw. U. L. Rev. 6 (1975).

Since PSROs are authorized to establish norms of care and treatment based on patterns of medical practice and immunize health care providers from failure to provide care beyond these norms, it is possible that PSROs might be used as a vehicle for validating withholding treatment from infants. 42 U.S.C. § 1320(c) (1974).

43. Some hospitals have ethics committees which may review the decision to withhold treatment, but such reviews are not common. Moreover, the ethical review may be advisory only and the committee may not have an opportunity to review the decisions before treatment is withheld. See note 213 *infra*.

ally quietly made by parents and physicians and seldom subject to outside review. Currently, therefore, enforcement of legal standards appears to be difficult, if not impossible. If a physician disagrees with the decision of a parent to withhold treatment, he may seek a court order for treatment;⁴⁴ if parents discover that a physician has held back treatment without their consent, they may seek civil damages or even criminal sanctions.⁴⁵ Court review of decisions to withhold treatment, however, occur infrequently. Hospital personnel may discover physicians and parents are withholding lifesaving treatment and independently seek state intervention, but such action is almost unheard of.⁴⁶

The absence of any formal review of decisions to withhold lifesaving treatment from infants has meant that they are made on an *ad hoc* basis. Principles which are not acceptable to the law may be applied *de facto* in reaching these decisions. For example, if lifesaving treatment which is routinely given to normal infants is not given to mentally retarded or other abnormal children, life and death treatment decisions would be permitted which are based on I.Q. or disfigurement.⁴⁷ The decision not to provide lifesaving treatment is so profound that it should be based on principles which are clear and generally acceptable.⁴⁸

B. Privacy Interests in Medical Treatment of Infants

Two general types of potential privacy interests in nontreatment decisions can be identified: the interest of the parents in child rearing, and the interest of the infant in autonomy. The right of privacy, how-

44. The physician is generally in the best position to know when the parents are refusing lifesaving treatment. Presumably the physician has initiated, or asked the hospital to initiate, most efforts to obtain court ordered treatment for infants. See generally cases cited in note 29 *supra*.

45. See W. PROSSER, LAW OF TORTS § 18 (4th ed. 1971); RESTATEMENT OF TORTS § 59(1) (1934); Brown & Truitt, *The Right of Minors to Medical Treatment*, 28 DEPAUL L. REV. 289, 289-90 (1979); Robertson, *supra* note 1, at 217-44.

46. The Department of Health and Human Services has recently suggested that hospitals may have an obligation to ensure that infants are not denied treatment based on physical or mental handicap (such as Down's syndrome). Failure to provide services to the handicapped, the Department has warned, could result in a hospital being ineligible for federal funding. See notes 223-36 and accompanying text *infra*.

47. *Medical Ethics Hearings*, *supra* note 2, at 29 (testimony of Dr. Robert E. Cooke). See generally RAMSEY, *supra* note 5, at 189-267.

48. The principles used in making infant treatment decisions should be consistent with legal doctrines we are prepared to apply generally. For example, if it is proper to make life and death decisions based on the "value of life" of the infant or on the cost of the infant to the family or on the cost of treatment, then the law must be prepared to consider many other value of life and cost factors in life and death decisions for others as well.

ever, is not absolute,⁴⁹ and a review of the right of privacy does not suggest that the parents have an unrestricted right to refuse medical treatment for their children. It is also doubtful that parents can exercise their children's right of autonomy on behalf of their children by refusing treatment. Even if parents have a privacy right to refuse treatment for themselves, they may not be privileged to exercise a similar right on behalf of their children.

C. *Autonomy Privacy*

The Supreme Court first recognized a specific constitutional right of privacy⁵⁰ in *Griswold v. Connecticut*.⁵¹ In striking down a statute prohibiting married couples from using contraceptives⁵² the Court noted, among other things, the private nature of the relationship between a couple and their physician.⁵³ The Justices could not agree, however, whether the right of privacy emanated from the penumbras of several constitutional guarantees,⁵⁴ or was derived from the ninth⁵⁵ or fourteenth amendments.⁵⁶

49. See, e.g., *Carey v. Population Services Int'l*, 431 U.S. 678 (1977).

50. The historical development of the right of privacy has been documented. See generally Clark, *Constitutional Sources of the Penumbra Right of Privacy*, 19 VILL. L. REV. 833 (1974); Emerson, *Nine Justices in Search of a Doctrine*, 64 MICH. L. REV. 219 (1965); Griswold, *The Right to be Let Alone*, 55 NW. U.L. REV. 216 (1960); Henkin, *Privacy and Autonomy*, 74 COLUM. L. REV. 1410 (1974); Heymann & Barzelay, *The Forest and the Trees: Roe v. Wade and Its Critics*, 53 B.U. L. REV. 765 (1973); O'Connor, *The Right to Privacy in Historical Perspective*, 53 MASS. L.Q. 101 (1968); Note, *Toward a Right of Privacy as a Matter of State Constitutional Law*, 5 FLA. ST. U. L. REV. 633 (1977); Note, *Formalism, Legal Realism, and Constitutionally Protected Privacy Under the Fourth and Fifth Amendments*, 90 HARV. L. REV. 945 (1977); Comment, *Roe v. Wade and In re Quinlan: Individual Decision and the Scope of Privacy's Constitutional Guarantee*, 12 U.S.F.L. REV. 111 (1977).

51. 381 U.S. 479 (1965).

52. *Id.*

53. *Id.* at 482.

54. *Id.* at 484-85. The opinion of the Court, written by Mr. Justice Douglas, suggested that "specific guarantees in the Bill of Rights have penumbras, formed by emanations from those guarantees that help give them life and substance. . . . Various guarantees create zones of privacy. . . . The present case, then, concerns a relationship lying within the zone of privacy created by several fundamental constitutional guarantees." *Id.* (citations omitted).

55. *Id.* at 486-99 (Goldberg, J., concurring). Justice Goldberg, while joining the opinion of the Court, emphasized the importance of the ninth amendment: "To hold that a right so basic and fundamental and so deep-rooted in our society as the right of privacy in marriage may be infringed by the first eight amendments to the Constitution is to ignore the Ninth Amendment and to give it no effect whatsoever." *Id.* at 491.

56. *Id.* at 500 (Harlan, J., concurring), 502 (White, J., concurring). Justice Harlan stated that the proper issue was "whether this Connecticut statute infringes the Due Process Clause of the Fourteenth Amendment because the enactment violates basic values 'implicit in the concept of ordered liberty.'" *Id.* at 500 (Harlan, J., concurring) (cit-

In recognizing the right of privacy, the Court relied upon earlier decisions recognizing privacy-like rights, including decisions related to child rearing.⁵⁷ In *Roe v. Wade*,⁵⁸ the Court ultimately traced the first recognition of the right of privacy to its 1891 decision of *Pacific Railroad Co. v. Botsford*.⁵⁹

In *Eisenstadt v. Baird*⁶⁰ and *Roe v. Wade*,⁶¹ the Court again recognized the right of privacy. In *Roe*, the Court struck down criminal abortion laws and clearly identified the right of privacy with the fourteenth amendment's "concept of personal liberty and restrictions upon state action."⁶² The Court stated that "only personal rights that can be deemed 'fundamental' or 'implicit in the concept of ordered liberty' . . . are included in this guarantee of personal privacy."⁶³ It also noted that the right of privacy, like other fundamental rights, is not absolute and may be limited by narrowly drawn laws which protect compelling

ing *Palko v. Connecticut*, 302 U.S. 319, 325 (1937)).

57. See, e.g., 381 U.S. at 482; *id.* at 495 (Goldberg, J., concurring). Justice Goldberg cited the following cases: *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944) (state statute prohibiting minors from selling merchandise in public places overrides a parent's claim of authority in her own household); *Pierce v. Society of Sisters*, 268 U.S. 510, 534-35 (1925) (recognizing the right to make certain decisions regarding the education of one's children); *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923) (state law prohibiting the instruction of elementary school children in a foreign language unconstitutionally interferes with the power of parents to control their children's education). 381 U.S. at 495. The Court has acknowledged the privacy aspects of all these decisions. See *Carey v. Population Services Int'l*, 431 U.S. 678, 684-85 (1977).

58. 410 U.S. 113, 152 (1973).

59. 141 U.S. 250 (1891) (a court of the United States cannot order a plaintiff in a personal injury action to submit to a physical exam in advance of the trial).

60. 405 U.S. 438 (1972).

61. 410 U.S. 113 (1973).

62. *Id.* at 153. Contending that the specific constitutional basis for the right of privacy was not determinative of the petitioners' entitlement to protection, the Court stated:

This right of privacy, whether it be founded in the Fourteenth Amendment's concept of personal liberty and restrictions upon state action, as we feel it is, or, as the District Court determined, in the Ninth Amendment's reservation of rights to the people, is broad enough to encompass a woman's decision whether or not to terminate her pregnancy.

Id.

63. *Id.* at 152. Although Justice Stewart agreed that the state laws were constitutionally infirm, *id.* at 170-71 (Stewart, J., concurring), he rejected the concept of a constitutionally protected right of privacy. *Id.* at 167 n.2 (Stewart, J., concurring). Crediting the Court's decision in *Griswold v. Connecticut* for influencing his views, he premised his conclusion on the concept of "liberty" protected by the due process clause. *Id.* at 168 (Stewart, J., concurring) (citing *Griswold v. Connecticut*, 381 U.S. 479, 499 (1965) (Harlan, J., concurring)). Justice Rehnquist, dissenting, also criticized the majority's acceptance of a constitutional right of privacy. 410 U.S. at 172-73 (Rehnquist, J., dissenting).

state interests.⁶⁴ The woman's right of privacy in seeking an abortion, for example, is not absolute and may be limited by the state when a compelling interest in the life of the fetus is present.⁶⁵

Although the nature and extent of the right of privacy has remained far from clear,⁶⁶ post *Roe* decisions have reaffirmed the right of privacy particularly as it relates to procreation and home and family life.⁶⁷ The emphasis on family life, child rearing, and medical decisions in privacy law is not surprising since these decisions are among the most fundamental and vital that people make. The criteria for invoking the right of autonomy have been suggested, and child rearing and lifesaving medical decisions would appear to fall squarely within the interests protected by such right.⁶⁸ While it is apparent that parents have a strong privacy interest in the medical treatment their children receive, it is just as clear that this privacy interest is not absolute.⁶⁹

A state interest which is legitimately compelling will justify interference with the right of privacy,⁷⁰ provided the means chosen to further the state interest is the least restrictive reasonable alternative available to the state. In addition, the interest of the state must be advanced to a greater degree than the harm inflicted upon the right of privacy.⁷¹

64. *Roe v. Wade*, 410 U.S. at 155-56 (citing *Eisenstadt v. Baird*, 405 U.S. 438, 460, 463-64 (1972) (White, J., concurring)); *Griswold v. Connecticut*, 381 U.S. 479, 485 (1965); *Aptheker v. Secretary of State*, 378 U.S. 500, 508 (1964); *Cantwell v. Connecticut*, 310 U.S. 296, 307-08 (1940).

65. 410 U.S. at 159.

66. See generally Fried, *Privacy*, 77 *YALE L.J.* 475 (1968); Gerety, *Redefining Privacy*, 12 *HARV. C.R.-C.L. L. REV.* 233 (1977); Gross, *The Concept of Privacy*, 42 *N.Y.U. L. REV.* 34 (1967); Lusky, *Invasion of Privacy: A Clarification of Concepts*, 72 *COLUM. L. REV.* 693 (1972); Parker, *A Definition of Privacy*, 27 *RUTGERS L. REV.* 275 (1974); Soler, *Of Cannabis and the Courts: A Critical Examination of Constitutional Challenges to Statutory Marijuana Prohibitions*, 6 *CONN. L. REV.* 601, 694-714 (1974).

67. See, e.g., *Planned Parenthood of Missouri v. Danforth*, 428 U.S. 52, 60-61 (1975); *Cleveland Bd. of Educ. v. LaFleur*, 414 U.S. 632, 639-40, 648 (1974).

68. Smith, *Constitutional Privacy in Psychotherapy*, 49 *GEO. WASH. L. REV.* 1, 21 (1980) [hereinafter cited as *Constitutional Privacy*].

To invoke the right of autonomy, an individual must satisfy three criteria: first, the government intrusion must invoke a vital personal interest concerning the most fundamental human matters; second, the government action must significantly—not merely incidentally—interfere with this personal interest; and, third, either the government action must not be necessary to advance a compelling state interest, or the governmental action must be more invasive of the personal interest than is required to advance the state interest.

Id.

69. *H.L. v. Matheson*, 450 U.S. 398, 410 (1981).

70. See, e.g., *Roe v. Wade*, 410 U.S. 113, 155-56 (1973).

71. For a more thorough evaluation of the compelling state interest doctrine, see *Constitutional Privacy*, *supra* note 68, at 32-41.

D. Privacy and Withholding Treatment

The decisions to accept or reject lifesaving medical treatment are "fundamental" decisions. They involve serious questions of bodily integrity as well as the critical issue of whether the life of the person should continue. Few questions could be more fundamental or basic.⁷²

There has been a great deal of discussion concerning the state's interest in interfering with a decision to withhold lifesaving treatment.⁷³ Among the most important interests of the state is the preservation of life.⁷⁴ This interest, as important as it is, has increasingly been viewed as insufficient to overcome the privacy or religious interests of a competent adult in deciding to refuse lifesaving treatment.⁷⁵ The interest of the state in preserving life may not be as strong as the individual's interest in being able to choose what invasive medical treatment he will or will not receive.⁷⁶

When the privacy interest of parents in child rearing is compared with the state's interest in preserving life, however, the state's interest is more compelling. The parents may have a right that extends to refusing blood transfusions for themselves.⁷⁷ That they would have a privacy right which extends to refusing a lifesaving blood transfusion for their infant child is less clear.⁷⁸ The state has a stronger interest in

72. The parents' privacy interest in child rearing is undoubtedly fundamental. *See, e.g., Griswold v. Connecticut*, 381 U.S. 479, 480 (1965); *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942); *Pierce v. Society of Sisters*, 268 U.S. 510, 518 (1925). This interest pales when compared with a person's interest in life. A state may clearly interfere with the parents' non-treatment decision in order to preserve human life. *See Roe v. Wade*, 410 U.S. at 163-64, where the state's interest in preserving a viable fetus, whether or not defined as a "human being," is sufficient to justify interference with a woman's child bearing and bodily integrity privacy interests. At some point the state has not only the right, but also the obligation (e.g., due process or equal protection obligation), to protect the lives of wards (children). *See U.S. CONST. amend. XIV, § I*. It has been written that "the right to life is the basis of all other rights and in the absence of life other rights do not exist." *Commonwealth v. O'Neal*, 367 Mass. 440, 449, 327 N.E.2d 662, 668 (1975).

73. *Custody of a Minor*, 375 Mass. 733, 754-56, 379 N.E.2d 1053, 1066-67 (1978); *Raleigh Fitkin-Paul Morgan Memorial Hospital v. Anderson*, 42 N.J. 421, 423, 201 A.2d 537, 538, *cert. denied*, 377 U.S. 985 (1964); *State v. Perricone*, 37 N.J. 463, 477-78, 181 A.2d 751-55 (1962) (describing the criminal law consequences of withholding treatment); *Sokolosky, supra* note 32 at 72; *Judicial Limitations, supra* note 32, at 1113-14.

74. *See* note 73 *supra*.

75. *See* note 10 *supra*.

76. *See, e.g., United States v. George*, 239 F. Supp. 752 (D.C. Conn. 1965); *In re Brooks' Estate*, 32 Ill. 2d 361, 205 N.E.2d 435 (1965); *Brant, supra* note 15, at 340-47 (1981). *But see* *Application of Presidents and Directors of Georgetown College*, 331 F.2d 1000 (D.C. Cir. 1964), *cert. denied*, 377 U.S. 978 (1964).

77. *See* note 76 *supra*.

78. *See, e.g., Wallace v. Labrenz*, 411 Ill. 618, 104 N.E.2d 769 (1952); *State v. Perricone*, 37 N.J. 463, 181 A.2d 751 (1962); *Santos v. Goldstein*, 16 A.D.2d 755, 227 N.Y.S.2d 450 (N.Y. App. Div.), *appeal dismissed*, 12 N.Y.2d 672, 185 N.E.2d 904, 233

preserving the life of an individual against the choices or actions of another than it does in preserving the life of an individual against the individual's *own* choices.

Central to the concept of autonomy is the idea that a person can choose to do things to himself that he cannot choose to do to others.⁷⁹ Even when legally empowered to make decisions for others (i.e., a parent for a child, a guardian for a ward) he cannot exercise the same range of decisions for others as he can for himself. The state's strong interest in preserving the lives of children is certainly strong enough to justify it in interfering with the child rearing decisions of parents.⁸⁰

It might be argued that the state has a less compelling interest in protecting the life of a defective infant than it does a "normal" infant.⁸¹ To the extent that such a claim is based on a view of the relative value of "normal" as compared with "defective" life, the distinction appears to be inappropriate. To suggest that the state interest in preserving life is somehow reduced by a defect would be to alter seriously the traditional legal view of the value of human life.⁸² If a disgruntled employee of a hospital enters the nursery and stabs two infants at random, and if the children die, the attacker is equally guilty of homicide in the death of the normal child and the severely defective child. The victim may not defend against a charge of killing the defective child by claiming that the state interest in protecting the life of the defective child is not as strong as it is in the normal child. If both children are only injured, but require blood transfusions to live, it would be anomalous to suggest that the state may properly order the transfusion (over parental objection) for the normal child, but not the defective child because the state does not have a strong interest in pre-

N.Y.S.2d 465 (1962).

79. The full protection of autonomy interests may require that the state not assist the efforts of one person to interfere with the privacy rights of another. For example, the state cannot properly require that all minor women have their parents' permission to obtain an abortion. *Planned Parenthood of Missouri v. Danforth*, 428 U.S. 52 (1976).

80. See note 78 *supra*.

81. There would be no justification . . . for coercive intrusion by the state [in ordering treatment] in those life-or-death situations . . . in which, even if the medical experts agree about treatment, there is less than a high probability that the . . . treatment will enable the child to pursue either a life worth living or a life of relatively normal healthy growth toward adulthood.

Goldstein, *supra* note 32, at 653.

82. RAMSEY, *supra* note 5, at 224-26; Kelsey, *Which Infants Should Live? Who Should Decide?*, 5 HASTINGS CENTER REP. 5 (1975) (interview with Dr. Raymond Duff); Robertson, *supra* note 1, at 252-55. Cf. *Gleitman v. Cosgrove*, 49 N.J. 22, 227 A.2d 689 (1967) (infant could not recover damages where doctor failed to inform mother of the substantial possibility of serious birth defects).

servicing the life of the defective child.⁸³

Nor does the fact that a defective infant's life expectancy is less than that of a normal infant necessarily reduce the state's interest in preserving that life. The state has a strong interest in avoiding the death of even the very elderly who have a short life expectancy.⁸⁴ There is no suggestion in the homicide statutes that it is less evil to kill a one hundred year old person than it is a thirty year old. The state's interest in preserving life does not appear to be reduced either by some perception of the value of life or the length of one's life expectancy.⁸⁵

E. Substituted Autonomy Privacy

The question whether the state has a sufficiently compelling interest to order treatment over the objections of the parents has been answered in the affirmative.⁸⁶ A more fundamental question has not been adequately examined: *whether autonomy privacy has any meaning in medical treatment decisions regarding children*. Parents, of course, are exercising their own privacy right in child rearing when they make treatment decisions for their children, but are they exercising the *child's* right of autonomy in making medical decisions for the child? The "substituted autonomy privacy" question may be important since the right of autonomy to make medical decisions for oneself seems to be of greater weight than the child rearing privacy interests.⁸⁷

There has been some suggestion that the right of privacy is something that can be exercised for an incompetent by a guardian. In *In re Quinlan*⁸⁸ it was suggested that patients do not lose their right of pri-

83. Nor does it appear that the parents of a defective infant have a stronger privacy interest in child rearing than do the parents of a normal child, or parents seeking to deny treatment for religious reasons.

84. It might be argued that there is a stronger interest in preventing the early death of an infant with a short life expectancy than there is in preventing a similarly "early" death for an elderly patient. There may be a decreasing marginal utility of life in the case of the elderly person, so that each hour of life for an infant with a short life expectancy is more valuable than an hour for the elderly person with a similar life expectancy. The child's opportunity to experience life (of whatever "value" or "quality") is very limited, but the elderly person has had a substantial opportunity to experience existence. Of course, such a theory is purely speculative; there is no way to judge the marginal utility of lives in these situations.

85. While some criminal statutes determine penalties based, in part, on the age of the victim, see, e.g., N.Y. PENAL LAW §§ 130.25-130.35 (McKinney 1975) (penalties for rape dependent on the age of the victim), no penal law in the United States considers the age of the victim of a homicide as a significant factor.

86. See cases cited in note 78 *supra*.

87. Compare the cases permitting adults to refuse treatment for themselves, at note 77 *supra*, with those in which they were not permitted to withhold treatment from their children, at note 78 *supra*.

88. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976). In

vacy when they become incompetent.⁸⁹ Therefore the court permitted a decision to refuse lifesaving treatment to be made by a guardian based on the patient's right of privacy. In *Eichner v. Dillon*, it could be argued that the guardian was protecting the privacy interest of the patient because he was implementing a decision which the patient had expressly said he hoped would be made if he were in a vegetative state.⁹⁰ In both *Quinlan* and *Eichner*, the patients had, in effect, made and expressed judgments about the medical treatment they wished to receive, if in a nonsapient state.⁹¹ These decisions can be viewed as implementing a right of privacy of the patients. To the extent, however, that the guardians were making *independent* choices for the wards based on the wards' right of privacy, serious conceptual problems arise. These same problems concerning the right of privacy arise when the right of privacy is exercised on behalf of an infant.

Autonomy privacy is, at its core, the right to make for oneself decisions about intensely personal matters, and to make these decisions without substantial interference from the government. It is a right of self determination.⁹² The right of privacy undoubtedly has other aspects to it, such as information privacy.⁹³ The right to make personal decisions, however, is the primary focus of autonomy privacy. The

Quinlan, the court permitted the parents of a 22 year-old woman in a nonsapient state to remove her from a respirator, even though it was possible that the removal would result in her death.

89. *Id.* at 25, 355 A.2d at 664.

90. 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (1981). In *Eichner*, Brother Joseph Fox, while undergoing surgery, suffered cardiac arrest and substantial brain damage, resulting in a nonsapient state from which there was no hope of recovery. Father Eichner sought permission to have Brother Fox removed from the respirator which was keeping him alive. Noting Brother Fox's wishes, expressed while he was competent, the court granted permission for removal from the respirator. The court expressly stated that it was not reaching the issue of the patient's right to privacy. *Id.* at 376-77, 420 N.E.2d at 73, 438 N.Y.S.2d at 272-73. *See also* *Severns v. Wilmington Medical Center, Inc.*, 421 A.2d 1334 (Del. 1980) (guardian may vicariously assert the rights of a comatose patient, including the right to refuse or discontinue medical treatment).

91. There are serious difficulties in determining whether a patient actually would have refused treatment. If he or she has not clearly indicated when treatment should be withheld, the guardian may be speculating about what the patient would have decided had he or she thought about it. This "what the patient would have decided" of "substituted judgment" standard should be based on the general beliefs and values of the patient. It is, of course, impossible to apply such a standard when dealing with infants. They could not have developed values and beliefs upon which their decisions regarding treatment could be predicated.

92. *See* the discussion of autonomy privacy and the criteria for applying it, notes 50-71 *supra*.

93. The Supreme Court has identified information privacy as a branch of the right of privacy. *Whalen v. Roe*, 429 U.S. 589, 598-600 (1977). *See* *Nixon v. Administrator of General Services*, 433 U.S. 425, 457-59 (1977); *Constitutional Privacy*, *supra* note 68, at 27-32.

right of privacy recognizes and gives meaning to the fact that individuals have different belief systems, fears, goals, feelings about the nature and value of life, and judgments about the quality of various aspects of their lives. Privacy protects the right of individuals to make important personal choices based on these and other highly individual factors.

If individual choice is seen as the core of the right of autonomy, such right does not necessarily protect the *autonomy interests* of a patient to transfer decision making authority over to a guardian. The transfer may protect the "best interests" (e.g., physical health interests) of the ward, but it does not necessarily protect his autonomy interests. If the guardian attempts to make decisions based on such factors as the ward's belief systems and personal feelings (as the guardians in *Eichner* and *Quinlan* arguably did),⁹⁴ then the autonomy interests of the ward might be exercised by the guardian. When, on the other hand, a guardian uses his own values, fears and beliefs to make decisions for a ward, he is not protecting the ward's right of self determination or autonomy nor necessarily implementing the ward's personal feelings and choices.

It is just as futile to talk of parents exercising the autonomy privacy interests of an infant as it is to have them exercise the religious interests of the infant. Parents may exercise their own privacy interests in child rearing and may be given the obligation of protecting the child. They, however, cannot exercise an independent right of the child to self determination because they cannot apply all of the personal beliefs and feelings upon which autonomous decisions depend. Just as the parents could not refuse a blood transfusion based on the *infant's* beliefs as a Jehovah's Witness,⁹⁵ so they also cannot refuse the transfusion based on the *infant's* right of privacy.

II. THE NATURE OF LIFE AND DEATH DECISIONS FOR INFANTS

Life and death decisions for infants are of greater variety and complexity than is often recognized.⁹⁶ Treatment decisions are not one dimensional. By recognizing the variety of situations which arise involving life and death decisions in infants, some of the issues in withholding lifesaving treatment may be more easily identified.

Three general divisions of factors involving life and death decisions for infants may be suggested: (1) the status of the infant; (2) the action or inaction proposed for the infant; and (3) the effects on the

94. See notes 88-90 *supra*.

95. See note 29 and accompanying text *supra*.

96. Often a fair number of the complexities are considered by commentators and courts, at least implicitly. However, the full range of complexities and variables has neither been clearly identified nor fully described. See, e.g., RAMSEY, *supra* note 5, at 145-267; Horan, *supra* note 1; Mueller & Phoenix, *supra* note 1.

family and the family's reasons for the decision.

A three dimensional matrix can be constructed by arraying each of the three general factors along an axis of the matrix. Along the horizontal axis the proposed actions or inactions are presented, such as "Refuse Extraordinary-Experimental-Treatment," and "Refuse Extraordinary-Nonexperimental-Treatment."⁹⁷ Along the vertical axis are arranged the various statuses of the infant, ranging from a life threatening condition which is fully correctable to an immediate life threatening condition which is correctable plus an uncorrectable terminal condition. The reasons for the actions of the parents or others for refusing treatment are along the third axis and include "Family Disruption or Promotion," "Financial Consideration," and "Religious Beliefs."⁹⁸

A relatively simple matrix is set out on page 1148. (The third dimension is not fully drawn.) The notes at the end of the matrix explain other factors which would complicate the matrix.

"Life-Threatening" on the chart refers to a condition or disease which will most likely result in the death of the infant in the foreseeable future if not treated.⁹⁹ It is a correctable condition in the sense

97. The use of an experimental/non-experimental distinction to differentiate between ordinary and extraordinary treatment is discussed at notes 122-26 and accompanying text *infra*.

98. Whether the reasons for parental refusal of treatment are relevant or not may be debatable. It may be that the focus should be on the child and the child's need for treatment, rather than on the parents' reasons for nontreatment. See Bennett, *supra* note 5, at 301-03. On the other hand, some claims to parental decision-making undoubtedly have a stronger basis than others, e.g., a parental decision based on first amendment religious rights might be given greater weight than a parental decision based solely on financial considerations. When life and death decisions are involved, of course, the interests of the state (and the child) in preserving life have generally been thought to be strong enough to overcome even first amendment rights and privacy rights of the parents. See notes 1, 5 & 29 *supra*. The consequences for the family of ordering treatment or of the continued existence of the defective infant are also presented along the third axis. The extent to which the "consequence" for the family is a legitimate factor in treatment decisions is considered at notes 131-38 and 167-72 and accompanying text *infra*.

99. The difficulty of determining with precision whether a condition will result in death in the foreseeable future, and is, therefore, life threatening, is illustrated by *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980). There, a 12-year old with Down's syndrome required surgery to correct a hole between the ventricles of his heart. Without the surgery he would suffer increasing lung damage which would probably result in his death within twenty years. With the surgery, he would have a chance for a normal life expectancy. The court refused to order the surgery in part because of the risks inherent in the procedure.

Is this type of treatment lifesaving when death will not occur for perhaps another twenty years, but the irreversible deterioration begins immediately? It would seem that the direct and irreversible consequences of nontreatment in such a case justify classifying the condition as life threatening. Given the severity and intractability of the consequences to the child, the court's decision is difficult to justify and has been criticized as

3rd Dimension-Reason for Decision (and Consequences for the Family)		Status of Child						Life Threatening (correctable) Normal child	Life Threatening (correctable) + Chronic (uncorrectable) Condition:	(a) (b)	Life Threatening (correctable + Terminal Disease)(c)	Well Child (no life threatening)		Child With Terminal Disease (c)					
		Religious Beliefs		Family disruption or strengthening	Quality of Life of the Infant	"Too Danger- ous"	Finan- cial Consd.- erations					Do Not Want Child	physical condition	mental condition	physical & mental	Normal	Chronic uncorrectable condition (d)	Normal	Another chronic uncorrectable condition (d)
		Body	Soul																
"Treatment" Decisions																			
"Passive Euthanasia"	Refuse "Extraordinary" <u>Experimental (F)</u>													a					
	Treatment (e) <u>Nonexperimental</u>													A					
	Refuse <u>With Substantial Risk</u>													b					
	"Ordinary" <u>Pain</u>													a					
	Treatment <u>Without Substantial Risk</u>													b					
	<u>Pain</u>													c					
"Active Euthanasia"	<u>Pain</u>													d					
	Refuse <u>Nonmedical Necessities</u>													C					
	Administer <u>Dangerous Pain Palliative Measures</u>													D					
	Administer <u>Direct Euthanasia</u>													E					
														1					
														2					
													I						
													1						
													2						
													3						
													4						
													5						
													6						
													III						
													1						
													2						
													IV						
													1						
													2						
													V						

Notes to A Decision Matrix

- (a) The effect of the child on the family (and the family's feelings about the child) could be listed as another factor affecting the status of the child, but this is presented in the third dimension.
- (b) The continuance of the seriousness of chronic conditions is not set out fully, but is represented by "mild" and "profound" categories.
- (c) An array of the life expectancy could be present here ranging from one day to more than a year.
- (d) The variations described in II, 1 to II, 6 could be arrayed here but are removed from simplicity.
- (e) The substantial pain and risk categories expressed in E (ordinary treatment) may also be applicable in extraordinary treatment but are removed here for simplicity.
- (f) "Extraordinary" may, or may not, be the same thing as "experimental" treatment. See notes 111-115.

that through treatment the condition can be eliminated or improved to the extent that it does not present a threat of death, that the probability of survival is significantly improved, or that the life expectancy of the infant is measurably improved.¹⁰⁰ Examples of life threatening conditions are serious bacterial infections, bowel obstructions and the loss of blood.

A chronic condition is a disease or defect which is not directly life-threatening but is not correctable¹⁰¹ because current medical knowledge cannot substantially eliminate the problem. Chronic conditions are divided into physical and mental conditions.¹⁰² The infant, however, may and often does have chronic physical and mental conditions

failing to realistically consider the child's best interests. See, e.g., Robertson, *Legal Aspects*, *supra* note 1, at 221-22.

100. In dealing with life threatening conditions, there is little difference between "lifesaving" treatment and "life prolonging" treatment. See Note, *No-Code Orders vs. Resuscitation: The Decision to Withhold Life-Prolonging Treatment from the Terminally Ill*, 26 WAYNE L. REV. 139, 149-51 (1979). All treatment is ultimately only life prolonging. Therefore, using a distinction between lifesaving and life prolonging does not appear to be a very useful basis on which to make medical treatment decisions. To the extent that "life prolonging" is meant to refer to treatment which cannot ultimately fully cure a condition, such a definition would cover too wide a range of disorders, running from diabetes to life threatening cancers. "Life prolonging" might also refer to treatment which will add only a very insignificant time to the length of the patient's life. See *A Standard for Nontreatment*, *supra* note 1, at 624 (suggesting that treatment which would only extend life six months to a year should be at the option of the parents). This concept of "life prolonging" treatment raises issues similar to those in "terminal" patient treatment. See notes 173-75 and accompanying text *infra*.

101. There are many conditions with which a short life expectancy is associated, although they are not directly and immediately life threatening. Conditions such as these are considered to be chronic, although at some point the condition may be one with a life expectancy so short that it must be considered terminal, e.g., trisomy 13. It is not at all clear that the classification of a disease as terminal rather than chronic should have any treatment implications.

102. The mental conditions (although they also have physical aspects) which have received the most attention regarding lifesaving treatment are Down's syndrome, trisomy 13 and similar genetic defects. See, e.g., Mueller & Phoenix, *supra* note 1, at 502.

Physical conditions commonly considered are myelomeningocele and spina bifida (an incompletely formed spinal column and exposure of the spinal column through the back). *Id.* at 502-03. There is treatment for these cases, although it is likely to be protracted and there is no assurance of success, particularly in severe cases. See Robertson, *supra* note 1, at 214. Lifesaving treatment for a child with spina bifida was ordered in *In re Cicero*, 101 Misc. 2d 699, 421 N.Y.S.2d 965 (N.Y. Sup. Ct. 1979); see Lorber, *Results of Treatment of Myelomeningocele*, 13 *Develop. Med. & Child Neurol.* 279, 300 (1971) [hereinafter cited as Lorber]; Matson, *Surgical Treatment of Myelomeningocele*, 42 *PEDIATRICS* 225 (1968) [hereinafter cited as Matson]; Zachary, *Ethical and Social Aspects of Treatment of Spina Bifida*, 2 *LANCET* 274 (1968). Jonsen points out that the most common medical treatment problem in the nursery is prematurity which often involves respiratory difficulties and brain damage. Jonsen, *Ethics, the Law, and the Treatment of Seriously Ill Newborns*, in *LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS* 236-38 (A.E. Doudera & J.D. Peters eds. 1982).

simultaneously and this is recognized in the matrix.¹⁰³ Chronic conditions, whether physical or mental, are of varying degrees of seriousness. Mental retardation, for example, may be very mild or extremely profound. The degree or seriousness of a chronic defect is in reality a continuum, but because the continuum cannot be adequately presented in a matrix it is represented by the extremes of "mild" and "profound."

A terminal condition is a life-threatening disease or defect which is not correctable.¹⁰⁴

The first three major divisions on the vertical axis present the circumstances where lifesaving treatment decisions must be made. In the first column (column I), a normal child with no chronic or terminal (nontreatable) conditions, requires medical services. For example, a normal child is badly cut and requires a blood transfusion to survive. In the columns in the second division a child with the need for lifesaving treatment (e.g., the same blood transfusion) also has another condition which is chronic and uncorrectable ranging from a mild physical condition (column II, 1) to profound physical and mental conditions (column II, 6). An example (column II, 4) is the severely mentally retarded child who is cut and needs a blood transfusion. The third column refers to a child with a condition immediately life-threatening and who also has a terminal illness. There are, of course, a variety of terminal illnesses and the life expectancies of infants with treatment available may vary with different terminal illnesses. The matrix does not include separate categories for the various lengths of life expectancy that "terminal condition" includes. In one sense, of course, life is a terminal condition, but in the context used here terminal condition ordinarily suggests a very limited life expectancy, e.g., less than one year.¹⁰⁵ The life-threatening condition may or may not be related to the terminal illness. For example, a child with a deadly childhood cancer may require a transfusion because of a serious injury or because of the pro-

103. The presence of a chronic condition is often a critical factor in treatment decisions. Infants with chronic conditions are, essentially, what is commonly referred to as defective newborns. See, e.g., Brant, *supra* note 15, at 365. The legitimacy of using a chronic condition as a basis for making treatment decisions is a major consideration in much of the rest of this article.

104. See notes 105 & 173-75 and accompanying text *infra* for a discussion of terminal illness as it relates to treatment decisions.

105. The one year period is arbitrary, although it has been suggested that when there is a life expectancy of less than one year the parents should have greater latitude in rejecting treatment. A *Standard for Nontreatment*, *supra* note 1, at 624. The use of the word "terminal" in making treatment decisions is a problem because it is often difficult to reliably determine whether a condition is terminal until after the subject has died. *United States v. Rutherford*, 442 U.S. 544, 556 (1979). The difficulty also arises with the suggestion that life expectancy of an infant is an appropriate basis on which the law may begin to remove its protection from infants. See text accompanying notes 173-75 *infra*.

gress of the disease. In either case the failure to provide the blood is likely to be fatal.

The last two major divisions, columns IV and V, do not suggest situations in which lifesaving treatment is necessary. Rather, they will help clarify some issues regarding children similarly situated who do require lifesaving treatment.¹⁰⁶

The horizontal rows set out the treatment decisions, or perhaps more accurately the nontreatment decisions, which may be made in response to life-threatening situations. The first two major divisions, rows A and B, suggest the refusal of "extraordinary" and "ordinary" medical treatment. Although poorly defined and confusing, the extraordinary/ordinary distinction is commonly used,¹⁰⁷ and is therefore represented in the matrix. As the ordinary/extraordinary distinction is replaced by more precise concepts, these concepts would replace ordinary/extraordinary in the matrix. Experimental treatments would undoubtedly be considered extraordinary, but there may be nonexperimental, standard treatment forms such as respirators which some would consider extraordinary.¹⁰⁸ Medical treatments may vary considerably in terms of risk to the patient, and of the pain and discomfort they cause.¹⁰⁹ Again a continuum, risk and pain in this instance, is represented by two points: the presence of and absence of substantial risk or pain. Row C involves the withholding of nonmedical necessities for life, e.g., food or water.¹¹⁰

The first two or three major divisions of the horizontal rows (A, B, C) refer to what are often described as forms of "passive euthanasia." The last two or three major divisions (C, D, E) deal with what may be

106. The clarification comes, for example, by comparing a "well" child (infant without a current life threatening illness) who has a chronic uncorrectable condition, e.g., profound retardation (IV,2) with a similarly situated child who also has a life threatening illness (II,2; II,4; or II,6). Would it be any more appropriate to withhold treatment or nonmedical necessities from the child who has an easily correctable life threatening disease (II,4) than it would be to withhold nonmedical necessities from a child without the immediate life threatening illness (IV,2) or from an otherwise normal child who has a life threatening illness (V,1) or no such illness (IV,1)?

107. The wisdom of such a distinction is considered at notes 119-50 and accompanying text *infra*.

108. The ordinary/extraordinary distinction probably is not commonly made on the basis of whether or not treatment is experimental. Respirators, although hardly experimental, may be viewed as extraordinary treatment. See *In re Quinlan*, 70 N.J. 10, 48, 355 A.2d 647, 668, cert. denied, 429 U.S. 922 (1976).

109. The risk of death (reduced life expectancy) or substantial pain may be appropriate matters to be considered in making infant treatment decisions. See notes 196-200 and accompanying text *infra*.

110. In many respects, withholding nonmedical necessities may not be substantially different from withholding medical necessities. See notes 190-92 and accompanying text *infra*.

considered types of "active euthanasia."¹¹¹ Withholding nonmedical necessities (Row C) may be considered active or passive euthanasia.

The fourth major division, row D, describes the application of treatment aimed solely at alleviating pain or suffering rather than improving or curing a life-threatening condition. This pain palliation may be dangerous in that it may shorten the life of the infant. An example would be the administration of strong pain medications which might ultimately interfere with the cardiac centers of the child, causing death sooner than it would have occurred without the pain medication.¹¹²

The final division, row E, is "Direct Euthanasia" which is taking direct steps, such as injecting a toxic substance into the infant, to cause death. It serves no medical purpose and it is different from row D in that it is not given as a pain palliative (although some might suggest that it is the ultimate pain palliative).¹¹³

The third dimension involves the reasons for and the consequences for the family withholding treatment, and is represented in the upper left hand corner of the matrix.¹¹⁴ The reasons presented are only illustrative of the range of reasons for withholding treatment. Parents may have religious reasons for withholding treatment. For example, they may believe that ordinary medical treatment should be withheld because religious healing offers a better chance of curing the child.¹¹⁵ This belief is included on the chart under "Body." The par-

111. It might be argued that the "refusal of nonmedical necessities" should be considered passive euthanasia because it involves inactivity rather than taking active measures to cause death. On the other hand, passive euthanasia more commonly refers to withholding medical treatment. See notes 176-87 and accompanying text *infra*.

Drawing a clear line between active and passive euthanasia may not be critical because there is serious doubt that it provides an appropriate legal standard in these care decisions. *Id.*

112. See notes 199-200 and accompanying text *infra*.

113. Direct euthanasia, or active euthanasia, is discussed at notes 185-88 *infra*.

114. The reasons for treatment decisions are likely to be complex combinations of the considerations listed plus a number of other factors, e.g., the psychological dynamics of the parents and the advice of the physician. See Kindregam, *supra* note 24, at 933.

115. In *Mitchell v. Davis*, 205 S.W.2d 812 (Tex. Ct. App. 1947), a mother refused to provide medical treatment for her child because of her absolute faith in the power of religion to overcome disease. The court permitted custody to be transferred to a juvenile officer who could consent to medical treatment for the child. Furthermore, in *People v. Pierson*, 176 N.Y. 201, 68 N.E. 243 (1903), the court upheld a conviction for willful neglect in the death of a child when the parents failed to get medical help because of their belief in divine healing. These cases are similar to the situations in which the parents wish to select an unconventional therapy for a life-threatening condition when conventional therapy is available. For example, in *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978), the court ordered that custody be transferred to the public welfare department so that consent could be given to conventional chemotherapy for a child with leukemia after the parents insisted on stopping chemotherapy and limiting treatment to a special dietary plan. *But see In re Hofbauer*, 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979) where the parents were permitted to choose to treat their child

ents may believe it is better that the child's life be placed in jeopardy rather than risking the child's, or their own, soul for violating what they believe to be God's commandments.¹¹⁶ The chart column "Soul" designates this belief. Treatment might also be declined by parents because it would be too expensive, or the treatment or child too disruptive to the rest of the family.¹¹⁷ Conversely, of course, the infant, or the tribulations associated with treatment, may strengthen the family. The effect on the family and financial costs of treatment are also the consequences of a treatment decision. These consequences may be important to the extent that a broad cost/benefit analysis is used in making treatment decisions.¹¹⁸

III. ORDINARY/EXTRAORDINARY DISTINCTION

A distinction between ordinary and extraordinary medical treatment has been drawn by several courts and commentators.¹¹⁹ The theory is that one has the responsibility to accept ordinary medical care but not the duty to accept or provide "heroic" measures to sustain life.¹²⁰ Presumably, heroic measures are the same as extraordinary care.

There are several problems with using the ordinary/extraordinary distinction in making treatment decisions. It seems difficult to translate whatever the general ordinary/extraordinary distinction means into practical decisions; it is difficult to define and apply. An even more fundamental problem is that there does not seem to be a common and

who had Hodgkin's disease with "metabolic therapy" rather than conventional therapy.

116. The refusal of blood transfusions is commonly of this type—the transfusion is refused because it is felt that there is a Biblical injunction against consuming blood, and that the risk of death is less important than the eternal risk of violating the Biblical injunction. *See note 29 supra*.

117. It is sometimes suggested that the effect on the family is a legitimate consideration in making lifesaving treatment decisions. This author's conversations with several infant care physicians indicate that this is, in fact, a common consideration in decisions to treat seriously ill newborns, particularly defective neonates. *See generally* Duff & Campbell, *supra* note 2; Duff & Campbell, *On Deciding the Care of Severely Handicapped or Dying Persons: With Particular Reference to Infants*, 57 *PEDIATRICS* 487 (1976).

Such an approach is not fully consistent with the "best interest of the child," a standard which is commonly used as the proper standard for decisions concerning infants. *See note 136 and accompanying text infra*. The use of "all the circumstances" (whether or not related to the child) standard is discussed at notes 132-40 and accompanying text *infra*.

118. *See notes 140-41 and accompanying text infra*.

119. *See, e.g., In re Severns*, 425 A.2d 156 (Del. Ch. 1980); *Satz v. Perlmutter*, 379 So. 2d (Fla. Sup. Ct. 1980); *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976); Horan, *supra* note 1, at 82-85; Levin & Levin, *supra* note 1, at 568-71; *Substituted Judgment*, *supra* note 19, at 798-807.

120. The term "heroic" is of course no more specific or clear than "extraordinary."

clear understanding of what the *basic concept* of extraordinary treatment is.

Extraordinary treatment may mean, or has been taken to mean, a wide variety of things. At the very least this results in the risk that the term will be used in one way in one instance, but mistakenly used in another instance to withhold treatment in a manner which suggests an entirely different legal concept.¹²¹ Extraordinary might mean experimental, generally accepted, customary treatment under the circumstances, a very high cost/benefit ratio, very invasive, or treatment that most people would reject.¹²²

If extraordinary care means experimental treatment,¹²³ then the justification for not requiring that a legally incompetent patient be given extraordinary treatment which may or may not be beneficial, should be viewed as a protection of the incompetent patient.¹²⁴ The law should not impose an obligation to make an incompetent person a human guinea pig.¹²⁵ The interests of an infant are not, for example,

121. A court determining that parents are justified in not consenting to experimental lifesaving treatment, but couching that decision in terms that parents need not accept "extraordinary treatment," might be mistaken by other parents to mean that treatment with a high cost/benefit ratio need not be accepted. The court's ruling would then have been expanded presumably well beyond what was initially intended. See notes 123-47 and accompanying text *infra*.

122. Other concepts also might be labeled "extraordinary." The more definitions of "ordinary" and "extraordinary" that are developed, the more confusing the term becomes. For example, in dealing with defective infants, one definition of ordinary is "those medical and surgical procedures that would apply in situations not involving physically or mentally handicapped persons." Robertson, *supra* note 1, at 213 n.1.

Another definition, however, states that "[o]rdinary means all medicines, treatments, and operations, which offer a reasonable hope of benefit . . ." and defines extraordinary as "those treatments which cannot be obtained or used without excessive expense, pain . . . or which, if used, would not offer a reasonable hope of benefit." Kelly, *The Duty to Preserve Life*, 12 THEOL. STUDIES 550, 550 (1951). This very broad definition might presumably permit treatment with a high probability of success to be withheld because it involves "excessive" expense or pain.

123. Determining when a treatment is "experimental" is sometimes difficult. Prescription drugs may be considered experimental if they are not approved for marketing by the Food and Drug Administration (i.e., if they are in Phase I, II or III of testing). See E. MARTIN & R. MARTIN, HAZARDS OF MEDICATION 44-49 (1978). Since Phase III involves extensive clinical testing, some might consider Phase III not to be experimental.

Determining the experimental nature of treatments not involving new drugs is particularly difficult. Those treatments might be considered experimental until there is sufficient experience with them to indicate that they are effective and relatively safe.

124. See, e.g., Ramsey, *supra* note 5, at 208-12; Bennett, *supra* note 5, at 326.

125. See generally Capron, *Informed Consent in Catastrophic Diseases Research and Treatment*, 123 PA. L. REV. 340 (1975); Bartholome, *Proxy Consent in the Medical Context* in National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *Research Involving Children* 3-23-54 (1977) [hereinafter cited as National Commission].

necessarily advanced by requiring that parents accept all the experimental treatment available.¹²⁶

Ordinary care may be taken to mean generally accepted or commonly used treatment.¹²⁷ The use of common antibiotics to cure certain bacterial infections, surgery to remove a bowel obstruction, and blood transfusions to replace lost blood are examples of "ordinary" care. On the other hand, there are some techniques or treatments which are not experimental because there is sufficient experience with their use, but which are new and not commonly accepted as standard treatment. Newly approved drugs often fit in this category.¹²⁸ Determining whether a treatment is experimental, new, or standard and generally accepted, is not always an easy task, although these distinctions periodically play an important role in medical malpractice cases.¹²⁹ When treatment is lifesaving there does not appear to be strong justification for not requiring the utilization of available treatment, even if new. If extraordinary means "new but not experimental," a rule requiring that infants never be given extraordinary (i.e. new) lifesaving treatment would not be justified.¹³⁰ When no satisfactory standard treat-

126. The decision to accept lifesaving treatment that is truly experimental may then be seen as within the range of decisions properly left to the parents. There are, of course, limits on the experimentation that can be done on children even with the consent of their parents. When the experiment may save or prolong the life of the infant, parents should have broad authority to consent to experimental treatment. See National Commission, *supra* note 125, at 73-123.

When a life threatening condition is present and there is no conventional treatment available, parents will presumably accept many forms of experimental treatment as a last hope.

If all experimental treatment may be withheld even in life threatening situations, it is probably desirable to narrowly define experimental treatment.

127. Dowben, *Prometheus Revisited: Popular Myths, Medical Realities, and Legislative Actions Concerning Death*, 5 J. HEALTH POL., POL'Y & L. 250, 258-59 (1980) [hereinafter cited as Dowben]; Robertson, *supra* note 1, at 213 n.1.

128. The first use of drugs following F.D.A. licensing would be an example of a new, nonexperimental use. Arguably, Phase III testing of a drug (broad clinical testing prior to licensing) would also fit in this category. See E. MARTIN & R. MARTIN, HAZARDS OF MEDICATION 45-49 (1978).

129. See generally *Karp v. Cooley*, 493 F.2d 408 (5th Cir. 1974); *Salgo v. Leland Stanford Univ. Bd. of Trustees*, 154 Cal. App. 2d 560, 317 P.2d 170 (1957); *Fortner v. Koch*, 372 Mich. 273, 261 N.W. 762 (1935). See note 121 *supra*.

130. But see *In re Green*, 12 CRIME & DEL. 377 (Child. Ct., Milwaukee County, Wisc., March 18, 1966).

When action is necessary to save a life, the fact that a treatment is new does not seem to justify refusing such treatment at least as long as it is not experimental. This does not, however, suggest that the parents are completely free to accept a "new" treatment as opposed to a widely accepted conventional therapy. See *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978). But see *In re Hofbauer*, 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979). A treatment might be considered "new" if it has substantial scientific support even though it has not received sufficiently wide acceptance to be

ment is available and the result of nontreatment is death, the risks inherent with a new (but nonexperimental) treatment are generally going to be dramatically lower than the risk of nontreatment (death).

Extraordinary might instead refer to care not customarily given to patients for a disorder *under the circumstances presented by this patient*.¹³¹ Unlike the previous definition, circumstances other than a life-threatening medical condition may be taken into account. The other "circumstances" which would be considered might be limited to the physical and mental condition of the patient, or it might be broad and include the family, social and economic circumstances of the patient.¹³² Under this definition what is ordinary for one patient might be extraordinary for another with the same medical condition. Consider, for example, surgery to correct an infant's bowel obstruction, a standard procedure. Utilizing this definition of extraordinary care, such treatment might be required to be given to the normal infant. The same surgery on another infant who is retarded or deformed and whose family cannot cope with his condition and the needed medical treatment, might not be required.¹³³ One difficulty with this concept of extraordinary is that the "circumstances" which may be legitimately considered are not identified.¹³⁴ The circumstances might reasonably be limited to factors which make the surgery medically unsound (e.g., the infant would surely die from the trauma of surgery) or futile (e.g., the infant

considered the standard treatment.

It has been suggested that parents should be permitted to legally refuse lifesaving treatment if the parents "are confronted with conflicting medical advice about which, if any, treatment procedure to follow." Goldstein, *supra* note 32, at 653. One of the difficulties with such a standard is that it would appear to prevent courts from ordering medical treatment to save the life of an infant if any medical authority, even a very limited minority of the profession, is at odds with the overwhelming majority of medical authority. See *In re Hofbauer*, 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979).

131. See generally *In re Quinlan*, 70 N.J. 10, 48, 355 A.2d 647, 668, *cert. denied*, 429 U.S. 992 (1976).

132. Strong arguments against using such factors are presented in *RAMSEY*, *supra* note 5, at 201-08. It is not possible to tell how frequently family, social and financial factors play a major role in nontreatment decisions. See *Medical Ethics Hearings*, *supra* note 2, at 5-7.

133. Such a case arose in *Maine Medical Center v. Houle*, No. 74-145, (Super. Ct., Cumberland County, Me. Feb. 13, 1974), *reported in Brant*, *supra* note 15. Because the parents of a defective newborn refused to consent to heart surgery, the court made the infant a ward of the state and ordered surgery.

134. As indefinite as this definition of "extraordinary" may seem, it is a model of clarity when compared to the definition contained in the North Carolina Natural Death Act. That statute provides that "[e]xtraordinary means' is defined as any medical procedure or intervention which in the judgment of the attending physician would serve only to *postpone artificially* the moment of death by sustaining, restoring, or supplanting a vital function." N.C. GEN. STAT. § 90-321(a)(2) (1980 & Cum. Supp. 1981) (emphasis added). Presumably the purpose of most medical treatment is to interfere with natural forces and thereby "artificially postpone" death.

will die at about the same time from another condition which is untreatable).¹³⁵ It may, however, permit factors to be considered in making the nontreatment decision, which are arguably unacceptable (e.g., some perception of the quality of life) or not necessarily in the best interest of the child (e.g., financial or family considerations).¹³⁶ Another problem with this definition is that it requires the medical community to define by custom what is essentially a legal or social issue with medical aspects: when may lifesaving treatment be legally withheld? This is a question of the legal rights of infants and children, not one of medical science.¹³⁷ Because this definition relies on medical custom it is critical to know what medical custom is. This, however, may be difficult to determine with any precision in many circumstances.¹³⁸

"Extraordinary" care might also be taken to mean care in which the costs are greater than the benefits. A cost/benefit analysis of extraordinary which would consider whether the costs are greater than the benefits, poses problems similar to those involved in the "under the circumstances" definition.¹³⁹ The delineation of the proper costs and benefits to be considered becomes central, but difficult since one must look at whether all "costs" to the family, the doctors, and society should be considered or only costs to the child.¹⁴⁰ In addition, of course, it is difficult to recognize all of the benefits when dealing with an infant and impossible to realistically weigh them. Even using the

135. In practice it is virtually impossible to predict when another condition will cause death in the immediate future. Homicide is ultimately, of course, nothing more than "shortening life." W. LAFAVE & A. SCOTT, *HANDBOOK ON CRIMINAL LAW* § 35, at 250 (1972). A medical-feasibility standard which would allow lifesaving treatment to be withheld if life expectancy is short is also dangerous. Since the decision to terminate treatment is irreversible, the medical prognosis must be made with a high degree of certainty. Although it would appear to diminish the degree of certainty, some commentators have suggested extending the boundaries of the definition of "imminent death" to six months, a year, and even longer. See *A Standard for Nontreatment*, *supra* note 1, at 624.

136. The best interest of the child is the standard which is commonly a matter of statute and decision. *Finloy v. Finloy*, 240 N.Y. 429, 148 N.E. 624 (1925); A. FREUD, J. GOLDSTEIN & A. SOLNIT, *BEYOND THE BEST INTEREST OF THE CHILD* (1973).

137. See notes 1-4 and accompanying text *supra*. Similarly, the decision of a woman to have an abortion may have a substantial medical component, but her right to do so is properly a question for the legal system. See *Roe v. Wade*, 410 U.S. 113, 143 (1973).

138. Medical customs, often difficult to establish, usually play a central role in medical malpractice cases. For an excellent consideration of the problems inherent in relying solely on medical custom in establishing an appropriate standard of care, see *Helling v. Carey*, 83 Wash.2d 514, 519 P.2d 981 (1974). See also Keeton, *Medical Negligence—The Standard of Care*, 10 TEX. TECH. L. REV. 351 (1979); King, *In Search of a Standard of Care for the Medical Profession: The "Accepted Practice" Formula*, 28 VAND. L. REV. 1213 (1975); Pearson, *The Role of Custom in Medical Malpractice Cases*, 51 IND. L.J. 528 (1976).

139. See notes 131-35 and accompanying text *supra*.

140. See notes 152-70 and accompanying text *infra*.

very interesting analysis process proposed by Wesley Sokolosky¹⁴¹ it would be extremely difficult to perform such an analysis in infant non-treatment decisions in a way that would provide a consistent definition of extraordinary and would eliminate nonlegitimate considerations from the decision.¹⁴²

The broad cost/benefit analysis has a superficial utilitarian appeal. Making life and death decisions based in part on whether the death of one person would be good for others, however, has not generally been the basis for legal decisions. The "best interests of the child" has been the prevailing standard in child treatment and custody cases. Under a broad cost/benefit approach standard, life and death decisions would be determined by considering the best interests of the family and of the state. However, including the avoidance of emotional or financial problems ("costs") to another in the best interests of the family or state, would substantially alter the law's emphasis in the sanctity of life and the individual. Allowing life to be terminated involuntarily to avoid nonlife-threatening harm to others would establish a dangerous principle which could not necessarily be limited in its application to defective children.

Ordinary treatment might also be defined in terms of what treatment the average person would want to have if he were in a similar position.¹⁴³ There is some difficulty, of course, in determining what the average person would want in terms of treatment. A Gallup poll on the issue might be fascinating but of little value given the number of variables involved. Even information about what treatment the average person would want for himself might be of limited value in deciding what to do when treatment is required for an infant with a life-threatening disease, particularly if the infant has another serious chronic condition. This is a situation which is not a part of the experience or even reasonable imagination of most people. Even speculating as to what one would want in such circumstances is difficult and unreliable.

Extraordinary might be taken to mean "extremely invasive."¹⁴⁴ An

141. Sokolosky, *supra* note 32. Sokolosky has suggested an approach to treatment decisions based on Bayes' theorem, aimed at ensuring that all relevant factors are considered. All alternative courses are clearly defined, the risks and benefits, including the likelihood and desirability of each alternative are established and the alternatives are compared. *Id.* at 85-95. This process requires that numerical values be assigned to the likelihood of an outcome or event, and to the consequences of proposed treatment or nontreatment. *Id.* at 86-87.

142. Sokolosky recognizes that the "difficulty establishing a numerical probability or desirability for any given consequence of a medical treatment alternative would limit its [Bayes' theorem approach] usefulness." *Id.* at 86.

143. One court has noted that the fact that most people would accept the proposed treatment may be a relevant factor in determining "ordinary treatment." Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417, 432 (Mass. 1977).

144. See *In re Spring*, 1980 Mass. Adv. Sh. 1209, 405 N.E.2d 115 (1980); Brant, *supra*

extremely invasive procedure might be defined as one which requires substantial, extensive, and perhaps long term, interference or manipulation of the body accompanied by great pain and discomfort.¹⁴⁵ Withholding extraordinary treatment in this sense might be based on the proposition that there are some proposed forms of treatment that will be accompanied by so much pain, discomfort and interference with the body that even lifesaving treatment is not worth the suffering.¹⁴⁶ This definition of extraordinary depends upon a situation where pain or discomfort may overwhelm any opportunity to enjoy or appreciate life.¹⁴⁷

Extraordinary treatment might refer to such a variety of different concepts that it cannot legitimately be used in making nontreatment decisions for infants or other legally incompetent patients. Some of the concepts which may be included in extraordinary are unclear and virtually impossible to apply consistently,¹⁴⁸ or are open to interpretations permitting treatment to be withheld in circumstances which are, at the very least, arguably unacceptable.¹⁴⁹ Therefore, the use of extraordinary by courts and commentators is confusing and dangerous. Since it may mean different things, the approval of the use of the concept in making treatment decisions may be expanded well beyond what is intended by a forum using it.¹⁵⁰ The use of extraordinary treatment confuses the debate regarding withholding treatment and should be eliminated and replaced by a term or phrase more clearly identifying the idea intended.

IV. STANDARDS FOR NONTREATMENT DECISIONS

The Decision Matrix demonstrates not only the complexity of infant care decisions, but also a number of the factors or standards which might be applied in making lifesaving treatment decisions.¹⁵¹ In this

note 15, at 366.

145. See generally Symonds, *Mental Patients' Rights to Refuse Drugs: Involuntary Medication as Cruel and Unusual Punishment*, 7 HASTINGS CONST. L.Q. 701 (1980) (discussion of the constitutional limits of involuntary treatment).

146. See Brant, *supra* note 15, at 344-47.

147. See *Substituted Judgment*, *supra* note 19, at 798-99. See also notes 195-217 and accompanying text *infra*.

148. See, e.g., notes 127 & 141 and accompanying text *supra*, and the discussion of "generally accepted" and "cost/benefit" as defining terms of extraordinary treatment.

149. See notes 195-217 and accompanying text *infra*.

150. See note 121 *supra*.

151. Sokolosky has suggested that a matrix based on Bayes' theorem could be constructed in infant treatment cases to compare the desirability of alternative treatments and nontreatment. Sokolosky, note 141 *supra*. Ellis has suggested that legislatures construct a treatment matrix as part of the process of defining situations in which treatment may be withheld from infants. The matrix proposed by Ellis lists specific infant medical conditions along one axis and the nature and consequences of the treatment/nontreatment along the other axis. Ellis, note 141 *supra* at 418-20.

section these factors are considered to determine if there are any reasonable bases upon which infant treatment decisions can be made.

A. Normal and Abnormal Infants

One essential issue posed by the matrix is whether otherwise normal infants with life-threatening conditions should be treated differently than children with the same condition who are in addition physically or mentally abnormal; or in other words, whether it is proper to draw treatment distinctions between infants based on a condition of the child not directly related to the life-threatening disease. In addition, the question is raised whether it matters that the abnormality is profound or mild. Much of the quality of life discussion collapses to these kinds of questions.¹⁵² Recall the situation posed earlier where simple surgery to remove a bowel obstruction is required by an infant.¹⁵³ Death, often occurring after a long and painful period of time, is the almost certain result of nontreatment. Suppose one of the infants is normal, one has been born without legs, and another is a profoundly retarded baby. We may assume that the law would require that the first child be given treatment to save its life. But should the second child or the third child be treated differently because of the abnormalities?¹⁵⁴

Permitting life and death decisions to be made on the basis of physical or mental capacities is a position that our law has not traditionally taken and should not adopt.¹⁵⁵ It raises the most serious policy, and even constitutional, issues.¹⁵⁶ There appear to be two ratio-

152. Issues regarding the position of the infant relative to his family and the burden placed on the family and society may also play a role in these decisions. See notes 130-41 and accompanying text *supra* and notes 168-70 and accompanying text *infra*.

153. See note 133 and accompanying text *supra*.

154. The question may also be stated in terms of parental autonomy: may the family in one instance be permitted to withhold lifesaving treatment (e.g., where the child is severely retarded), while the family with a normal child is not permitted to withhold the same treatment? The issue is whether the existence of even profound mental retardation is a basis on which the state should remove its protection of life.

155. In *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977), for example, the court noted that it was improper to consider the "value" of life in making treatment decisions. *Id.* at 760, 370 N.E.2d at 432. The court did, however, permit a reduction in the quantity of life to avoid a significant loss in the quality of the life remaining. *Id.*

The suggestion has been made that the selection of patients for treatment is a substituted judgment about the quality of life. *Substituted Judgment*, *supra* note 19, at 797-98. A decision to treat in every case may not represent a decision about the quality of life. It may represent, however, a decision that the quality of life is too speculative or too dangerous a concept to play a legitimate role in making such decisions.

156. Fourteenth amendment equal protection and due process issues come to mind. When nontreatment will result in death, for the law to require treatment for normal

nales for permitting the refusal of treatment to an abnormal child which would be required for a normal child: (1) the life of the child is not worth living because of the abnormality; and (2) the burden placed on the rest of society (e.g., the family, hospital, financial institutions) by the continued existence of the child is not worth the life itself. In either case it is not a decision about treatment that is being made so much as it is a decision whether to take advantage of the fortuitous presence of a life-threatening disease to cause the death of the infant.

Terminating or permitting the termination of another's life because of a feeling that the life is not worth living poses very serious dangers.¹⁵⁷ It rests on the assumption that reasonable judgments about the quality of another's life can be made, and the assumption that the life of an abnormal child is less acceptable or meaningful than that of a normal child to the point that allowing or causing the death of the abnormal child is justified.¹⁵⁸ The tradeoff is *not* between the "quality

children but not defective children suggests a rule of profound consequences based upon mental retardation or physical deformity. Cf. *Mills v. Board of Educ.*, 348 F. Supp. 866 (D.D.C. 1972) (failure of school board to provide special education to mentally retarded and emotionally disturbed children violates fourteenth amendment).

There does not appear to be any strong state interest to support different treatment on the basis of physical or mental condition. See generally Sherlock, *Selective Non-Treatment of Newborns*, 5 J. MED. ETHICS 139 (1979); Sherlock, *Selective Non-Treatment of Newborns: A Critique*, 7 J. MED. ETHICS III (1980).

157. "Slavery, witchhunts and wars have all been justified by their perpetrators on the grounds that they held their victims to be less than fully human." Bok, *Ethical Problems of Abortion*, 2 HASTINGS CENTER REP. 33, 41 (Jan. 1974). Tooley's suggestion that equal treatment need only apply to those with a capacity for a "sense of self" is dangerous in that the right to treatment would be subject to the definition of a "sense of self." Tooley, *Abortion and Infanticide*, 2 PHIL. & PUB. AFFAIRS 37, 49 (1972). Having adopted this concept of equal protection one needs only to determine how to define "concept of self" in the proper way to remove the protection of law from many groups. The state's interest in avoiding unnecessary expenses of caring for defective, as opposed to normal, infants does not appear to be strong enough to justify the normal/defective distinction in treatment decisions. The protection of parental interests in decision-making seems no stronger in the case of a defective child than for a normal child. The medical community's interest in not having to treat or associate with defective infants does not seem adequate to draw these life and death distinctions. For a discussion of state interests in these decisions, see Bennett, *supra* note 5; Sokolosky, *supra* note 32, at 72-73; *Judicial Limitations*, *supra* note 32, at 1113-14.

158. The judgment is actually between a life which is less than normal and no life at all. The degree to which this can be taken is illustrated by *Zepeda v. Zepeda*, 41 Ill. App. 2d 240, 190 N.E.2d 849 (1963). In *Zepeda*, an illegitimate child sought damages from his biological father for having caused his birth, suggesting that it would be better never to have been born than to be born illegitimate. While the court denied relief in deference to the legislature's role of establishing this type of tort action, it did recognize the validity of the child's argument. *Id.* at 243, 190 N.E.2d at 853. If the *Zepeda* child had needed lifesaving treatment at birth, could the mother appropriately refuse the treatment because it would be better for the infant not to survive than to survive as an illegitimate child? That illegitimacy might be thought to be sufficient to make "no life at all" better

of life"¹⁵⁹ and "quantity of life"¹⁶⁰ or the giving up of some length of life to obtain a more active and happier, albeit shorter, life.¹⁶¹ Often the choice in these decisions is between continuing a life of uncertain or unknown quality and bringing an end to the life without increasing the quality of life.

In fact, we often do not know enough about the quality of the life of a defective newborn to make these judgments. Some may view the quality of life prospects for a child born to a large, uncaring family living in poverty to be quite limited, but it does not seem proper to withhold lifesaving treatment on that basis.¹⁶² Yet it is not clear that the quality of life of a profoundly mentally retarded infant is any less than it is for the other child. There is such a variety of views about what is valuable in life that it is unlikely that there could be any agreement on what was "valuable" even if we could fully understand what a defective child was experiencing or going through.¹⁶³

Consider the most extreme form of mental abnormality, anencephaly.¹⁶⁴ It might be argued persuasively that human life requires consciousness of higher brain activity which children with anencephaly do not possess and therefore that they are not really alive.¹⁶⁵ A definition of life requiring the presence of *higher* brain activity is not consistent with the current brain death standards in which any brain activity is enough.¹⁶⁶ The real point regarding the perma-

than "living" demonstrates the potential range of the "life worth living" decisions.

159. See Hyde, note 19 *supra*.

160. *Id.* at 1088.

161. There are circumstances in which a legitimate tradeoff is called for between the quality of life and quantity (length) of life. See notes 185-89 and accompanying text *infra*.

162. Some may view the prospects of life in the current world as very bleak. A psychiatrist relates that he has seen a patient who was very caring and even loving toward his child. At the same time the psychiatrist believed that there was some danger that the patient might try to kill the child to protect the child from the great pain and suffering associated with living. It was difficult for the patient/father to understand what pleasure the child may find in life. In a different way, it is difficult for us to appreciate what the life of a defective newborn is like. But the perspective from which we view the value of a life may be considerably different from the one actually experiencing the life. See *People v. McQuiston*, 12 Cal. App. 3d 584, 90 Cal. Rptr. 687 (1970). The defendant killed his two normal children. He described it as a mercy killing which he would repeat because he believed they would be better off dead than to continue living with their mother dead and their father in prison.

163. See Hyde, note 19 *supra*.

164. See note 17 and accompanying text *supra*.

165. See note 16 *supra*.

166. Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, *A Definition of Irreversible Coma*, 205 J.A.M.A. 337 (1968). The use of the brain death standard is detailed in note 15 *supra*. See also A Collaborative Study, *An Appraisal of the Criteria of Cerebral Death*, 237 J.A.M.A. 982 (1977); Ad Hoc Committee of the American Electroencephalographic Society on EEG Criteria for Determination

nently unconscious patient (e.g. the anencephalic) is not that he has a low quality of life, but that he has no life at all. Thus the issue is the definition of human life, not of treatment.

It is also unacceptable to withhold treatment from infants to cause death when the basis for withholding treatment is, in part, the negative financial, social or economic impact the infant will have on the family or others. The proposition that one person's life should be ended by others to avoid potential social or economic harm is contrary to the most fundamental concepts of individual rights and protection central to our laws and constitution.¹⁶⁷ It would surely be unacceptable as a general rule of law and there seems to be no legitimate reason to apply such a principle to defective infants.¹⁶⁸ Some suggest, perhaps unfairly,

of Cerebral Death, *Cerebral Death and the Electroencephalogram*, 209 J.A.M.A. 1505 (1969). See generally Abram, *The Need for Uniform Law on the Determination of Death*, 27 N.Y.L. SCH. L. REV. 1187 (1982).

167. These predictions and calculations involved the value of the child's life with a defect versus a quick end to life, the life expectancy of the infant, and the effect of the infant's life or death on the family. These factors, in addition to the relative value (cost/benefit) of each effect, the financial impact on a family or a hospital of treating the infant, and the tradeoffs between these factors are not possible for physicians and other interested parties to determine.

"If physicians are going to play God under the pretense of providing relief for the human condition, let us hope they play God as God plays God." RAMSEY, *supra* note 5, at 203.

168. The fact that a continuation of treatment will socially or financially harm others does not appear to be a strong basis for state sanctioning of invasive, let alone life threatening, action. In comparison, parents who wish to have a minor committed to a mental hospital, not for the benefit of that child, but for some general benefit to other children, could not have the child involuntarily committed. Most states require mental illness and serious danger to others to justify involuntary commitment. See *Suzuki v. Yuen*, 617 F.2d 173, 178 (9th Cir. 1980); A. STONE, *MENTAL HEALTH AND LAW: A SYSTEM IN TRANSITION* 47-51 (1975); Developments, *Civil Commitment of the Mentally Ill*, 87 HARV. L. REV. 1190, 1201-07 (1974); Note, *Overt Dangerous Behavior as a Constitutional Requirement for Involuntary Civil Commitment of the Mentally Ill*, 44 U. CHI. L. REV. 562 (1977). Even voluntary commitment of a child requires more than just the consent of the parents. An independent decision-making process is needed, although this need not be in the form of an adversary or judicial proceeding. An independent medical and psychiatric investigation will protect children who should not be admitted. See *Parham v. J. R.*, 422 U.S. 584, 613 (1979).

Even when the benefit is saving the life of another at the cost of physical invasion involving limited risk to a child or incompetent adult, courts have only reluctantly consented to kidney transplants. The situation arises when a child or incompetent is the only compatible donor so that if consent to donate the kidney is refused, the patient, often a brother or sister, will probably die. Even when the courts have sanctioned a guardian's approval of the transplant, they have done so reluctantly, often by finding that the transplant is really in the best interest of the incompetent donor. *Hart v. Brown*, 29 Conn. Supp. 368, 289 A.2d 386 (1972); *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. 1969). Other courts have refused to permit the transplant to occur. *In re Richardson*, 284 So. 2d 185 (La. App. 1973); *In re Pescinski*, 67 Wis. 2d 4, 226 N.W.2d 180 (1975). If it is improper to permit a kidney transplant donation to save the life of another, it appears to

that such decisions raise the spectre of Nazi treatment of life.¹⁶⁹ Should the principle be established that treatment may be refused for infants when their lives are too costly to others, there would be no strong reason not to apply the same principle broadly, to the mentally ill, the seriously handicapped, the elderly infirm, and so on.

The calculation of the value of an infant's life and the negative consequences of life to others becomes very complex and extremely speculative.¹⁷⁰ It in part requires a prediction of the "net utility" (broadly defined pleasure, less displeasure) that the infant will experience from life, and that this be calculated on the basis of how the infant *himself* will perceive this pleasure and pain; and finally that the infant's predicted net utility be compared with the predicted pleasure and pain the infant will bring to the family and any number of other individuals viewed, again, from their perspectives. This calculation is, of course, so speculative as to be impossible. In part it is this kind of speculation that makes a "too costly to society" principle dangerous. Without any reliable information on which to make these decisions, they are made on the basis of hunches, fears, suspicions and prejudices and often a feeling that lives substantially different from our own are imperfect. These are generally inappropriate bases on which to make life and death decisions and may often cause us to undervalue considerably the lives of those who are different.

The speculative nature of quality/cost of life decisions might be viewed as a reason to leave this calculation within the sphere of parental childrearing decision-making; when we cannot predict with certainty what is in the best interest of the child or the family, we should leave it to the parents to decide. To one degree or another, of course, the future quality of life of any child is uncertain and speculative. The degree to which that uncertainty increases in abnormal children is far from clear; many Down's syndrome children are said to be quite happy, for example. While uncertainty about the future of a child or the desirability of some forms of treatment does create substantial latitude in the family, it does not create a general power in the family to withhold treatment when that would cause the child's death, even when the family claims to be acting in what they perceive to be the broadest best interests of the child. A parental decision that it is better for a child to die for lack of blood than to violate God's commands by accepting a

be improper to cause the death of an infant to avoid social or financial burdens to the family. *But see* R. Veatch, *Guardian Refusal of Life-Saving Medical Procedures*, unpublished manuscript cited in *Substituted Judgment*, *supra* note 19, at 803 n.96. *See* note 192 *infra*.

169. *Medical Ethics: Hearings*, *supra* note 2, at 7 (testimony of Dr. Raymond Duff).

170. *See* Silving, *Euthanasia: A Study in Comparative Criminal Law*, 103 U. PA. L. REV. 350, 356-58 (1954); *but see* *Medical Ethics Hearings*, *supra* note 2, at 7-8 (statement of Dr. Raymond Duff).

transfusion cannot be supported on the basis of the uncertainty or speculative nature of what is in fact in the long term best interests of the child. Nor could a decision be upheld to withhold a transfusion because the parents believe that a child's life will not be worth living due to a missing limb. Furthermore, the parents of defective infants may be in a particularly bad position to make speculative quality or cost of life calculations when life and death decisions are involved; they may have conflicting interests or emotionally be unfit to make the decisions.¹⁷¹

The law cannot accept, as a basis for denying lifesaving treatment, the claim that a child will not have a life worth living or that the child will have negative social or economic effects on the family. The utilization of mental or physical abnormality as a basis for making life and death decisions is inconsistent with the belief that human life should be protected without regard to status, form or defects.¹⁷² To make decisions for others based on the quality of life or social and economic costs to others establishes a most dangerous principle. It is at odds with our most basic concepts of individual rights and freedoms, it invites abuse, and it is basically impractical because it requires the calculation of the net utility of the lives of others in a way which is so speculative as to be impossible.

171. See notes 241-43 and accompanying text *infra* for a discussion of parental decision-making.

172. On this point the medical and legal systems seem to be diverging. Medical opinion appears to be moving in the direction of approving the withdrawal of treatment with the purpose of causing death in light of the expected quality of life, broadly defined to include effects on those close to the patient. This viewpoint was emphasized by Dr. Warren Reich in his testimony before the Congress:

[T]here is growing within the medical profession a quality of life ethic according to which only those who have the capability of a meaningful life deserve protection and the requirements for a meaningful life seem to be constantly expanding to include such qualities as self awareness, self-direction, substantial use of one's faculties, social relatedness and so forth.

Medical Ethics Hearings, supra note 2, at 30 (statement of Dr. Warren Reich). In conversations with physicians about withholding treatment the "quality of life" was routinely used as an important criterion for making infant nontreatment decisions. See Duff & Campbell, *supra* note 2, at 890.

On the other hand, contemporary legal authorities often reject quality or value of life, especially when broadly defined, as a basis for treating or not treating infants and incompetents. In *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 754, 370 N.E.2d 417, 432 (1977), the court rejected quality of life as the basis for withholding treatment of a mentally retarded adult. See *Maine Medical Center v. Houle*, No. 74-145 (Super. Ct., Cumberland Co., Me. Feb. 13, 1974), reported in Brant, *supra* note 15, at 366 n.150; *Gleitman v. Cosgrove*, 49 N.J. 22, 227 A.2d 689 (1967); Robertson, *supra* note 1, at 252-55; *A Standard for Nontreatment, supra* note 1, at 620-23.

B. Terminal Illnesses

Children with terminal illnesses may present different considerations.¹⁷³ Treatment for a correctable life-threatening condition may become futile in that the terminal illness is likely to cause death before, or at about the same time as the treatable condition would if left untreated. Terminal illnesses may also make common treatment for other generally treatable conditions impossible, or very risky, or extraordinarily painful.¹⁷⁴ The fact that an infant has a terminal condition should not, in and of itself, justify all refusal of treatment, nor does it justify routinely treating children who have a chronic uncorrectable condition as well as a terminal condition any differently than "normal" children with terminal diseases.¹⁷⁵

C. Active and Passive Euthanasia

The horizontal rows of the Decision Matrix may be broadly divided into active¹⁷⁶ and passive¹⁷⁷ euthanasia with the refusal of treatment, and perhaps nonmedical necessities, being passive euthanasia. The difference between active and passive euthanasia is essentially based on the distinction between action and inaction. Broadly defined, passive euthanasia is death caused by inaction.¹⁷⁸ Active euthanasia is taking direct action which causes death.¹⁷⁹ While there has been some

173. *In re Green*, 12 Crim. & Rel. 377 (Ct. Milwaukee County, Wis. March 18, 1966), reported in Brant, *supra* note 15, at 366 n.150. It has, however, been suggested that "terminal" is not a concept that can be used in making medical decisions because the term cannot be defined with any accuracy. *United States v. Rutherford*, 422 U.S. 544, 556 n.14 (1979).

174. See notes 195-200 and accompanying text *infra*.

175. "Terminal" illness or condition plays a role in some natural death statutes. See notes 36 & 37 and accompanying text *supra*. California, New Mexico, Texas and other states, require that the patient's condition be terminal before a life-support system is removed. Terminal is not defined, however, leaving a substantial ambiguity in the legislation.

176. By definition, active euthanasia would include row E, the administration of direct euthanasia. The administration of pain palliative measures, row D, would probably also be included when these measures are likely to have the effect of shortening life, even though their purpose is to improve the quality of life that remains. Some also view the withholding of nonmedical necessities, row C, as active euthanasia. Even though row C involves inaction, the duty to provide basic food and water is clearly established. As this section of the article suggests, the author sees no strong reason to treat the withholding of nonmedical necessities any differently from the withholding of lifesaving treatment, at least that lifesaving treatment which does not involve extensive severe pain.

177. Passive euthanasia includes the withholding of medical treatment, whether extraordinary or ordinary (rows A and B), and perhaps withholding nonmedical necessities (row C).

178. See notes 202-07 and accompanying text *infra*. See generally Abrams, *Active and Passive Euthanasia*, 53 *PHILOSOPHY* 257 (1978).

179. *Id.*

support for passive euthanasia,¹⁸⁰ there has been little support for active euthanasia, at least as it relates to infants.¹⁸¹ Superficially, at least, the action/inaction distinction seems to be based on the traditional legal concept that one may legally permit something to happen even when it would have been illegal to cause it to happen.¹⁸² Even in life-threatening situations one may be permitted to refuse to rescue another when the rescue could be accomplished safely and easily.¹⁸³ The action/inaction distinction starts to break down, however, when one has a duty to care for another.¹⁸⁴ A parent, for example, would probably not have the privilege of refusing to rescue his or her child from a swimming pool when the rescue could be accomplished without risk.

The active/passive euthanasia distinction appears to be somewhat artificial in many infant care decisions. Where care is refused for the purpose of causing death and when death is virtually certain to result from the refusal of treatment there seems to be no real difference between withholding treatment and taking direct action to cause death.¹⁸⁵ The decision to withhold treatment is being made by those responsible for the care of the child and the failure to provide for medical care necessary to sustain life is a breach of the duty of care.¹⁸⁶

180. See Fletcher, *Prolonging Life*, 42 WASH. L. REV. 999 (1967); Levin & Levin, *supra* note 1, at 572-74.

181. This type of active euthanasia may be viewed as infanticide. See note 214 and accompanying text *infra*. But see Rachels, *Active and Passive Euthanasia*, 292 NEW ENG. J. MED. 78 (1975).

182. See RESTATEMENT (SECOND) OF TORTS §§ 314, 315 (1965).

183. W. PROSSER, LAW OF TORTS 340-48 (4th ed. 1971).

184. RESTATEMENT (SECOND) OF TORTS §§ 314A(4), 320 (1965). See Frankel, *Criminal Omissions: A Legal Microcosm*, 11 WAYNE L. REV. 367 (1965); Perkins, *Negative Acts in Criminal Law*, 22 IOWA L. REV. 659 (1937).

185. The distinction between action and inaction in lifesaving or life prolonging treatment has received strong support. Horan, *supra* note 1, at 76 (quoting Louisell, D., 1972 Pope John XXIII guest lecturer, Catholic University Law School).

It is difficult to see the value of the distinction when the almost certain result of inaction is death. The concept of "letting nature take its course" (e.g., letting an untreated infection or bowel obstruction cause the death of an infant) suggests that it is appropriate to permit death to occur by inaction (natural causes) when it would be inappropriate to directly cause death. As a general principle, however, this broad "let nature take its course" proposition is unacceptable. We surely are not willing to "let nature take its course" by letting an infant starve to death, nor drown if he or she fell into a lake alone, nor freeze to death by letting an infant wander into the elements. In fact, we are not prepared to let nature run its course by refusing to treat a serious infection with antibiotics if the infant is normal. The principle being proposed then must be more in the way of letting nature run its course (cause the death of an individual) through inaction when the individual is one who we perceive not to have a worthwhile life and when the inaction is the withholding of medical treatment.

186. Of course, there still remains the question of what the extent of that duty ought to be. For example, should it extend to providing experimental care, or customary care, or noninvasive care?

Indeed, a parent who knowingly refuses to provide an antibiotic to cure a life-threatening infection and intentionally causes the death of the child, may be criminally liable.¹⁸⁷

If, *arguendo*, a parent does not have a duty to provide medical treatment because the life of the infant is viewed as not worth living, there seems to be no good reason why the parent has a duty not to administer active euthanasia. Indeed the administration may be viewed as humane for the same reasons that withholding treatment is viewed as humane: active euthanasia permits the infant to avoid a life not worth living or filled with pain. In the example of the infant with the bowel obstruction, the failure to perform surgery will result in a period of painful waiting for an almost certain death.¹⁸⁸ This pain could be avoided by the administration of euthanasia. Certainly if the quality of life of the infant with treatment will be so bad as to justify refusing treatment, the quality of life preceding death in this example must be viewed as even worse.¹⁸⁹

Active euthanasia would also avoid the merciful shortening of the lives of *only* those infants with poor life quality who fortuitously develop other life-threatening diseases. If a Down's syndrome or trisomy 13 child has such a poor quality of life that lifesaving treatment can legitimately be withheld, it seems unreasonable, and even unfair to the infant, to require that he develop a life-threatening disease to accomplish the goal of ending his life.

The above should not, of course, be taken as a general endorsement of active euthanasia. It is meant only to suggest that the blanket distinction between active and passive euthanasia cannot be fully supported when the purpose of withholding treatment is to cause the cessation of a life viewed as not worth living or as socially or economically too costly. Such decisions are not merely treatment decisions. They are decisions to use the life-threatening condition as the means of terminating the life and, when made by those with the duty of care this nontreatment is similar to direct euthanasia.

D. Medical Treatment/Nonmedical Necessity Distinction

Parents have the obligation to provide nonmedical necessities, such as food and water, for their children.¹⁹⁰ If it is permissible for

187. See note 1 and accompanying text *supra*.

188. A review of the medical literature discloses cases where the parents of a child with Down's syndrome refused consent for surgery to remove a bowel obstruction. The child died of starvation after fifteen days of withholding treatment. Rowe, *Infanticide: Who Makes the Decision?*, 73 Wisc. Med. J. 10, 10 n.5 (1974). See note 41 *supra*.

189. See generally cases cited at note 41 *supra*.

190. The withholding of food and shelter from children has served as the basis of criminal liability for parents and guardians. See, e.g., *State v. Crawford*, 188 Neb. 378,

parents to withhold medical treatment for the purpose of causing the death of the infant, the reasons for not permitting the withholding of nonmedical necessities to accomplish the same end should be explored.¹⁹¹

Perhaps one reason to require that parents uniformly provide non-medical necessities such as food and water, even if they may withhold lifesaving treatment, is that the obligation to provide sustenance has a longer tradition than medical care.¹⁹² Another reason may be that the withholding of nonmedical necessities will likely lead to a slow painful death while withholding medical treatment is likely to be less painful and more humane.¹⁹³ These reasons do not provide a strong justification for permitting the withholding of lifesaving medical treatment while not permitting the withholding of nonmedical necessities. Failing to give an infant water, which will surely result in his death, is not substantially different from failing to give him an antibiotic for a life-threatening infection. If it is acceptable to refuse to provide lifesaving medical treatment to an infant for the purpose of causing his death, it seems just as acceptable to deny nonmedical necessities under the same circumstances.

E. Risk and Pain and Palliative Measures

There may be some circumstances in which the withholding of nonexperimental treatment is reasonably justifiable.¹⁹⁴ The circum-

196 N.W.2d 915 (1972); *Zessman v. State*, 573 P.2d 1174 (Nev. 1978); *State v. Zobel*, 81 S.D. 260, 134 N.W.2d 101, *cert. denied*, 382 U.S. 833 (1965).

191. The withholding of nonmedical necessities such as food, water and shelter may be viewed as infanticide by exposure. Other types of euthanasia that might be considered infanticide are active euthanasia and withholding treatment from infants for the purpose of causing their early deaths.

Infanticide has been widely reviewed. *See, e.g.*, Burt, *Authorizing Death for Anomalous Newborns*, GENETICS AND THE LAW 435 (A. Milunsky & G. Annas eds. 1975); Damme, *Infanticide: The Worth of an Infant Under Law*, 22 MED. HIST. 1 (1978); Montag & Montag, *Infanticide: A Historical Perspective*, 62 MINN. MED. 368 (1979).

192. Many forms of medical treatment, such as antibiotics, are of fairly recent origin. It may therefore be less traditional to require parents to provide these treatments. The parental duty to provide lifesaving medical care is well established. *See* note 1 and accompanying text *supra*.

193. Food and water may have to be withheld from an infant until it dies *because* of decision to withhold treatment. If an infant, for example, has an esophagus which is not connected to his stomach, it cannot be fed or given water. The decision not to connect the esophagus to the stomach means that it cannot be given food or water by mouth. (The infant could be "fed" intravenously or through a tube to the stomach, at least for a short time). Reportedly Baby Doe, whose esophagus did not empty into his stomach, was not given nutrition or water, and died about six days following birth. *See* note 41, *supra*.

194. As a general matter, there should be no obligation to accept experimental treatment for an infant. This may be viewed as a matter of protecting infants from being human guinea pigs. *See* notes 123-26 and accompanying text *supra*.

stances in which treatment may be futile have previously been mentioned.¹⁹⁵ There may be other instances in which the risks to the infant of treatment do not justify the treatment. The risks may include the further reduction of the length of life of the infant, or the very substantial reduction of the ability of the infant to enjoy or appreciate life.

When the risk is that the treatment may significantly reduce the infant's life expectancy, the decision is based upon a comparison of the relative chance for survival as a result of treatment or nontreatment. This choice is fundamentally different from most of the situations discussed in previous sections.¹⁹⁶ Here the choice is to promote the life of the infant, and treatment may be withheld to *maximize* the chances for the longest survival. The other decisions described generally involved a decision whether or not to refuse treatment in order to *minimize* the life expectancy of the infant.

When the risk is that the treatment will dramatically reduce the ability of the infant to appreciate and enjoy life, then a true "quality of life" versus "quantity of life" issue is presented. The quality of life, for example, may be threatened by enormous pain. These decisions are fundamentally different from the decision to withhold treatment to cause death. These decisions, in effect, result in trading some length of life, or risk shortening life, with the hope of improving the life that remains. Such a tradeoff is common in medical treatment. Any corrective surgery that is done on an infant, for example, carries with it some risk of death. These tradeoffs are reasonable in infant nontreatment situations as long as the improvement in life quality is substantial compared with the level of risk to life.¹⁹⁷ There is some indication,

195. See text accompanying note 167 *supra*.

196. We have previously noted situations in which treatment was refused in order to end life without substantially improving the remaining life. See notes 124-65 and accompanying text *supra*. In some circumstances, the effect of refusing treatment would be both to decrease the length of life and worsen the quality of life. The refusal of surgery to correct an intestinal obstruction is one example.

197. Within the ambit of this kind of decision making, parents may make reasonable medical treatment decisions for their children. Although any tradeoff between life expectancy (risk) and the quality of life (benefits) must be reasonable, parents should be given considerable freedom of choice in determining what treatment their child will receive.

Courts should proceed with caution when determining whether a medical treatment decision is reasonable. In the remarkable decision, *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980), the court permitted parents to withhold lifesaving treatment. The treatment carried a 5 to 10 percent risk of death; without the treatment the child would suffer debilitating heart and lung diseases which will ultimately result in premature death. The court's decision was partly based on the risks of the procedure. In fact, Phillip's parents, in out-of-court statements, indicated that their reason for withholding treatment was that he had Down's syndrome. Note, *The Outer Limits of Parental Autonomy: Withholding Medical Treatment from Children*, 42 OHIO ST. L.J. 813, 825 (1981). Courts should review the potential benefits of a medical procedure with a view toward the rights of the child. Claims of risk should not

however, that the range is limited within which parents can make decisions about refusing traditional lifesaving treatment, even when that treatment is unpleasant.¹⁹⁸

Giving pain palliatives when there is some risk that they may cause the early death of an infant may be justified on the same grounds that the quality of life is improved even at the risk of shortening it somewhat. This is, of course, a much different concept from giving the pain palliative, even in the absence of significant pain, for the purpose of causing the death of the infant.¹⁹⁹

These treatment decisions raise some of the same issues discussed earlier about judgments concerning the quality of infant life.²⁰⁰ It is difficult to understand the quality of life of infants, particularly of defective infants. Treatment decisions that risk shortening life for the sake of the quality of life, e.g., a life with less pain, require a comparison of a life with pain to a shorter life without some of the pain. The comparison does require some speculation about the relative comfort and pleasure of the two lives. Comparing two lives, particularly when the comparison involves pain and length of life, although difficult appears to call for judgments closer to the range of human experience than would be an effort to judge, in some absolute terms, whether a life is worth living at all.

F. Proposed Standards for Decisions

Several standards for withholding lifesaving treatment have been suggested by commentators. It has been proposed that treatment may be legitimately withheld if: the child cannot have higher brain activity;²⁰¹ the cost and disruption to the family of the treatment and the life of the child are greater than the value of the life of the child;²⁰² the child cannot hope to have a worthwhile life;²⁰³ the treatment is exces-

be permitted to go unreviewed. See *In re Seiferth*, 309 N.Y. 80, 127 N.E.2d 820, N.Y.S. (1955); *In re Hudson*, 13 Wash. 2d 673, 126 P.2d 765 (1942).

198. For example, in *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978), the Supreme Judicial Court of Massachusetts affirmed a judgment requiring that parents allow their child to undergo chemotherapy treatments for leukemia.

199. Overdosing for the purpose of causing death would be active euthanasia.

200. See notes 158-62 and accompanying text *supra*.

201. The same result would occur if human life were defined as requiring higher brain activity. This would eliminate any requirement that a child without higher brain activity be treated since he would not be considered a human being. See McCORMICK, *supra* note 19; Kluge, *supra* note 16, at 246-49. See also note 15 *supra*.

202. *Medical Ethics Hearings*, *supra* note 2, at 5-7, 18, 27-28 (testimony of Dr. Raymond Duff, Dr. Robert Cooke, Dr. Warren Reich, and Dr. Lewis Scheiner); Duff and Campbell, *supra* note 5, at 894; ENGELHARDT, *Ethical Issues in Aiding the Death of Young Children*, BENEFICENT EUTHANASIA 180 (1975); Lorber, *supra* note 102, at 300; Matson, *supra* note 102, at 226.

203. Goldstein suggested that a decision to withhold treatment would be justified if

sively risky or is likely to cause substantial pain or suffering without correspondingly increasing the length of life;²⁰⁴ the proposed treatment is experimental,²⁰⁵ the treatment is futile in that it cannot have a significant effect on the length of the infant's life;²⁰⁶ and the treatment is not customary under the circumstances.²⁰⁷ A variety of other standards for nontreatment have been proposed.²⁰⁸ These standards are not mu-

"there is less than a high probability that the . . . treatment will enable the child to pursue either a life worth living or a life of relatively normal growth toward adulthood." Goldstein, *supra* note 32, at 653. See also Conference Report, *Critical Issues in Newborn Intensive Care: A Conference Report and Policy Proposal*, 55 PEDIATRICS 756 (1975); Heyman & Holtz, *The Severely Defective Newborn: The Dilemma and Decision Process*, 23 PUB. POL'Y 381, 395 (1975).

204. See notes 195-200 & 203 and accompanying text *supra*.

205. See notes 123-26 and accompanying text *supra*.

206. See generally R. Veatch, Guardian Refusal of Lifesaving Medical Procedures 5-7 (1976) (unpublished manuscript) quoted in *Substituted Judgment*, *supra* note 19, at 801 (suggesting that treatment should not be required if it is useless or inflicts "grave burdens"); *A Standard for Nontreatment*, *supra* note 1, at 623-25 (suggesting a "medical feasibility" standard); *Judicial Limitations*, *supra* note 32, at 1112-25.

Ramsey referred to Lesch-Nyam disease as an example of another instance in which care may be futile. Ramsey, *supra* note 5, at 215. When children afflicted with this disease develop teeth they gnaw through their lips and bite off or mutilate any part of their body they can reach. Since "care [to prevent the effects of this condition] cannot be conveyed, it need not be extended." *Id.*

207. See notes 127-30 and accompanying text *supra*.

A variation of this standard requires that lifesaving treatment be provided if "a reasonably prudent parent would consent" to it. Sokolosky, *supra* note 32, at 95. This standard would apparently involve an assessment using many of the same criteria employed by the cost/benefit standard. See note 202 and accompanying text *supra*.

208. Other standards for non-treatment decisions which have been suggested include the following. Goldstein recommended that care may properly be withheld (i.e., the state would not intervene) if: (a) there is no *proven* medical procedure or (b) there is conflicting medical opinion concerning the treatment procedure to follow or (c) there is less than a high probability that the treatment will enable the child to pursue relatively normal growth toward adulthood or a life worth living. Goldstein, *supra* note 32, at 653. This is, of course, an extraordinarily permissive standard which would permit treatment to be withheld from a wide range of sick children. For a critical response to this standard, see Sokolosky, *supra* note 32, at 76-84.

Lorber suggested that care ought not be required for defective children for whom no known therapy could prevent multi-system handicaps, a short life expectancy and a low quality of life. Lorber, *supra* note 102, at 288. This appears to be essentially a "worth of life" standard. See note 203 and accompanying text *supra*.

Coburn would permit active or passive euthanasia in cases where the infant will not survive the first several years of life, the life will be of no value or negative value and death will confer a "net benefit" to those most directly affected by it. Coburn would also permit active or passive euthanasia if the life will not be worth living, the infant would have to undergo significant suffering in order to reach the age of reason and the death of the infant would confer a "net benefit" to those most directly affected by it. Coburn, *supra* note 5, at 354. Although these standards are creative and carefully drawn, they appear to permit active and passive euthanasia in a fairly broad range of situations.

Shatten and Chabon suggest that treatment should always be required if "the medi-

treatment decisions are made which violate what the law apparently requires in terms of treatment.²¹⁹ At the very least, these medical decisions are being made without any serious effort to determine whether they conform to the requirements of the law. This in turn suggests that enforcement of legal standards in treatment decisions deserves the attention of the legal system.

A. Decision-Makers

Nontreatment decisions are commonly made by physicians or physicians in consultation with the parents.²²⁰ Nontreatment decisions, however, are rarely reviewed by a hospital treatment or ethics committee.²²¹ The Department of Health and Human Services has taken the position that hospitals have an obligation to help ensure that infants are not denied treatment because of physical or mental handicaps.²²² The Department has informed hospitals that they risk the loss of federal funding for failing to treat infants because of physical or mental handicap.²²³ The Department based its position on the Rehabilitation

219. See notes 1 & 2 and accompanying text *supra*.

220. Physicians often play a key role in non-treatment decisions by either making the decisions themselves, Waldman, *Medical Ethics and the Hopelessly Ill Child*, 88 J. PEDIATRICS 890 (1976); or by presenting information that discourages treatment, Duff & Campbell, *supra* note 1, at 892. See also *Medical Ethics Hearings*, *supra* note 2, at 11-12 (statement of Dr. Lewis Scheiner).

221. See generally *In re Quinlan*, 70 N.J. 10, 54-55, 355 A.2d 647, 671-72, cert. denied, 429 U.S. 922 (1976). Accord Veatch, *Hospital Ethics Committee: Is there a Role?*, 7 HASTINGS CENTER REP. 22 (June 1977); Note, *No Code Orders vs. Resuscitation: The Decision to Withhold Life-Prolonging Treatment from the Terminally Ill*, 26 WAYNE L. REV. 139, 168-69 (1979).

222. On May 18, 1982, the Director of the Office for Civil Rights for the Department of Health and Human Services sent a "Notice to Health Care Providers" concerning "Discriminating Against the Handicapped by Withholding Treatment or Nourishment." This letter followed shortly the report that lifesaving treatment and nourishment had been withheld from a Down's syndrome infant, Baby Doe, in Bloomington, Indiana. See note 41 *supra*.

223. The following letter was sent by the Department of Health and Human Services on May 18, 1982 to health care providers regarding discrimination against handicapped persons.

NOTICE TO HEALTH CARE PROVIDERS

SUBJECT: Discriminating Against the Handicapped
by Withholding Treatment or Nourishment

There has recently been heightened public concern about the adequacy of medical treatment of newborn infants with birth defects. Reports suggest that operable defects have sometimes not been treated, and instead infants have been allowed to die, because of the existence of a concurrent handicap, such as Down's syndrome.

This notice is intended to remind affected parties of the applicability of section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794). Section 504 provides

Act of 1973²²⁴ which provides that the handicapped may not, solely because of the handicap, be denied the benefits of or subject to discrimination under any program receiving federal assistance. Handicap is broadly defined in the statute as a "physical or mental impairment which substantially limits one or more . . . major life activities."²²⁵

that "No otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. . . ." Implementing regulations issued by the Department of Health and Human Services make clear that this statutory prohibition applies in the provision of health services (45 C.F.R. 84.52) and that conditions such as Down's syndrome are handicaps within the meaning of section 504 (45 C.F.R. 84.3(j)).

Under section 504 it is unlawful for a recipient of Federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition, if:

- (1) the withholding is based on the fact that the infant is handicapped; and
- (2) the handicap does not render the treatment or nutritional sustenance medically contraindicated.

For example, a recipient may not lawfully decline to treat an operable life-threatening condition in an infant, or refrain from feeding the infant, simply because the infant is believed to be mentally retarded.

We recognize that recipients of Federal financial assistance may not have full control over the treatment of handicapped patients when, for instance, parental consent has been refused. Nevertheless, a recipient may not aid or perpetuate discrimination by significantly assisting the discriminatory actions of another person or organization. 45 C.F.R. 84.4(b)(1)(v). Recipients must accordingly insure that they do not violate section 504 by facilitating discriminatory conduct.

In fulfilling its responsibilities, a Federally assisted health care provider should review its conduct in the following areas to insure that it is not engaging in or facilitating discriminatory practices:

Counseling of parents should not discriminate by encouraging parents to make decisions which, if made by the health care provider, would be discriminatory under section 504.

Health care providers should not aid a decision by the infant's parents or guardian to withhold treatment or nourishment discriminatorily by allowing the infant to remain in the institution.

Health care providers are responsible for the conduct of physicians with respect to cases administered through their facilities.

The failure of a recipient of Federal financial assistance to comply with the requirements of section 504 subjects that recipient to possible termination of Federal assistance. Moreover, section 504 does not limit the continued enforcement of State laws prohibiting the neglect of children, requiring medical treatment, or imposing similar responsibilities.

224. 29 U.S.C. § 794 (1976). Regulations implementing the statute are at 45 C.F.R. § 84 (1981). Programs receiving any form of federal financial assistance are covered, including federal funds, services of federal personnel or property. *Id.* at § 84.2, § 84.3(h). Services provided in a facility which has been constructed or altered in part with federal money are also covered by the regulations. *Id.* at § 84.4(b)(6).

225. 29 U.S.C. § 706(6)(B)(1976).

tually exclusive. For example, treatment might be refused if it is both futile and experimental.

The discussion of lifesaving decisions in this article implies several principles relevant to the appropriate legal standards for making such decisions.²⁰⁹ The ordinary/extraordinary (heroic) distinction is of little value in describing legal standards for treatment, but experimental treatment, as a form of extraordinary treatment, generally ought not to be required.²¹⁰ The presence of physical or mental defects in an infant (which are often referred to as quality of life issues),²¹¹ or the consequences of the infant's existence on the family, society or others are not, in and of themselves, bases on which the law has made, or easily can make, life and death decisions.²¹² The fact that an infant has a terminal disease does not by itself suggest that lifesaving treatment may automatically be withheld, although the terminal condition may make common treatment impossible or futile.²¹³ Distinctions between active and passive euthanasia and medical and nonmedical necessities are of questionable validity when the purpose of withholding lifesaving treatment, or passive euthanasia, is to cause the death of the infant.²¹⁴ Treatment may legitimately be withheld when it is too risky or when it

cal profession agrees on a proper course of treatment, *and* if treatment will enable the child to make progress in growth and development, *and* if the failure to treat would result in the child's death." Shatten and Chabon, *Decision-Making and the Right to Refuse Lifesaving Treatment for Defective Newborns*, 3 J. LEGAL MED. 59, 74 (1982).

Other standards that have been proposed are noted by Shatten and Chabon. *Id.* at 73.

209. See notes 119-200 and accompanying text *supra*.

210. Requiring experimental treatment would provide a source of research subjects but would not necessarily be in the best interest of the child. Parents of a child suffering with a life threatening condition will often seek experimental treatments as a last hope, but such treatment should not be imposed against the parents' will. See notes 123-26 *supra*.

211. Predicating decisions to provide lifesaving treatment on the infant's "quality of life" is impractical since it cannot be determined with any degree of certainty and is inconsistent with the notion of equal protection of human life. See notes 152-65 *supra*.

212. It is inappropriate to base a decision to permit or cause the death of an individual who is unable to act in his own behalf (e.g., an infant) upon hardships that are not life threatening. See notes 132, 168-69 & 202 and accompanying text *supra*.

213. For example, a child afflicted with a terminal illness may have received treatment which is incompatible with certain other medicines. As a result, the use of drugs which would conventionally be used to treat a life threatening condition would become either ineffective or dangerous.

214. I have previously argued that it is misleading to attempt to justify passive euthanasia (inaction) as simply allowing nature to "take its own course." We are generally unwilling to sanction a "let nature run its course" standard, particularly where infants are involved. See note 185 *supra*. When there is a duty to safeguard the interests of another person, there is very little difference between action (an act) and inaction (an omission) which is likely to ultimately cause the same result. See notes 181-87 and accompanying text *supra*.

will substantially lower the opportunity for appreciation and enjoyment of life without a corresponding increase in the length of life.²¹⁵

A standard for nontreatment decisions can be suggested based on these principles. Lifesaving treatment may appropriately be withheld if: (1) the treatment would be futile in that there is no reasonable hope that it can more than insignificantly extend the life of the infant; (2) the proposed treatment is experimental; (3) the treatment is excessively risky in that it will not maximize the infant's life expectancy; or (4) the probability that the treatment will cause substantial pain or suffering is not offset by a corresponding probability that it will increase the length of life.

The proposed standard appears to be consistent with the current law,²¹⁶ although not fully consistent with some current medical practices.²¹⁷ It rests on the premise that causing the death of an infant through inaction is not appropriate when the decision is based on the fact or assumption that the infant will be disruptive of, or in some way harmful to, the family or others, or that the infant's life is not worth living.

V. DECISION-MAKERS AND ENFORCEMENT

The legal standards governing nontreatment decisions which are adopted will be effective only if those making treatment decisions actually apply the proper standards.²¹⁸ As noted earlier, a number of non-

215. See notes 195-200 and accompanying text *supra*.

216. The legal principles concerning withholding treatment are examined in note 1 *supra*. It may be argued that the law views the unprivileged shortening of a life as impermissible regardless of the extent to which the life span has been reduced. Consequently, speaking of "insignificantly" shortening a life is, at best, marginally within the limits of contemporary legal standards. See *Custody of a Minor*, 385 Mass. 697, 434 N.E.2d 601 (1982) (court ordered that "invasive" and painful resuscitation techniques be withheld from a terminally ill infant when they could extend the life of the infant for only a short time). It may also be argued, albeit not very persuasively, that the present law does not permit the failure to provide treatment based upon a tradeoff of quantity for quality of life. See notes 195-98 and accompanying text *supra*. When such a tradeoff is legitimate, i.e., there is a risk of shortening life with a correspondingly real and substantial probability of an improved quality of life, the law does permit such decisions. In fact many kinds of medical treatment involve this tradeoff. Much corrective surgery (for example, cosmetic surgery for a deformed infant) has some risk of death associated with it.

217. Modern medical practice probably results in withholding treatment in a somewhat broader range of cases, especially those involving seriously defective children who may have a negative impact on the family. See notes 2 & 40 *supra*.

218. If legal standards are to be effectively administered, those who will apply them must be able to understand them, be able and willing to apply them in good faith, and have a means of ascertaining that each decision made conforms with the law. It appears that physicians and parents at the present time do not fully understand their responsibilities under the law, are sometimes unwilling to strictly apply legal standards, and seldom seek guidance from courts to ensure that their conduct conforms with the law.

"Physical or mental impairment" and "major life activities" have been defined by the Department by regulation.²²⁶

Among the actions which are prohibited by the regulations are providing the handicapped with benefits or services which are not as effective as those provided the nonhandicapped, or significantly aiding other agencies or persons that discriminate on the basis of handicap and that provide services to the "beneficiaries of the recipients program."²²⁷ Since hospitals are often constructed with some federal aid or operate federally funded programs, many hospital programs are under the obligation not to discriminate or aid others in discrimination based on handicap.²²⁸ Under current regulations, the services provided the handicapped must "afford handicapped persons equal opportunity to obtain the same result [or] to gain the same benefit" even if the services do not produce the "identical result or level of achievement for handicapped and nonhandicapped."²²⁹

In the context of handicapped infants, the Department has taken the position that it is unlawful for a recipient of federal financial assistance to withhold medical or surgical treatment or nourishment from an infant because the child is handicapped unless the handicap renders the "treatment or nutritional sustenance medically contraindicated."²³⁰ Although not entirely clear, "medically contraindicated" apparently means that treatment is inadvisable because the physical condition of the infant makes it too risky or futile. Presumably, the notion that the infant would not have a life worth living or would be too great a burden on others because of the handicap would not be within the Department's concept of "medically contraindicated."

226. 45 C.F.R. § 84.3 (j)(2)(1981). 'Physical or mental impairment' means

(a) any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological; musculoskeletal; special sense organs; respiratory; including speech organs; cardiovascular; reproductive; digestive; genito-urinary; hemic and lymphatic; skin; and endocrine; or

(b) any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities.

(ii) 'Major life activities' means functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working."

Id.

227. 45 C.F.R. § 84.4 (b)(1)(iii), (iv)(1981).

228. It may still be a matter of debate whether the federal law would apply to neonatal care if the hospital has received funds for other purposes but not for the specific care which the hospital is withholding. The discrimination may have been in connection with the part of the hospital (the specific program) which is receiving federal funding. See generally *American Pub. Transit Assoc. v. Lewis*, 655 F.2d 1272 (App. D.C. 1981); *Miller v. Abilene Christian Univ. of Dallas*, 517 F. Supp. 437 (N.D. Tex. 1981).

229. 45 C.F.R. § 84.4(b)(2)(1981).

230. See note 223 *supra*.

To avoid aiding others in discriminating against handicapped infants, hospitals were instructed not to counsel parents to withhold treatment and not to allow the infant to remain in the hospital if the parents refuse treatment. Hospitals were also told they are responsible for the conduct of physicians practicing in the hospital.²³¹ This may impose a substantial burden on hospitals. Hospitals often have some obligation to oversee treatment provided by physicians.²³² The responsibility of hospitals for the conduct of physicians suggested by the Department goes beyond that and might be difficult under the current treatment review structures of many hospitals. Furthermore, the obligation of a hospital not to allow an infant to stay in its facilities if the parents wish to withhold treatment because of a handicap seems all but impossible to implement. The hospital might be expected to seek court ordered treatment if the parents refuse lifesaving treatment, but it is not at all clear how a hospital can remove a sick newborn from its facilities when the parents refuse treatment. For these reasons the Department's position has been criticized by the health care industry.²³³

Although it is unlikely that any hospital risks the immediate loss of federal funds,²³⁴ through federal or state regulation hospitals may be expected to exercise greater control over decisions to withhold lifesaving treatment from infants. The use of the physician/attorney interdisciplinary panel or team,²³⁵ applying the standards for nontreatment suggested here,²³⁶ might permit hospitals to discharge this treatment review responsibility.

The current decision process can be criticized on several grounds.²³⁷ To the extent that treatment is withheld without consultation with the parents it is contrary to basic concepts of informed con-

231. *Id.*

232. See generally, *Darling v. Charleston Community Memorial Hosp.*, 33 Ill. 326, 211 N.E.2d 253 (1965), *cert. denied*, 383 U.S. 946 (1966).

233. The American Hospital Association stated that it feared that the Department would "create an adversarial relationship between hospitals and parents . . ." Quoted in Correspondence, 10 *L., Med. & Health Care* 142 (1982).

234. The issue whether federal funds must be expended for the specific treatment which is being denied to the infant to make the federal regulations applicable is discussed in note 227, *supra*. In addition the process for removing federal funds is complex and probably can be implemented only after an effort has been made to remove the discrimination through less drastic means. See *Fells v. Brooks*, 522 F. Supp. 30, 33 (D.D.C. 1981).

235. See notes 244-48 and accompanying text *infra*.

236. See notes 209-16 and accompanying text *supra*.

237. The decision-making process has been criticized because some life and death decisions are apparently made without any reference to the requirements of the law. Rather, these decisions are often made by individuals who are in highly emotional states. Such decision-makers (i.e., the parents) may conflict with the best interests of the child. Moreover, very few of these important decisions are effectively reviewed by uninvolved third parties or groups to ensure such decisions meet with the requirements of the law.

sent, even though motivated by a desire to avoid having to trouble the parents with making a decision.²³⁸ Such unilateral decisions may subject the physician involved to liability.²³⁹ Some physicians may also view these as medical decisions in which the parents should play a small role and the law plays no role at all.²⁴⁰ It is, of course, true that medical judgments have an important role in the decisions, but the standards for determining when lifesaving treatment may legally be withheld must be established by the legal system. The establishment of standards for nontreatment as opposed to the application of the standards, is not a medical judgment, but rather a legal or value judgment.²⁴¹

The decision-making process may be inadequate even when nontreatment decisions are made by the physician in consultation with the parents. The parents, as well as the physician, may have interests which are in conflict with the interests of the child, and these conflicts may prevent them from being able to apply the proper legal standard.

238. The physician's motivation in withholding treatment without parental consultation, is not a relevant factor in determining the legal propriety of his actions. There is little legal basis for withholding treatment without fully consulting both parents, or at least one parent in extraordinary circumstances.

239. Parents have the authority to consent to medical treatment for their children and a physician who renders treatment without obtaining such consent may be liable for negligence or battery. See authorities cited in notes 20-22, *supra*. The withdrawal of treatment is also presumed to be a treatment decision requiring informed consent. A physician holding back such treatment without obtaining the consent of the parties, or at least giving them notice of such action, may be liable for abandonment. See note 1 *supra*. A hospital may also be held liable when treatment has been withheld without adequate consent. See *Bonregois v. Dade County*, 99 So. 2d 575 (Fla. 1957). See also notes 222-34 and accompanying text *supra*. Physicians may also have a duty, as well, to report suspected cases of child neglect or abuse even if the parents are involved in the decision. A physician failing to make such a report may be criminally or civilly liable. See *Kohlman, Malpractice Liability for Failing to Report Child Abuse*, 49 CAL. ST. B.J. 118 (1974).

240. The debate over whether the courts or medical review boards are the proper forum for adjudicating non-treatment decisions has resulted in charges of medical paternalism (directed to those advocating that physicians should make the decisions) or legal imperialism (directed to those maintaining that the courts should be involved). See *Baron, Assuring "Detached but Passionate Investigation and Decision": The Role of Guardians Ad Litem in Saikewicz-Type Cases*, 4 AM. J.L. & MED. 111 (1978); *Baron, Medical Paternalism and the Rule of Law: A Reply to Dr. Relman*, 4 AM. J.L. & MED. 337 (1979); *Buchanan, Medical Paternalism or Legal Imperialism: Not the Only Alternatives for Handling Saikewicz-Type Cases*, 5 AM. J.L. & MED. 97 (1979); *Relman, The Saikewicz Decision: A Medical Viewpoint*, 4 AM. J.L. & MED. 233 (1978); *Relman, The Saikewicz Decision: Judges as Physicians*, 298 NEW ENG. J. MED. 508 (1978).

241. See generally *Medical Ethics Hearings*, *supra* note 2, at 58 (statement of Dr. Warren Reich); *Gold, Wiser Than the Law?: The Legal Accountability of the Medical Profession*, 7 AM. J.L. & MED. 145 (1981); *Veatch, Generalization of Expertise*, 1 HASTINGS CENTER REP. 29 (April 1973); *Substituted Judgment*, *supra* note 19, at 807-08 (1978).

The parents may want a normal child and be unwilling to care for one with defects; they may not wish or be able to support the child; or they may see the child as disruptive of their family or marriage.²⁴² The physician, although dedicated and supportive, and parents, may find a defective infant emotionally difficult to accept. They may experience a sense of guilt and anger which interferes with their ability to make treatment decisions in the child's best interest.²⁴³ It is hard to imagine circumstances in which parents are less likely to be emotionally well suited to make life and death decisions in the best interest of a child than they are shortly after realizing that the child may be seriously defective.

If the current decision system is not working, a review mechanism may be needed.²⁴⁴ A judicial review to determine whether nontreatment decisions adhere to legal standards might be desirable,²⁴⁵ but such a system would undoubtedly be so cumbersome and slow to provide review that it would be ineffective in many cases.²⁴⁶ An ethics committee review might be able to respond more quickly, although the diversity of backgrounds which would make such a committee valuable

242. See Cohen, *The Impact of the Handicapped Child on the Family*, 43 Soc. CASEWORK 137 (1962); Note, *The Outer Limits of Parental Autonomy: Withholding Medical Treatment from Children*, 42 OHIO ST. L.J. 813, 829 (1981). But see Duff & Campbell, *supra* note 2.

243. Often parents must make the non-treatment decision at a time when they are emotionally upset over their child's condition. It has been suggested that parents who, at the time of birth, dreaded the thought of raising a defective child, may have an entirely different perspective and opinion several months later. See *Medical Ethics Hearings*, *supra* note 2, at 13 (statement of Dr. Robert Cooke); Ellis, *supra* note 1 at 414-15. See generally Fletcher, *supra* note 5.

244. See generally Kindregan, *supra* note 24. In a situation such as in *Maine Medical Center v. Houle*, No. 74-145 (Super. Ct., Cumberland Co., Me. Feb. 13, 1974), reported in Brant, *supra* note 15, the decision made could be routinely handled under the current process. See note 133 *supra*, for a discussion of the Maine case. It has been suggested that an alternative approach would be for the parties to try to reach a consensus on what treatment, if any, should be performed. See generally, Heyman & Holtz, *The Severely Defective Newborn: The Dilemma and the Decision Process*, 23 PUB. POL'Y 381 (1975).

245. Some jurisdictions differ on the advisability of judicial review of decisions to withhold lifesaving treatment. See *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 427 (1977) (judicial review required for non-treatment decision of non-infant); *A Standard for Nontreatment*, *supra* note 1, at 630-32 (need for judicial review and expedited hearing in emergency). But see *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976) (rejecting judicial review of decision withholding treatment to female adult); Horwitz, *Of Love and Laetrile: Medical Decision Making in a Child's Best Interests*, 5 AM. J.L. & MED. 271, 286-91 (1979).

246. Even if a judicial review of the decision is not required, a physician is free, of course, to seek a court determination of the physician's and parents' obligations prior to withholding treatment to provide protection against subsequent legal action. Given the conflicting decisions on withholding treatment, physicians would be well advised to seek judicial clarification of their responsibilities before suspending treatment.

might also make it extremely difficult to convene quickly.²⁴⁷ Such a group would not have great experience in applying legal standards. Similar groups, however, apply relatively complex legal standards to experimentation on human subjects.²⁴⁸

Adequate review before a nontreatment decision is implemented is difficult. In addition to an ethics advisory board, provision could be made for a swift *post hoc* judicial review of decisions when there cannot be a review before the decision is made. The inability of such a review to prevent errors in withholding treatment before the death of an infant would be a clear disadvantage of such a system.

Another alternative is to require that an independent physician certify that the criteria for nontreatment contained in the standards have been met before treatment can be withdrawn.²⁴⁹ This type of review has the advantage of being accomplished quickly and easily before action is taken, and the disadvantages of risking intra-professional "backscratching" and requiring physicians to apply legal standards.²⁵⁰

One variation on the physician review theme would be to have a team consisting of a physician and an attorney conduct the review. The attorney would provide expertise in applying the legal standards and the physician an independent medical view. Treatment could not be withdrawn or withheld unless both members of the team certified that nontreatment was appropriate, the attorney determining that legal standards were met and the independent physician determining that

247. New Jersey had provided for a review of decisions withdrawing lifesaving treatment. *In re Quinlan*, 70 N.J. at 49-51, 355 A.2d at 668-69. See *Medical Ethics Hearings*, *supra* note 2, at 17-18 (statement of Dr. Robert Cooke supporting ethics committee review of withholding treatment decisions).

248. Human studies committees (Institutional Review Boards) are required for experiments involving human subjects which are funded by federal agencies or which involve drugs currently being studied. 21 C.F.R. § 56 (1981). The committees should be comprised of individuals involved in such diverse disciplines as medicine, law, and philosophy and ethics, as well as laymen from the community. The responsibilities of the committees are to review protocols to ensure that the rights of human subjects (including the right of adequate informed consent) are protected and that the benefits of the experimentation exceed the costs. *Id.* The quality of these committee reviews varies considerably. See Robertson, *The Law of Institutional Review Boards*, 26 U.C.L.A. L. REV. 484 (1979). The inconsistency of the decisions, as well as the time it would take for a board to deliberate, emphasizes the problems that would result if these committees were relied upon too heavily to review treatment decisions. An ethics committee can have review authority to make or veto decisions or simply have an advisory role. See Note, *No Code Orders vs. Resuscitation: The Decision to Withhold Life-Prolonging Treatment from the Terminally Ill*, 26 WAYNE L. REV. 139, 168-71 (1979).

249. See notes 222-36 and accompanying text *supra*.

250. Such a process would permit a second medical opinion as to the success of a treatment but might not significantly provide a way of ensuring that withholding treatment would conform to legal standards. See generally *Parham v. J.R.*, 422 U.S. 584 (1979).

the medical condition of the infant had been assessed correctly. If appointed by a court, with the responsibility of reporting back to the court, this process would provide for a timely review and, at the same time, significant assurance to the treating physician that he was not violating the law in withholding treatment. In appropriate cases the attorney could be made responsible for bringing unresolved legal issues to the attention of the courts. Such an approach would, of course, require physicians treating infants to give notice before withholding life-saving treatment.

This last option, the attorney and independent physician review, appears to have real promise. It avoids cumbersome court and committee procedures and allows an informed interdisciplinary review of critical nontreatment decisions. Such a review process, using narrowly defined nontreatment standards, might be established by hospitals in an effort to meet the obligations that they have, to avoid discrimination against handicapped infants.²⁵¹

B. Enforcement

Enforcement of legal standards regarding nontreatment has been difficult for two reasons: (1) the decisions to withhold treatment have generally been hidden from the view of the public²⁵² and the legal system, and (2) prosecution of the few nontreatment and nonmalicious active euthanasia cases has been unsuccessful.²⁵³ Juries have been understandably reluctant to return homicide convictions where parents or physicians have in desperation caused the death of an unfortunate child. It is, of course, also possible that this demonstrates an acceptance of euthanasia by jurors and the public which is not reflected in

251. The suggestion here and at notes 240-41 *supra*, is not that physicians are unfit or unable to adopt legal standards but simply that they are not trained to know and interpret legal standards. See Robertson, *supra* note 1, at 264 n.271 (physicians receive no training and lack the background which "qualifies them to identify, assess, and balance all interests involved—in short, to 'play judge'").

252. There is no public review committee which is likely to know of or review these decisions. Nor have internal hospital review committees been very active in bringing cases of withholding infant treatment to the attention of the public or government agencies.

253. See *United States v. Repouille*, 165 F.2d 152 (2d Cir. 1947) (applicant for U.S. citizenship killed defective son with chloroform and was convicted of second degree manslaughter with recommendation of "utmost clemency" and accepted for citizenship); Robertson, *supra* note 1, at 217 n.27 (reporting Arizona case where sustenance withheld from child by parents and physician; following death, coroner's jury found that child had died of meningitis, and physician and parents not prosecuted); *A Standard for Nontreatment*, *supra* note 1, at 615 n.84 (listing cases). See also Sanders, *None Dare Call It Murder*, 60 J. CRIM. L.C. & P.S. 351, 355 (1969). But see *Eaglen v. State*, 249 Ind. 144, 231 N.E.2d 147 (1967).

the legal system.²⁵⁴ Whatever the reason, successful enforcement of legal standards regarding nontreatment does not appear to lie with homicide prosecutions. Even in this day of deregulation, some additional review and reporting of nontreatment decisions seems more likely to promote adherence to the legal standards.²⁵⁵ The review by the physician/attorney team previously described would be one method of review.²⁵⁶

The decisions to withhold lifesaving treatment from an infant should be recorded along with the reasons and basis for the decisions.²⁵⁷ Under this system, the records would be subject to court review and failure to follow adequate standards or process would leave the physician or parents open to legal sanctions, although not necessarily charges of criminal homicide. Unless criminal action is undertaken, the reports would be confidential and not available to the public, thus protecting the privacy of the infant and parents.²⁵⁸

Reports to the state concerning prescription drugs and abortions must be made in some states.²⁵⁹ Withholding lifesaving treatment is a matter of even greater concern than either of these areas because it involves the death of a human being. Requiring a report of such nontreatment seems quite reasonable in light of the gravity of the decision

254. It might be that there is a willingness to withhold treatment to cause the death of infants whose lives seem worthless or whose presence is frightening or disconcerting but yet an unwillingness to admit this because it is inconsistent with our moral and legal principles.

255. All states now have child abuse reporting statutes requiring medical personnel to report suspected child abuse cases to state authorities. Given the importance of decisions to withhold lifesaving treatment and the potential for these decisions to become "neglect" reporting seems appropriate. See V. DEFRANCIS & C. LICHT, *CHILD ABUSE LEGISLATION IN THE 1970's* (6th rev. ed. 1974); Paulsen, *Child Abuse Reporting Laws: The Shape of Legislation*, 67 COLUM. L. REV. 1 (1967); Thomas, *Child Abuse and Neglect, Part I: Historical Overview, Legal Matrix, and Social Perspectives*, 50 N.C. L. REV. 293 (1972); *Protecting Children from Parents*, *supra* note 32.

256. See text following note 250 *supra*.

257. Dr. Robert Sheiner suggests that decisions to withhold treatment should be made public. "We act our best, our noblest, when someone else is looking. . . . Difficult decisions should be published, and commented on by doctors and laymen." *Medical Ethics Hearings*, *supra* note 2, at 21-22 (statement of Dr. Robert Sheiner).

258. As with other medical information, data concerning the withholding of treatment is likely to be considered highly private by many people. While there is a public need to know about these decisions, this interest probably would be best served if the courts and appropriate government agencies had access to the data on a confidential basis.

259. See *Whalen v. Roe*, 429 U.S. 589 (1977) (physician required to report information concerning prescriptions for "dangerous" drugs); *Planned Parenthood v. Danforth*, 428 U.S. 52 (1976) (physicians required to report information about abortions). In each instance, the state provided for the confidentiality of the data. 429 U.S. at 601; 428 U.S. at 81.

and the difficulty of adequately enforcing legal standards without such reports.

VI. CONCLUSIONS

Although parents are generally empowered to make medical decisions concerning their infant children, this right is not absolute and may be limited to protect a strong state interest.²⁶⁰ There is a state interest in reviewing decisions to withhold treatment, particularly when the decision would put the infant's life in jeopardy.²⁶¹

The two potential privacy interests in infant nontreatment decisions are the interests of the parents in child rearing and the interest of the child in autonomy.²⁶² As noted, child rearing interests do not extend to unnecessarily putting the life of the child at substantial risk.²⁶³ There are serious conceptual problems in suggesting that parents can exercise a right of privacy on behalf of an infant. Autonomy privacy is, at its core, the right to make for oneself decisions about intensely personal matters. Therefore, the parents can no more exercise autonomy privacy for a child than they can exercise the religious freedom of the infant.

Decisions to withhold lifesaving treatment are a great deal more complex than has been commonly recognized. The Decision Matrix presented²⁶⁴ demonstrates the complexity of such decisions.

A distinction has been drawn by many between ordinary and extraordinary treatment. This distinction is confusing and potentially dangerous. There is no common and clear understanding of what the basic concept of extraordinary treatment is. It might mean experimental, generally accepted, customary under the circumstances, a very high cost/benefit ratio, very invasive or treatment that most people would reject.²⁶⁵ Some of these concepts are amorphous and virtually impossible to apply consistently, or are open to interpretation which would permit treatment to be withheld, at least arguably, inappropriately.²⁶⁶ As demonstrated, the use of the ordinary/extraordinary distinction is not useful and extraordinary should be supplanted in favor of terms or phrases which more clearly identify the concept intended.

Other distinctions which are at times made in nontreatment decisions are between normal and abnormal infants,²⁶⁷ active and passive

260. See notes 20-38 and accompanying text *supra*.

261. See notes 33-38 and accompanying text *supra*.

262. See notes 49-95 and accompanying text *supra*.

263. See notes 78-80 and accompanying text *supra*.

264. See notes 97-118 and accompanying text *supra*.

265. See notes 119-49 and accompanying text *supra*.

266. See note 121 and accompanying text *supra*.

267. See notes 150-58 and accompanying text *supra*.

euthanasia,²⁶⁸ and medical and nonmedical necessities.²⁶⁹ These distinctions do not appear to be very useful in defining circumstances in which lifesaving treatment may be appropriately withheld. Lifesaving treatment might be withheld from a mentally retarded or physically defective infant because the life of the child is not worth living, the infant's existence or treatment places too great a burden on the family and society, or the risks of the procedure are too great.²⁷⁰ The first two reasons are not so much treatment decisions as they are decisions whether to take advantage of the presence of a life-threatening condition to cause the death of the infant. Nontreatment decisions, in such situations, should not be legally permissible.²⁷¹

Based on the analysis in this article, standards for withholding lifesaving treatment are suggested. Treatment may properly be withheld if: (1) the treatment would be futile because there is no reasonable hope that it would extend the life of the infant significantly; (2) the proposed treatment is experimental; (3) the treatment is excessively risky in that it will not maximize the infant's life expectancy; or (4) the probability that the treatment will cause substantial pain or suffering is not offset by a corresponding probability that it will increase the length of life.²⁷²

The legal standards governing nontreatment will be effective only if they are recognized and applied by those making treatment decisions. Current practice seems to have produced a system where there is frequent unrecognized deviation from what the legal standards appear to be. A reasonable review mechanism could be used to ensure that legal standards are followed in a timely fashion. An attorney, independent physician team which is responsible for reviewing and approving decisions to withhold lifesaving treatment from infants, would bring unresolved legal issues to the attention of the courts. Hospitals might adopt such a process to meet any obligations they might have to avoid discrimination against handicapped infants. Decisions to withhold lifesaving treatment from infants should be recorded, along with the reasons for the decisions. Unless legal action is undertaken, the reports should be confidential and not available to the public. Such an approach would help assure that lifesaving treatment is withheld from infants only when it is legally justified.²⁷³

268. See notes 162-87 and accompanying text *supra*.

269. See notes 188-91 and accompanying text *supra*.

270. See notes 114-16 and accompanying text *supra*.

271. See notes 162-87 and accompanying text *supra*.

272. See notes 200-16 and accompanying text *supra*.

273. As this symposium was in the final stages of publication, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research released its final report and the Department of Health and Human Services issued "interim final" rules regarding withholding lifesaving treatment from defective

infants.

In a companion paper to the final report, the President's Commission proposed fairly narrow standards for withholding treatment from infants. They suggested a "net benefit" best interest of the child standard and also recommended that these decisions be left to parents and their physicians. PRESIDENT'S COMMISSION 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 127-28, 218-19 (1983). Given the potential conflict between these decision-makers and the infant, it appears that the decision process would make it very difficult to ensure that the proposed standard is used in practice.

The federal regulations, which became effective March 22, 1983, provide for the posting of infant care notices in maternity and pediatric hospital facilities. The notice requests anyone knowing of the denial of "customary medical care" or food to handicapped infants contact the Department. A toll-free number is provided. 48 Fed. Reg. 9630-32 (1983) (to be codified at 45 C.F.R. 84.61). This regulation should increase the incentive for hospitals to provide internal procedures to ensure that infant care decisions are consistent with legal standards.