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Neonatal Intensive Care

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May, 1989

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Developments in neonatal intensive care over the past 25 years have led to dramatic decreases in infant mortality, to treatments for physical and mental conditions, and to improvement in the quality of life for the infants who survive. Currently, about six percent of infants who are born alive enter neonatal intensive care units; financial and human costs can be substantial, but net financial as well as human benefits generally result.

Some infants with severe congenital abnormalities and/or very low birth weights are treated at great cost despite poor chances for survival. If they do survive, it is often with severe handicaps and a seriously impaired quality of life. The great costs to the infant, the family, the care providers and society have led some to conclude that the withholding or withdrawal of intensive treatment is at times ethically acceptable.

Ethical discussion of neonatal intensive care has developed over the past 15 years, addressing both substantive and procedural issues. Substantive issues focus on appropriate standards for making treatment decisions and present various options. One basic option would be to treat every newborn as aggressively as possible. A second option is selective treatment based in the balance between direct benefits and burden of care. Another set of approaches, focusing on the best interests of the infant, argues that treatment should be limited only if suffering or a radically diminished quality of life would make existence a net burden to the infant. A fourth approach considers the personal and financial costs to the family and to society (at least in extreme cases). Alternatively, some argue that there are limitations on personal and societal obligations to help in such cases because the resources used might save or improve the lives of others.

Procedural issues focus on how decisions should be made. Potential decision makers include parents, physicians and other care providers, ethics or infant care review committees, and the courts. The authority of the decision maker is generally seen to be that of a proxy for the infant, but parents in particular are seen as having their own intrinsic authority as well. Some writers give priority to procedural over substantive criteria due to the complexity of the cases, the lack of a current consensus on standards, and the basic pluralism in society.

Related policy concerns include preventing neonatal disabilities, financing neonatal intensive care, and providing continuing care for the disabled.

This Scope Note focuses on neonatal intensive care (NIC), though many of the concerns expressed about severely handicapped infants are shared across a spectrum of decisions to withhold or withdraw treatment. In order to provide a fuller understanding of the issues involved in the discussion of the treatment of handicapped newborns, I have included literature of historic significance from the 1970s together with more recent material. Section I presents regulations and committee statements; Section II includes books about NIC, generally in the context of selective nontreatment, and is intended to be fairly comprehensive; Section III has essays and articles selected for: A. Ethical Issues in Neonatal Intensive Care, B. Discussions of Newborn Treatment in General, C. Legal Considerations, and D. Suggested Additional Readings. Court cases (which generally concern decisions about surgery) and newspaper articles are not included.

I. Regulations and Committee Statements

U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, **Seriously Ill Newborns**. *In its: DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON THE ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS*. Washington, U.S. Government Printing Office, 1983, pp. 197-229.

The development of newborn care is surveyed, with attention to infants "at risk," neonatal intensive care, and post-hospital needs. The current practice of decision making by parents and physicians is generally satisfactory, but problems involving communication, understanding and informed approval may arise. Decisions should be made on the basis of the best interests of the infant, with treatment provided unless handicaps are so severe that continued existence would not be beneficial from the infant's own perspective. Parents would normally make decisions, with internal institutional review. Long-term implications for society include the obligation to provide continuing care that makes a meaningful life possible.

U.S., **CHILD ABUSE AMENDMENTS OF 1984**, Public Law 98-457.

The law says that "medical neglect" is a category of child abuse, and agencies and courts should prevent "the withholding of medically indicated treatment from disabled infants with life-threatening conditions." Exceptions may be made if the infant is irreversibly comatose, treatment would "merely prolong dying" or be otherwise futile, or would be "virtually futile" and "inhumane."

U.S., Dept. of Health and Human Services, Office of Human Development Services. **45 CFR Part 1340, Child Abuse and Neglect Prevention and Treatment Program; Final Rule**. *Federal Register* 50(72): 14878-14892, 15 April 1985.

This is the final rule associated with Public Law 98-457 (above), and includes an appendix, with an extensive discussion of the formulation of the rule and public comments. "Medically indicated treatment" is that which in the physician's "reasonable medical judgment will be most likely to be effective in ameliorating or correcting all" life-threatening conditions. The rule states that nutrition, hydration, and medication must never be withheld.

U.S., Dept. of Health and Human Services, Office of Human Development Services. **Services and Treatment for Disabled Infants; Model Guidelines for Health Care Providers to Establish Infant Care Review Committees; Notice**. *Federal Register* 50(72): 14893-14901, 15 April 1985.

In the guidelines, hospitals are encouraged to establish committees to educate hospital personnel and families, recommend policies, offer counsel and review on cases, and improve coordination with state child protective services. Cases involving disagreements, or considering the withdrawal of treatment, should be reviewed prospectively.

American Medical Association, Council on Ethical and Judicial Affairs. **CURRENT OPINIONS OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS OF THE AMERICAN MEDICAL ASSOCIATION**. Chicago: American Medical Association, 1986. Sections 2:

16-19.

The Council states that when treatment decisions concern the “seriously deformed newborn...the primary consideration should be what is best for the individual patient and not the avoidance of a burden to family or to society.” Quality of life should be considered, though “life should be cherished despite disabilities and handicaps, except where the prolongation would be inhumane and unconscionable.” The opinion says that the choice of the family is normally decisive.

American Academy of Pediatrics, Committee on Bioethics. **Treatment of Critically Ill Newborns.** *Pediatrics* 72(4): 565-566, October 1983.

The Committee notes that cases involving imminent death or absolute impairment are tragic but not controversial. In general, the pediatrician’s primary obligation is to the child, whose “best interests” are decisive; family concerns are weighed if the infant’s prospects are “for a life dominated by suffering.” The report states that parents should be involved in the decision, as should medical, legal, ethical and social experts, and institutional ethics committees.

American Academy of Pediatrics, Infant Bioethics Task Force and Consultants. **Guidelines for Infant Bioethics Committees.** *Pediatrics* 74(2): 306-310, August 1984.

The Task Force suggests that functions of hospital-based infant bioethics committees include education, policy development, prospective review and consultation, and retrospective review. Guidelines are offered for committee structure and procedural matters.

Hastings Center Research Project on the Care of Imperiled Newborns. **Imperiled Newborns.** *Hastings Center Report* 17(6): 5-32, December 1987.

This work discusses the history of neonatal intensive care, including standards of judgment, decision making, forgoing treatment, and the role of the family and society. It encourages an individualized approach in the “best interest of the child,” though this may be superseded in exceptional cases in which relational potential is minimal. Greater attention should be given to decisions after the newborn period, particularly

to society’s role in providing care and support.

II. Books

Frohock, Fred M., **SPECIAL CARE: MEDICAL DECISIONS AT THE BEGINNING OF LIFE.** Chicago: University of Chicago Press, 1986. 263 p.

A political scientist reports on life in a newborn intensive care unit (NICU), and argues that decisions about treatment should be made through negotiation between parents and physicians, with concern for the prevention of harm rather than with rights.

Guillemin, Jeanne Harley and Holmstrom, Lynda Lytle, **MIXED BLESSINGS: INTENSIVE CARE FOR NEWBORNS.** New York: Oxford University Press, 1986. 317 p.

Based on eight months’ experience in an NICU, the authors describe the sociology of the unit. Sections of the book are devoted to professional roles and responsibility, clinical decisions and the patient’s career, family, and the national/international context. The authors advocate better coordinated policies, broader involvement in decisions and a concern with the newborn’s well-being rather than with organizational efficiency and medical progress.

Gustaitis, Rasa and Young, Ernlé W.D., **A TIME TO BE BORN, A TIME TO DIE: CONFLICTS AND ETHICS IN AN INTENSIVE CARE NURSERY.** Reading, MA: Addison Wesley, 1986. 267 p.

A journalist and a chaplain/ethicist write about their experience with NICU cases at Stanford, and recommend an inclusive perspective for decision making, balancing the right to life with other rights including the right to die, and consideration of the needs of the family and necessary continuing care.

Harris, Chandice C. and Snowden, Fraser, eds., **BIOETHICAL FRONTIERS IN PERINATAL INTENSIVE CARE.** Natchitoches, LA: Northwestern State University Press, 1985. 131 p.

These published proceedings of a 1984 conference offer philosophical, anthropological, theological and legal perspectives.

Horan, Denis J. and Delahoyde, Melinda, eds.,

INFANTICIDE AND THE HANDICAPPED NEWBORN. Provo, UT: Brigham Young University Press, 1982. 127 p.

The book presents papers on medical, legal, and ethical issues related to non-treatment, and generally offers information and arguments to support aggressive treatment.

Jonsen, Albert R. and Garland, Michael J., eds. **ETHICS OF NEWBORN INTENSIVE CARE.** Berkeley. University of California, Institute of Government Studies, 1976. 193 p.

Papers from the landmark Sonoma Conference provide interdisciplinary perspectives on such NIC topics as clinical reality, social context, and policy questions; a survey of participants' attitudes is included.

Kuhse, Helga and Singer, Peter, **SHOULD THE BABY LIVE? THE PROBLEM OF HANDICAPPED INFANTS.** New York: Oxford University Press, 1985. 228 p.

Case descriptions and arguments are offered to support the active killing of some newborns with severe disabilities, if limited to infants without self-awareness and in accord with parental consent. The authors say that interests of the family, the "next child" and society must be considered.

Magnet, Joseph Eliot and Kluge, Eike-Henner W., **WITHHOLDING TREATMENT FROM DEFECTIVE NEWBORN CHILDREN.** Cowansville, Quebec: Brown Legal Publications, 1985. 306 p.

Canadian NIC practice and related legal issues are described, and the acceptance of selective passive euthanasia is noted. Parents should make decisions, following objective standards. Active euthanasia, at parental request with internal committee review, would be appropriate in many cases.

McMillan, Richard C.; Engelhardt, H. Tristram; and Spicker, Stuart F., eds. **EUTHANASIA AND THE NEWBORN: CONFLICTS REGARDING SAVING LIVES.** Boston: D. Reidel, 1987. 313 p.

Included in this collection are essays on the historical background and current policy regarding defective neonates, proposals for changes in public policy, and a discussion of religious and

moral values in the context of tragic choices.

Murray, Thomas H. and Caplan, Arthur L., eds. **WHICH BABIES SHALL LIVE? HUMANISTIC DIMENSIONS OF THE CARE OF IMPERILED NEWBORNS.** Clifton, NJ: Humana Press, 1985. 223 p.

The authors present perspectives from the humanities on attitudes to those "less than" normal, and cover topics such as the child, its suffering and respect for the "abnormal."

Shelp, Earl E., **BORN TO DIE? DECIDING THE FATE OF CRITICALLY ILL NEWBORNS.** New York: Free Press, 1986. 250 p.

Focusing on the parent-child relationship, Shelp supports the view that parent decisions based on beneficence and justice should generally be decisive, in light of society's pluralism. Noting that infants are persons only in a social sense, and not in a strict sense, the author goes on to argue that an active, merciful death could be an acceptable choice.

Sparks, Richard Craig, **THE ETHICAL CRITERIA INVOLVED IN DECISIONS TO ACCEPT OR FOREGO TREATMENT OF HANDICAPPED NEWBORNS.** Ann Arbor: University Microfilms International, 1985. (Ph.D. diss., Catholic University of American, 1985.) 498 p.

Four approaches to NIC decisions are examined here: medical indications, the ordinary/extraordinary means distinction, the projected quality of the patient's life, and a socially weighted benefit/burden calculus. The author advocates a criterion of the "patient's best interest, holistically viewed."

Stinson, Robert and Stinson, Peggy, **THE LONG DYING OF BABY ANDREW.** Boston: Little, Brown, 1983. 375p.

In this chronological account of their son's seven-month life, the parents bitterly criticize poor communications and the making of decisions for heroic treatment against their wishes.

Swinyard, Chester, A., ed., **DECISION MAKING AND THE DEFECTIVE NEW BORN: PROCEEDINGS OF A CONFERENCE ON SPINA BIFIDA AND ETHICS.** Springfield, IL: Charles C. Thomas, 1978. 649 p.

The collected proceedings of a conference on spina bifida and ethics offers 27 papers on the medical background, decision making, attitudes toward the newborn, legal and ethical considerations, and proxy consent.

U.S. Congress. Office of Technology Assessment. **THE IMPLICATIONS OF COST-EFFECTIVENESS ANALYSIS OF MEDICAL TECHNOLOGY; CASE STUDY #10: THE COSTS AND EFFECTIVENESS OF NEONATAL INTENSIVE CARE.** Washington: U.S. Government Printing Office, 1981. 51 p.

Needs, supply, utilization, costs, and reimbursement are surveyed in this work. NIC evaluation indicates that newborn survival increases and handicaps generally decrease, though more marginal infants survive. The report calls attention to the larger issues which include reducing premature births and risk, and goes on to say that NIC cutbacks would disproportionately affect newborns of lower socioeconomic status.

Voigtlander, Bonnie D., **AN ETHICAL THEORY FOR MEDICAL DECISION MAKING WITH SPECIAL REFERENCE TO NEONATAL INTENSIVE CARE.** Ann Arbor: University Microfilms, 1979. (Diss., University of Tennessee, Knoxville, 1978.) 186 p.

The author's doctoral dissertation develops "an act utilitarian theory of right acts combined with a qualitative hedonistic theory of intrinsic good" applied to ethical decision making in the NICU.

Weir, Robert F. **SELECTIVE NONTREATMENT OF HANDICAPPED NEWBORNS.** New York: Oxford University Press, 1984. 292 p.

Weir carefully presents positions of physicians, lawyers and ethicists concerning the NICU. Relevant ethical and clinical criteria, including viewing neonates as potential persons, support selection by diagnostic category. The author argues that parents should have rebuttable authority as proxy decision makers, with NICU committees playing a crucial role.

A. Neonatal Intensive Care

Annas, George J., **Ethics Committees in Neonatal Care: Substantive Protection or Procedural Diversion?** *American Journal of Public Health* 74(8): 843-845, August 1984.

Lawyer Annas writes that individual case adjudication, assuring due process and protection of the patient, is an appropriate role for NIC ethics committees; committee members should not act as experts or policy makers.

Arras, John D. **Toward an Ethic of Ambiguity.** *Hastings Center Report* 14(2): 25-33, April 1984.

The author supports a standard of the infant's best interest, and urges that the perspective should be that of the impaired infant with medical but not social differences considered morally significant. He writes that a supplementary standard of human capacities is required; radically impoverished existence marginally in the infant's interest may not be worth sustaining at great cost.

Baker, Robert, **Ceasing to Save: An Analysis of the Moral Methodology of One Neonatal Intensive Care Unit, With Special Reference to the Killing/Allowing-Death Controversy.** In: **REPORTS OF THE INSTITUTE FELLOWS, 1977-1978**, edited by Thomas K. McElhinney. Philadelphia: Society for Health and Human Values, 1978, pp. 145-180.

The NICU and actions in eight cases are described, and the underlying moral methodologies are analyzed. Distinctions should be made between killing, allowing [preventable] death, and desisting from unsuccessful rescue.

Bogdan, Robert; Brown, Mary Alice; and Foster, Susan B., **Be Honest but Not Cruel: Staff/Parent Communication on a Neonatal Unit.** *Human Organization* 41(1): 6-16, Spring 1982.

The article points out that the NICU has a complex communication system with many levels and perspectives. Observing that parents undergo a life-changing experience, the authors urge that greater priority be given to full communication between physicians, staff members and the parents.

Childress, James. F., **Protecting Handicapped Newborns: Who's In Charge and Who Pays?**

III. Articles and Essays

In: GENETICS AND THE LAW III, edited by Aubrey Milunsky and George Annas. New York: Plenum Press, 1985, pp. 271-281.

Philosopher Childress writes that just decisions are those taken in the infant's best interest with a presumption for prolonging life. Parents have a rebuttable authority as proxy decision-makers, but ethics committees should review decisions for non-treatment.

Childress, James F., **Triage in Neonatal Intensive**

Care: The Limitations of a Metaphor. *Virginia Law Review* 69(3): 547-561, April 1983.

Noting that triage decisions are based on medical and social utility, the author argues that, in neonatal intensive care, society's interest in equal value of life calls for consideration only of medical utility. He states that similar chances for survival and comparable consumption of resources should result in equal access for all who need care.

Duff, Raymond F. and Campbell, A.G.M., **Moral and Ethical Dilemmas in the Special-Care Nursery.** *New England Journal of Medicine* 289 (17): 890-894, 25 October 1973.

In this landmark article, 299 NICU deaths are considered: 14% were related to withholding treatment, generally involving congenital disorders where "prognosis for meaningful life was extremely poor or hopeless." The study recommends that decisions should be made by "families and their professional advisers."

Hauerwas, Stanley, **The Demands and Limits of Care — Ethical Reflections on the Moral Dilemma of Neonatal Intensive Care.** *American Journal of the Medical Sciences* 269(2): 222-236, March-April 1975.

The roles and responsibilities of parents, physicians, and society are considered in this article. Hauerwas argues that rights language is inappropriate, though the neonate's life has great value. He says that parents are obligated to care for their children, but technology has expanded the limits of care so that the extent of parental and societal obligations is unclear. The author suggests that a moral community is needed to develop understandings of responsibilities of roles.

Hernandez, Jacinto A.; Offut, Joan; and Butterfield, L. Joseph. **The Cost of the Less-Than-1000-Gram Infant.** *Clinics in Perinatology* 13(2): 461-477, June 1986.

The experience of a NICU with the management and costs of preterm infants is presented and analyzed, with thorough references to the relevant literature.

Jonsen, Albert R., **Justice and the Defective Newborn.** *In: JUSTICE AND HEALTH CARE*, edited by Earl E. Shelp. Boston: D. Reidel, 1981, pp. 95-107.

Ethicist Jonsen notes that if similar cases are treated equally, selective non-treatment meets the criteria of justice. Quality of life considerations should be limited to the clinical situation and its immediate consequences.

Kipnis, Kenneth and Williamson, Gailynn M., **Nontreatment Decisions for Severely Compromised Newborns.** *Ethics* 95(1): 90-111, October 1984.

The authors recommend that criteria for non-treatment should be the best interest of the infant and subjectively valuable life. They propose that nontreatment is obligatory, despite parental desires, if the quality of life would be harmed and recovery be unlikely. Treatment is obligatory, they say, if it is "likely that the patients will survive and have lives they will want to live," though parents can decline to support heroic actions.

McCullough, Laurence B. and Myser, Catherine. **Recent Developments in Perinatal and Neonatal Ethics: A U.S. Perspective.** *Seminars in Perinatology* 11(3): 216-223, July 1987.

Concepts of personhood and quality of life are seen as dominant in current ethical discussion. The language of patients, supporting appeal to beneficence and a context for consideration of quality of life, is advocated, as is a longterm care model analogous to that used for elderly patients.

Moskop, John C. and Saldanha, Rita L., **The Baby Doe Rule: Still a Threat.** *Hastings Center Report* 16(2): 8-14, April 1986.

This work expresses concern that current regulations will lead to the unjustified prolongation

of life, unfairly singling out infants, and causing physicians to inflict harm. Resources for NIC and continuing care will be further strained, the authors believe.

Ragatz, Stephen C. and Ellison, Patricia H., **Decisions to Withdraw Life Support in the Neonatal Intensive Care Unit.** *Clinical Pediatrics* 22(1): 729-735, November 1983.

Ragatz and Ellison write that withdrawing treatment should be considered for “infants who are so severely brain damaged that they are likely to be severely retarded and dependent later in their lives,” creating unjustified costs and difficulties for parents. Procedures at one NICU, and current and developing methods for medical assessment, are discussed.

Reiser, Stanley J., **Survival at What Cost? Origins and Effects of the Modern Controversy on Treating Severely Handicapped Newborns.** *Journal of Health Politics, Policy and Law* 11(2): 199-213, Summer 1986.

The background of technological innovation, ethical debate, and social change is discussed. The author suggests that current regulations represent “government overreach,” leading to greater concern with rules than patients. Committees may advise, he writes, but parents should bear responsibility for making decisions; he recommends that society should provide financial support.

Singer, Peter. **A Report from Australia: Which Babies Are Too Expensive to Treat?** *Bioethics* 1(3): 275-283, July 1987.

Differing practices in the treatment of low birth weight infants are noted. A system is needed to compare different outcomes as the basis for rational allocation of health care resources; the QALY (quality-adjusted life year) provides one possible criterion.

Strong, Carson, **The Neonatologist’s Duty to Patient and Parents.** *Hastings Center Report* 14(4): 10-16, August 1984.

While arguments for paternalism are invalid, the writer argues that the physician’s duty to the infant casts him or her in a role of infant advocate, justifying unilateral decision making in some cases. He goes on to suggest that when heavy burdens to the family are involved, par-

ents should have an important voice and family interests should be considered.

Strong, Carson, **The Tiniest Newborns.** *Hastings Center Report* 13(1): 14-19, February 1983.

When aggressive treatment is initiated at birth for very low weight infants, the author points out that time is provided for prognosis, lives are saved and adverse effects are generally reduced. The infants’ interests mandate treatment, he says, since some survive at near normal levels and suffering is generally limited and controllable. He notes that social justice supports NIC, because the disadvantaged tend to need it disproportionately, and that the total cost to society is reasonable, though limits may be reached in particular cases.

Walters, James W., **Approaches to Ethical Decision Making in the Neonatal Intensive Care Unit.** *American Journal of Diseases of Children* 142(8): 825-830, August 1988.

Walters considers four influential approaches in neonatal decision making and then adds a fifth, proximate personhood. Key criteria include present condition, the probability of self-awareness, and projected net physiological benefit.

Whitelaw, Andrew, **Death as an Option in Neonatal Intensive Care.** *Lancet* 2(8502): 328-331, 9 August 1986.

At a regional NICU, the author reports, decisions for withdrawal of treatment result from a unanimous consensus of medical and nursing staff on “virtual certainty, not just of a handicap, but of total incapacity.” Whitelaw believes that with “good communications and trust,” parents generally accept such decisions, so that “recourse to such outside bodies” as ethics committees should be unnecessary.

B. Discussions of Newborn Treatment in General

Bleich, J. David, **Theological Considerations in the Care of Defective Newborns.** *In: DECISION MAKING AND THE DEFECTIVE NEWBORN*, edited by Chester A. Swinyard. Springfield, IL: Charles C. Thomas, 1978, pp. 512-561.

Rabbi Bleich presents the Jewish tradition’s

values of life and healing, mandating “aggressive treatment of defective newborns regardless of the extent of their impairments or the quality of life.” Procedures may be omitted only if they involve risk or lack proven therapeutic value, or if death is imminent.

Engelhardt, H. Tristram, **Infanticide**. *In his: THE FOUNDATIONS OF BIOETHICS*. New York: Oxford University Press, 1986, pp. 228-236.

Bioethicist Engelhardt writes that infanticide is not inherently immoral, as the child is not a person, though consequentialist considerations might limit the use of euthanasia to cases with questionable quality of life and substantial costs. He goes on to state that parental autonomy would generally be decisive.

Fletcher, Joseph, **Four Indicators of Humanhood — the Enquiry Matures**. *Hastings Center Report* 4(6): 4-7, December 1974.

The author considers criteria for personhood, including self-consciousness and relational ability. He advocates neocortical function as more inclusive and conservative, and medically determinable.

Gustafson, James M., **Mongolism, Parental Desires, and the Right to Life**. *Perspectives in Biology and Medicine* 16(4):529-557, Spring 1973.

Parental refusal for surgery on a Down’s Syndrome infant is considered from the perspective of all involved, and the author indicates that, in this case, the values and rights of the infant outweigh the parents’ desires.

Koop, C. Everett, **The Handicapped Child and His Family**. *Linacre Quarterly* 48(1): 23-32, February 1981.

Dr. Koop says that each newborn infant, perfect or deformed, is a uniquely precious human being, and that suffering and sacrifice may have meaning; the physician must be authoritative and supportive of the family.

Lorber, John, **Results of Treatment of Myelomeningocele: An Analysis of 524 Unselected Cases, with Special Reference to Possible Selection for Treatment**. *Developmental Medicine and Child Neurology* 13(3): 279-303, June 1971.

This early article asserts that medical criteria can forecast minimum future handicaps. Lorber argues that nontreatment in selected cases may be in the infant’s best interests and that other patients might benefit from freed resources.

McCormick, Richard A., **To Save or Let Die: The Dilemma of Modern Medicine**. *Journal of the American Medical Association* 229(2): 172-176, 8 July 1974.

Theologian McCormick writes that guidelines are a needed accompaniment to the new medical technologies, and decisions should be made in the infant’s best interests, including letting die if relational potential is completely absent.

Pellegrino, Edmund D., **The Anatomy of Clinical-Ethical Judgments in Perinatology: A Substantive and Procedural Framework**. *Seminars in Perinatology* 11(3): 202-209, July 1987.

Pellegrino presents “substantive and procedural schemata that can make clinical-ethical judgments more orderly and more explicit,” helping the neonatologist to fulfill his or her duty as physician. Substantive issues include the physician-patient relationship, basic principles and theories of ethics, and the ultimate source of morality. A proper “ethical work-up” includes establishing facts, determining the patient’s best interests, defining ethical issues, reaching a concrete resolution, and justifying the decision.

Ramsey, Paul, **“Euthanasia’ and Dying Well Enough,” “The Benign Neglect of Defective Infants,” and “An Ingathering of Other Reasons for Neonatal Infanticide.”** *In his: ETHICS AT THE EDGES OF LIFE: MEDICAL AND LEGAL INTERSECTIONS*. New Haven: Yale University Press, 1978, pp. 145-267.

According to Ramsey, justice and the value of human life mandate full and equally vigorous treatment for all infants unless the patient is immediately dying or no treatment is possible.

C. Legal Considerations

Gorski, Sandra L., **Premature Infants: A Legal Approach to Decision-Making in Neonatal Intensive Care**. [Comment] *University of San Francisco Law Review* 19(3/4): 261-281, Spring/

Summer 1985.

The article indicates that current laws on termination of treatment are inadequate for certain premature infants, and recommends statutory guidelines with narrowly drawn substantive and procedural standards, including general parental authority.

Holder, Angela R., **The Child and Death. In her: LEGAL ISSUES IN PEDIATRIC AND ADOLESCENT MEDICINE**, 2nd ed. New Haven: Yale University Press, 1985, pp. 82-122.

Medical, political, and legal aspects are considered, including criminal and civil liability of parents and physicians. Holder argues rights come to humans at birth and treatment should be mandated if it can cure a specific condition, but she suggests that risky or noncurative treatment is not necessary.

Macmillan, Elizabeth S., **Birth-Defective Infants: A Standard for Nontreatment Decisions. Stanford Law Review** 30(3): 599-633, February 1978.

A medical feasibility standard is advocated as protecting the best interest of the infant, accommodating interests of parents and the state, and providing consistency without undermining societal values.

Robertson, John A., **Involuntary Euthanasia of Defective Newborns: A Legal Analysis. Stanford Law Review** 27(2): 213-269, January 1975.

The author writes that failure to provide ordinary life-saving treatment involves criminal liability of parents, physicians, and hospital staff.

Robertson, John A., **Legal Aspects of Withholding Treatment from Handicapped Newborns: Substantive Issues. Journal of Health Politics, Policy and Law** 11(2):215-230, Summer 1986.

Legal principles and court decisions involving parental authority, state intervention and physician obligations are examined; a patient-centered approach is advocated.

Rhoden, Nancy K., **Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts. Southern California Law Review** 56(6):

1283-1347, September 1985.

A range of cases and issues is presented and government policies are reviewed. Considerations such as life span, prognosis and potential for cognitive development and human interaction are deemed appropriate and not conflicting with current law.

Shapiro, Robyn S. and Frader, Joel E., **Critically Ill Infants. In: MEDICOLEGAL ASPECTS OF CRITICAL CARE**, edited by Katherine Benesch, *et al.* Rockville, MD: Aspen Publishers, 1986, pp.61-86.

This chapter indicates that parents have the right to make decisions in the best interest of the child, and that generally they are overruled only when undue harm would result.

D. Additional Readings

Allen, David M., *et al.* **Mortality in Infants Discharged from Neonatal Intensive Care Units in Georgia. Journal of the American Medical Association** 261(12): 1763-1766, 24/31 March 1989.

Barry, Robert L. **Infant Care Review Committees: Their Moral Responsibilities. Linacre Quarterly** 52(4): 361-374, November 1985.

Blustein, Jeffrey. **Morality and Parenting: An Ethical Framework for Decisions about the Treatment of Imperiled Newborns. Theoretical Medicine** 9(1): 23-32, February 1988.

Boyle, Michael H., *et al.* **Economic Evaluation of Neonatal Intensive Care of Very-Low-Birth-Weight Infants. New England Journal of Medicine** 308(22): 1330-1337, 2 June 1983.

Campbell, A.G.M., **Which Infants Should Not Receive Intensive Care? Archives of Disease in Childhood** 57(8): 569-571, August 1982.

Coulter, David L. **Neurological Uncertainty in Newborn Intensive Care. New England Journal of Medicine** 316(14): 840-844, 2 April 1987.

Drane, James F. **Playing God in the NICU: Ethical Guidelines on What Seems Best for the Handicapped Infant. Health Progress** 70(2):

26-31, March 1989.

Fischer, Allen F. and Stevenson, David K., **The Consequences of Uncertainty: An Empirical Approach to Medical Decision Making in Neonatal Intensive Care.** *Journal of the American Medical Association* 258(14): 1929-1931, 9 October 1987.

Fletcher, John C., **Abortion, Euthanasia, and Care of Defective Newborns.** *New England Journal of Medicine* 292(2): 75-78, 9 January 1975.

Fletcher, John C., **Attitudes Toward Defective Newborns.** *Hastings Center Studies* 2(1): 21-32, January 1974.

Fost, Norman, **Ethical Issues in the Treatment of Critically Ill Newborns.** *Pediatric Annals* 10(10): 16-22, October 1981.

Frader, Joel E., **Withdrawal of Life Support in the Neonatal Intensive Care Unit: An Editorial Comment.** *Clinical Pediatrics* 22(11): 735-736, November 1983.

Freeman, John M. **To Treat or Not to Treat: Ethical Dilemmas of Treating the Infant with Myelomeningocele.** *Clinical Neurosurgery* 20: 134-163, 1973.

Glasow, Suzanne B. **Establishing Decisionmaking Standards for Medical Treatment to Protect the Civil Rights of Handicapped Newborns.** [Comment] *Journal of Contemporary Health Law and Policy* 2: 255-274, Spring 1986.

Griffin, Andrew and Thomasma, David C., **Triage and Critical Care of Children.** *Theoretical Medicine* 4(2): 155-163, June 1983.

Johnson, Paul R., **Selective Nontreatment and Spina Bifida: A Case Study in Ethical Theory and Application.** *Bioethics Quarterly* 3(2): 91-111, Summer 1981.

McCormick, Richard A., **The Best Interests of the Baby.** *Second Opinion* 2: 18-25, 1986.

McCormick, Marie C. **Long-term Follow-up of Infants Discharged from Neonatal Intensive**

Care Units. *Journal of the American Medical Association* 261(12): 1767-1772, 24/31 March 1989.

Michaels, Richard and Oliver, Thomas K., **Human Rights Consultation: A 12-year Experience of a Pediatric Bioethics Committee.** *Pediatrics* 78(4): 566-572, October 1986.

Moreno, Jonathan D., **Ethical and Legal Issues in the Care of the Impaired Newborn.** *Clinics in Perinatology* 14(2): 345-360, June 1987.

Raphael, D.D. **Handicapped Infants: Medical Ethics and the Law.** *Journal of Medical Ethics* 14(1): 5-10, March 1988.

Reich, Warren T. **Caring for Life in the First of It: Moral Paradigms for Perinatal and Neonatal Ethics.** *Seminars in Perinatology* 11(3): 279-287, July 1987.

Rhoden, Nancy K., **Treating Baby Doe: The Ethics of Uncertainty.** *Hastings Center Report* 16(4): 34-42, August 1986.

Rostain, Anthony, **Deciding to Forgo Life Sustaining Treatment in the Intensive Care Nursery: A Sociologic Account.** *Perspectives in Biology and Medicine* 30(1): 117-134, Autumn 1986.

Smith, George P., **Long Days[sic] Journeys into Night: The Tragedy of the Handicapped At-Risk Infant.** In: **MORAL ISSUES IN MENTAL RETARDATION**, edited by Ronald S. Laura and Adrian F. Ashman. Dover, NH: Croom Helm, 1985, pp. 129-160.

Smith, Steven R., **Life and Death Decisions in the Nursery: Standards and Procedures for Withholding Lifesaving Treatment from Infants.** *New York Law School Law Review* 27(4): 1125-1186, 1982.

Stahlman, Mildred T., **Implications of Research and High Technology for Neonatal Intensive Care.** *Journal of the American Medical Association* 261(12): 1791, 24/31 March 1989.

Stahinian, Mildred T., **Newborn Intensive Care: Success or Failure?** *Journal of Pediatrics* 105(1):

162-167, July 1984.

Strong, Carson, **Defective Infants and Their Impact on Families: Ethical and Legal Considerations.** *Law, Medicine and Health Care* 11(4): 168-172, 181, September 1983.

Theis, E. Charlotte, **Ethical Issues: A Nursing Perspective.** *New England Journal of Medicine* 315(19): 1222-1224, 6 November 1986.

Todres, I. David, **Infant Doe: Federal Regulations of the Newborn Nursery Are Born.** *In: GENETICS AND THE LAW III*, edited by Aubrey Milunsky and George Annas. New York: Plenum Press, 1985, pp. 253-257.

U.S. Commission on Civil Rights, **PROTECTION OF HANDICAPPED NEWBORNS, Hearings, 12-14 June 1985.** Washington: U.S. Government Printing Office, 1986. 250 p.

Weir, Robert F., **Pediatric Ethics Committees: Ethical Advisers or Legal Watchdogs.** *Law, Medicine and Health Care* 15(3): 99-109, Fall 1987.

Weir, Robert, **Selective Nontreatment — One**

Year Later: Reflections and a Response. *Social Science and Medicine* 20(11): 1109-1117, 1985.

Yu, Victor, **Extremely Premature Infants: To Treat or Not to Treat?** *Bioethics News* 3(4): 6-12, July 1984.

Zachary, R.B. **Life with Spina Bifida.** *British Medical Journal* 2: 1460-1462, 3 December 1977.

Young, Ernlé W.D., **Caring for Disabled Infants.** *Hastings Center Report* 13(4): 15-18, August 1983.

SCOPE NOTE 11 was prepared by Aaron L. Mackler, who is a graduate student in Philosophy with a concentration in Bioethics at Georgetown University.

This publication is supported by funds provided under Grant Number LM044 92 from the National Library of Medicine, National Institutes of Health.

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