Responding to Parental Requests to Forego Pediatric Nutrition and Hydration

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THE CASE OF RANDY

Randy, the first baby of married parents in their 30s, was born at 36 weeks with severe perinatal asphyxia. He developed seizure activity within 12 hours of birth, which was controlled with Phenobarbital and Dilantin. His EEG [electroencephalogram], CT [computerized tomography scan], and MRI [magnetic resonance imaging scan] led the consulting neurologist to state, “there is no chance for appreciable neurologic recovery and near certain likelihood of profound neurological disability.” Apart from the brief period following delivery, Randy did not need artificial respiratory support. The parents and NICU [neonatal intensive care unit] staff agreed that CPR [cardiopulmonary resuscitation] would not be performed if Randy’s heart or breathing stopped. He had been receiving nasogastric feedings until his parents requested that they be stopped. He had sleep-wake cycles but did not cry. Neonatal suck and gag reflexes appeared to be intact. The staff and family asked for an ethics consult to discuss whether it would be ethically permissible to withhold nutrition and hydration from Randy—both nasogastric and bottle-feeding.

Feeding infants and children is central to the care they receive from health professionals as well as their parents, whether by bottle, spoon, or, for sick children, by tube or other medical device. Nutrition and hydration in some form is almost always medically and ethically indicated. Nevertheless, we believe there are limited circumstances in which it may be ethically justifiable for health professionals to withhold or withdraw medically administered nutrition and hydration (MN&H) and, rarely, oral feeding from a child at the request of the parents. We note, however, that there is greater uncertainty as to when withholding food and fluid from children, especially newborns, is legally permissible.

PARENTAL AUTHORITY AND RESPONSIBILITY

Most of the time nurses, doctors, and other health professionals appropriately presume that parents are morally responsible for making healthcare decisions for their sick children. Parents are customarily recognized as their children’s “natural guardians” and so serve as surrogate decision makers in regard to medical care for several reasons. First, parents are typically committed to caring for their children, and base their decisions on what they believe to be their children’s best interests. In addition, they usually
understand best their children's particular needs and the value-structure and culture within which they will be raised. Moreover, parents usually create the environment in which their children will find meaning. The priority given to parental decisions was emphasized by The Report of the President's Commission on Forgoing Life-Sustaining Treatment, which concluded that parents may decide whether to accept or forgo medical treatment for their children if the benefits of treatment are ambiguous or uncertain. Only if treatment is clearly beneficial should unwanted treatment be provided, while the parents' decision is reviewed.1

The authority of parents to make medical decisions for their children is also well established under the law. The right of parents generally to direct the upbringing of their children in a way that is consistent with their values has been recognized as a fundamental one, protected by the Constitution.3 State court decisions have recognized that this right applies to medical decision making.4 In most cases involving choices about medical care, "the State simply is not an adequate surrogate for the judgment of a loving, nurturing parent."4 The Guidelines for State Court Decision-Making in Life-Sustaining Medical Treatment Cases, issued by the Coordinating Council of the National Center for State Courts, indicate that, in order for a state to override a parental decision, the benefits of treatment and its potential for success must be substantial. If serious burdens accompany treatment that may be unacceptable in light of the expected benefits, most courts will defer to parental judgment.5

THE LIMITS OF PARENTAL AUTHORITY

Nevertheless, in certain circumstances, it is ethically acceptable—even obligatory—to challenge parental decisions. Although health professionals generally are ethically obligated to respect a competent patient's decision, even when they consider it to be harmful to the patient, the obligation to respect competent parents' decisions for their incompetent children is not as strong. Because children are especially vulnerable and because they have been exploited in the past, pediatric health professionals are typically understood to have a stronger duty of nonmaleficence toward these never-competent patients, which may override their duty to respect surrogate decisions made by parents. Health professionals are also widely believed to have a positive obligation to advance their patients' interests and welfare, although the extent of this duty of beneficence in pediatric care is not well-delineated

when it is in conflict with the duty to respect parental values and choices. In pediatrics, beneficence-based responsibilities more frequently supersede the duty to respect "autonomy" (as exercised by parents) than is the case in adult care, even when an adult's autonomy is being effectuated through a surrogate. Finally, in a few cases, parents simply lack the capacity to make informed decisions for their children or are unavailable, despite persistent good-faith efforts to inform and engage them, and are thus disqualified as surrogate decision makers.

Similarly, the law recognizes that the right of parents to make decisions for their children is not absolute.6 The state may override parental decisions in order to protect society's interests, the state's interest in preserving life, or the child's interests.7 State law varies, but, in general, in those cases in which the benefits of treatment are clear, and risks are minor, parental refusals of care have been overridden. Even when the treatment may be risky, if there is medical consensus that the prognosis with treatment is very good, courts may order that treatment be provided.8 Such decisions reflect a social consensus that curing a child's illness, or sustaining the life of a child who can form human ties, or relieving a child's suffering, are legitimate goals for medicine and for society, which can outweigh parental rights.

In cases in which medical judgments differ about whether treatment will cure the patient or alleviate all of the symptoms, the courts show greater deference to parental judgment.9 When the condition and prognosis are very poor, and, in particular, when the child is in a persistent vegetative state, courts have deferred to parental refusals of treatment.10 Similarly, in the clinical setting, parents' decisions to refuse life-extending procedures for their dying or severely devastated infants and children have often been respected by health professionals and, more recently, supported by ethics committees. Such deference to parental refusals of, for example, complex surgeries, the use of ventilators, or less obviously burdensome treatments such as vasopressors or antibiotics, reflects a lack of social consensus about the value of simply maintaining physical existence or of prolonging dying. Social views are in direct conflict in this area: to some, every form of human life should be preserved as long as possible; to others, maintaining physical functioning in the absence of relational potential degrades human dignity.

But what is the ethical responsibility of those who work in the neonatal nursery when parents who are present, concerned, fully informed, and capable of
making decisions do not consent to MN&H, such as intravenous or nasogastric tubes? And is their ethical responsibility any different when parents refuse oral feedings?

THE ETHICS OF FORGOING MN&H

While there is ethical consensus that life-sustaining treatment need not be provided in every circumstance, there are those who believe that MN&H must always be provided. They argue that feeding, however it is provided, is not medical care, but is ordinary care, for infants. Food is universally required to sustain the life of dependent infants, however, MN&H differs significantly from breast or bottle-feedings. The infant does not experience the pleasure of sucking and taste, and may actually experience discomfort from needles, the passage of nasogastric tubes, or surgery, which all require medical judgment and skill to administer.

Further, food is no more basic than air, and most health professionals believe that it is ethically permissible to withhold mechanical ventilation from some babies who cannot breathe on their own. It might be countered that ventilators are more invasive and burdensome than MN&H; however, all forms of MN&H are invasive to some extent, and carry medical risks of error, infiltration, and infection. Moreover, intravenous delivery of antibiotics and vasopressors is not particularly burdensome either, and many believe it is ethically justifiable to withdraw these treatments when the patient is dying or will no longer benefit from them.

Another arguable distinction is that, in other cases, such as withdrawal of ventilators, vasopressors, or antibiotics, the patients die of their underlying diseases, whether it is from pulmonary or cardiac failure, or from infection. In contrast, some argue that when MN&H is withheld, death occurs because babies—healthy or not—are inherently unable to feed themselves without help. Yet infants who cannot suck, swallow, or metabolize food will die of their impairments just as surely as children who cannot breathe will die of their impairment. While death is certain when MN&H is withheld, death may be virtually certain when other treatments, such as mechanical ventilation or dialysis, are withheld. In each instance, if health professionals agree to withhold treatment, they must believe that it is ethically justified to do so, even when the patient will die without the treatment.

Still, feeding has a particular symbolic value, especially with newborns, and especially for nurses, whose very profession—nursing—refers both to the practice of a profession and to the act of feeding infants. The failure to feed a baby may be seen to imply a lack of basic human virtues, especially the traditional caregiving virtues, of compassion and nurture. The symbolism of feeding as caring must be recognized, and, as with any instance of withholding treatment, other forms of caring for these children should continue, expressed in other ways, such as cuddling, bathing, massaging, holding, and rocking.

In the end, the purported differences between MN&H and other forms of medical treatment are not logically or ethically compelling.

THE LEGAL FRAMEWORK FOR FORGOING MN&H

The so-called “right to die” cases have established that competent patients have the right to refuse life-sustaining medical treatment. Further, virtually all appellate courts that have considered the issue have found that MN&H is medical treatment. Most courts have also ruled that the right to refuse treatment extends to incompetent persons, including minors, for whom that right may be exercised by appropriate surrogates. While the right to refuse treatment can be outweighed by the state’s interests, particularly the interest in life, and while the state’s interest in life may be particularly high when the patient is a child, this interest will not necessarily prevail when the child is terminally or irreversibly ill, or lacks consciousness.

Thus, under the analytic framework of the right-to-die cases, children arguably have the legal right to forgo MN&H, a right that can be exercised by parents on their behalf. In cases involving children who have never formed preferences, most state courts apply the best-interest test, considering factors such as prognosis, including the chance for cure and normal life, and the risks and invasiveness of treatment. In addition, quality of life, solely as experienced by the patient (and not the social value of his life), may be a relevant consideration.

Despite this reasoning from case law, federal law indicates—through the Child Abuse Amendments and implementing regulations (to be referred to as the Amendments)—that a different standard should be applied in cases involving infants. These Amendments, also called the Baby Doe rules, require that states that
accept federal funding for child protection services regard withholding "medically indicated" treatment from handicapped infants with life-threatening conditions as "medical neglect." Some states have adopted policies incorporating the Amendments' requirements, some have passed their own legislation to protect handicapped infants, and some did not, at least initially, accept federal funds. 

The Amendments appear to diverge from case law in a number of ways. For example, they apply only to a select class of children—generally, infants under one year of age (although the Amendments are also to be "consulted thoroughly" regarding older infants who have been continuously hospitalized since birth, who were born extremely prematurely, or who have a long-term disability). They also reject considerations of "quality of life," although the term is not defined, and they appear to distinguish between nutrition and hydration and other forms of medical treatment. Medical treatment need not be provided if: (1) the infant is chronically and irreversibly comatose; (2) treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of survival of the infant; or (3) treatment would be virtually futile in terms of survival and would be inhumane. Even in these circumstances, however, "appropriate nutrition and hydration" must be provided. Although the term "appropriate" is not defined, the most sensible interpretation may be that it means necessary for the comfort of the infant. Yet such an interpretation is not necessarily supported by the Amendments or legislative history. Arguably, the Amendments may be seen to assume that nutrition and hydration would be provided in virtually all cases in which they sustain life.

The Amendments, and state laws that incorporate them or contain similar provisions, add ambiguity to decision making for handicapped infants and children. In evaluating decisions for minors, most courts have continued to rely on a traditional "best-interest" analysis. In regard to infants, there are few reported cases, and they rarely discuss the Amendments. State child protection agencies, which constitute the principal enforcement mechanisms, appear not to receive many reports alleging medical neglect of handicapped infants. It is possible that, if challenged, the Amendments and similar state laws would be found unconstitutional on grounds that they deprive handicapped infants of rights accorded to other children and to adults. Or a court might find that the Amendments should be read to incorporate the principles found in judicial cases, particularly the right to refuse treatment.

While these legal issues complicate decisions about MN&H, it does not appear ethically justifiable to deprive infants of the right to refuse MN&H (through their surrogate decision makers), if such treatment is not in the best interests of the children. Nonetheless, it is possible that such decisions might be legally challenged, particularly in certain jurisdictions.

PARENTAL REFUSAL OF MN&H

We believe that because MN&H are not ethically distinguishable from other forms of life-sustaining medical treatment, and because most state courts have viewed them as medical treatments, parents' refusal of MN&H for their children should be evaluated in the same manner as refusals of other forms of life-sustaining treatment. The presumption should be that the decisions of parents will be respected if based on their children's best interest (unless parents are incompetent or are otherwise disqualified as surrogate decision makers).

Because MN&H generally provide comfort and are minimally invasive, most parents elect to provide such treatment. If parents refuse MN&H, health professionals should consider whether the medical evidence shows that MN&H serves the children's interests by improving their underlying condition, restoring function, relieving suffering, or affording the opportunity to experience life beyond mere physical existence—legitimate goals of medicine and society. If it does, health professionals are justified in refusing to comply with parental wishes and in seeking court intervention. On the other hand, if children are dying, comatose, or permanently lacking experiential capacity and will not suffer from forgoing MN&H, parents may ethically refuse such treatment on behalf of their children, as they may refuse other life-sustaining medical treatments.

WITHHOLDING ORAL FEEDING

Withholding oral feedings from a child who wants them and can take them safely is not ethically acceptable behavior for anyone, including health professionals. A child who is able to suck and swallow, who would experience pleasure or comfort from feeding, or who would experience suffering from its absence, should be fed orally, even if the prognosis is grim. But there are some infants and children who cannot handle oral feedings safely and who do not indicate
any desire to be fed or any suffering when not fed. In that case, under specifically limited circumstances, we believe it may be ethically permissible to respect parents' refusal of oral feedings as well as MN&H. At the same time, there are, we believe, some cases in which a child's inability to take oral feedings may trigger health professionals' ethical and legal duties to protect children by overriding the parents' refusal of MN&H, despite the child's poor prognosis.

SPECIFIC CIRCUMSTANCES

In our view, refusal by competent, caring parents of nutrition and hydration for their child—whether it is medically or orally delivered—may be ethically permissible in at least four specific circumstances.

First, health professionals and parents are ethically permitted, indeed obligated, to withhold nutrition and hydration that would be harmful. It would be wrong, for example, to administer nasogastric or bottle feedings to a child with an intestinal blockage, or total parenteral nutrition to some children with fulminant liver failure. Children who cannot take any form of nutrition and hydration and appear to be suffering from hunger or thirst should be given appropriate analgesic medication until the cause of their inability to take sustenance is removed or the child dies of underlying problems that cannot be repaired. For example, a child who is in multi-organ failure, including congestive heart failure, short gut with necrotizing enterocolitis, and liver failure, and cannot therefore receive adequate nutrition and hydration in any form, should be medicated if awake and suffering until liver transplantation or, if transplantation is unavailable or appropriately refused by parents, until the child dies of organ failure.

Second, intravenous feeding and other MN&H need not, and probably should not, be given to dying children who would experience them as painful, burdensome, or diminishing the quality of their remaining life, as these burdens may outweigh the tenuous benefit of extending life for a short time. Even if MN&H do not cause suffering, they may be withheld in dying children who will neither suffer from their absence nor benefit from their presence, such as the somnolent child imminently dying of cancer. Similarly, if such a child rejects or does not express any desire for oral feedings, it is not ethically necessary to force him or her to take them. Rather, a palliative approach of providing food and fluid as desired for pleasure and comfort is preferable.

Third, it is ethically permissible to withhold food and fluid from permanently unconscious infants and children if they are refused by their parents. Clearly the child who cannot suck or swallow need not—indeed cannot—be fed orally. And MN&H cannot restore health or function, nor relieve suffering, when the child is permanently unconscious. Many people believe that such children cannot experience any benefit from any medical treatment, including MN&H, though they can be kept biologically alive by MN&H and assiduous nursing care. Parents whose views of human dignity and purpose would be violated by continued maintenance of their child's body, without any chance of cognition or pleasurable sensation, should be allowed to refuse nutrition and hydration on their child's behalf. Nevertheless, decisions made by parents whose views of human worth and responsibility would be violated by failure to provide MN&H, which sustains their child's existence, should also be respected.

Finally, we believe that in certain very limited circumstances it can be ethically permissible to withhold orally and medically administered nutrition and hydration from children who are not permanently unconscious, but have such profound and irreversible neurological damage that they will never gain cognition or relate to others, provided that: (1) they cannot suck and swallow, or they have such weak, uncoordinated, or inconsistent suck, swallow, and gag reflexes that they are not able to take oral feedings in sufficient amounts safely; (2) they do not show any desire to be fed (by crying, lip smacking, restlessness, or wakefulness); (3) they do not suffer from the absence of nutrition and hydration; and (4) the diagnosis can be made with a high degree of certainty. The differences between these children and those who are permanently unconscious do not justify overriding parental values. While such profoundly devastated newborns may have some physiological reflexes, they lack fundamental capacities—such as the experience of pleasure or the potential for awareness and human relationship—that would mandate overriding parental refusal of medical treatment. In the language of the President's Commission, the harms and benefits of medical treatment are "uncertain or ambiguous." Because there is no social or moral consensus about whether using medical treatment to extend such a life is beneficial, the decision should fall within the domain of parental, rather than medical, decision making. In addition, because oral feeding is ineffective and/or unsafe, neither family nor staff are required to at-
tempt to force sufficient fluids into the child to sustain or extend life.

In our experience, however, a serious dilemma arises when a profoundly neurologically devastated infant or child has some ability to suck and swallow, but cannot take sufficient amounts orally, and may be able to experience suffering from the absence of nutrition and hydration—but the parents have refused MN&H. In such a case, the process of dying could take a considerable period of time. If another form of treatment were being withdrawn, such as a ventilator or dialysis, the child’s suffering would be relieved by medication. Although possible suffering from the absence of nutrition and hydration could be treated with medications while the child died from dehydration, such a course of action, to many, could never be characterized as in the child’s best interests, and, in fact, to some, it would constitute euthanasia. In the face of such moral uncertainty, we believe it is better to attempt to override the parents’ refusal of MN&H, in order to prevent the child’s suffering or prolonged dying, and to meet professional standards and social norms of care for infants.

MORE ON RANDY

Initially, Randy was unable to suck from a bottle. Because there was concern that his inability to take oral feedings might be caused by the Phenobarbital used to treat his neonatal seizures, a nasogastric tube was temporarily inserted to provide MN&H, despite his parents’ objections. It was also considered essential to obtain a clear evaluation of his baseline neurological functioning, unaffected by medication. After the Phenobarbital level had declined, EEG, CT, MRI and repeated neurological exams confirmed Randy’s severe bilateral hypoxic ischemic injury involving the cerebral cortex, white matter, and basal ganglia, as well as likely damage to his upper brainstem, with no expectation of recovery. The nasogastric tube was then removed at the request of his parents.

At that time, Randy was able to suck and swallow enough to take some small oral feedings from experienced neonatal nurses, but not in amounts sufficient to sustain life. He did not cry, nor express any obvious desire to be fed even after a six-hour interval. Randy’s parents and clinical team then raised the additional question of whether it was ethically acceptable to attempt bottle-feeding.

An ethics consult team met with the parents and grandparents, and with the clinical team. Some of the treating health professionals and Randy’s parents, along with at least one member of the ethics consult team, believed that Randy was terminally ill and dying as a result of his brain injury and that it was appropriate to provide palliative care, including oral feedings offered on demand. Because of the novelty and difficulty of this question about the ethical permissibility of respecting parents’ refusal of oral feedings for a child who had some capacity to suck and swallow, the hospital’s full Ethics Advisory Committee was convened to discuss the case.

In its report, the committee stated that it did “not think that oral feedings should be regarded as a medical treatment that may be refused. Oral feedings are a basic component of humane care that should be made available to all patients.” Although these opening statements in the committee’s report could be construed as inconsistent with the categories we suggest above, in which it is ethically permissible to honor parental refusals of orally as well as medically administered nutrition and hydration, we believe they are not when viewed in light of other comments in the report. For example, the committee also wrote that Randy “should be offered and given bottle feeds to the extent that he indicates a desire to be fed” (emphasis added).

The report added that Randy need not be “force-fed.” That is, the consult team did not consider it ethically necessary to feed Randy orally using various nursing techniques to keep the child awake, part the jaws, and stimulate reflexive sucking and swallowing until an adequate amount is ingested, despite no indication of a desire to be fed. Thus, if Randy had not been able to suck and swallow adequately to sustain life and did not appear to desire, or suffer from the lack of, nutrition and hydration—as initially appeared to be the case—the ethics committee (as well as the authors) may have supported his parents’ refusal of orally as well as medically administered nutrition and hydration. The ethics committee further recommended that health professionals who morally objected to withholding MN&H and to providing oral feedings only on demand should be allowed to decline to participate, and stated that its “recommendations are not a legal opinion” which, if desired, should be obtained through the office of general counsel. The committee’s report was placed in the medical record and a copy was given to the parents and staff.

When the clinical staff met with the hospital ethicist [CM] to discuss the consult report, they anticipated that Randy’s “demand” for oral feeding could be interpreted differently by various health professionals. While the nurses were especially concerned about what would constitute “caring” for this child if he did not receive natural...
rally, they also understood and respected the parents’ refusal of nutrition and hydration. A detailed nursing care plan was therefore developed that included bundling and holding, as well as diaper changes and repositioning every four to six hours. In less than 24 hours, Randy began to be awake for prolonged periods after diapering and repositioning. Though he did not cry, he would smack his lips, and nurses began offering Randy a bottle when he did not settle back to sleep. At first, his parents were distressed by this development, saying that he should be fed only if he cried. The staff and ethicists responded that Randy might never cry, but as long as he was awake, able, and seemed to want a bottle—and was not being force-fed—they thought that a bottle should be offered. His parents’ reluctance agreed. For a few days, it appeared that Randy might take small feedings, which began to raise the prospect of a prolonged death by starvation. Had that pattern continued, we expect there would have been further questions about whether staff should have continued insufficient oral feedings until death, or should have adopted a different treatment plan, such as stopping oral feedings completely, or trying to force-feed in adequate amounts, or supplementing or substituting oral feedings with M&H despite the parents’ refusal. According to our earlier analysis, the authors would suggest that adequate oral feedings be attempted or that M&H be provided rather than allowing a prolonged death by slow starvation, unless the evidence was compelling that Randy was not suffering and did not experience comfort from feeding.

Actually, Randy’s mother also began feeding him when he was awake, and she thought that he might, at some level, enjoy eating. In less than a week, he began taking sufficient calories to sustain growth. He was discharged home on “full feeds,” though he had not gained any additional neurological capacities. Randy is alive today. Perhaps it should be added that the family could not obtain affordable childcare and the mother has, therefore, not been able to return to work, which was the source of the family’s health insurance.

**RECOMMENDATIONS**

First: decisions about withdrawing or withholding nutrition and hydration are so ethically controversial and legally untested that each one requires very careful deliberation and discussion among all the clinical staff and the family involved in a child’s care. There should not, for example, simply be a doctor’s order to discontinue intravenous or nasogastric feeding without discussion with the nurses and other staff who will actually care for a baby who is not being fed. In addition, there is sometimes a tendency among staff or in parents to try to keep such decisions “secret,” which is both impossible and untenable. Because staff and family need to examine their own values and consciences, and because the reactions and reasons of others may change their minds, or at least bring about sympathetic understanding, it is important to discuss difficult ethical decisions openly.

Attention to the parents’ privacy is, of course, warranted, but respect for the moral responsibilities of involved staff is also important. Staff who do not understand or accept the parents’ decision to refuse nutrition and hydration for their child may feel a responsibility to report their concern to social agencies or to other parties. In our opinion, staff have a duty to inform parents of the strength of their concern prior to involving other parties. Like any other decision about life-sustaining treatment, the clinical and ethical reasons for withholding nutrition and hydration from a child should be able to withstand public scrutiny. Although few institutions require consultation by an ethics committee for particular cases, such consultation is probably most clearly indicated in these cases.

Second: we have found that the clinical facts about an infant’s neurological status and prognosis are often elusive, and may change rather quickly. Randy, for example, changed within a few days from having a weak suck, having an uncoordinated swallow, and “dying,” to taking adequate oral feedings safely and going home to live. Often a second neurological opinion is helpful, especially given the value that many place on the capacity to interact with others and with the environment. We also recommend caution about treating some diagnoses and prognoses as empirical facts rather than as more or less substantiated predictions. A waiting period for a newborn’s (or child’s) neurological picture to evolve and stabilize is usually indicated.

Finally, we acknowledge that such cases pose profound moral dilemmas and distress for all those involved. We recommend, therefore, that staff who believe it would be wrong to withhold nutrition and hydration from a child be encouraged to express their concerns and participate in discussions about the child’s condition and care, and that they are permitted to provide care or to withdraw from care for the child according to their conscience. Similarly, parents should be encouraged to seek religious, moral, psychological, and legal counsel if they wish, and staff
should cooperate with informing and discussing a
child's care with these advisors to the extent that par-
ents authorize them to do so. Ethics consultation in
these cases, as in many difficult cases, is not merely a
single event, but, rather, a process of deliberating thor-
oughly with the family and staff, providing written
analysis and recommendations, and continuing to
provide support and advice as the child and circum-
stances change.

NOTES

1. The President's Commission for the Study of Ethical
Problems in Medicine and Biomedical and Behavioural
Research, Deciding to Forego Life-Sustaining Treatment
1983), 218.


3. See, for example, M. V. and V. N. v. Southern Baptist
Hospital of Florida, Inc., 648 So. 2d 769 (Fla. 1994); In Re:
Rosenthal, 491 N.W. 2d 633 (Michigan 1992); In Re: Hofbauer,


5. Coordinating Council, National Council for State
Courts, Guidelines for State Court Decision-Making in Life-
Sustaining Medical Treatment: Cases, 2nd ed. (St. Paul, Minn.:


7. Ibid. See also, Matter of McCauley, 565 N.E.2d 441

8. See note 5 above, pp. 118-9.

9. Ibid. See also, In Re: Nikolas E., 720 A. 2d 562 (Me.
1998); In the Matter of Matthews, 650 N.Y.S.2d 373 (1996);
M.V. and V.N. v. Southern Baptist Hospital of Florida, Inc.,
see note 3 above.

10. See, for example, C.A. v. Morgan, 603 N.E. 2d 1171
(Ill. 1992); In Re: Rosenthal, see note 3 above; In Re: Doe, 418
S.E. 2d 3 (Ga. 1992); In Re: Barry, 445 So. 2d 365 (Fla. 1984);
In Re: L.H.R., 521 S.E. 2d 716 (Ga. 1998). Also, C.R. Leicher
and F.J. DiMarino, Jr., "Termination of Nutrition and Hyd-
ration in a Child With Vegetative State," Archives of Pedia-

11. Concerning pediatrics, see, for example, American
Academy of Pediatrics Committee on Bioethics, Policy State-
ment: Ethics and the Care of Critically Ill Infants and Chi-
Forgoing Life-Sustaining Medical Treatment, 93:3, 1994, 532-
6.

12. C.E. Koop, "Ethical and Surgical Considerations
in the Care of the Newborn with Congenital Abnor-
malities," in Infanticide and the Handicapped Newborn, ed. D.J.
Horan and M. Delahoyde (Provo, Utah: Brigham Young
University Press, 1982), 89-106; Association for Persons with
Severe Handicaps, "Nutrition and Hydration Resolution,
Newsletter, 15:2, 1987; H.E. McHarg et al., "Withholding/
Withdrawing Treatment from Neonates: Legislation and
Official Guidelines Across Europe," Journal of Medical Eth-

13. See Cuzan v. Director, 497 U.S. 261 (1990), and
cases cited therein.

14. A. Meisel, The Right to Die, 2nd ed. (New York:
Wiley and Sons 1993, Suppl. 2003), pp. 46, 595. The
U.S. Supreme Court, in the Cuzan case, assumed that arti-
ificial nutrition and hydration would be considered medical
treatment, see note 13 above.

15. See, for example, Gray v. Romes, 697 F. Supp. 580
(D.R.I. 1988); In Re: Crum, 580 N.E.2d 876 (Ohio, 1991);
Rasmussen v. Fleming, 741 F. 2d 674 (1987); Matter of Conroy,
486 A. 2d 1229 (N. J. 1985); In Re: Barry, see note 10 above;
In Re: L.H.R., see note 10 above; Superintendent of
1977); In Re: Quintana, 355 A. 2d 647 (N. J. 1976).

16. See, for example, C.A. v. Morgan, see note 10 above;
In Re: Rosenthal, see note 3 above; In Re: Doe, see note 10
above; In Re: Barry, see note 10 above; In Re: L.H.R., see
note 10 above.

17. See note 5 above, pp. 116-7.

18. Meisel, The Right to Die, see note 14 above, pp. 324,
337.

42 U.S.C. § 5106a-5106b, 5106g); 45 C.F.R. 1340.15.


21. Meisel, see note 14 above, p. 320.

22. 45 C.F.R. 1340.15.

23. Appendix to 45 C.F.R. 1340.15.

24. See note 23 above.

25. Meisel, see note 14 above, p. 333.


27. A. Caplan, "Hard Cases Make Bad Law: The Legacy of
the Baby Doe Controversy," in Compelled Compassion,
ed. A. Caplan, R. Blank, and J. Merrick (Potowa, N.J.:

28. We are assuming, throughout, that parents are in
agreement regarding their refusal of nutrition and hydra-
tion. When this is not the case, each is deciding from a
sense of ethical responsibility toward the child, we would
usually recommend against overriding the parent who
wishes her or his child to be fed, though there is not space
to explicate the reasons here.