Autonomy of Dying Problematic in Bioethics

By Tom L. Beauchamp

The obligation to respect the autonomy of persons so that they are free and informed has proved particularly controversial in medical ethics when applied to the right to refuse life-sustaining medical interventions. That is because this obligation can easily be used to defeat normal presumptions in favor of providing care and sustaining life. Modern medical advances have confronted us with this problem: Human bodies can now be kept alive for years without whole brain death and without consciousness. Dying can be extended indefinitely. Diseases that would have efficiently killed in the past now may paralyze or slowly sap life away. Medicine can keep us alive, but at an unacceptable cost to our quality of life. As a consequence, we are thrust into debate over the acceptability of suicide, assisted suicide and euthanasia.

Recognition of a strong patients'-rights premise as authoritative in matters of refusing treatment could have a pervasive and unsettling effect on hospitals, where decisions to forgo treatment are still generally viewed as suspect and disruptive. At the same time, however, we live in an era in which state legislatures write natural death statutes, the Hemlock Society writes do-it-yourself guides for patients who wish to commit suicide, and voluntary euthanasia is increasingly viewed as an autonomy right.

A logical question in this setting concerns the exact demand the principle of respect for autonomy makes in decisionmaking—for example, as to requirements that certain kinds of information be disclosed so that patients might choose to reject a recommended therapy. Almost certainly the major problem to arise in recent years, and one that may substantially alter the traditional understanding of the patient/provider relationship, is the withholding or withdrawal of hydration or nutrition.

Fairly early in the discussion of withholding or withdrawing high-technology medical equipment—in the mid to late 1970s—both physicians and lawyers seemed to agree that respirators and dialyzers could be removed, but that IVs could not. The thought seemed to be that respirators and dialyzers were extraordinary and that IVs were ordinary. But before long this distinction was undermined by careful analysis. By 1984 the question of whether it was ever acceptable to withhold fluids and nutrition was being treated more as a practical ethical dilemma, one suggesting that we examine our criteria of what counts as appropriate and necessary medical care, especially when a treatment might be burdensome to the patient, might fail to provide any benefit, or might be unreasonably expensive in light of the expected benefits.

Intravenous tubes, nasogastric tubes, and gastronomy tubes, are viewed by some as typical forms of medical treatment and as such relevantly resembling respirators. But where they see a resemblance, others see a difference. Many see water and food as basic forms of care that can never be justifiably withheld or withdrawn. Withholding or withdrawing hydration and nutrition is ordinarily meant to end life—not, presumably, as an act of killing, but as an act of allowing to die. Those who see withholding nutrition and hydration as hastening the time of an imminent death by not using a technology that cannot reverse damage already done have no problem with this practice. But others see such acts as the proximate cause of death, thus raising questions about the appropriateness of killing, of euthanasia, and of the involvement of health-care professionals in such activities.

At the moment there is no consensus resolution of this problem, although there are numerous court decisions and pronouncements by professional organizations. One prominent view was advanced by the President's Commission for the Study of Ethical Problems in a volume titled "Deciding to Forego Life-Sustaining Treatment" (March, 1983). The commission maintained that "for almost any life-threatening condition, some intervention can now delay the moment of death.” It concluded that no particular treatments, no matter how ordinary, including special feeding procedures, were mandatory in all cases. The American Medical Association has also clearly concluded that "medical treatment including medication and artificially or technology supplied respiration, nutrition, or hydration" may be withheld in cases of confirmed irreversible coma. Some commentators have gone (continued on page 2)
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even further, extending the discussion to the withdrawing of fluids from the terminally ill and even some nonterminally but seriously ill patients.

Clearly our intuitions and considered judgments are divided on these matters. Many health professionals find it difficult to starve someone to death no matter what the circumstances. Some contend that there is more than emotion at work. They deny that there is a morally relevant difference between denying food and fluids and denying medical therapies. For one thing, death is certain when nutritional needs go unmet. They also believe that the medical profession should not be in the business of balancing quality-of-life considerations and cost concerns against the compassionate standards of medicine.

There are some more specific worries that accompany these general concerns. For example, the idea is troublesome that physicians, families, courts, or various other third parties, can properly make a decision that the "burdens" of continuing fluids and nutrition can outweigh the "benefits" of sustaining life. In considering a variety of treatment denials, the courts have exhibited considerable confusion about how to handle these cases. Appellate courts have reversed lower courts right and left. There is no clear and applicable law, and so we should not be surprised that the bench reflects our own ambivalence and uncertainty.

Books
Recent Acquisitions

(New additions to the collection of the National Reference Center for Bioethics Literature.)

Australia. Parliament. Senate. Select Committee on the Human Embryo Experimentation Bill 1985. HUMAN EMBRYO EXPERIMENTATION IN AUSTRALIA. Canberra: Australian Government Publishing Service, 1986. 158 p. In its report the committee explains how it reached the conclusion that all human embryos should be protected from "destructive non-therapeutic experimentation." Other recommendations concerning legislation on experimentation in reproductive technologies are also presented.


Jordan, Shannon M. DECISION MAKING FOR INCOMPETENT PERSONS: THE LAW AND MORALITY OF WHO SHALL DECIDE. Springfield, IL: C.C. Thomas, 1985. 142 p. The author explores the rights of incompetent persons in decision-making situations. The rights of minors to abortions and other circumstances involving legal rights are discussed. The pros and cons of courts, families, physicians, and ethics committees as decision makers for the incompetent person are discussed.

Lawler, Ronald; Boyle, Joseph M.; and May, William E. CATHOLIC SEXUAL ETHICS: A SUMMARY, EXPLANATION, AND DEFENSE. Huntington, IN: Our Sunday Visitor, 1985. (Shriver Collection of Christian Ethics) The Church’s teachings on sexual morality are explained.


Nicholson, Richard H., ed. MEDICAL RESEARCH WITH CHILDREN: ETHICS, LAW, AND PRACTICE. New York: Oxford University Press, 1986. 265 p. The Institute of Medical Ethics' Working Group on the ethics of clinical research investigations on children prepared this re-

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Living Wills Pose Tough Dilemmas For Hospital Staff

By Abigail Rian Evans

The following case, occurring in 1986-87, illustrates the complexities of decisions concerning death. The names have been deleted for purposes of confidentiality.

Medical History

The patient was a 76-year-old male. In 1984 he had a left cardiovascular accident (CVA) with right hemiparesis. He also suffered from peripheral vascular disease, cardiac arrhythmias (for which he was on Digoxin), diabetes (for which he was on insulin), and S/P cancer of the prostate. He had been in a rehabilitation center for five weeks, went to a nursing home and then was transferred to a major hospital to reduce the drain on the family's dwindling resources.

Presenting Clinical Situation

When the patient was admitted to the hospital center, he was alert and oriented most of the time. He needed assistance getting in and out of bed, but spent most of his day in a wheelchair. He was able to feed himself with some assistance. Two and a half weeks after admission the patient became unresponsive. He was found to have a right CVA with left hemiparesis. He was deeply comatose and his condition was critical. Two days later his family insisted that the hospital honor his living will, which had been written two years earlier before his first CVA. The will had been drafted according to the Natural Death Act in the state in which he then resided. The will directed that "if the situation should arise in which there is no reasonable expectation of my recovery from physical or mental disability, I request that I be allowed to die and not be kept alive by artificial means or heroic measures." The family requested discontinuation of feedings by nasogastric tube and withholding of all medications.

The physician in charge, however, contended that two days was not adequate time to determine whether the patient had a "reasonable expectation" of recovery. The staff was also concerned about honoring a living will that had been written two and a half years earlier, that had been written before the first CVA, and that was in conflict with the Natural Death Act of the state in which the hospital was located.

Discussion of Case

The hospital staff, while desiring to honor the family's wishes, faced several questions:

1. Was the living will legally binding?
2. Had sufficient time elapsed to determine beyond reason-
Living Will

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While reviewing these criteria, one should ask if any of the information received creates an over-riding rationale for a particular action. In the end, of course, this will depend on the priority one gives various values such as legal precedents and patients' rights that might come into conflict.

Roundup

• The Kennedy Institute conducted a symposium on May 7 and 8 for 30 of its members from around the country. The members attended dialogue groups with institute scholars on subjects such as informed consent and autonomy, human genetic engineering, geriatric ethics, ethics and foreign policy, care of the terminally ill, reproductive technology, AIDS and gene therapy, and the literary imagination as it relates to bioethics. The two-day event also included training by the library staff in the use of Bioethics-line, and a bioethics film festival. The capstone of the event was an address to a dinner seminar by Paul Ramsey titled “Reflections on Medical Ethics.” A reprint of the address will be available from the institute after June 15 for $2.50 a copy.

• The Society for Bioethics Consultation has announced three regional conferences for professionals interested or involved in the provision of ethics consultation in health care institutions. The conferences are to be held in St. Louis from Sept. 13-15; in Danville, CA. from Dec. 13-15; and in Baltimore from March 20-22, 1988.

• Concern for Dying is offering an accredited seminar for physicians, nurses, social workers, lawyers and allied health professionals on “Death, Dying and Decisionmaking: Psychological Care of Patients and Families.” It will be held from Sept. 25-28 at Lake Tahoe, Tahoe City, CA.

Books

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port over a three-year period. Institutional review boards in England and Wales were surveyed to provide information on basic practices of IRBs for the study.

Ross, Judith Wilson. HANDBOOK FOR HOSPITAL ETHICS COMMITTEES. Chicago: American Hospital Association, 1986. 164 p. An excellent source for planning an ethics committee. Problems and purposes as well as precedent-setting legal decisions are discussed in this work.

U.S. Congress. Senate. Committee on Labor and Human Resources. ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS). Washington: U.S. Government Printing Office, 1986. 383 p. These hearings, which were held April 16, 1986, examine the issues involved in halting the spread of AIDS.

VanDeVeer, Donald and Regan, Tom, eds. HEALTH CARE ETHICS: AN INTRODUCTION. Philadelphia: Temple University Press, 1987. 464 p. Twelve essays introduce some of the major issues in the field of bioethics, such as euthanasia, informed consent, human experimentation, abortion, and health care delivery.

Veatch, Robert M. THE FOUNDATIONS OF JUSTICE: WHY THE RETARDED AND THE REST OF US HAVE CLAIMS TO EQUALITY. New York: Oxford University Press, 1986. 210 p. Theological discussions about equality are used to show how it is possible to meet fairly the unending needs of the handicapped.

(By Marlene Fine and Doris Goldstein)