

MEDICAL HUMANITIES REPORT

MEDICAL HUMANITIES PROGRAM

MICHIGAN STATE UNIVERSITY

WINTER 1989

ETHICS OF TREATMENT REFUSAL: SAYING WHAT WE MEAN IN COURT

Since the New Jersey Quinlan decision, a fairly comfortable relationship has emerged between the pronouncements of medical ethics on the right to refuse medical treatment, and the decisions of state high courts in cases of treatment refusal. This relationship was marred in 1988 by two decisions which appeared to go markedly against the emerging legal trends and to unduly restrict the rights of patients and their families in the process. I wish to argue that it is dangerous for physicians and students of medical ethics to dismiss these two cases as aberrant decisions, containing no message of importance. Instead, we should take them as timely warnings to review precisely what we mean when we speak of patient rights, medical judgments, and treatment refusal. In the past we have been happy to let the courts put words into our mouths; but now that those words are receiving renewed critical scrutiny, that submissive attitude may become counter-productive for humane medical practice.

TWO DECISIONS: CRUZAN AND O'CONNOR

The major challenge of the established post-Quinlan trend occurred in a 4-3 Missouri Supreme Court decision. The family of Nancy Cruzan, a 30-year-old woman who has been maintained in a persistent vegetative state for 5 years, was refused permission to withdraw the gastrostomy tube, despite evidence that the patient, prior to her accident, had expressed wishes not to be maintained in that fashion. The court noted that Cruzan was not terminally ill and that the gastrostomy feeding appeared to constitute no burden to her. However, in the most significant part of their ruling, the court rejected the nearly universal holding of other state courts that a right

to refuse life-prolonging treatment could be grounded either in the constitutional right to privacy, or else in common law rights. Missouri court claimed that such a broad right to refuse (or to allow proxies to refuse on one's behalf if one is incompetent) can be justified only if the state's interest in preserving life is seen as greatly attenuated in these cases. They denied that this was so in a case where treatment presented no great burden and a prolonged life expectancy was possible; and they rejected arguments that permanent loss of consciousness, or diminished quality of life, sufficed to weaken the state's interest in preserving life.

It is worth recalling in connection with Cruzan that many decisions in other states endorsing a right to refuse treatment in similar cases were the result of equally narrow votes. In retrospect, it is surprising that a decision like Cruzan did not appear earlier.

Less broad in its implications was the decision in New York, refusing a family's request to forego nasogastric feeding in a 77-year-old woman severely incapacitated by multiple strokes. Here the reasoning was that conversations in which the patient had stated her objections to being maintained artificially, using "machinery," and losing her dignity were insufficient to establish clear and convincing evidence of the patient's own prior wishes regarding nasogastric feeding. The court indicated by contrast that a written document ("living will") would have been acceptable.

MEDICAL DECISIONS AND LEGAL TERMINOLOGY

The withholding of nutrition and hydration in cases like Cruzan and O'Connor have become accepted medical options in the eyes of thoughtful physicians and hospital

ethics committies, and have been endorsed by well-reasoned reports and guidelines. Opinion polls consistently show that more than 80 percent of the American populace favor such policies and indeed fear overzealous terminal care more than they fear medical neglect.

I would argue that the medical reasonableness of these treatment strategies lies in a network of related factors, including a renewed respect for the rights of patients and families to make their own choices; an awareness of the limits of medical technology in ameliorating terminal conditions, dementia, and the persistent vegetative state; realization that some sort of quality-of-life judgments are an irreducible feature of medical management; and an understanding of the specific facts of particular cases, which reveal both the undesirability of other treatment options and the absence of misinformation or improper motives. Indeed, I would suggest that when other physicians or hospital staff disagree with the treatment refusal, they usually do so less because of differing moral principles and more because of differing assessments of the facts of the case. For instance, a nurse may object to not feeding a persistently vegetative patient because she believes that she has seen signs of purposive movement, and thinks the patient to be recovering.

Because the courts have thus far made reasonable judgments about these sorts of cases, we have perhaps been too accepting of the terminology in privacy vs. state's interest in preserving life; substituted judgment; insistence that treatment refusal is totally different from homicide or suicide; and ritualistic denials that quality of life judgments play any role whatsoever. Admittedly, philosophers have subjected each of these concepts to careful scrutiny, but the larger medical community has viewed those debates as academic issues of no practical concern. Now, however, the Cruzan and O'Connor decisions contend that this terminology may be much less defensible, in legal terms, than has previously been thought. In Cruzan, the too-ready transition from privacy rights to treatment refusal by proxy was in dispute. In O'Connor, a "by the book" application of the "substituted judgment" standard raises the fear that the legal standard for advance directives will be set so high that only the most farsighted and articulate patients will be able to meet it.

TOWARD IMPROVED CHARACTERIZATION OF MEDICAL ISSUES

Nancy Rhoden, an attorney, has recently called for a rejection of the "substituted judgment" reasoning, in a way that would negate the problem of O'Connor. Fundamentally, Rhoden calls for open recognition of the basic principle that families are the most appropriate decision-makers on behalf of incompetent patients. Were a family request to be rejected, it should be because another interested party (which might be the physician) has presented clear evidence of the family's incapacity to choose or to respect the wishes and rights of the patient. The O'Connor and Cruzan courts stood Rhoden's plausible suggestion on its head by demanding, in effect, that the families prove that they were the appropriate proxies for the patient, instead of placing the burden of proof on others to show why they were not.

The Cruzan ruling suggests further that it will be valuable to challenge outright the so-called state's interest in preserving life--at least so long as this interest is interpreted in the abstract fashion that Cruzan typifies. The idea that medicine has some sort of duty to preserve life in the abstract has by now been roundly rejected as a coherent or practical bit of advice. If medicine has no such duty, it is not clear why courts should use that interest as a standard in reviewing medical care decisions.

It seems quite reasonable to say that the business of courts should be not to preserve life in the abstract, but instead to protect persons. Faced with a case like Cruzan, it seems very clear what it means to preserve life; and almost all the medical facts about persistent vegetative state, and the psychological facts about Nancy Cruzan's and her family's own wishes and interests, are irrelevant to that judgment. But to ask what it would mean to protect Nancy Cruzan and her family from various possible medical abuses is a different matter. The latter question requires immersion in the facts and circumstances of the case, to determine what counts as an abuse; and it recognizes that both over-treatment and under-treatment could be abusive in different circumstances.

All would agree that the right to refuse treatment must be balanced against the possibilities that the patient's rights and interests will be abused in various ways. To ask courts to review such matters insures that courts will take into consideration

precisely those facts and circumstances which families, physicians, and hospital ethics committees would have taken into account in making the decisions to begin with. By contrast, to ask the courts to weigh the right to refuse treatment against the state's interest in preserving life might lead to one of two undesirable outcomes. Either the court will offer a ritualistic nod toward life preservation along the way to affirming a reasonable treatment refusal (as the Cruzan court claims occurred with Quinlan). Or else the court will go the Cruzan route, and ignore the important facts of the case while addressing abstract principles.

The emerging thinking in medical ethics defends allowing physicians and patients (or their families) to have discretion in making treatment decisions after considering the complex facts and circumstances of particular cases. Because abuses can occur, sound reasons for these decisions should be required, and the decision process should be open enough to admit impartial review--ideally by a local body, like an ethics committee, which is close to the participants and the facts of the case at hand. Those of us to think this strategy is medically sound have a stake in encouraging the use of legal terminology and concepts which promotes rather than thwarts these sorts of reasonable decisions.

Howard Brody

Transition from Program to Center

In November 1988, the Provost approved the re-organization of the Medical Humanities Program into the Center for Ethics and Humanities in the Life Sciences. In many ways, this is a change in name only. However, the re-organization does mark both a strengthening of our program as well as a tentative new direction.

While a Program must renew its budget each year with all involved deans, a Center has a guaranteed budget (in our case, for a five year period). After five years, the Provost will review our accomplishments and the question of whether to continue the Center on a more permanent basis will be reviewed by the Board of Trustees.

While the Center gives us enhanced visibility within the University structure, and while the guaranteed budget is an aid to program planning, service to the involved colleges is still the number one priority of

the Center. We will still report to the deans of Human Medicine, Osteopathic Medicine, Nursing, Veterinary Medicine, Arts and Letters, Natural Science, and Social Science to assist with team-teaching and curriculum development.

The name of the new center reflects one area for future activities. The transition from a "medical" program to one aimed at "the life sciences" signals an expansion of our role, from health care alone, to the biological sciences more generally. Ethical issues in biotechnology, and improved ethics and humanities studies for future biological sciences, is an important area of growth and development to which we can make a contribution. The name change suggests that we wish to be ready to take advantage of opportunities on this campus to explore these developments.

We are very pleased with the University's recognition of the high quality of work carried out by the Medical Humanities Program over the past ten years. Achievement of Center status is a major milestone for us. However, faculty and students who work with us on a day-to-day basis will, at least in the short run, find nothing different in our activities and our orientation.

Howard Brody, Director

Misunderstanding Death

Required request, whether mandated by law or by hospital policy, requires that the families of all potential organ donors be asked whether they would be willing to donate the transplantable organs of the patient, who is usually brain-dead and supported by a respirator. The actual success of required request will depend not only upon the willingness but also the ability of physicians and nurses to lay a suitable foundation for families' decisions to donate. Unfortunately, there is reason to believe that too often health care providers do not have the necessary skills and knowledge to facilitate the work of field transplant coordinators or designated hospital personnel. In particular, there is anecdotal evidence that physicians and nurses misunderstand and/or miscommunicate the status of brain-dead respirator patients, encouraging the desperate hope of family members that somehow the patient is still alive and may miraculously recover. There has been virtually no systematic

effort to uncover how physicians and nurses think and communicate about the status of brain-dead respirator patients. It would be useful to know the variety of ways in which confusion over brain death contaminates language, thought, and policy, so that appropriately targeted corrective steps could be taken.

With support from the Transplant Policy Center, I undertook a series of interviews with physicians and nurses who had experience caring for brain dead respirator patients and their families. The purpose of the interviews was to elicit the subjects' natural, habitual, and unprompted manners of thought and speech regarding these patients. This purpose dictated heavy reliance on open-ended rather than fixed-choice questions. This in turn made extensive statistical analyses impossible (as well as irrelevant to the project's goal of extracting a rich description of the language used by the subjects in their thought and communication about brain-dead patients.)

Twenty subjects were interviewed, affiliated with thirteen hospitals in southern lower Michigan, which had an average size of 522 beds. Included were thirteen ICU nursing staff (RN) and seven physicians (M.D.), all but one board-certified in neurology or neurosurgery. Subjects' ages ranged from 26-46, with an average age of 35.8 years. Subjects were in general well-trained and experienced in working with brain-dead respirator patients and their families.

What follows are selected results of the interviews, taken from the subjects' responses to some of the interview questions (which bear their original numbering). A complete report of the results is available on request.

2. Imagine a patient named Mr. Johnson, who is on a respirator following cardiac arrest. Although there was initially some hope for his recovery, he has not regained consciousness, and it has now been determined that he is brain-dead. The family is at the hospital anxious for word of his condition. You have been asked to inform them of his present status. What would you say?

Throughout the interview, many subjects regularly used language suggesting that the brain-dead respirator patient is alive. Among the responses to Question 2 were the following:

"At this point in time, it doesn't look like the patient is going to survive."

"The machine is the way he would have to live the rest of his life."

"The machine is basically what's keeping him alive."

"I'd ask what the patient's own desires would be. Would he want the respirator?"

"If kept on the ventilator, the patient will die of sepsis."

Nine subjects made remarks similar to these. Surprisingly, two of the nine also said that the patient was dead, without any visible awareness of the contradiction.

The prevalence of such expressions is confirmed by the subjects' responses to other interview questions. For example, thirteen subjects reported that the expression "The machine is the only thing keeping him alive" is used by physicians; fourteen reported it used by nurses.

6. Imagine that the brain-dead patient Mr. Johnson is not a candidate for organ donation. Would he be removed from the respirator prior to cardiac death? If so, what would you say to the family about the removal of the respirator?

12. When a respirator is withdrawn from a brain-dead patient, is the patient declared dead before or after withdrawal of the respirator?

Responding to Question 6, sixteen subjects indicated that such patients were always or usually removed from the respirator. But opinion was more divided on the manner in which family would be approached about this decision. While ten of the subjects felt that no consent was required for the removal, the other ten reported that family permission would be sought and documented before the respirator would be removed. In addition, five subjects reported that brain-dead respirator patients might remain coded, and that family consent would also have to be sought for a DNR order.

In answering Question 12, twelve (12) subjects reported that a brain-dead respirator patient is declared dead before removal of the respirator. Three of these, however, said that this is true only when the patient is an organ donor. Thus, a majority of the subjects (11) did not consistently make the declaration of death before removal of the respirator.

These and other results of the survey are disturbing because they are at odds with the consensus established in law, medicine, and bioethics that whole brain-dead patients are plain dead, not "just" dying.

If his death is now the most salient fact about the patient, the common habit of

referring to the brain-dead patient as if he were still alive clearly frustrates clear and unambiguous communication with the family. "The machine is the only thing keeping him alive" and its variations are the obvious examples, but there are others which are less apparent. A case in point is the practice of one of the subjects of asking the family whether the patient would want to continue being maintained on the respirator. This may usually get the family to make the decision which the physician wants (to remove the respirator), but it does so by suggesting that this decision is a decision about continuing life-prolonging treatment of a still living person; only on this assumption would the patient's wishes be the morally central consideration.

The families of brain-dead respirator patients should be told in plain language that their loved one is dead; anything else is misleading. Saying simply that the patient is "brain dead", as is the common practice among these subjects, is not an acceptable alternative. Even if this expression were unambiguously synonymous with "dead" within the vocabulary of the medical profession, to the lay person it most certainly connotes something different than "death" of the ordinary kind. "Court permits starvation for brain-dead man" was the headline for a Lansing newspaper story on the case of Paul Brophy, a man in a persistent vegetative state whose family had been authorized to withdraw artificial fluids and nutrition by the Massachusetts Supreme Court. This common association of "brain death" with persistent vegetative state can encourage false hopes of a recovery for those who've read popular accounts of miraculous awakenings by comatose persons, and make it very difficult to convince family members that the brain dead patient is dead, not just permanently unconscious.

If the brain-dead respirator patient is indeed dead, then the sort of hospital policies which came to light during the interviews are also unjustifiable. Chief among these is the common practice at the hospitals studied of procuring and recording family consent or permission for a DNR order on a brain-dead patient, or for removing that patient from the respirator. If the brain-dead patient is indeed dead, as the law and medical ethics assert, then these practices are not only morally unjustified, they are harmful. They are unjustified because the ethical basis for seeking consent is to respect the role of the

patient's values in determining those choices which may affect his or her interests or welfare. A dead patient no longer has any interests to be affected by a DNR order or the removal of the respirator. Although we recognize other obligations to honor the wishes of dead persons (e.g., in executing their wills), there is no socially-recognized obligation to provide medical "treatments" for the dead. The practices are harmful because they imply to the family that the patient continues to have such interests, and so is still alive; and because they lay an unnecessary burden of decision-making, and possible guilty regrets, on grieving and emotionally vulnerable people, who are led to believe that by their decision they have let a loved one die.

For these reasons, major policy recommendations concerning the treatment of brain-dead patients have rightly advised against seeking consent for the removal of the respirator or other treatment from these patients. By no means, of course, does this lessen the duty to seek the family's understanding of the medical decision to cease treatment, nor does it imply that the family should not be given the time necessary to come to terms with the fact of death.

Although one should be properly cautious in generalizing from a small sample, these subjects are obviously highly trained and experienced compared to most other health professionals. These findings may not bode well for the performance of primary care physicians or others who do not regularly practice in the ICU setting. Yet their ability to discuss these patients coherently will be crucial as required request regulations expand the numbers of patients, families and primary care physicians who are drawn into discussions about the brain-dead. There should be appropriate revisions and additions made not just to specialized training for ICU staff and designated organ donation personnel, but to undergraduate medical and nursing education as well.

It has now been twenty years since the Harvard Ad Hoc Committee first established tests for the use of whole-brain death as a criterion of death. Yet health care professionals continue to have difficulty in thinking and communicating clearly about the death of brain-dead patients. Their difficulty may be rooted in the difficulties we all feel in leaving behind ancient cultural images of the dead person: images which the respiring corpse contradicts, but

which still hold sway over us all--families, the lay public, and health professionals. Nevertheless, if the larger society is to move toward a fuller philosophical and emotional acceptance of the new images of death which high-technology medicine requires, the health professions will have to lead the way.

Tom Tomlinson

IPHH Specialization Outlined

In late September of 1988, MSU's Academic Council announced final approval of the undergraduate Specialization in Health and Humanities--the fruit of years of effort by faculty associated with the Medical Humanities Program. In the months since, a small core of students have officially enrolled in the Specialization, and several others have requested information about the logistics of the program. (Academic advisors from across the campus have been instrumental in making initial contact with many potential Specialization enrollees, for which the IPHH office is grateful.)

The Specialization is not a "major"; rather, it supplements students' academic majors with an integrated series of junior and senior level courses. The goal is to offer students the opportunity to expand their understanding of the broad context of health, illness, and healing in society--within the context of their regular course of study. Upon fulfillment of the requirements for the Specialization, a notation of completion will appear on the student's transcript.

Enrollment in the Specialization is available to all undergraduates, and we encourage participation by students from many disciplines. In most cases, the twenty-four credits of coursework required to complete the Specialization can also be used to partially fulfill "cognate area" or "elective" requirements of students' major programs.

SPECIALIZATION REQUIREMENTS

Students who elect the Specialization in Health and Humanities must complete a minimum of 24 credits as follows:

REQUIRED COURSES (4 cr. each, 12 cr. total)

PHL 340* Moral Problems in Medicine
HST 409* History of Modern European and
or American Medicine
LBS 409

SOC 423 Sociology of the Health Care System

ANP 356 Culture, Health and Illness

*Available through Overseas Study Program in London, England.

ELECTIVE COURSES (minimum of 12 credits)

At least one course from each of the 3 following areas:

1. Arts and Humanities

LBS 377 The Natural Environment: Perceptions and Practices
LBS 378 Popular Culture and Technical Change
N E 511 Women and Health in the U.S.
PHL 344 Ethical Issues in Nursing

2. History and Philosophy of Science and/or Technology

LBS 361 Philosophy of Technology
LBS 373 Introduction to the Philosophy of Science
LBS 374 Historical Problems in the Biological Sciences
LBS 376 Historical Problems in Technical Change
LBS 484 Philosophy of Biological Sciences
PHL 380 The Nature of Science
PHL 381 Science, Values, and Decision Making
PHL 480 The Nature of Scientific Theory and Explanation
PHL 481 Foundations of Scientific Inference

3. Social Dimensions of Health

ANP 356* Culture, Health and Illness
SOC 423* Sociology of the Health Care System
ANP 439 Anthropology of Birth
ANP 482 American Folk Medicine
E C 410 Medical Economics
GEO 470 Geography of Health and Disease
N S 325 Biological and Social Aspects of Human Reproduction
SOC 424 Sociology of Mental Health
PHL 485 Philosophy of the Social Sciences

*Either ANP 356 or SOC 423 can be applied as a Specialization required course. If a student enrolls in both courses, one of

the two can be counted as a "Social Dimensions" elective. Neither course can "double-count" as both a requirement and an elective.

By University regulation, Multi-Titled, Studies, and Special Topics Courses cannot officially be included on the "list" of Specialization Requirements. Periodically, such courses address subjects directly related to the Specialization, as in the case of "Asian Medical Systems" and "Work, Economy, and Health", both offered as ANP 495. With written approval by the Director of IPHH, offerings of this sort can substitute for courses on the list. Additionally, other courses may be added to the official list in the future, pending approval by Academic Council.

Students, faculty, or others wishing further information about the Specialization should contact Peter Vinten-Johansen or Brian Brown at the IPHH office in 328 Morrill Hall, 353-9417.

Brian Brown

W. Donald Weston

The faculty and staff of the Center for Ethics and Humanities in the Life Sciences were saddened by the recent resignation of Dean Weston, who has been a consistent supporter of our activities throughout his tenure.

In 1977, Dean Weston actively supported the creation of the Medical Humanities Program and its leadership under his immediate predecessor, Andrew Hunt. More recently, Dean Weston aggressively supported our reorganization under the status of a Center, working hard with both his fellow deans and the Office of the Provost to accomplish this.

Dean Weston's support of medical humanities extended to the national scene. When the Society of Health and Human Values was in particularly difficult financial straits one year, Dean Weston was one of a handful of medical school deans to pledge special institutional contributions to the Society and thereby keep it alive.

Weston's vision for the College of Human Medicine consistently espoused a strong role for ethics and humanities in the training of future physicians, and the creation of strong teaching and research programs at MSU to accomplish this. His influence and his support will be missed.

Howard Brody

Literature Review

Medical Ethics and Economics in Health Care, ed. Gavin Mooney and Alistair McGuire, Oxford University Press, 1988.

This volume results from a workshop that brought together British and European scholars to discuss the implications of economic constraints and the rationing of medical care for medical ethics. While the health-care systems of those countries naturally form the basis for much of the discussion, there are frequent references to the USA as well.

The main themes are raised in the first essay, by the editors. They contend that the physician-patient interaction can be of an efficient system of health care. In reply, Henk ten Have distinguishes "ethics as a product" (e.g., codes of professional ethics) from "ethics as a process" (what is now taken to be medical ethics in most U.S. teaching programs), and also urges that the physician's obligation to protect the good of the individual patient cannot allow the consideration of economic or social factors. But Bryan Jennett and Raanan Gillon dispute this "two-tiered" approach to rationing. Jennett points out that many economically inefficient treatments are also unwise or inhumane from the patient's perspective as well, so that the conflict of ethics and economics is often more apparent than real. Gillon goes farther, analyzing general practice to show that the good physician is continually assessing tradeoffs between the needs of the patient immediately before him and the needs of other patients and of society generally. For Gillon, both of ten Have's "tiers"--the physician only concerned for the individual patient; the administrator as a fairly crude utilitarian--represent oversimplifications.

Other essays address a critique of traditional medical ethics; economics, ethics, and law; the history of physicians' conception of themselves as professionals and as wage-earners; uses of expert computer systems to enhance efficiency; and ethics and economics in medical education.

Howard Brody

Calendar

<u>When/where</u>	<u>To whom</u>	<u>By whom:Subject</u>
March 27 Flint	Hurley Medical Center Medical Residents	Tom Tomlinson: A Heretic's View of Confidentiality
April 11 Battle Creek	Calhoun County Medical Society	Tom Tomlinson: Ethical Considerations in AIDS
April 20 Grand Rapids	Michigan Society for Respiratory Care	Tom Tomlinson: Ethical Dilemmas of Life Support
April 21-22 Grand Rapids	2nd Annual Meeting MERN of Michigan	Len Fleck: Health Care Cost Containment
April 27-29 Little Rock, AK	SHHV Spring Meeting	Len Fleck: Justice, Age Rationing and the Problem of Identifiable Lives
May 10 Alma	Gratiot Community Hosp. Nursing Workshop	Len Fleck and Tom Tomlinson: Withdrawing Life Sustaining Treatment: Ethical Issues
May 22 Flint	Internal Medicine Noon Conference	Len Fleck: Maternal-Fetal Conflicts

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