NETWORK NEWS

The newsletter of the Florida Bioethics Network

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FUTILITY: THE MEDICAL PROFESSION'S BACKLASH AGAINST PATIENT AUTONOMY. KOCH, K.A.

Submitted by **Kathryn A. Koch, M.D.,** F.C.C.P., Associate Professor of Medicine, Director, Critical Care Services, Chief, Division of Critical Care Medicine, University of Florida Health Science Center, Jacksonville.

Futility: 1. the quality or state of being futile: USELESSNESS. 2. a useless act or gesture. (Merriam Webster's Collegiate Dictionary, 10th edition, 1993).

Background

Much has been written about the concept of medical or physiologic futility over the past several years. Current medical technology has changed the appearance of the border between life and death, yet ultimately 100% of people die. Nothing is more certain than death and taxes. Yet, medical treatment can create a "limbo" where the process of dying can be forestalled, sometimes indefinitely, and sometimes even reversed, as long as certain technologic and therapeutic interventions are continued. This technology has created chronic ventilator dependence for months or years. It has increased the numbers of patients surviving critical illness to develop cerebral palsy, the persistent vegetative state, and other conditions of varying severities of disability and dependence. It has also saved functional lives which we cannot imagine having saved before the availability of this technology.

In response, society has developed a number of competing grass roots movements emphasizing patient autonomy. The hospice movement, the Hemlock Society, proposals to legalize physician-assisted suicide, as well as "right to life" groups illustrate this response. The Cruzan case, the subsequent Patient Self Determination Act (PSDA), and advanced directive statutes in all states have reinforced the strength of patient autonomy. Locally, Florida has revised its Advanced Directive Statute to no longer specify decisions about nutrition and hydration as being different than any other medical decision, while also specifying that consent for resuscitation is assumed.

At the same time, national concerns regarding the increasing percentage of the Gross National Product being spent on health care, particularly at the end of life, have resulted in national debate about health care reform. Business interests in the delivery of health care have begun to restrict access to specialized treatment and increase access to primary care providers through health maintenance organizations and capitated health care. The state of Florida has instituted community bargaining agencies and reorganized Medicaid, as steps towards economizing on medical care. Universal health care in Florida is a political issue in the coming election now that those mechanisms are in place. These are issues of distributive justice.

This schizophrenia is the balancing act our society is attempting in order to accommodate both the principles of autonomy and distributive justice, which are in direct conflict with each other in our society's health care environment. Generating the greatest good for the greatest number cannot occur without some restriction of personal choice for the individual.

Health care workers, who are as much members of society as are patients, are experiencing increasing restriction of the exercise of their professional judgement and autonomy, increasing demands and expectations by their patients, and increasing conflict of interest between the needs of their patients and the limitations of payers. It is no wonder that the medical profession has generated its own grass roots backlash against these changes with the concept of medical or physiologic futility.

Futility as Backlash

This backlash is a manifestation of the waste that health care workers feel occurs when expensive medical treatment is continued as the chances of a functional recovery decline and the outcome begins to appear inevitably dismal. It is also a manifestation of an overriding principle of medical practice to cure rarely, to relieve frequently. and to comfort always (taken from a statue of Edward Livingston Trudeau). This is a principle of the Hippocratic tradition, reflecting the medical profession's commitment to beneficence and non-maleficence. If we develop increasing certainty that we cannot cure or heal despite our available technology, then continuing that treatment is in direct conflict with our commitment to comfort and to avoid prolonged pain or misery.

Part of the issue here is also one of medical certainty, or medical uncertainty. Despite vigorous efforts to learn how to objectively predict the outcome of treatment, we remain unable to predict with objective certainty for individuals who are severely ill. Scoring systems have been developed, such as APACHE, to objectively quantitate risk of mortality. These systems have been shown to be good predictors for populations. The ultimate failing of a statistical analysis, however, is its inability to predict with certainty for the individual. Brain death is the only medical condition that is with certainty 100% fatal.

The Support Project: A Simulation of Mandatory Futility Policy

Preliminary data from the SUPPORT project (a multi-institutional study of outcome in critical illness correlated with expense sponsored by the Robert Wood Johnson Foundation with Dr. J. Teno as Principal Investigator) was reported in October at the Ethics Mega-Meeting in Pittsburgh. The article is currently in press with the Journal of the American Geriatric Society (Teno, JM, Murphy, D. Lynn. J, et al. Prognosis-Based Futility Guidelines: Does Anyone Win?).

The study questions were: 1. Can we identify persons with poor prognoses? 2. Do such persons die after a substantial period of time in the hospital? 3. Is this period prolonged by treatment? 4. Could treatment be foregone in this situation? 5. Would stopping or foregoing treatment result in earlier death and save resources? The purpose of the study was to simulate the impact of enforced futility guidelines in seriously ill hospitalized adults.

A total of 4,301 seriously ill patients cared for at 5 hospitals for a 24 month period were evaluated. An objective prognostic model was used to identify persons with 1% or less predicted survival for 2 months, assuming that life sustaining treatments would be stopped or not initiated after the 3rd study day. Only 115 (3%) had 1% prognosis. The primary diagnosis in this group was acute respiratory failure/multiple system organ dysfunction from sepsis (40%). The prediction model was accurate; only 1 out of 115 patients (1%) actually survived hospitalization. The hospital stay for these 115 patients

was 1,688 days with total hospital charges of $8.7 million. If treatment had been altered at 72 hours, according to the simulation "futility guideline," the model would have predicted 199 hospital days and $1.2 million charges saved. Of note is that of the 115 patients with 1% prognosis, only 5 patients (10%) were collectively responsible for 75% of the potential savings. In fact, in 69% of patients with 1% prognosis, a DNR order was actually written, in 81% resuscitation was withheld, and in 30% the ventilator was withheld. In other words, the decisions which were actually made already limited care in many of these patients. An enforced futility guideline would have only contributed to modest savings. If this same model were extended to patients with a 5% or less prognosis, 183 patients (4%) would have been included, with a prediction of 465 hospital days foregone and $2.5 million charges saved. That formulation of the model was also accurate; 12 out of 183 patients (5%) survived.

Discussion

True hospital cost has little relationship to final hospital charge. The magnitude of the predicted savings in the SUPPORT simulation would therefore be different. In the 1% model, a fraction of the patients with 1% prognosis accounted for the majority of the medical expense. Predicting these individual patients would be as difficult as predicting which individual would actually survive if treatment were not altered. In the 5% model, more savings could have been realized at the expense of the lives of 12 individuals who would have almost certainly died if treatment were altered. It should also be observed that in the real life medical management of these patients, medical treatment was limited in a majority of the cases, without the presence of a mandatory futility policy.

This study does not address the potential polarization between health care workers and patient/family which might be engendered by a mandatory futility policy. Many of us have experienced the occasional situation where the health care workers unanimously harden in their position that treatment is inappropriate, in direct opposition to the patient/family who have unanimously hardened in their position that treatment should be continued anyway. This adversarial positioning of individuals who should be working together as a team, if in fact the best possible outcome is to be realized, is detrimental. Medical professionals should avoid any position which suggests that the patient has a "duty" to die. That position is truly the beginning of a slippery slope.

For these reasons, Stuart Younger proposed the idea of "physiologic" futility in an editorial discussing unilateral medical futility determinations (JAMA, 260: 2094-5, 1988). The value of a prolonged life, even with a certainly mortal outcome, is measured in the patient's terms, not in terms of ultimate medical benefit or value. He argued, as I do and others have done, that individual physicians confuse their responsibility when they embark on decisions based on health policy and economic concerns which have not reached public consensus. Further, without objective predictive models, the individual clinician runs a great risk of participating in actions which are ultimately disparate from one patient to another with a resultant discriminatory effort.

Individual medical professionals or medical teams are not in a position to make unilateral determinations regarding the futility of continued medical treatment. They are, however, in a position to make determinations as to what treatments are not medically indicated. They should not administer unindicated treatment and should also avoid putting themselves, their team, and their institution in an adversarial position with the patient/family. Arbitration/negotiation, such as through the assistance of an institutional ethics committee, may assist in generating compromise in the treatment plan if the individual clinician is unable to reach a

reasonable compromise with the patient/ family. This is a delicate balancing act which may still result in "medical waste". Only one such patient may generate significant "waste" for an individual institution, but patient autonomy still supersedes distributive justice in our current social context. If continued treatment which is not indicated is demanded, and no mediation nor negotiation can result in reasonable compromise, then the medical professional should at least be sure that the patient is as comfortable as possible during the prolonged treatment.

Meanwhile, public forums of medical professionals and the community should initiate discussions regarding this issue in order to develop a community-wide standard. We were successful at doing this in Jacksonville several years ago with respect to the management of brain death in pediatric patients. Denver is now embarking on such a discussion of futility with a consortium of hospitals and the community. Only public dialogue and social consensus, which may be as different from region to region as the different states have been in their formulations of advanced directive statutes, will generate an environment supportive of decisions based on medical futility. The Florida Bioethics Network might serve to develop a forum for such discussion if its membership is so inclined. Social consensus is needed to determine what level of predicted mortality is a reasonable cut-off, recognizing that by doing so some patients will die who otherwise might have survived.

Conclusion

At this time the individual medical professional or the individual institution would be unwise to generate a mandatory futility policy. Savings from such a policy appear to exist, but additional emotional and financial expense is risked if an adversarial situation develops, not to mention risk of bad publicity. Finally, medical uncertainty is a fact of medical practice, and perhaps we should not be certain that we are always right.

ETHICS COMMITTEES GUIDELINES

Submitted by **Glenn R. Singer, MD,** Chairman, Bioethics Committee, Broward General Medical Center, Ft. Lauderdale.

The mission of the FBN is to serve as a resource for the State of Florida in bioethical issues. It is clear that most health care institutions are developing or have already developed Ethics Committees to serve this purpose on site. Dr. Glenn Singer, past Member-at-Large of the Board of the FBN and Chair of the Bioethics Committee at Broward General Medical Center, is spearheading the effort to establish Guidelines for Ethics committees. The following is an outline of the document that he and his ad-hoc committee are developing. Please direct suggestions for any additional areas of concern which you feel need to be addressed, and any offers of assistance, to Dr. Singer.

Guidelines for Ethics Committees

I. Mission Statement

II. Committee Composition/Terms of Office

III. Frequency of Meetings

IV. Education and Training of Committee Members

A. Orientation

B. Background Readings

C. Audiovisual Education

D. Classic Literature

V. Education and Training of Committee Members

A. Policy and Procedures: Living Wills, DNRO, Withholding and Withdrawing, Consent, Organ Donation, etc.

B. Monitoring Compliance with PSDA

C. Institutional Staff Education

D. Community Education

E. Organizational Ethics

VI. Consultations

A. Define Access

B. Consistency of Consultation Process

1. Methodology: Individual Consultations, Ad Hoc Committees, Full Committees

2. Documentation of Consults:

a. On Patient Chart
b. Archives Protected From Discovery (Medical or Surgical Auditor Committee Model)
c. Comprehensively reported in committee minutes

3. Review/Follow up of Committee Consults Mechanism for Appeal; Due Process

VII. CQI for Policies, e.g., Patient Rights, Confidentiality, and Consultation

VIII. Remuneration for Ethics Committee Members and Consultations

MEMBERSHIP SURVEY

Please fill out the enclosed membership survey and return to the Florida Hospital Association by November 21. The board will be meeting on November 18 and would like to have as many responses available to assist in their planning efforts. This is an opportunity for you to help shape future projects and services for the FBN. The board appreciates your input and your willingness to serve in the organization.

MEETING CALENDAR

REGIONAL MEETINGS: November 4-5, 1994: Medicine, Ethics, and Economics, Atlantic Beach, sponsored by the University of Florida; November 4-5, 1994: Choices at the End of Life, Sarasota, sponsored by University of South Florida College of Medicine and the Florida Mental Health Institute; January 13, 1995: JCAHO Organizational Ethics, Orlando, sponsored by JCAHO, FHA, and FBN; February 9-10, 1995: AIDS & Medical Futility, Tampa; March 9-10, 1995: Geriatrics, JCAHO and the Ethics Committee, Miami, sponsored by the Forum for Bioethics & Philosophy, University of Miami; April 12, 1995: Reproductive Ethics, Jacksonville, sponsored by University of Florida; March 11, 1995: Second Annual Pediatric Conference, Pediatric Clinical and Moral Dilemmas, sponsored by Lee Memorial Hospital, Ft. Myers, contact: Shirlee Buck, 813/598-1303.

NATIONAL MEETINGS: November 3-4, 1994: Perspectives on Medical Futility, Chicago, IL, sponsored by the Park Ridge Center for the Study of Health, Faith, and Ethics; November 18, 1995: Dying in America: Choices at the End of Life, Charleston, South Carolina, sponsored by the Medical University of South Carolina; December 9-10, 1994 (Marina del Ray, CA) and January 27-28, 1995 (New York, NY): Ethics Committees and the Elderly: Hospitals and Nursing Homes, sponsored by American Society of Law, Medicine & Ethics, the American Geriatrics Society, the Hastings Center, and the Pacific Center for Health Policy and Ethics.

INTERNATIONAL MEETINGS: July 16-20, 1995: The Fourth International Conference, Health Law and Ethics in a Global Community, Amsterdam, the Netherlands, sponsored by the American Society of Law, Medicine & Ethics and the University of Amsterdam.

*Information will be updated as it becomes available. Please contact Luanne MacNeill for registration information at 407/841-6230 x106.

WELCOME NEW MEMBERS!

The Florida Bioethics Network welcomes **Dr. Karl Andersen,** Director, Department of Pastoral, Sarasota Memorial Hospital, Sarasota, 813/917-1355; **Dr. Charles Culver,** Coral Gables; **S. Evans,** Executive Director, The Heart Institute at Tallahassee, Tallahassee, 904/681-5022; **Dr. John Galloway,** Coordinator of Chaplaincy, Sarasota Memorial Hospital, Sarasota, 813/917-1355; **Suzanne Gammon,** Dir./Critical Care-Cochair Ethics, Medical Center/Port St. Lucie, Port St. Lucie, 407/335-4000; **Dr. Julto Gonzalez-Trapaga,** Medical Ethics Fellow, Internist, University of South FL College of Medicine, Tampa, 813/251-7469; **Vicki Marsee,** Dir./Critical Care & Admn. Nursing, H. Lee Moffitt Cancer Ctr./ Rsrch. Institute, Tampa, 813/979-7203; **Anne Meiring,** Director, Social Services, Leesburg Regional Medical Center, Leesburg, 904/323-5432; **Mary Reardon,** Director/Medical Surgical Nursing, H. Lee Moffitt Cancer Ctr./Rsrch. Institute, Tampa, 813/972-8438; **Mary Spremulli,** Medical Center Hospital, Punta Gorda, 813/625-3342; **Merlin Starr,** Director of Pastoral Care, Florida Hospital Waterman, Eustis, 904/589-3389; and **Kathleen Weldon,** Vice President, Nursing Services, Wuesthoff Hospital, Inc., Rockledge, 407/636-2211 x5040.

FBN OFFICERS AND BOARD MEMBERS

Enclosed with this issue of Network News, is a current listing of board members, as installed at the September 1994 FBN Annual Meeting.

A MEDIATION AND MEDICAL ETHICS TRAINING TAPE

For those interested in the training videotape mentioned by Joan McIver Gibson, Ph.D. at the annual meeting, attached is an order form for your use. This videotape, "The Case of Rachell Ward," also is in the FHA Audio Visual Library (VT #275). Please contact Amy Barnhill, Florida Hospital Association, at 407/841-6230 x123, for more information about viewing this video.