NETWORK NEWS

The newsletter of the Florida Bioethics Network

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THE LINE BETWEEN LIFE AND DEATH

Submitted by **Arthur S. Berger, J.D.**, International Institute for the Study of Death.

This issue's feature article is from **Arthur Berger, J.D.**, attorney, and member of the Ethics Bioethics Committee at Broward General Medical Center, Ft. Lauderdale. He presents an interesting review of the book, "Raising the Dead," by Richard Selzer, M.D. His contribution to the FBN newsletter is appreciated.

Raising the Dead (1994. Viking Penguin) by Richard Selzer, M.D., a retired surgeon and author, raises two issues, both sham but provocative. The book is Dr. Selzer's eloquent account of what happened to him when he had Legionnaire's Disease. For twenty-one days, he lay in coma, ventilated, defibrillated, infused. The coma was "like being encased in a layer of wax that separates him from the rest of mankind" (p. 37), but while encased he still thinks, dreams, imagines, collects impressions (p. 34). Sometimes he feels as if he is in the upper berth of a train racing through the darkness (p. 37), sometimes like someone descending into an underworld (p. 40).

On the twenty-third day, he suffers ventricular tachycardia. His EKG goes flat. All resuscitation efforts fail and are stopped. He is certified dead. He is "dead" for ten minutes during which time he feels his eyeballs roll and he shudders. Then he draws breath. His vital signs return.

This book suggests that, although we generally think that comatose patients are unable to experience pain and suffering, they seem to be able to dream and imagine and to live in some strange underworld we cannot perceive. If this is true, we are faced in the cases of comatose patients with no advance directives with this ethical question: How we can decide to withdraw or withhold life-sustaining treatment from them when their lives are not meaningless, even though the quality of their lives may seem to us marginal? It seems pitiless to argue about cost containment as a justification for such a decision as if we had the right to compare the value of a human life against the amount of money needed to sustain it.

But it turns out that this issue is only a false alarm. Dr. Selzer's description (written in the third person) of what he saw and heard in coma is not factual. In a conversation with me, he said he did not know exactly what had happened to him and that he tried to reconstruct it as a literary, poetic narrative. Indeed, in his book, he writes of the account of his illness: "Perhaps it is truer than had it been woven from the facts. The facts are not always where the truth lies" (p. 115).

Dr. Selzer also tells readers that he was certified dead because his vital signs had ceased and he had a flat EKG and that after ten minutes, like Lazarus, he rises from the dead. Again, however, the author is fabricating. He really had Legionnaire's Disease and was in a coma but he never "died." He invented his death and rising. It is another false alarm but it jolts us and calls to our attention the difficulties of drawing any line between life and death and raises anew old but real issues. With any patient certified as dead, it is possible that the certification is erroneous - a mistake made in determining that vital signs and brain function had stopped when actually they had not. But if there is no mistake, then we have to wonder whether our cardiopulmonary and neurological criteria for determining death are adequate. Should alternate ones be adopted? It is vital to realize the difference between the criteria of death and our understanding of it. Since any guidelines for determining death must depend on how we conceive of death, what is our concept of death?

CONFERENCE ANNOUNCEMENTS

Please note upcoming conferences related to ethical issues.

May 22	The Ethics of Health Care Reform, Washington, D.C., sponsored by the American Association of Bioethics
May 23	The Role of Bioethics in Health Care Policy
May 24	Broadening the Bioethics Agenda, Washington, D.C., sponsored by the Center for Biomedical Ethics, University of Minnesota

Registration information about the above three meetings can be obtained from the University of Minnesota -- 612/626-9756.

Sept. 21-23	FBN Annual Meeting & Conference, Clarion Hotel, Orlando

PRESIDENT'S LETTER

James T. Wagner, Ph.D., Director of Pastoral Services, Shands Hospital at the University of Florida, Gainesville.

The FBN Board met on April 26. The annual meeting in Orlando, September 21-23, entitled "Diversity - The Challenge to Ethics Committees," is in its final stages of planning. Mark your calendar!

One important agenda item for this year is now resolved. Beginning in 1995, membership and/or participation as an officer in FBN will no longer be contingent upon your being employed by an institution affiliated with the Florida Hospital Association. Fees will not differ as a result of FHA association either. However, FBN must decide whether to contract with FHA for a continuation of member services, or seek another affiliation. Your suggestions/recommendations would be welcome. A formal proposal from the Board will be presented at the September Annual Meeting.

Initial discussion is also underway regarding FBN publishing a "Pamphlet on Ethics Committees," which would highlight alternative approaches to the most frequent challenges in establishing/growing your ethics committee. We would want to avoid efforts to establish standards by which everyone will be measured. However, there are a range of responsible approaches from which a committee could be patterned. Enough information and experience exists to provide suggestions about some circumstances to avoid as well.

We are seeking feedback on all of these issues, particularly from our members. A future issue of our newsletter will contain a survey for your newsletter impressions. In the interim, please write or call me at Department of Pastoral Services, Shands Hospital at the University of Florida, P.O. Box 100323, Gainesville, FL 32610-0383 -- 904/395-0123 with your impressions.

JCAHO AND BIO-ETHICS: A RECENT EXPERIENCE

Submitted by **James T. Wagner, Ph.D.**, Director of Pastoral Services, Shands Hospital at the University of Florida, Gainesville.

The Joint Commission surveyed our hospital from March 17-23, 1994. This was the first year of a new approach by the JCAHO, which was more unit based, involving most disciplines providing care to the patient/family. On several units, the surveyor began with a particular patient or the medical record and then pursued issues as they became prominent. At other times, the unit interview would occur in a conference room with representatives from the care team present to respond to questions.

The survey began with several hours of document review, including the material provided by our Ethics Committee. An annual report, minutes of monthly meetings, policies reviewed, case consult reports, advance directive information, and educational programs were contained in this folder reviewed by the surveyors. Established in 1981, our committee is respected throughout most of the hospital. We do policy review/recommendations, continuing education for staff, and case consultations, averaging 80 prospective case reviews annually. In addition, the committee coordinates implementation of the Patient Self-Determination Act.

From the first unit based visit to the last, with few exceptions, some questions pertained to activities of the ethics committee. Who could access the committee? How would the committee become involved? What were some examples of the types of issues resulting in a case consult? What principles did the committee use to address these issues? What were the committee's recommendations? Did patients know about/attend ethics consults? What was the plan for introducing advance directives to patients? What had we done about public education on the Self Determination Act? On several units, the opening question was, "Tell me about a recent ethics case consultation?" Specific staff members who had been involved in a consultation were questioned about his/her role, as well as the process used by the committee. The chart was called for on a discharged pediatric patient where an ethics consultation had occurred to review the written entry in the record which summarized advisory recommendations.

On another chart review, when a patient had a "Living Will," the question was asked, "Does the patient also have a DNR order?" It was necessary to schedule a "special session" to resolve this surveyor's concern. Some confusion seemed to exist about the relationship between a patient having an advance directive and whether s/he should also have a DNR order. Several assumptions seemed to lead to the surveyor's lack of understanding. First, it was assumed that when a patient had an advance directive s/he was terminally ill. Second, it was assumed that an advance directive always meant the patient did not want dying prolonged. These misunderstandings led to the surveyor assuming that every patient who had an advance directive ought to also have a DNR order.

In the focused ethics interview, which was separate from the "special session" described above, most of the questions centered on issues surrounding DNR orders. First, how did we identify patients with DNR orders? Second, what would happen when a patient with a DNR order was taken to surgery? The first question has been discussed at length with no satisfactory solution to date. We have ruled out arm bands, color coded items such as stickers on the chart, and other identifying symbols. The surveyor acknowledged that most hospitals find the issue very challenging to resolve.

The "DNR in the O.R." is an issue we have resolved, at least as far as policy is concerned. A DNR order cannot be canceled for any reason without express conversation with the patient and/or proxy consenting, even when a surgical procedure is planned. Steps for conflict resolution, should any arise, are spelled out, including consulting the ethics committee. These practices are reflected in our DNR Hospital Policy.

We intend to revise one of our hospital policies as a result of the survey. When a patient has a "traditional" advance directive, where the preference is that s/he does not want dying prolonged, and is terminally ill, we are going to require that discussion about a DNR order occur. This discussion will need to be documented in the medical record and include an indication of the patient's wishes, as well as a written DNR order, if appropriate. We have an occasional situation, when the patient's preferences are clear, and a DNR would be appropriate, that such a discussion and/or order has not occurred. We are hopeful that this policy change will address that concern.

The surveyors were complimentary of our way of introducing advance directive information to patients. The admitting nurse has been given that responsibility in our hospital, referring to pastoral services or social work services if the patient requires assistance. One surveyor commented that some hospitals attempt to manage this function through admissions and it has usually not worked well and/or been viewed by the JCAHO as a "sensitive" approach.

Overall, there was a great deal of emphasis placed upon patient rights and ethics committees. This attention was far more specific and focused than had been reported to us by other recently surveyed hospitals. Most of those hospitals got only cursory questions, such as, "Do you have an ethics committee?" This was not our experience. Whether the specificity we experienced was related to our having a developed, mature committee, as evidenced in the documents available for review, or a trend everyone can expect, is not known.

THE BIOETHICS RESOURCE CENTER

Submitted by **Ray Moseley, Ph.D.,** Medical Humanities Program, University of Florida College of Medicine, Gainesville.

The FBN is now a co-sponsor of The Bioethics Resource Center (BRC) and the services of that Center are now available to FBN members. This Center is affiliated with the Medical Humanities Program at The University of Florida College of Medicine. The holdings include over 1000 books, 10,000 articles and subscriptions to 15 journals. The Center also has an extensive collection of hospital and ethics committee policies on issues ranging from withdrawal of treatment, DNR orders, Advance Directives to HIV testing. Additionally, the latest versions of Florida (and selected other states) law, regulations, and court cases are available. Faculty of the Medical Humanities Program are available to answer your questions or to direct you to additional resources.

The Resource Center is open 8:00 a.m. to 5:00 p.m., Monday through Friday (if you are in Gainesville, please feel free to visit). Please note that the Resource Center and The Medical Humanities Program are located in the Department of Community Health and Family Medicine, so do not be surprised when the telephone is answered "Family Medicine!" An answering machine is available for afterhours and weekend telephone requests. There is no charge for this service to FBN members, although you may be asked to cover copying costs if you request large amounts of printed information.

FBN members may request information from the Bioethics Resource Center as follows: **Ray Moseley, Ph.D., Medical Humanities Program, Box 100222, University of Florida College of Medicine, Gainesville, Florida 32610 -- Phone #: 904/392-4321 -- Fax #: 904/392-7349 -- E-mail address: Moseley @ chfm.health.ufl.edu**

Submitted by **Ray Moseley, Ph.D.**, Director/Medical Humanities Program, University of Florida College of Medicine and Bioethics Advisor, Florida Bioethics Network.

Why has the concept of "medical futility" become so controversial in the last couple of years?

Medicine is now in a period where the appropriate limits of the decisionmaking roles of patients (families or the appropriate surrogate) and physicians are quite fluid. On the one hand, it is clear that patients should be the prime decisionmaker when the decision involves their quality of life, since these decisions are rooted in a patient's basic moral values. The important role of the physician in these cases is to provide treatment alternatives, information, and advice based on his/her experience. This "patient autonomy" view has been greatly expanded in recent years as the legal and ethical grounding of informed consent has been explored. On the other hand, when the treatment is "medically futile," the physician is under no obligation to inform a patient about that treatment or to provide that treatment to a patient, even if it is requested by the patient. This determination has been traditionally seen as the physician's to make, since he/she is the one with expert medical knowledge as to which treatments might be appropriate.

Although these issues are theoretically distinct, significant problems have arisen. Some patients/family members are now insisting that "everything be done," even when medical treatments offer little hope for the patient. One extreme example of this dilemma is the recent Florida case where the parents of a "brain dead" child insisted that the physicians and hospital continue ventilation and feeding tubes.

There is a great deal of debate over what should be the appropriate and precise meaning of "medical futility." Definitions range from the conservative, i.e. "no impact on either the length or quality of a patient's life," to having no quality of life (e.g. coma), to being in the dying process, to the treatment having little hope of working, to the treatment having more burdens than benefits, to the treatment not alleviating the underlying disease. Not only are there difficulties in deciding which definition is most appropriate, there is the additional problem of determining how medically certain the physician must be about the treatment meeting any particular definition of "futile." The ethical problem on this front is that without a precise and accepted definition of "medical futility," "futile" treatment that is withheld by one physician may be provided by another who deems the treatment as "not futile." Leaving this up to chance, of course, violates a basic principle of justice, namely that similar cases should be treated in a similar manner. Additionally, many who have written on this issue consider that allowing an individual physician to decide on futility without satisfactory institutional safeguards in place may lead to possibilities for abuse.

In general, a designation of "medical futility" should be avoided unless it is backed by a hospital policy which contains a precise definition of "medical futility," comments on medical certainty (how clearly does a particular patient meet the definition), and contains clear safeguards in place to avoid misuse of the "futility" designation.

I am in the process of collecting hospital policies on medical futility and developing a model "medical futility" policy. If your institution has such a policy or if you have some views on what provisions such a policy should contain, please forward them to me. Your help would be much appreciated!

For further reading on "medical futility":

Alpers A, Lo B. "Futility and the Ethics of Resuscitation", Law, Medicine and Health Care 1992; 20: 327-329.

Angell M. "The Case of Helga Wanglie: A New Kind of `Right to Die' Case" NEJM 1991; 325: 511-512.

Schneiderman LJ, Jecker NS, Jonsen AR. "Medical Futility: Its Meaning and Ethical Implications" Annals Intern Med 1990; 112: 949-954.

Solomon MZ. "How Physicians Talk About Futility: Making Words Mean Too Many Things" J Law, Med and Ethics 1993; 21: 231-237.

Truog RD, Brett AS, Frader J. "The Problem With Futility" NEJM 1992; 326: 1560-1564.

Youngner SJ. "Who Defines Futility?" JAMA 1988; 260: 2094-2095.

FILMS/VIDEOS

"A Matter of Life or Death," Withdrawing Life Support, and "Who Lives, Who Dies?," Rationing Health Care, both narrated by James Earl Jones, are available from: Filmakers Library, 124 East 40th Street, New York, New York 10016 -- Phone: (212) 808-4980 -- Fax: (212) 808-4983.

WELCOME NEW MEMBERS!

The Florida Bioethics Network welcomes **Gregory Dickinson**, Co-chair, Bioethics Committee, Sarasota Memorial Hospital, Sarasota, 813/366-1883; **Joseph Doyle**, Chief of Health Services, Florida Department of Corrections, Tallahassee, 904/922-6645; **Patsy Myers**, Vice President, Baptist Hospital, Pensacola, 904/469-2323; **Stephan Oosterman**, LCDR, Naval Hospital/Jacksonville, Jacksonville, 904/777-7963; **Steven Paquet**, Florida Hospital - Premier Health, Orlando, 407/897-5570; **Dawn Schmidtman**, Doctors Hospital of Sarasota, Inc., Sarasota, 813/366-0044; and **Scott Warner**, Regional Health Services, State of Florida, Gainesville, 904/955-2035.

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Howe, E. G. (1994). Clinical dilemmas when patients want assistance in dying. The Journal of Clinical Ethics, 5, (1), 3.

Kirkland, L. (1994) Neuromuscular paralysis and withdrawal of mechanical ventilation. The Journal of Clinical Ethics, 5, (1), 38.

Silverman, H. J., Fry, S. T., Armistead, N. (1994) Nurses' perspectives on implementation of the patient self-determination act. The Journal of Clinical Ethics, 5, (1), 30.

Sugarman, J. (1994) Outcomes research and advance directives. The Journal of Clinical Ethics, 5, (1), 60.

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