NETWORK NEWS

The newsletter of the Florida Bioethics Network

a Health Service Group of the Florida Hospital Association - P.O. Box 531107 - Orlando, Florida 32853-1107 - 407-841-6230

October 1997 **97-4**

MESSAGE FROM THE PRESIDENT

COMPASSIONATE CARE AT THE END OF LIFE

*By **Glenn R. Singer, MD,** Chairman-Bioethics Comm./Pulmonologist, Broward General Medical Center, Ft. Lauderdale.*

The greatest satisfaction for most of us in pulmonary and critical care medicine is the critically ill patient that is appropriately diagnosed and treated, then recovers to return to his or her family, job, and/or community. Fascination with the physiology, molecular biology, and whiz-bang technology were often the motivation for choosing this field. There were many strong, charismatic role models to follow. There were many exciting articles, lectures, symposia.

The patients who do not respond to treatment, however, may never be able to return to a satisfactory condition. Their disease process may be the final chapter in their life. Their goals may include withdrawing of life-sustaining treatment and compassionate or palliative care. These patients have always been present in our intensive care units and hospital wards. Unfortunately, there were few, if any, strong role models or teachers on this subject and not many articles orlectures.

My personal interest in bioethics evolved from the desire to be a better pulmonologist/intensivist and serve this second group of patients and their families. Some of my warmest, most touching thank you letters have come from the families of patients that died under my care. It is often hard to separate the concept of patient death from physician failure, but these letters and other expressions go a long way.

A recent article by Brody, Campbell, Faber-Langendoen, and Ogle (New England Journal of Medicine 1997; 326: 652-657) offers the basis for a policy and procedure on the withdrawal of life-supporting treatment and provision of compassionate care. They point out that the suboptimal withdrawal of treatment may increase distress at a time when alleviation of suffering should be paramount.

Several paradigms in critical care are stood on end for end of life care. Opiods and benzodiazepines are usually prescribed gingerly because they may cause respiratory depression and arrest. In terminal patients, though, their use is necessary to relieve pain. In the Brody article, they point out that subcutaneous administration with butterfly needles can be simply done without further uncomfortable search for intravenous access.

Many health professionals are uncomfortable with high doses of these medications. The dose in these patients should be titrated to relieve pain and dyspnea. If the patient dies during or shortly after the administration, it should be considered the result of the underlying disease and not the palliative drug.

Discontinuation of ventilators, dialysis, and nutrition and hydration may present emotional problems for health care workers. The duration of survival after coming off the ventilator may range from minutes to days. The authors point out that in one study of "terminal" ventilator patients, 11% actually survived to discharge. Detailed communication and support help in this transition. Turning off monitors such as oximeters and EKGs may help focus care on comfort needs rather than physiology which is irreparable.

Withholding nutrition and hydration may be a problem for some health care workers and families. It may be an even greater problem to restrain patients on tube feeding who are confused, or manage fluid problems in patients on parenteral nutrition. As pointed out in the article, there is general agreement that terminal patients do not suffer because of ketosis, natural opioids (endorphins) and the uremic state.

Often these patients cannot be feasibly transferred to hospice. It behooves the whole health care team to bring a hospice-like atmosphere, then, to these patients and families.

This is my last article as President of the Bioethics Network. I want to thank those of you kind enough to respond to my previous articles, those of you who regularly attend our annual conference and share your experiences, and my fellow board members for their energy and talents.

Case Presentation

*By **Michael L. Walker, MD,** Panama City.*

Harry was a 56 year old male who was brought in by EMS because of progressive shortness of breath. He has a known history of COPD and when he did not respond to initial efforts at relieving his hypoxia was intubated, placed on a ventilator, and admitted to the intensive care unit. He subsequently developed intermittent cardiac arrhythmias including atrial fibrillation and ventricular tachycardia, and despite aggressive management, proceeded to develop adult respiratory distress syndrome. Renal function began to deteriorate and the patient's mental state decreased as did his liver functions. He was begun on hemodialysis and with "multi-speciality care" he had an improvement in his neurologic condition to where he was intermittently conscious and able to communicate with his family.

He became septic with periods of hypotension despite antibiotic therapy and pressure support. It was the opinion of the treating physicians that the patient had multi-system failure and despite maximal support would not survive the illness.

The patient's daughter approached the nurse pointing out that her father had "never wanted to be on machines." When asked, the patient was able to communicate that he wanted nothing further done if he did not have a reasonable chance of recovery.

Cardiology, nephrology, and infectious disease specialists all agreed that the patient had no chance of recovery and a discontinuation of aggressive support in their areas was not inappropriate. The pulmonary consultant stated that he would simply "not assist in the patient's suicide" by removing the ventilator. He stated that he had never taken a conscious patient off of the ventilator when they were unable to sustain themselves and would stand by the bedside to prevent anyone else from doing it. The patient's youngest of three sons arrived from out of town and disagreed with the family's desire to discontinue support. He stated "Dad is a fighter" and wanted "everything done."

Case Presentation (continued)

At this time, an ethics consult request was made. The consult team reviewed the record and met with all available family members. During their visit with the patient who was quite coherent and lucid, he expressed repeatedly, to the satisfaction of the committee, that he understood his situation and wanted all treatment discontinued. It became apparent that the patient, and subsequently the family, did not understand the immediate consequences of discontinuation of each type of support. When the benefit of each aspect of his therapy was explained and what would happen if that particular treatment were discontinued, the patient and family came to a unanimous decision that they would like to have dialysis, pressor support, and antibiotics discontinued but to maintain intubation and ventilation. Over the next 24 hours the patient became comatose and expired without any apparent discomfort in the presence of his family.

Comment:

While there are many ethical issues in this particular scenario, the critical feature seems to be that which is often underlying most consultations for hospital ethics consults and that is communication. The patient and family had assumed that their only decision was total support or none at all and were not aware of the implications of each particular action individually. Each consultant understood that their efforts were not going to produce the patient's ultimate goal of survival and reasonable quality of life. The pulmonary specialist continued to believe that the patient did not understand truly what he would endure if ventilatory support was discontinued but had no concerns about removing the other types of assistance.

Current References #11

Submitted by ***Francille M. MacFarland, MD,*** *Winter Park.*

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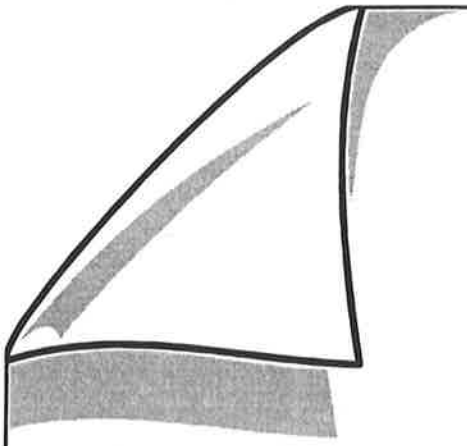

LETTER FROM A MEMBER

July 21, 1997

Editor: Florida Bioethics Network News
Florida Hospital Association
P.O. Box 531107
Orlando, FL 32853-1107

Dear Sir:

Dr. Singer presented an interesting case review in the July 1997, issue of *Network News* under the title, "Has Autonomy Gone Mad?" I believe this case is better understood not as one in which there was an attempt to carry respect for autonomy to an extreme, but rather as one in which the treating physician appropriately respected patient autonomy in spite of external pressures to ignore it.

In the case presented, an elderly patient had executed a living will indicating she would refuse life-sustaining medical therapy if she should become seriously ill with no chance for recovery. Subsequently, when the patient required ventilatory support, her daughter urged the physician to discontinue care despite the physician's assurances that the patient has a reasonable chance at recovery. Treatment was continued and the patient did recover.

Respect for the principle of patient self-determination dictates that, when confronted with difficult choices regarding medical treatment, the first step in making a decision is generally to identify the decision maker. In this case, the physician accurately identified the patient as her own decision maker through her living will and declined to allow another family member to usurp that authority. If we wish to build public confidence in the use of advance directives, we must continue to educate patients and their families on their meaning and respect the conditions they set forth, as was done in this case.

Sincerely,

Bruce J. McIntosh, M.D.
Chairman, Ethics Committee
St. Vincent's Medical Center

Annual Conference Highlights "Daily Practice" Theme

*By **Ken Goodman, Ph.D.**, Director/Forum for Bioethics & Philosophy, Jackson Memorial Hospital, Miami.*

With topics to include Alzheimer's disease, pediatrics, clinical futility, and sexual behavior in health care institutions, the Seventh Annual Conference of the Florida Bioethics Network promises to be one of the most informative and interesting ever.

The conference — **"BIOETHICS IN FLORIDA: CHALLENGES IN DAILY PRACTICE" — IS SCHEDULED FOR OCTOBER 8-10, 1997, IN TAMPA.** The program includes ample "networking opportunities" so attendees can share information and experiences with others from around the state.

Keeping with custom, the first day of the gathering constitutes a popular "preconference" emphasizing core issues, basic themes, and introductory material. This year's preconference topics are the foundations of bioethics, use of outcomes data and statistics, JCAHO standards for ethics committees, documenting ethics consultations, and the structure of cases in bioethics. There also will be an open forum on the roles and functions of institutional ethics committees.

On Thursday, October 9, the conference kickoff will be a presentation by **Cecil McIver, M.D.,** the Hobe Sound physician and key figure in the recent Florida Supreme Court ruling on assisted suicide. While the court ruled that a patient of Dr. McIver's did not have a constitutional right to assisted suicide, the case continues to engender intense interest, and Dr. McIver will describe his role in the case and give his perspective on this important issue.

Also, the conference will, for the first time, address ethical issues in public health research with a presentation by leaders of the Florida Department of Health's IRB. Other sessions will address ethics and the Alzheimer patient, clinical futility in pediatrics, truth-telling in clinical contexts, and alternative approaches to bioethics.

On Friday, October 10, attendees will hear presentations on errors in practice, maternal-fetal conflict, clinical hopelessness, ethical tensions in long-term care, religious and cultural issues, ethics committees in hospice and home health, and sexual behavior in inpatient settings.

The conference has been approved for 15.5 Category 1 CME credits, 17.5 CEUs for nurses, 15 CEUs for clinical social workers, marriage and family therapists and mental health counselors, and 18.5 CLER hours for attorneys.

Special room rates of $99 single or $109 double occupancy have been secured at the conference hotel, the Hyatt Regency Westshore at 6200 Courtney Campbell Causeway in Tampa. Reservations must be made by September 30 to ensure availability. The hotel's phone is 813/874-1234.

FBN members enjoy substantial discounts on registrations fees (e.g., members pay only $185 for all three days), and group registrations are subject to additional discounts. For information about registration, to receive a conference brochure, or to inquire about other matters, call **Sherry Greenhalgh or Diane Bennett** of the Florida Hospital Association at 407/841-6230.

Conference fees are kept as low as possible with the help of supporters from around the state. This year, educational grants were received by the following organizations:

Philosopher Level

- ☆ Baptist/St. Vincent's Health System, Jacksonville
- ☆ Forum for Bioethics and Philosophy, University of Miami
- ☆ North Broward Hospital District, Ft. Lauderdale
- ☆ Shands Hospital at the University of Florida, Gainesville
- ☆ St. Joseph's - St. Anthony's Health System, Tampa

Ethicist Level

- ☆ Boca Raton Community Hospital
- ☆ Miami Jewish Home and Hospital for the Aged
- ☆ Sarasota Memorial Hospital
- ☆ Spiritual Services Dept., Lee Memorial Health System, Ft. Meyers
- ☆ Wuesthoff Memorial Hospital, Rockledge

Utilitarian Level

- ☆ Catholic Health Services, North Miami
- ☆ Hospice Care of Broward County, Ft. Lauderdale
- ☆ Munroe Regional Medical Center, Ocala

Essential Readings #11

*Submitted by **Francille M. MacFarland, MD**, Winter Park.*

Legal Issues:

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Welcome New Members!

The Florida Bioethics Network welcomes **Deborah Beaton, RN,** Case Manager, Columbia Doctors Hospital of Sarasota, Inc., Sarasota -- 941/342-5567; **Everett Dameron, LCSW,** Social Worker, St. Joseph's Hospital, Inc., Tampa -- 813/977-2330; **Barbara Frye,** Ethicist, Tallahassee Memorial Regional Medical Center, Tallahassee -- 904/893-1238; **Elaine Gorman,** Emergency Management Director - Tampa, UKHCTD, Key Largo -- 305/451-2766; **Karen Reich, LCSW,** CVI Specialist, St. Anthony's Hospital, Inc., St. Petersburg -- 813/825-1768; **Joyce Richard, RN, BS,** Ethics Specialist, Hospice by the Sea, Boca Raton -- 561/395-5031.

Enclosed is a *Network News* Readership Survey. Please complete and return. WE WANT TO HEAR FROM YOU!