

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

July 1997

97-3

MESSAGE FROM THE PRESIDENT

HAS AUTONOMY GONE MAD?

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

Autonomy is one of the cornerstone principles in bioethics and derives from the strong tradition of self determination. A patient has the right to formulate decisions about his/her health care. We, in the medical profession, have an obligation to make recommendations and formulate plans for diagnosis and treatment based on our training, knowledge, and experience. Patients and their surrogate decision-makers may accept or reject those recommendations based on their values, beliefs, goals, and their own personal experiences. Sometimes this may conflict.

More than 20 years ago in the Quinlan case, the issue was the autonomous request of the family to discontinue ventilator support in a vegetative patient. We now routinely accept termination of care and encourage our patients to have advance directives to help guide families and care givers if patients cannot speak for themselves.

Recently, though, I was involved in a case which made me wonder if autonomy has gone into irrationality. Briefly, the patient was a 66 year old female in reasonably good health, living by herself, who suffered an anterior myocardial infarction leading to pulmonary edema and renal insufficiency. Prior to this event she had been on chronic anxiolytics in

moderate doses, but appeared to have sound decision-making capacity. The patient had a standard living will with language that if the physicians felt there was no chance for recovery, she did not wish to be kept alive artificially. Her daughter, who lived in another state, was her surrogate decision-maker. Due to the infarct, the interventional cardiologist felt the best course of action was to proceed to the cath lab for angiogram, possible stent placement, and insertion of intraaortic balloon pump. The nephrologist and cardiologist felt this could not be accomplished without intubating her and supporting her on the ventilator.

After one week the patient improved and the balloon pump was removed, inotropic support was being weaned and the patient improved, but still required ventilatory support. Her daughter, at this time, began showing unhappiness over her mother's continued respiratory failure. The cardiologist, nursing, and I, as pulmonologist, went to great lengths to keep her informed about her mother's progress and our hope that she would come off the ventilator soon. When asked how long, we declined to give a specific answer. We agreed that if the patient had any further setbacks that we would provide only palliative care and wrote a DNR order.

We reassured the daughter that we did not expect this to go on indefinitely, and if her mother did not improve, then we understood the living will. We pointed out that the living will stated that the patient wanted supporting efforts stopped if her physicians felt there was no chance for recovery. Therefore, she did not meet the criteria in the advance directive. We also pointed out that we were using sedation as much as possible to keep the patient comfortable, but from time to time we had to back off to allow her respiratory muscles to retrain for independent breathing.

After not more than two or three days of continued weaning attempts from the ventilator, the daughter demanded that the ventilator be removed. She did not care if her mother survived or not. She was sure we were torturing her. Our best efforts at communication had failed. The fact that she was improving and probably ready for extubation that day anyway was lost in the confrontation of the moment.

The patient was subsequently extubated and actually did quite well going home in a few more days.

What went wrong? Is the public mistrust of the medical community so vast that no rational explanation is acceptable? How did the notion of autonomy and the living will get so contorted that efforts to help a patient with a reversible and objectively improving problem were rejected by the surrogate decision-maker? An elderly friend of the patient's daughter said that if this is what a living will meant, she was going home to change hers so she would never end up on a ventilator.

One problem with this piece is that the patient and daughter are not here for their side of this story. The patient, however, two days after being extubated in the telemetry unit said she had no recollection of being on a ventilator - a not uncommon experience. We had, indeed, informed the daughter early on that many patients have little or no memory of their ICU experience if they recover.

Was our attempt to inform the patient's daughter of the process inadequate? How much communication is enough? Why could we not get the message through that this situation did not meet the condition of the advance directive?

The refusal of treatment that is clearly beneficial is often difficult for health care workers. We accept the refusal, however, after satisfying ourselves that the patient has decision-making capacity. Surrogate decision-making may be more problematic, but also is accepted if the surrogate is stating what the patient would have or if we feel the surrogate is acting in the patient's best interest.

In this case, the daughter felt she had the right as surrogate decision-maker to demand that the ventilator be removed. Sorry, but I think this was autonomy gone mad.

CURRENT REFERENCES

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

1. Wear S., et al. Clinical Ethics and the Suffering Christian. *Christian Bioethics* 1996; 2:239-252
2. McCullough, L.B. Bioethics in the Twenty-first Century: Why Should We Pay Attention to Eighteenth Century Medical Ethics. *Kennedy Institute of Ethics Journal* 1996; 6 (4):329-333.
3. Loewy, E.H. Justice, Society, Physicians, and Ethics Committees: Incorporating Ideas of Justice into Patient Care Decisions. *Cambridge Quarterly for Healthcare Issues* 1996; 27 (1):29-37
4. Truog, R.D. Is It Time to Abandon Brain Death: *Hastings Center Report* 1997; 27 (1):29-37
5. Bernat, J.L. Physician Assisted Suicide Should Not Be Legalized. *Archives of Neurology* 1996; 53:1183
6. Brody, H. Physician Assisted Suicide Should Be Legalized. *Archives of Neurology* 1996; 53-1182
7. AMA to Supreme Court - No Suicide Aid. *American Medical News* 25 Nov 1996: 1

CASE PRESENTATION

By Kathleen M. Weldon, RN, MN, CNA, Senior Vice President, Patient Care Services, Wuesthoff Hospital, Rockledge.

Most hospital ethics committees will agree that sometimes the best ethics consults come in after 5:00 p.m. on Friday. The beeper went off as I drove to a hospital-sponsored function where I would soon see several members of the ethics committee. Therefore, the discussion and recommendations were done by the committee in a small hallway outside a meeting room which truthfully did not impact decision-making.

The Issue

The consult was from an obstetrician. The patient was a 30 year old female gravida 3, para 1 with previous live birth of a 27 week delivery secondary to premature labor. Because of the difficulties associated with the first birth, which produced a very premature baby that had stayed in a high risk nursery for a number of weeks, the mother had sought genetic counseling. An ultrasound revealed intracerebral ventriculomegaly and a lumbosacral meningocele or spina bifida at about the level of L3. Fetal age approximately 22 weeks.

The perinatologist discussed with the patient and the baby's father that the neural tube defect was significant and along with the hydrocephalus what the baby's chances would be. Patient was offered options including genetic counseling, amniocentesis, and termination. Patient was given time to understand the gravity of the diagnosis and chose to terminate the pregnancy rather than go to an abortion center. The patient returned home and called the obstetrician to see if he would assist her in terminating the pregnancy.

Since neither the physician nor our facility routinely participate in elective abortions, that became the initial dilemma. The next question was, at 22 weeks with the named anomalies the fetus would probably die just from the trauma of delivery, but the next question, what if the baby had some neuro-reflexive movement after delivery - would the labor nurse feel obligated to perform any resuscitative efforts.

Question 1: The patient was well known to the physician. She had great faith and trust and therefore, her decision to ask him to help her. The committee also believed that it was not our decision as to whether this was right or wrong morally, but to assist the physician and the patient in their decision.

Question 2: The physician had clearly discussed with the patient how he would induce her and what to expect. It also was made very clear that the baby would probably not live through the delivery but that when born the baby may have some movement but that even if resuscitated the child would not live and this would only extend the moments till death.

Question 3: The physician was on the nursing unit when the call was made. We asked that he discuss with the staff, particularly since the 12 hour night staff was just arriving, what would be taking place. This was all done prior to him calling the patient in for the induction. We collectively felt that all elements must be understood before calling the patient and agreeing to follow through with her wishes. One of the nurses, a long time labor nurse agreed to be the patient's primary nurse. Over the years, she had seen babies born with spina bifida and had seen many die during delivery. With clear expectations of outcomes and education to the parents, she felt that even if the baby had some neuro-reflexive movement, she could refrain from resuscitation as this was not a birth but an elective termination.

The physician assured everyone that the patient was very clear and when he called her again presented the possibility of some movement after delivery but that all efforts to resuscitate would be futile.

Therefore, we had a physician who wanted to assist his patient, a patient who was clear on the outcome, and a nurse who would be attending the patient for the next 12 hours who was committed to the process and felt comfortable in her decision. Copies of the ultrasound and the consult from the perinatologist were obtained and placed in the chart.

Outcome

The patient was called and was admitted within the hour, induction began with cytotec. She labored throughout the night not really moving too quickly through the stages of delivery. Physician stayed in-house the entire time. At 7:00 a.m. labor was progressing and the night nurse felt a continued commitment to the patient and stayed with her until approximately 10:00 a.m. when the fetus was delivered. Fortunately, the baby made no movements and had no respirations. It weighed 515 gms. Except for the spina bifida and some slight hydrocephalus the baby appeared normal. The baby was bathed by the nurse and given to the parents to hold. The event was very emotional for all involved. The patient was discharged at approximately 4:00 p.m. and she was very pleased that she

had been allowed to terminate her pregnancy in this dignified manner rather than in an abortion clinic.

At our next ethics committee meeting, we discussed our decision, the elements of the patient's care, and the outcome. The physician involved posed a question for another meeting. What if the fetus is delivered and moves, should the medical team feel responsibility towards resuscitative efforts since it is an elective abortion, and what if someone panics and does so?

We decided to research elements of the situation and discuss another time. Due to clear communication, education, and willingness to participate and support the patient, the committee felt that a good decision had been made in this case as presented.

AMERICAN GERIATRICS SOCIETY OUTLINES PRINCIPLES FOR MEASURING THE QUALITY OF CARE AT THE END OF LIFE*

(Printed with Permission from the American Geriatrics Society, this summary appeared in the March/April 1997 AGS Newsletter.)

1. Physical and emotional symptoms. Pain, shortness of breath, fatigue, depression, fear, anxiety, nausea, skin breakdown, and other physical and emotional problems often destroy the quality of life at its end. Symptom management is regularly deficient. Care systems should focus upon these needs and ensure that people can count on a comfortable and meaningful end of their lives.
2. Support of function and autonomy. Even with an inevitable and progressive decline with fatal illness, much can be done to maintain personal dignity and self-respect. Achieving better functional outcomes and greater autonomy should be valued.
3. Advance care planning. Often, the experience of patient and family can be improved just by planning ahead for likely problems, so that decisions can reflect the patient's preferences and circumstances rather than responding to crises.
4. Aggressive care near death-site of death, CPR, and hospitalization. Although aggressive care is often justified, most patients would prefer to have avoided it when the short-term outcome is death. High rates of medical interventions near death should prompt further examination of provider judgment and care system design.
5. Patient and family satisfaction. The dying patient's peace of mind and the family's perception of the patient's care and comfort are extremely important. In the long run, we can hope that the time at the end of life will be especially precious, not merely tolerable. We must measure both patient and family satisfaction with these elements: the decision-making process, the care given, the outcomes achieved, and the extent to which opportunities were provided to complete life in a meaningful way.
6. Global quality of life. Often a patient's assessment of overall well-being illuminates successes and shortcomings in care which are not apparent in more specific measures. Quality of life can be good despite declining physical health, and care systems which achieve this should be valued.

7. Family burden. How health care is provided affects whether families have serious financial and emotional effects from the costs of care and challenges of direct caregiving. Current and future pressures on funding health care are likely to displace more responsibility for services and payment onto families.

8. Survival time. With pressures upon health care resources likely to increase, there is now reason to worry that death will be too readily accepted. Purchasers and patients need to know survival times vary across plans and provider systems. In conjunction with information about symptoms, satisfaction, and the other domains listed here, such measures will allow insights into the priorities and tradeoffs within each care system.

9. Provider continuity and skill. Only with enduring relationships with professional caregivers can patient and family develop trust, communicate effectively, and develop reliable plans. The providers also must have the relevant skills, including rehabilitation, symptom control, and psychological support. Care systems must demonstrate competent performance on continuity and provider skill.

10. Bereavement. Often health care stops with the patient's death, but the suffering of the family goes on. Survivors may benefit with relatively modest interventions.

**The full text of the statement on Measuring Quality of Care at the End of Life, A Statement of Principles,* was published in the AGS Newsletter in the May/June/July 1996 issue, Vol. 25, No. 3. For copies of the Full Statement, write to AGS, attention, Communications Director, 770 Lexington Ave, Suite 300, New York, NY 10021*

REFLECTIONS OF A COMMUNITY BIOETHICS COMMITTEE MEMBER

By *Elizabeth O. Harmon Ed. D., C.H.E.S.*

For the last year, I have had the opportunity and privilege to serve on the Lee Memorial Health System's Ethics Consultation Committee. As a community lay person and a Certified Health Education Specialist who has been a career educator, the learning process has been extensive. To be quiet and be a good listener is always a challenge for anyone, especially a teacher!

The question of what an educator has to offer an Ethics Consultation Committee is constant at each meeting. The answer has begun to take substance in the following format:

The individual consumer must take responsibility for his own health and well being, in charge of prevention and a partner with the health care provider in intervention and treatment. Education plays an important roll in this venture. Education should go well beyond information and be founded in attitudes and behaviors with the outcome of good positive decision-making skills. Making life and

death decisions will be in greater demand for the health consumer, whether it be for their own person or for a loved one. Education found in positive attitudes will enable well thought out decisions, rather than decisions based on emotions of fear and guilt. I say this after enduring the accidental death of our 16 year old son and having to make the decision of removing life support from my 88 year old mother who loved life. The adage, "And the truth shall set you free," is so relevant!

Wellness and spirituality are becoming a popular twosome in the health care field and have great potential in facing reality of the Alpha and the Omega of life. Faith and education are able to be partners in this arena.

I look forward to the future; being part of a diverse, community team facing "cutting edge" decisions and making a positive difference in the life of individuals and their health care.

**LETTER TO GLENN R. SINGER, MD,
FBN PRESIDENT**

*Printed with permission by Dr. William Morgan, QI
Physician Advisor, Sarasota Memorial Hospital,
Sarasota.*

Dear Dr. Singer:

Thank you for your very comprehensive article on Assisted Suicide in the April 1997 *Network News*. As you know from previous experience with me, I love to comment.

I thought your article was well written and certainly presented a discussion I have no problem with.

The only reason I'm writing you is to give you a recap of the only valid argument for assisted suicide that I have run into. The comments were those attributed to the nurses who were taking care of Nancy Cruzan during her final week. Paraphrasing the comments they were asking "by starving her, she is condemned to die. Death is the endpoint. (They had no problem with the decision.) But once this is decided, why not end it then for her and the family? Why does she and the family (and us) have to suffer through the next four to fourteen days?" When a person is ventilator dependent and the decision is made to stop the ventilator, death can occur quickly. When a person in a permanent vegetative state has their feedings withdrawn, death is certainly the endpoint, but it takes longer. I actually can see their side of the question. These nurses and this family loved and cared for Nancy Cruzan. She was certainly going to die without being given any sustenance. I have read that death by starvation may not be a totally unpleasant experience for the patient, but I think that "dragging out" the death process for the family and the caregivers can be viewed as cruel and unnecessary.

So since I agree with and appreciate your article so much, I thought I would pass on the one circumstance that would tempt me to participate in an assisted suicide. Perhaps you have a different read on this situation and if so, I would be interested in hearing your views.

Sincerely,
William C. Morgan, MD

**RESPONSE TO
DR. WILLIAM MORGAN'S LETTER**

Dear Dr. Morgan:

Your comments on Nancy Cruzan are well taken. This poor woman was in persistent vegetative state without chance for recovery of cognitive and sapient function. Her condition, however, prevented her from being a candidate for assisted suicide. She was unable to independently end her own life. Either her family or physicians would have had to administer a lethal dose of medication (barbiturates? KCl?) to end her life.

While this may strike many as a trivial distinction, it is well-recognized to be separate from assisted suicide. It is, in fact, active euthanasia. While active euthanasia may seem appropriate in PVS patients such as Cruzan, others have worried that legalized euthanasia may be easily abused and used on patients with poor prognoses or terminal conditions without clear consent. (Hendin, H., Zyllicz, Z. Physician-assisted Suicide and Euthanasia in the Netherlands: Lessons from the Dutch. *JAMA*. 1997; 277:1720-1722.)

Glenn R. Singer, M.D.

POSITION OF MEDICAL ETHICS COMMITTEES WITHIN INSTITUTIONAL ORGANIZATIONAL STRUCTURE

By *Francille MacFarland, MD, Winter Park.*

A few weeks ago the question of "Who has the authority to break up a hospital ethics committee?" was presented to me. I have attended quite a few medical ethics meetings, but had not heard this question asked before. Although I was pressed for an answer, all I could do was ask more questions.

The first question I posed was, "When the committee was organized, who gave the committee its charter?" I believed that the answer to this question would lead to the answer of the first question. The response I was given led me to believe that some hospital ethics committee members may not have clearly identified the position of the committee within the hospital's organizational structure at the time that the committee was originally formed.

The next question I raised was to whom is the committee accountable? At some point in the initial formation of the ethics committee, a decision should be made concerning the placement of the committee within the institution's organizational structure. Due to the multi-disciplinary nature of medical ethics committees, it is important to position the committee where it will be accepted by the medical staff, institution, and its personnel. All members of the committee must be recognized as equal participants.

Traditionally, ethics committees derive their authority, and report to one of the following groups: medical staff, the institution's administration, or its governing board. An advantage of placing the committee within the medical staff is that it may have better acceptance from the physicians. But, since the ethics committee includes non-physicians, bylaws may need review. As a physician's committee, it would be important to stress that all members are equal participants and "should not be excluded as officers, chairs, or co-chairs of such panels". (1)

The inclusive nature of an ethics committee would fit best as an administration panel. Unfortunately, it could be viewed as another administrative imposition on the staff. As a committee of the board of trustees, the medical ethics committee may be perceived as being "more 'outside' than an administrative committee would be." (2)

Other structures where hospital ethics committees have been placed include: nursing, pastoral care, or social services committees. Inclusion within these structures would identify the committee as only "representing a part of the hospital rather than the whole. Physicians might be unlikely to participate." (2)

The original question was hypothetical. It was raised to point out the importance of process early on in the formation of an ethics committee. But, if a hospital ethics committee should be disbanded, one would have to look at the position of the committee within the institution, to whom the committee is accountable, then look at hospital bylaws or regulations. One question that would have to be answered is: What triggered the decision to break up the committee?

(1) Guidelines For Ethics Committees. Florida Bioethics Network 1996, p.4

(2) Kelly, David F., Hoyt, John W., Ethics Consultation. Critical Care Clinics, 1966; 12:53.

SEVENTH ANNUAL FLORIDA BIOETHICS NETWORK CONFERENCE!!

Make plans now to attend this important conference, October 8-10, 1997, at the Hyatt Regency Westshore, 6200 Courtney Campbell Causeway, Tampa, FL 33607 -- 813/874-1234. **Call early for room reservations!** The popular Wednesday pre-conference will once again focus on issues important to new and developing bioethics committees. Thursday morning's keynote will include **Cecil McIver, MD**, physician of the patient whose case is before the Florida Supreme Court on the issue of physician assisted suicide. Other scheduled presentations include:

- ◆ Ethics and Alzheimer Patients
- ◆ Futility in Pediatrics
- ◆ Paternalism
- ◆ Ethics in Long Term Care
- ◆ Maternal-fetal Conflict
- ◆ Religious and Cultural Considerations in Bioethics
- ◆ Alternatives to the 4-Principles Approach
- ◆ Sex in the Hospital

The full program, listing sessions on important ethical issues that face health care professionals in a variety of settings, will be mailed to all FBN members later this summer. Continuing education credits will be available for a full variety of health care professionals. Make plans now to attend and bring fellow bioethics committee members along!

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

Justice in Healthcare Issues: Allocation of Scarce Resources

1. Alexander, S. They Decide Who Lives, Who Dies. *Life Magazine*; Nov.9, 1962:102-125
2. Katz, A.H. et al. Social-Psychological Characteristics of Patients Receiving Hemodialysis Treatment for Chronic Renal Failure. *Public Health Service, Kidney Disease Control Program*; July 1969
3. Kilner, J. Selecting Patients When Resources Are Limited. *American Journal Public Health* 1988; 78:144-147
4. Kilner, J. *Who Lives, Who Dies?* New Haven: Yale University Press, 1990
5. Rescher, N. The Allocation of Exotic Medical Saving Therapy. *Ethics* 1969, vol. 69
6. Scheiderman, L.J. et al. Should a Criminal Receive a Heart Transplant? *Theoretical Medicine* 1969; 17 (1):33-44
7. AMA Council on Ethical and Judicial Affairs. Ethical Considerations in the Allocation of Organs and Other Scarce Medical Resources Among Patients. *Archives Internal Medicine* 1995; 155:29-40
8. Brock, D. Ethics Committees and Cost Containment. *Hastings Center Report* 1990; 20(2):29-31
9. Jecker, N. Caring for "Socially Undesirable" Patients. *Cambridge Quarterly for Healthcare Ethics*; 5(4):500-510
10. Childress, J.F. Ethics and the Allocation of Organs for Transplantation. *Kennedy Institute of Ethics Journal* 1996;6(4):397-401

**CAST YOUR VOTE
FOR THE
1997-1998
FBN BOARD OF DIRECTORS!**

Included with this issue of *Network News* is a ballot for the election of 1997-1998 FBN Board of Directors. Please take a few minutes to vote and return the completed ballot to **Luanne MacNeill** at FHA by **July 31, 1997**. (*FBN members are eligible to vote.*)

WELCOME NEW MEMBERS!

The Florida Bioethics Network welcomes
Ms. Angel Barber, Administration, Columbia Twin Cities Hospital, Niceville -- 850/729-9301;
Dr. Valerie Browne-Krimsley, Coordinator/ Assistant Professor, University of Central Florida, Cocoa -- 407/631-5440 x5558; **Ms. Corrinne Fields**, Social Worker, Vencor Hospital - Ft. Lauderdale, Ft. Lauderdale -- 954/764-8900; **Ms. Marilyn Goldaber**, Director of Social Work, Miami Jewish Home & Hospital, Miami -- 305/751-8626 x147; **Mrs. Cynthia Livering**, Family & Resident Services, The Pavilion/Shell Point Village, Ft. Myers -- 941/466-1111; **Mrs. Davis Tornabene**, Sarasota -- 941/377-9969.