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

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PRESIDENT'S MESSAGE

Submitted by **Hana Osman, LCSW, DCSW,** Education Team Leader, Tampa General Hospital, Tampa.

The 1995-1996 year is coming to a close with the 1996 Annual Conference marking the end of my year as President of the Florida Bioethics Network (FBN).

During this year, the FBN co-sponsored several educational activities including **Dr. Kathryn Koch's,** Past President of the FBN, April seminar in Jacksonville, which focused on the ethical concerns arising in the care of patients in the managed care environment. This conference, which featured national speakers, was an effort to communicate the breadth of issues and concerns health care practioners deal with daily. Dr. Koch's efforts to communicate with parties concerned with the ethics of managed care will continue in 1997.

Also, **Dr. Glenn Singer,** incoming President of the FBN, led the effort to publish the *FBN Guidelines for Ethics Committees*. Dr. Singer will be discussing these guidelines in the Friday session of the Annual Conference in Ft. Lauderdale.

1996 witnessed the Joint Commission for Accreditation of Healthcare Organizations (JCAHO) making an effort to recognize the responsibilities of health care organizations to address patient rights and organizational ethics. The patient-focused interviews specifically centered on ethical concerns such as advance directives and decision-making, pain management, handling ethical conflicts and end-of-life decisions. Many institutions preparing for JCAHO surveys benefited from the information published in the *Network News* and the FBN President provided leadership in preparing institutions for these JCAHO surveys.

The annual conference in 1995 introduced us to some of the 1996 activities and updates and reports on these activities will be presented at the 1996 conference in Ft. Lauderdale. I hope that you will attend the Annual Conference on October 23-25, 1996, meet new friends interested in medical ethics, and have the opportunity to network with colleagues to renew relationships that you have formed at previous meetings.

FBN ANNUAL MEETING ~ MORE TOPICAL THAN EVER

October 23-25, 1996
Ft. Lauderdale, Florida

Submitted by **Glenn R. Singer, MD,** FBN President-Elect.

Assisted Suicide, Managed Care, Confidentiality, Guidelines for Ethics Committees, Withdrawing Ventilator Care in Terminal Patients, Issues in Pediatric Consent, the Role of Depression in End of Life Decisions . . .

This year, the FBN Annual Meeting takes on new and even more important topics that we, in health care, face daily. Come and hear how your colleagues in the state handle these issues and others. Share with them your thoughts and ideas on these and other important ethical problems. This is the only meeting in the state of Florida where we can share information on important ethical problems in health care and not only take home new information, but be proactive.

For more information, call the FHA Meetings Department at 407/841-6230.

ETHICS CASE ANALYSIS

Submitted by **James T. Wagner, Ph.D.,**
Patient and Family Resource Counselor,
Gainesville.

Case Presentation:

Ms. G is a 47 year old white female admitted to the hospital due to complications from renal failure. In her mid-teens she began dialysis and in her early thirties received a kidney transplant. Her mother was the donor.

Six months prior to this hospitalization, Ms. G completed a "Living Will" type advance directive. Her specific instructions indicated she did not want her dying to be prolonged and she refused the artificial provision of food and nutrition. If unable to communicate, she did not want to be on a respirator.

The content of her Living Will was based on an earlier family experience with death. In Ms. G's opinion, her aunt suffered unnecessarily because her mother insisted that treatments be continued even after the physician indicated there was no benefit. This influenced Ms. G to appoint her aunt as her Living Will Surrogate. She wanted to protect other family members from these difficult decisions, particularly her 22 year old daughter. She wanted to protect herself from her mother.

At the present time, Ms. G has been an inpatient for six weeks. Fifteen days ago, she was moved to SICU following an a/k amputation of her right leg due to vascular problems. She has been comatose since the surgery, on a respirator, and is being provided nutrition/hydration artificially. She has multi-system organ failure and is septic. The toes on her left foot are turning black. The use of peritoneal dialysis is being discussed as well as surgery on her left leg.

Concerns Prompting Ethics Consult:

The SICU nursing staff believed that the wishes of the patient, as outlined in her Living Will, were not being respected. They communicated this concern through their supervisor to the patient's attending physician. The hospital ethics consultation team received a referral to assist in resolving this conflict.

The Ethics Consult Process:

The two-member team began by meeting with the attending physician and her staff to clarify the patient's diagnosis, treatment plan, and prognosis. The physicians were unanimous on several issues. The patient's condition was terminal. This had not been charted nor communicated to the patient's surrogate or family. Second they felt the surgery to amputate the right leg had a poor outcome and had probably contributed to the patient's current condition.

The one distinction among the physician team was that the attending physician used a very narrow definition of "terminal" and was known among nurses in particular, for never "giving up" on a patient. Although she agreed the patient was terminal, she expressed two concerns about the withholding/withdrawing (w/w) of any treatment. One related to her belief that w/w might interfere with a miracle. The second concern was a generalized fear of legal risk associated with any decision to w/w.

Family members were interviewed individually because they visited the patient separately or not in a group. The aunt-surrogate, the 22 year old daughter, and mother were all in agreement as to the treatment preferences of the patient if she were terminally ill. The patient had been careful to speak with each of them about her Living Will, including why she appointed the aunt as surrogate.

The mother refused to believe the patient was terminally ill. And, no one had told her anything to the contrary. She had seen her daughter recover from serious illness before and felt she would recover this time as well. She insisted that the attending physician continue to "do everything" and hinted that she would take legal action if her wishes were not followed.

The aunt-surrogate and daughter were not surprised by the position taken by the patient's mother. Each was of the opinion that the patient was probably dying. And, if this were true, each was prepared to support the wishes of the patient. However, neither the aunt-surrogate nor the daughter had been told that the patient was terminally ill. The aunt-surrogate said, "I'm not going to ask the physicians. They'll tell me when she is dying. After all, when the patient dies, I still have to live with my sister [the patient's mother]."

Other providers, such as nursing, pastoral care, and social work reported the same information found by the consult team regarding the positions of family members. Nursing staff on the unit where the patient was treated prior to surgery indicated the patient's views were accurately reflected in her Living Will.

Ethical Issues Identified:

1. Is the patient terminally ill?
2. Are we confident that the patient's preferences for treatment as expressed in her Living Will accurately reflect her wishes?
3. Are providers honoring the patient's autonomy?
4. Who is the appropriate decision-maker?

Discussion of Issues and Advisory Recommendations:

In this case, the clarification of whether or not the patient is terminally ill is crucial. The attending physician's private acknowledgement that the patient is terminal, but reluctance to chart that diagnosis or communicate with the family must be resolved. Her reluctance to do so is understood through several issues. She feels somewhat responsible for the patient's terminal condition because of the outcome of surgery. Second, she uses a very narrow definition of what it means to be "terminally ill," which is related to her religious faith in miracles. The patient's mother hinting at legal action also engages her generalized legal fears about w/w.

Ethically, however, especially in this case, none of these perspectives warrants the medical team sidestepping an acknowledgement of the patient being terminal. To do so violates several important values. First, it would be a paternalistic act, overriding the patient's autonomy, which cannot be justified. Second, it would be a violation of the physician's professional integrity. Some concerns of this attending physician are common. The challenges each poses must be successfully resolved or they will interfere with the physician-patient relationship. Some discussion of these issues may help.

There may be types of conditions patients bring to surgery where the results of surgery, particularly a poor outcome, are independent of the diagnosed condition. The surgeon may appropriately or inappropriately feel responsible. As a result, he may feel an obligation to continue treatment in the hope that a poor surgical outcome can be reversed, or not easily give in to it being the cause of death.

However, if this is the philosophy of the surgeon, it would be appropriate to discuss this with a patient as part of the pre-surgical informed consent process. This obligation carries greater weight with a patient like Ms. G, given her health history, her Living Will, and her serious condition going into surgery. It is no longer defensible for a surgeon to assume that an advance directive is automatically cancelled because a patient is going into surgery. If the surgeon desires that a

directive be cancelled, then it must occur through informed consent.

The problems which may result from the lack of a uniform definition of terms, including "terminal illness," are well documented in the literature. The findings indicate that a patient must understand specifically what a physician means or be vulnerable to either over or under-treatment. The nursing staff is arguing that the patient has already received burdensome over-treatment. Despite the attending's use of a very narrow definition, she has now determined the patient to be terminally ill. The reluctance to acknowledge this to the family seems to rest primarily with other concerns.

The religious group to which the attending physician belongs has very clear teachings about the reponsibility of health care providers in end-of-life situations. While it specifically prohibits active euthanasia, it supports the w/w of treatments when the patient is dying. Miracle hopes are acknowledged as always being valid. But these hopes do not justify or support the continued provision of burdensome treatments when medicine has determined the patient to be at end-of-life. The physician's faith, in this area, has become idiosyncratic and is an imposition on the physician-patient relationship, regardless of how well-intentioned the beliefs.

In this type of case, particularly where a hint of legal threat exists, the ethics consult team usually advises the physician to also seek a legal consultation. Legally, the key is to answer whether or not the patient is terminally ill. If she is, then the Living Will is in effect and the aunt-surrogate is the decision-maker. If the patient is not terminally ill, the 22 year old daughter is probably the decision-maker. If it was the patient's intent to shield the daughter from all decisions, then it might be argued that the aunt-surrogate's authority is broader than just end-of-life decisions. Regardless of the patient's condition, it should be the physician who takes the intitative to communicate with the patient's family or clarify these issues.

In either case, the patient's mother has no legal or ethical responsibility for decision-making. Providers and family should be appropriately sensitive to her. She undoubtedly loves her daughter and has stood by her many challenges, in addition to her wonderful gift of a kidney. It is understandable that she wants her daughter to live. Her concerns, however, do not warrant the physician overriding the preferences of the patient.

There have been very few consultations done by the ethics team where there was more clarity or agreement on our understanding of the patient's treatment preferences at end-of-life. It is hard to imagine a patient being more thoughtful in preparing a directive, accurate in uderstanding her family, or thorough in communicating with all family members. No reason is found to questions the patient's treatment preferences as expressed in her Living Will.

If Ms. G is terminally ill, then the appropriate decision-maker is the aunt-surrogate. This aunt appears ready to behave as an appropriate surrogate by representing the preferences of the patient as expressed in the Living Will. She is waiting for physician direction. If Ms. G is not terminally ill, then the appropriate decision-maker is the 22 year old daughter.

Summary Comments:

This case is an example which almost every hospital has experienced. At end-of-life, there are many hands played which come together to shape the course followed. The best scenario is when there is an absence of conflict and all hands are in agreement about which actions should be taken. This is the kind of scenario where advance directives are most successful.

The responsibility for this success rests with everyone. The patient must be clear about treatment preferences. Loved ones must understand and respect the patient's autonomy, even if personal wishes differ. Providers must make reasonable efforts to understand the patient's wishes, document them, and be prepared to act in accordance.

The facts of this case could be changed slightly and the advisory recommendations of the ethics consult team would differ. For example, what if the patient had put nothing in writing and none of the providers had an opportunity to speak with her about her Living Will. If disagreement existed between family members about what the patient wanted, it would have been paralyzing to advise with any clarity.

As is, this case is a paradigm of the courage a hospital must find to act responsibly on behalf of a patient whose wishes are clear. It is an example of how an ethics consultation and a legal consultation must find common ground on which to stand. In this case, it is indefensible to do anything other than stand on the ground of respect for the autonomy of the patient.

COLLEGE OF CHAPLAINS GUIDELINES FOR THE CHAPLAIN'S ROLE IN BIOETHICS CONSULTATION

Submitted by **Rev. Jerry J. Griffin, Th.M., BCC,** Director of Pastoral Care, Lee Memorial Hospital, Fort Myers.

In March of 1992, the College of Chaplains, Inc., issued *Guidelines for the Chaplain's Role in Bioethics*. This document outlined seven principles that should be integral to any health care institution's bioethical reflection process. These Principles are:

- The health care institution will include a certified chaplain on its Bioethics Committee.
- Chaplains will develop a continuing educational plan both for themselves and their colleagues, in bioethical principles as they relate to the spiritual, religious, cultural, and philosophical values represented in the persons served by their health care institution's educational program.
- Chaplains will participate in the bioethics consultation services of the facility.
- Chaplains will participate in assisting the institution in reviewing and recommending policies having bioethical implications in the services provided by the facility.
- Chaplains will provide pastoral care to those involved in the bioethical reflection process.
- Chaplains will provide specific evaluation of the process of bioethical reflection from a "spiritual perspective" as well as from a clinical perspective.
- Chaplains will provide for alternative coverage of the chaplain's role in the bioethical reflection process when it is appropriate for the chaplain usually designated to contribute to the process to exclude her/himself.

The College also issued *Bioethics Consultation Guidelines for Chaplains* in February of 1993 which included the following:

- Chaplains are the consistent contact with the patient and the family throughout the consultation.
- Chaplains assist in the group process as needed.
- Chaplains clarify specific theological beliefs and values which effect ethical decision making.
- Chaplains provide pastoral care to those involved in bioethics consultation.
- Chaplains provide professional and collegial liaison with the patient's own clergy person.
- Chaplains strive to understand how the bioethics process accomplishes each of these pur poses and how it views its role in the life of the institution.
- The chaplain seeks continuing education in health care ethics and ethical consultation in order to achieve a working knowledge of basic principles, ethical decision-making, current issues, and developing trends. This can be accomplished by attending seminars, subscribing to journals, and becoming a member of a bioethics organization/network.

These guidelines can offer information and assitance to institutions and to clergy in the bioethics process.

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ESSENTIAL READINGS #7

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

Institutional Ethics; Managed Care (2):

Barr, Donald A. The Effects of Organizational Structure on Primary Care Outcomes Under Managed Care. Annals of Internal Medicine 122 (5): 353-59, 1 March 1995.

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Scott, Robert A. et al. Organizational Aspects of Caring. Milbank Quarterly 73 (1): 77-95, 1995.

Gold, Marsha R. et al. A National Survey of the Arrangements Managed-Care Plans Make with Physicians. New England Journal of Medicine 335 (25): 1678-83, 21 December 1995.

Kassirer, Jerome P. Managed Care and the Morality of the Marketplace. New England Journal of Medicine 333 (1): 50-2, 6 July 1995.

Chervenak, Frank A. et al. The Threat of the New Managed Practice of Medicine to Patient's Autonomy. Journal of Clinical Ethics 6 (4): 320-23, Winter 1995.

Managed Care. Trends in Health Care, Law & Ethics 10 (1/2) [Special Issue], Winter/Spring 1995. 143 p.

Swartz, K. et al. Integrated Health Care, Capitated Payment, and Quality: The Role of Regulation. Annals of Internal Medicine 1996; 9: 442-48.

MEETINGS OF INTEREST

National Meetings:

☆ October 31, 1996

ICU Care at the End of Life: Ethics & Practice; Hyatt Regency Hotel in Minneapolis; Sponsored by the Center for Biomedical Ethics, University of Minnesota; For further information call 612/626-9756; Fax: 612/626-9786; or E-mail: holmboo6@maroon.tc.umn.edu.

☆ November 1 & 2, 1996

End of Life Health Care in Managed Care Systems; Hyatt Regency Hotel in Minneapolis; Sponsored by the Center for Biomedical Ethics, University of Minnesota; For further information call 612/626-9756; Fax: 612/626-9786; or E-mail: holmboo6@maroon.tc.umn.edu.

Welcome New Members!

The Florida Bioethics Network welcomes **Timothy Arsenault,** Regional Program Director, The Hospice of the Florida Suncoast, Largo -- 813/586-4432 x2710; **Robert Carlson,** Chaplain/Director of Patient Advocacy, Columbia Fawcett Memorial Hospital, Port Charlotte -- 941/629-1181; **Barbara Graeber,** Miami -- 305/256-5228; **Kathi Hansberry,** RN Consultant, Department of Corrections, Tallahassee -- 904/487-3353; **Janet Jones,** President & CEO, Catholic Hospice, Inc., Miami Lakes -- 305/822-2380; **Nicholas McLoughlin,** Columbia Fawcett Memorial Hospital, Port Charlotte -- 941/625-4754; **Larke Nunn,** Risk Manager/ Safety Director, Orange Park Medical Center, Orange Park -- 904/276-8628; and **Kathryn Ward-Presson,** Vice President/ Patient Services, Columbia Fawcett Memorial Hospital, Port Charlotte -- 941/627-6170.