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

June 17, 1996 **96-3**

PRESIDENT'S MESSAGE

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

The 1996 legislative session has ended with no revisions to the Florida Statute on Health Care Advance Directives, Chapter 765. There were, however, other bills that were passed which may be of special interest to the FBN readership.

The FHA summarized the 1996 session in its May 6, 1996, *Legisletter*. The following are a few excerpts from *Legisletter* of these particularly significant legislative changes.

1. HMOs, including Medicaid and MediPass, are prohibited from requiring prior authorization for emergency care (SB 910 & 886).

2. Nearly all Medicaid recipients will be enrolled in a managed care plan by January 1, 1997 (SB 886).

3. A health care surrogate may be appointed guardian advocate for the Baker Acted patient (SB 903).

4. HMOs will provide future enrollees with written information about the terms of the contract to allow for informed decision making (SB 910).

5. Maternity length of stay is to be determined by the attending physician according to medical necessity (SB 1860).

6. HRS may require name reporting of HIV infection by physicians and laboratories, like any other sexually transmissible disease (SB 474).

The FBN annual meeting will be held October 23-25, 1996, in Ft. Lauderdale. An update on laws and regulations will be presented as well as a wide variety of clinical and risk management issues. More information about the annual conference will be distributed to you over the next few months.

ETHICS CASE ANALYSIS

Submitted by **Mervin H. Needell, MD, MA,** Medical Director, Forum for Bioethics and Philosophy, University of Miami, Miami.

Dr. D.A. is a 70-year old cardiologist, now a nursing home resident, who was admitted several months ago following acute care for cerebral hemorrhage with left hemiplegia. He is now blind and severely mentally impaired. He is married to a second wife who is 20 years his junior.

Because his wife despaired of any reasonable hope for her husband's improvement, she requested that nutrition and hydration be discontinued. In asking the facility to withhold food, Mrs. A. said, "You should have known him before! He was such a vital man. Now look at him! What kind of life is this for him? The only reason he is still alive is because you keep feeding him. I want you to stop." However, the facility's staff refused, arguing that the patient had a normal food intake and unmistakably enjoyed eating. One RN noted that "he seems to attach an extraordinary importance to food, even on some kind of symbolic level. It's just real important to him and he spends most of the day asking for something to eat." After consultation with administration, the Head Nurse informed Mrs. A. that the facility would not comply with her wishes. Mrs. A. then demanded her husband's discharge to her care at home. Administration then informed Mrs. A. that she has a legal right to withdraw Dr. A. from the facility, but under the circumstances the facility would feel legally and morally obligated to report the case to HRS for follow-up. At this point, Mrs. A dropped her demand that the facility withhold food from Dr. A. and she made no further reference to withdrawing him from the facility.

After a few weeks, Dr. A. developed dysphagia, with choking upon any attempt to swallow. The attending physician then recommended either a nasogastric feeding tube or a PEG (feeding gastrostomy). Mrs. A. replied, "No tubes and no surgery. Absolutely not! Now maybe you'll let him die in peace." The doctor explained to her that Dr. A. was not terminally ill and that the swallowing problem may subside. But Mrs. A. remained adamant in her refusal. The nursing staff sided with the doctor, particularly because Dr. A. seemed to place so much importance on food.

Primary ethical issue:
Should Dr. A.'s nutrition be withheld or *not* be withheld?

Other ethical issues:

- May a surrogate medical decision maker ethically decide to decline life-preserving treatment for an incompetent patient who is not terminally ill?
- Of what ethical importance is patient's religion in this case?
- What weight should be given to an incompetent patient's apparent desire for a particular kind of care (such as food, in this case)?
- What action should a medical facility take when a patient (or surrogate) violates its ethical integrity by demanding or refusing some particular kind of care?

Analysis:
Making an ethical judgment that the institution's staff should uphold or deny Mrs. A.'s request to withhold Dr. A.'s nutrition requires that we evaluate whether or not the action she demands is (1) ethically permissible, and (2) consistent with valid surrogate decision-making criteria. In requesting that nutrition be denied, Mrs. A. intends Dr. A.'s imminent death. In denying nutrition to Dr. A., the staff also would intend his imminent death. Let us consider (1) and (2)

separately and then consider other relevant issues before making an ethical judgment on withholding nutrition to Dr. A.

Is withholding nutrition an ethically acceptable act?
Aside from some special exceptions such as war, self-defense, and capital punishment, most of us would judge that a deliberate act of killing another person is ethically impermissible. In the case of Dr. A., although the proposed decision is deliberate, it is not an act but a failure to act which would result in Dr. A.'s death. Some people do not make an ethical distinction between killing and letting die when the means to prevent death are available without incurring undue personal risk. They might judge that withholding nutrition in this case is ethically impermissible, because the means to prevent death through medical (artificial) administration of nutrition are available. Those who do make such a distinction (including common law) might find this distinction an opportunity to exercise humane judgement in allowing death, which would not otherwise ethically be available. They also would require plausible reasons to withhold nutrition. In this case, Mrs. A. seems to have argued that her husband has lost a critical dignity and quality of life. We may then weigh the merits of continued existence lacking critical quality vs. death. Thus the act of withholding nutrition would always be considered unethical to some, but could be acceptable to others for humane reasons.

Is withholding nutrition a valid surrogate option?
Surrogates cannot ethically make medical decisions arbitrarily. They must first be selected as appropriate decision makers for a particular patient and they must follow accepted cultural guidelines. Because of mental incapacity, Dr. A. needs a surrogate to protect his interests. Mrs. A. seems to be the unchallenged surrogate for her husband. Provided that we have no reason to suspect her of acting with ill-will in this case, I, also, do not challenge her right to serve as her husband's surrogate. In making a decision to discontinue nutrition, Mrs. A. should act with the patient's interests foremost. The fact that she is a second wife and is much younger than her spouse might arouse suspicion that she would want him out of the way for selfish reasons, but these facts alone do not seem to be sufficient grounds to raise an objection.

The most compelling criterion for surrogate decision making is the subjective standard; that is a decision that the patient himself/herself has made by written or oral advance directive. This information is not available in the case of Dr. A. Next to the subjective standard in ethical validity is the substituted judgment standard; this term refers to the decision that the patient would have made under the present conditions, had he/she but addressed the issue. In the case of Dr. A., we would have to decide whether or not Mrs. A. really knows clearly and convincingly what decision regarding withholding of nutrition her husband would make for himself at this time. That is, if the patient could express his wishes, would he prefer death to his present loss of dignity? If so, would he refuse nutrition? If we think that she does know, then we would accept the ethical validity of that decision as regards respect for the patient's autonomy. Finally, if a surrogate does not reliably know how the patient would choose under the circumstances, then he/she can do no better than to fall back on the least ethically reliable criterion; i.e., the best interests or alternatively, the reasonable person standard. Mrs. A. would then have to decide what action would serve her husband's best interests, or alternatively what choice a theoretical reasonable person would make under these circumstances. Notice that the wife's decision ethically must still be based on her husband's interests, not her own. Therefore, valid surrogate decision-making in this case would depend upon how much Mrs. A. really knows about her husband's wishes either by his advance directive or her trustworthy inference, or else by disinterested judgment.

Other relevant issues

Other ethical issues may influence these deliberations. However, reluctantly, we may respect the wish of a rational patient to refuse treatment, even if it puts an end to his/her own life. But can we ethically accept a decision of someone to end another person's life? Does the surrogate have any ethical prerogative to act or refrain from acting with the intention to cause the death of the very person he/she has been entrusted to protect? If the patient is going to die soon regardless of medical intervention, then the decision to withhold nutrition seems almost moot. And if the surrogate's decision merely echoes the desire of the patient to die under the circumstances, then the patient's autonomy will have been protected by withholding nutrition. Thus, we can honor Mrs. A.'s decision if it is based on a valid advance directive or substituted judgment. We would be less certain of the ethical propriety of Mrs. A.'s decision to let Dr. A. die if it were based solely on her view that her husband's dignity or life quality is not good enough to justify preserving his life.

What role does religion have in ethical decision making?

Dr. A.'s Jewish background might help in inferring his preference regarding preservation of his life if indeed he was known to have followed the doctrines of his religion. Uncertainty about the religious rules should be clarified by the patient's rabbi. Orthodox Jews place a high priority on life, regardless of quality, and would likely find ethically unacceptable any failure to preserve a viable life. Thus, if Dr. A. had been an orthodox Jew we would expect that he would insist upon continuation of nutrition, either by artificial or natural means. However, a Jew of reform persuasion, while holding a reverence for human life similar to that of the orthodoxy, would most likely hold that nutrition must be offered to but not forced upon an individual. Thus, if Dr. A. were a practicing reform Jew we would expect him to want to continue nutrition at least until he can no longer swallow and retain it. Any logical distinction between taking of sustenance and administration of medicine tends to disappear when nutrition must be forced into the body by non-natural means. Therefore, as a reform Jew, Dr. A. would probably feel ethically obligated to accept artificial means of nutrition until survival itself became intolerable to him, at which time he might consider refusal of artificial sustenance. Nevertheless, Dr. A's apparent desire to eat at this time makes withdrawal of nutrition seem contrary to his autonomous wishes. The fact that he is mentally incompetent to make rational medical decisions does not negate his ability to make non-rational decisions, such as to satisfy his appetite. Thus we have presumptive evidence that he does not wish nutrition to be withheld. We do not yet know how he would react to artificial nutritional intake, but I think that, when the time comes, a trial of artificial feeding could be illuminating to his surrogate decision maker.

What role ought the medical facility have in the decision?

The final concern in this case that I wish to address is the role of a medical facility which finds itself ethically opposed to providing some particular medical procedure. Assuming that the institution has already promulgated its rules and principles publicly, particularly among its staff and its patients, it does have a right to protect its integrity. No individual or group should be forced to do anything that it believes ethically wrong. In this case it should (and did) allow Dr. A.'s discharge. However, I do question the condition it placed on Dr. A.'s discharge, via., making a report to HRS. Was the message delivered to Mrs. A. in an innocent and factually informative way, intending only to apprise her of customary rules? Or did the institution intend to intimidate Mrs. A. for the purpose of having the institution's values prevail over hers; i.e., did the institution imply that the law would inflict some harm on her if she failed to maintain her husband's nutrition? If so, this condition of discharge would clearly be coercion, and therefore unethical. In resolution of a conflict between a medical institution and its patient and surrogate, I would expect each party to the controversy to try to accommodate the other's position and to search for a

mutually acceptable middle ground. I do not mean that anyone should violate his/her own integrity, but by taking the broadest view possible one can often modify one's position without ethical contradiction. In this case, Mrs. A. was willing to inconvenience her husband and herself by moving him out of the facility rather than insisting on having a procedure which was repugnant to that facility. On the other side, the medical facility might deem (by utilitarian calculus) that forcing its will on Mrs. A.'s decision making would do more harm to the A.s and to goodwill in the community than the good produced by force feeding a patient doomed to live his last few months in a mental stupor. Or (by deontologic calculus) that its obligation is to serve the best interests of its patients, which includes respecting their right to autonomously refuse treatment (here, by valid proxy) rather than impose its own rules on unwilling patients. Of course, the institution may decide that it cannot allow any act which would intend the death of a human being, and so withdrawal of nutrition would always compromise its ethical integrity. In that case, its only ethical recourse would be to acknowledge the right of others to hold contrary beliefs and allow Dr. A.'s discharge without undue interference.

Conclusion

Ethical certainty in any judgment varies directly with knowledge of the facts of an ethical dispute (including values of all relevant participants) and the ethical guidelines which apply to these facts. In the case of Dr. A., an ethics consultant would want to know the answers to several factual questions not given in the case history but indicated in the discussion above, before coming to an ethical conclusion. However, just pointing out the reasons for asking these questions may enable the participants to resolve the dispute amicably and equitably, independent of the consultants judgment. Given only the facts presented, I would want to respect the decision of Mrs. A. to withhold nutrition and allow Dr. A. to die, either as a resident of the nursing home with its permission, or else at home in the care of Mrs. A. If required by law, I would notify HRS.

ESSENTIAL READINGS #6

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

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Update From The American Geriatrics Society Conference

Submitted by **Catherine P. Emmett, RN, MSN**, Manager, Gerontology, Sarasota Memorial Hospital, Sarasota, Florida

I had the opportunity to attend the 1996 Annual Meeting of the American Geriatrics Society held in Chicago, May 1-5 of this year. Two sessions were of interest to those of us involved in Bioethics. The first was a paper session by G.A. Sachs, MD on **Communication with Physicians About Advance Directives.** The purpose of the study presented was to determine the extent to which patients involve their physicians in advance directive planning, both around the execution of an advance directive (AD) and subsequently. Out of the 218 patients with ADs, only 6 stated that they had talked with their physician prior to executing the document. Thirty-five percent reported talking with their physician about their AD and 28% had given their physician a copy of the AD. Patients were re-interviewed two years later. At that time, 57% still had not talked with their physician about their AD. The most frequently cited reason for not discussing AD with physicians was that the patient expected family to talk with the physician. In discussing this study, Dr. Sachs also discussed the fact that very few patients reported that the physician initiated any discussion about ADs.

The second session was on Palliative Care. Christine Cassel, MD discussed the American Board of Internal Medicine's Patient Care at the End of Life Project. The results of this project are contained in two publications. The first, **Caring for the Dying: Identification and Promotion of Physician Competency-Educational Resource Document** was developed primarily for program directors and faculty to use within the educational environment of residency and subspecialty training. It is the project's core work and is a companion to the second publication, Caring for the Dying: **Identification and Promotion of Physician Competency-Personal Narratives.** This document contains a collection of personal stories contributed by physicians and contains moving examples of the rewards of caring for patients at the end of life. Both volumes would be of value for those concerned with end of life issues and palliative care. For copies and/or information, contact Linda L. Blank, Vice President for Clinical Competence and Communication at 215-243-1567 or 215-382-4702 (fax) or through the ABIM Web site-http://www.abim.org.

Call For Nominations

FBN is preparing its slate of officers for the upcoming election. Positions up for nominations are:

President-Elect
Treasurer
Member-At-Large Representative
Secretary
Central Representative

If anyone is interested in submitting a nomination, please contact **Dr. Kathryn Koch** at 904/549-4075 by July 8, 1996.

MEETING CALENDAR

Regional Meetings

- **August 23-25, 1996:** *Ethical Issues in the Care of Incompetent Patients*; Rolling Hills Hotel & Golf Resort, Ft. Lauderdale, FL; Contact: Dr. Jos V.M. Welie, CEREC Center, P.O. Box 292932, Ft. Lauderdale, FL 33329. Tel./Fax: 305/424-9304. E-mail: jewlie@bcfreenet.seflin.lib.fl.us.

National Meetings

- **June 21-22, 1996:** *Care Near the End of Life*; Cambridge, MA; Call 617/432-1525 for further information.

- **July 14-19, 1996:** *Midwest Intensive Bioethics Course*; Sponsored by: Center for Biomedical Ethics, University of Minnesota; Center for the Study of Bioethics, Medical College of Wisconsin; and Program in Medical Ethics, University of Wisconsin, Madison; Riverwood Conference Center, Monticello, MN; For information and registration materials, contact: Center for Biomedical Ethics, University of Minnesota, Suite 110, 2221 University Avenue SE, Minneapolis, MN 55414. Telephone: 612/626-9756/Fax 612/626-9786 or E-mail at holmb006@maroon.tc.umn.edu.

WELCOME NEW MEMBERS!

Dr. Clifton Ford, Chaplain, Pastoral Care, North Bay Medical Center, New Port Richey; **Ruth Gent**, Chief Operating Officer, Hospice Care of Broward Co., Inc., Ft. Lauderdale; **Amanda Goff**, Director, Medical Social Work, Lee Memorial Health System, Ft. Myers; **Myra Hancock**, Member-Ethics Resource Committee, Arnold Palmer Hospital for Children & Women, Orlando; **Alfred Mazat**, Chaplain, Hospice of Central Florida, Palatka; and **Neil Ozer**, Chairman of Ethics Committee, Palm Beach Gardens Medical Center, Palm Beach Gardens