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

April 1998 **98-2**

Message From the President

Ken Goodman, PhD, Forum for Bioethics, University of Miami

Business Ethics for Bioethics Committees

Health care ethics committees customarily focus their attention on issues that touch directly on the practices of physicians, nurses, and social workers. No surprise there -- that is the tradition, and overwhelmingly these issues are (at least apparently) the greatest daily source of confusion, conflict, and moral challenge. It is becoming clear, though, that such emphasis is no longer adequate.

Motivated in part by the growth of managed care and the expansion of for-profit institutions, as well as by evolving standards of the Joint Commission for the Accreditation of Health Care Organizations, bioethics committees are increasingly finding themselves needing to address issues that fall outside their traditional bailiwick. In fact, the requirements of business ethics may lie outside the competence of many or most bioethics committees and their members.

What does this mean for ethics committees? Most simply and practically, it means that bioethics committee members need to learn some business ethics in addition to bioethics.

What I want to do here is outline a number of issues in business ethics that arise in health care institutions, and offer a few suggestions for educational activities.

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In This Issue

Patient Rights and Organization Ethics

Submitted by Hana Osman, LCSW, DCSW, Tampa General Hospital

In the JCAHO chapter on Patient Rights and Organizational Ethics, Standards RI.1 through RI.4.4 address four major areas: patient and family decision making, patients' rights related to research activities, communication, and policies and procedures related to organizational ethics.

This article will focus on standard RI.1.2.4: The hospital addresses advance directives, which states, "The hospital determines whether a patient has or wishes to make advance directives. The hospital also ensures that health care professionals and designated representatives honor the directives within the limits of the law and the organization's mission, philosophy, and capabilities. For example, if a patient elects to donate organs at the end of life, the organization must have a process to honor that directive. In the absence of the actual advance directive, the substance of the directive is documented in the patient's medical record. The lack of advance directives does not hamper access to care. The hospital, however, provides assistance to patients who do not have an advance directive but wish to formulate one."

To comply with the Patient Self-Determination Act of 1990, competent adult patients who do not have advance directives in the form of a living will or by designating another person to make medical decisions, and who wish to formulate directives, are assisted by trained hospital personnel.

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Business Ethics

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Issues in business ethics

There are a number of ways to categorize the business ethics issues that arise in health care settings. These issues have links to issues in bioethics in a number of ways, although some of these might be quite indirect. For our purposes we can group them under the following headings: conflicts of interest, public communication, and contracts and staffing.

Conflicts of interest: It is a commonplace belief -- often expressed as a platitude -- that health care professionals owe their greatest allegiance to their patients. Does the same hold true for hospitals, nursing homes, and hospices? That is, does a hospital, for instance, have primary obligations to patients? If so, how should these obligations be balanced against duties to taxpayers (who help support Medicare and Medicaid), staff members (who depend on the institution for their livelihoods), and, in the case of for-profit institutions, to investors and shareholders?

Conflicts arise when an individual or institution has competing interests, as between the interest in making money for personal use and the interest in making sound institutional or professional decisions. So if someone stands to receive a salary bonus or promotion by contributing to institutional cost-cutting, and simultaneously has authority over purchasing decisions (as for the pharmacy formulary), then we should be on the lookout for a possible conflict of interest. If this person adds or drops a drug from the formulary, this can have major consequences for prescribing decisions in the institution. Now it might be that our purchaser might not allow his or her personal interest to influence a professional decision -- she might have dropped that expensive drug anyway -- but the fact that there is the *appearance* of a conflict can be just as erosive of trust and credibility as an actual conflict.

Other examples may be found in the context of gift-giving, as from pharmaceutical companies; in capitation agreements under which individuals are reimbursed or rewarded for decisions that might conflict with clinical judgment; and, for institutions that conduct research, in the tension between duties to patients and the goals of human-subject research (note also the challenges posed by corporate sponsorship of clinical research).

Public communication: It is a rare hospital that does not have a public relations department, or at least someone who has responsibility for conveying, repairing or burnishing the institutional image. While we seem to be stuck with the unhappy phenomenon of health care institutions engaged in competitive marketing in newspapers, billboards and direct mailings, it is still fair to ask whether such efforts promote exaggeration over information.

Are "free screenings" a tool to promote public health or an effort to generate referrals? Does the institutional web site provide useful information or engage in corporate arm waving? Recall that the point here and throughout is to urge that ethics committees become more familiar with these issues and make them a part of their educational programs ... but how many members of the ethics committee have taken note of the advertisements or scrutinized the web pages?

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Business Ethics

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Further: What are the institutional policies for dealing with the news media? How much information is given to journalists interested in the fate of a newsworthy patient? How strong are the temptations to play fast and loose with patient confidentiality when presented with an opportunity for favorable publicity?

Contracts and staffing: Balancing high quality patient care with marketplace realities is one of the greatest challenges facing hospital administrators. Like it or not, hospitals are businesses and so should be run professionally. This requires difficult decisions in resource allocation, staffing, and vendor and provider relations.

If the nursing staff is reduced as a cost-saving measure, is this also impeding patient care? What is the evidence for answers to questions like this? Are there links (perhaps tacit) between staff privileges for physicians and referral volume? Are profits used to improve patient care?

It should go without saying that billing practices should be motivated by a commitment to accuracy and open to public scrutiny, but it is too often the case that hospital budgets are "black boxes" that resist analysis and oversight. Indeed, openness is a balm for the ethically perplexed; institutions and individuals that fear disclosure of deals, agreements and contracts should infer that their anxiety is grist for the mill of those who would include business ethics in the bioethics curriculum.

Educational opportunities

Here are some ideas for activities that ethics committees might undertake as a start in efforts to address business ethics.

First, in looking at (potential) conflicts of interest, committees should familiarize themselves with that part of the business ethics literature that examines conflicts and the appearance of conflicts. These are old problems (even if they are new to bioethics committees) and a number of helpful resources are available. Also consider inviting the director of purchasing to describe how his or her department handles conflicts and whether there is a policy to address them.

When it comes to communication, committees should take a look at how the institution markets itself, and whether public relations activities are truthful and tasteful. A visit from someone in the marketing office -- perhaps even a meeting with the local papers' or TV stations' health reporters -- can provide precious educational opportunities.

Contracts and staffing? How about a review of current staffing contracts and the algorithms used to determine optimal coverage? Surely in this day and age a bioethics committee should consider familiarizing itself with managed care contracts. Indeed, a presentation by an HMO medical director or business manager can provide valuable information and insight.

All these activities can be undertaken for the ethics committee and the entire staff. Many visitors would welcome the opportunity to share information and perspectives with their partners in the business of health care. This is good news, in part because it is the emerging responsibility of ethics committees to take an educated and proactive approach to making business issues a fixture in the bioethics firmament.

JCAHO Standards

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Patients who have advance directives and are able to make copies available to the hospital need to do so. Many individuals however, have formulated advance directives but have not made copies available for the medical record. Hospital policies and procedures need to be in place to address these individuals' situation. Since it is clear that these patients have expressed their wishes in written form, and the documents are not available with the patient during the admission process, JCAHO expects the admitting nurse or physician to:

> "First, make arrangements to immediately obtain a copy of the existing advance directive. Second, offer the patient assistance in completing a new written advance directive. Third, inform the patient that he or she may verbalize treatment preferences. That is, the patient may explain the 'substance' of his or her wishes concerning a minimum quality of life. If a patient chooses to verbalize treatment choices the hospital designee documents the conversation in the patient's medical record. At any point the patient may clarify, modify, or revoke the directives. Such conversations should be documented in the patient's medical record, and the patient's physician should be informed. It should be noted however, that obtaining of a verbal description of a written existing advance directive is not necessarily the same, under any applicable law, as possession by the hospital of the actual document."

A word of caution. Every effort to get a copy of the actual advance directive should be made (first option). Many patients expend much money and effort in formulating their advance directive. By "completing a new written advance directive" (second option) the patient nullifies the original, well thought out (hopefully!) document. In addition, the patient may not remember all the intricate and perhaps very important and meaningful details that are included in the original document. Simply getting the "substance" of the original directive documented in the medical record (third option) may trivialize the original document.

Although patients have the right to change their minds about the content of any advance directive, the substance of the directive which was formulated when the patient was not under the pressure of hospital admission, may more accurately reflect the patient's true wishes about health care decision making. Therefore, obtaining a copy is clearly the better choice of the three stated options.

Finally, the standard addresses the patient who does not wish to make a verbal or written advance directive and "this decision is noted in the patient's medical record." The standard states that "the lack of advance directives does not hamper access to care."

JCAHO, Patient Rights and Organization Ethics, CAMH Update 3, August 1997.

Journal Review

Submitted by Cathy Emmett, ARNP, CS, Sarasota Memorial Hospital

In October 1996, the American Geriatrics Society and the Hastings Center convened a Congress of Clinical Societies to address the ethical issues raised by the advent of managed care. The results of this conference are presented in the March 1998 issue of the Journal of the American Geriatrics Society. Joseph J. Fins, MD, from the New York Hospital-Cornell University Medical College and the Hastings Center served as Special Editor for the Ethics in Managed Care Series. The papers include:

- The Ethics of Managed Care: Report on a Congress of Clinical Societies
- Managed Care: The Third Reorganization of Health Care
- The Future of the Doctor-Patient Relationship
- Capitated Risk-Bearing Managed Care Systems Could Improve End-of-Life Care
- Revenue Streams and Clinical Discretion
- Conflicts of Interest and Accountability in Managed Care: The Aging of Medical Ethics
- When the Benefit Is in Doubt, Who Decides
- Drug Benefits in Managed Care: Seeking Ethical Guidance from the Formulary
- Closure, Fair Procedures, and Setting Limits Within Managed Care Organizations
- Letting the Patient Backstage: Informed Consent for HMO Enrollees
- Mediation and Managed Care
- A Medical Trust Fund for Managed Care: The Legacy of Hughley vs. Rocky Mountain Health Care Maintenance Organization
- Practice Guidelines: A Limited Role in Resolving Rationing Decisions
- Clinical Responsibility and Legal Liability in Managed Care Obligations and Opportunities: The Role of Clinical Societies in the Ethics of Managed Care
- Medical Education and Managed Care: Keeping Pace
- Managed Care and the Goals of Medicine

This Congress of Clinical Societies work was funded by a grant to the American Geriatrics Society from the Robert Wood Johnson Foundation. Correspondence and/or reprint requests regarding this series should be addressed to Joseph J. Fins, MD, Box 297, The New York Hospital-Cornell Medical Center, 525 East 68 th St., NY, NY 10021.

The Case of Mrs. H

Submitted by Kathryn Koch, M.D., Associate Professor of Medicine, Chief/Critical Care, University of Florida Health Science Center

Mrs. H is a 64 year old Vietnamese woman who immigrated to the U.S. 27 years ago as the wife of a serviceman. She presents to the emergency room with complaints of increasing shortness of breath over the past week, with a decline in general physical well-being and a weight loss of 30 pounds over the past 4-5 months. She denies subjective fevers, has a dry cough, and notes that she has been using her granddaughter's Primatene mist with increasing frequency over the past two months.

She is found to be hypoxic, afebrile, and mildly dehydrated. She has crackles and wheezes throughout both lung fields, and signs of consolidation in the right apex. The rest of her physical exam is within normal limits. Chest film reveals diffuse infiltrates throughout both lung fields and right upper lobe pneumonia with loss of volume. She is admitted for treatment of bronchospasm, hypoxia, and suspected post-obstructive pneumonia, and for diagnostic workup of her diffuse infiltrates. The admitting differential is tuberculosis versus lymphangitic spread of carcinoma, with all other possibilities being low on the list.

She speaks broken English and depends on her two daughters heavily for interpretation of complex concepts. She has been divorced for 8 years and grieves about that fact with her caregivers. She works as a seamstress, and lives by herself in a trailer. She does not smoke, drink, or utilize any drugs or medication other than Primatene. Her two daughters are clearly devoted and caring, and despite the fact that they are working mothers with commutes of over an hour, they both manage to spend most of every day with her at the hospital.

The daughters request that we do not mention the possibility of cancer to their mother, as they fear it would upset her needlessly. They also note that the antibiotic-associated diarrhea that their mother is experiencing is very distressing to her: She is trying to hold it in until they arrive, so they can help her to the bedside commode. She is too short of breath to get up to the commode herself, and is too private to ask the nurses for assistance. She has been thankful of her caregivers' every effort on her behalf, but has been too embarrassed to tell them about the diarrhea.

Mrs. H is informed that she has pneumonia and that she has other lung problems which require workup. A chest CT reveals a pattern highly suggestive of lymphangitic spread of carcinoma with a right upper lobe pneumonia. The two daughters are shown the chest CT and extensive discussion about the meaning is held with them so they can explain it to their mother. They immediately request a DNR for their mother as they feel that she would be profoundly emotionally damaged by being subjected to that level of care should she deteriorate. Machines would be torture and death would be preferable particularly if the death could be made comfortable.

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Case Study

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Bronchoscopy is performed after explaining to Mrs. H that we needed to know why she had pneumonia. A mass external to the right upper lobe bronchus is identified and biopsied; sputum is proved to be negative for tuberculosis and biopsy is positive for undifferentiated adenocarcinoma. She is very unstable with increased hypoxia and hemoptysis for the first 6 hours after the bronchoscopy.

During the interval between the bronchoscopy and the biopsy results, the daughters several times verbalize concerns to different members of the team about the possibility of cancer. Having seen the Chest CT they realize that surgery would be out of the question. They voice concerns that their mother is a very private and dignified individual. They note that she holds strong cultural imprinting which makes her personally responsible for any illness. They note that she still cries every night in grief and guilt over the failure of her marriage.

When informed of the diagnosis in preparation for a discussion with their mother, the daughters acknowledge that they had privately discussed this possibility and they are both convinced that it would be harmful to tell their mother about the diagnosis, and that it would be harmful to attempt palliative treatment. Mrs. H was already upset about her diarrhea; how would hair loss, nausea, and vomiting affect her?

If Mrs. H was told that she had cancer, she would feel guilt for her own illness, and would spend the remainder of her life grieving for her own evil misdeeds which had brought this illness upon her. Chemotherapy would not be possible without informing her of the diagnosis, and would be unlikely to palliate her for very long. The information about the diagnosis, and the proposed palliative treatment would be worse for her than death itself.

The daughters request that we not inform Mrs. H of the diagnosis. When Mrs. H is asked whether she wants to know more about the test results, she says, "no, no let my daughters know."

What are your comments? Have you had any similar situations with patients from other ethnic groups? How would you and/or your Bioethics Committee handle a consult like this? Send your responses to Cathy Emmett, 1700 S. Tamiami Tr., Sarasota, FL 34239, or fax to 941-917-6188 or e-mail to cathy_emmett@smh.com.

Upcoming Conferences:

Law and Ethics: Health Care Advance Directives-Problems and Strategies in Implementing Florida Statute 765.
May 14-15, 1998, Radisson Hotel, Gainesville

Sponsored by Medical Ethics, Law and Humanities, University of Florida College of Medicine, Florida Bioethics Network, and multiple Healthcare Systems and Organizations

The legal and ethical concept that persons do not lose their rights to refuse or accept medical treatments when they are incapacitated has been clearly recognized in Florida Statute and Case Law. Nevertheless physicians, patients, risk managers, hospital attorneys and others have continued to have significant difficulty both conceptually and in the practical application of this law. These problems range from the burden of finding two physicians to attest to whether a patient is "terminal", to whether "terminal" even conceptually makes sense as a requirement for implementing an Advance Directive. Other problems surround perceived difficulties of some physicians in respecting a patient's Advance Directive or with family members who aggressively desire treatment the patient has refused in their directive.

The purpose of this conference is to explore these and other problems with this law and to determine if consensus proposals can be identified which will resolve or ameliorate these difficulties. This conference has been designed for those professionals who work with the ethical, social, clinical and legal aspects of health care at the end of life. For more information, call 352-846-1097.

Ethical Issues in Medicine: 5th Annual Program
July 25-August 1, 1998, Tuscany, Italy

Sponsored by Montifiore Medical Center and Credit Issued by Albert Einstein College of Medicine

Seminar Topics include: Physician Assisted Suicide and the Doctor-Patient Alliance in an Era of Managed Care. For information call 718-655-2400.

FBN's Eighth Annual Conference
Oct. 21-23, 1998, Orlando Airport Marriott

Mark your calendars now! Our upcoming annual conference promises to be one of the best with a variety of topics that should pertain to all healthcare providers faced with ethical issues. As always, this unique conference offers participants from all over Florida an opportunity to network with and learn from others involved in the field of healthcare ethics. Our keynote speaker will be Thomas Krizek, M.D., noted surgeon who conducted and published key research in the field of adverse events. Our popular optional Wednesday format will continue to provide up to date information for those who are just beginning to serve on or start Bioethics Committees. Look for your conference brochure in the mail in August! Call 407-841-6230 for more information.

Response to “The Case of Mr. B”

(Case presented in the January issue of Network News)

By Ben Mulvey, PhD, Nova Southeastern University

Let me organize my response to this case around the questions raised at the end of the case presentation. The first question to address, then, *is How would your committee respond if asked to consult on this case?*

I'm a member of the ethics committee of a large community hospital and I will respond to this case from that perspective. I would caution those reading this, though, that my committee is just one model among many and that what makes procedural sense in our setting may not be readily transferable to all contexts. Nonetheless, I believe the important issues here to be of such a fundamental nature that the questions they raise may well be universal.

Typically a member of the health care team, often the treating physician, would contact the chairperson of our committee to request a consult. Of course, the committee would respond to a consult request from any of the principal parties, including family members. The chair would then quickly organize an ad hoc “consult team,” made up of a few experienced members of the full bioethics committee and ask them to meet with the principal parties whom he would also invite.

This case is interesting partly because the issue of who ought to be considered a principal party is controversial. Therefore, before I can address the second question posed at the end of the case presentation, *What questions would you ask?* One must first establish just who the principal parties are in this case. Only then can one determine what questions to ask them. Thus the importance of the third question posed at the end of the case presentation, *What persons would you want to talk to?* I will address these questions together.

The principle of autonomy states that respect for persons entails respecting their right to make choices regarding their own well-being. Paraphrasing Justice Benjamin Cardozo, adults of sound mind have a right to determine what happens to their own bodies. Since the case makes no mention of anyone having any reservations regarding the decision-making capacity of Mr. B., then the person most important to hear from is Mr. B himself.

Mr. B “... repeatedly expresses his wish to receive any necessary interventions to optimize his recovery and sustain his life.” The important questions to ask Mr. B are, does he understand the nature of his illness? Does he understand the consequences of his decision? In other words, does he truly grasp the nature of the quality of life that he is facing in the coming weeks or months? Does he really understand what each of the “necessary interventions” consists of?

I think it important to hear from Mr. B's immediate family as well, particularly since they apparently disagree with him regarding his care. “His physicians... encourage a DNR decision, and his wife and 3 children concur. He does not agree.” Does Mr. B and his family understand just what a DNR order means? Why do family members want such a thing for Mr. B? Is their choice motivated by concern for their loved one? Or is it more of a concern for their own well-being? After all, it's never a “comfortable” thing to watch a family member desperately clinging to life. Sometimes family members might think that when his suffering ends, so does theirs.

Certainly I think it important to hear from Mr. B's treating physician. Is the diagnosis relatively certain? The prognosis? What exactly are the treatment alternatives for Mr. B? Has all this been clearly articulated to Mr. B and his family? Do the treating physicians and associated staff understand what a DNR order means? Do they understand that such things as a “slow code” are not legitimate? That any half-hearted treatment in the hope that Mr. B will die before this conflict is settled is ethically unacceptable? Have any other members of the staff established a relationship with Mr. B such that they might have something of relevance to offer?

Once the important parties are gathered together, it is important to ascertain why an ethics consult was called in the first place. Who asked for the consult? Why? Is there a real difference of opinion as to what the right thing to do is? Is the ethics consult being used as an occasion for the kind of communication that should already be taking place between patients, families, and care-givers? Do those that called the consult? But if one were called in such circumstances, it may well then provide an occasion to educate all parties about the appropriate use of an ethics consult and the importance of thorough communication between all concerned in the patient's well-being.

Finally, we must address the issue of whether or not to invite the case manager for the managed care organization. We know that “the case manager from [Mr. B's] managed care contract has a meeting with his family and floor physicians regarding his code status. They are all in agreement that he should be a “no code.” One wonders why the case manager was involved in this prior meeting in the first place. Even in these days of shrinking resources and the increasing intrusion of financial concerns into medical decisions, I still believe the question regarding “who pays” should be clearly demarcated from the question of “what is the right thing (medically and ethically) to do for this patient?”

Aside from clarifying what Mr. B's managed care contract will and will not pay for, I believe there is no role for the case manager to play. Of course, the issue of how to pay for Mr. B's care is an important one. However, this is a political question more appropriate for debate in a democratic forum to be settled by the community at large. It should not be entangled with the immediate issue of how best to treat Mr. B, and it certainly should not be decided by care-givers and family members at Mr. B's bedside (or at an ethics consult).

But, “the case manager for the managed care contract demands that [Mr. B's] ICU physicians discuss his code status with him, and that she be present during the discussion.” Should the physicians have such a discussion with Mr. B? Of course. Should the case manager be present? Of course not.