

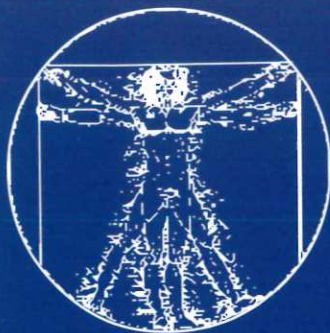
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Mid-Atlantic Ethics Committee
Newsletter, Spring 2003

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MID-ATLANTIC ETHICS COMMITTEE

NEWSLETTER

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
Published by the Law & Health Care Program, University of Maryland School of Law
and the Maryland Health Care Ethics Committee Network

Spring 2003

WHAT INFORMATION SHOULD BE DISCLOSED TO PATIENTS?

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Most people agree that patients should be given adequate information about their health and any planned medical interventions. The difficulty is defining what constitutes adequate information. Three standards of information disclosure have traditionally been used. All of them are flawed.

The professional standard requires disclosure consistent with the standards of other professionals in the same community acting in the patient's best interest. Standards defined in this manner risk disproportionately reflecting the values of professionals, not patients. Also, the question of how professional standards were justified in the first place is left unanswered.

The reasonable-person standard calls for the provision of information that a reasonable person would want. This standard suffers because of the difficulty gauging the needs of a hypothetical reasonable person; also, reasonable people may differ in their information needs.

The third standard—and my preference of the traditional models—is the subjective standard, which calls for information to be tailored to the needs of each patient. Physician and patient

The Mid-Atlantic Ethics Committee Newsletter is a publication of the Maryland Health Care Ethics Committee Network, an initiative of the University of Maryland School of Law's Law & Health Care Program. The Newsletter combines educational articles with timely information about bioethics activities in Maryland, D.C., and Virginia. Each issue includes a feature article, "Network News," a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing and related disciplines.

Diane E. Hoffmann, JD, MS
Editor

engage in dialogue; if more information is requested, it is given. The subjective standard is, however, fragile because it depends on the skill and willingness of the physician to engage in this sort of information exchange and on the ability of the patient to ask the right questions.

The existing disclosure standards are based on what professionals, reasonable people and individual patients choose to know or disclose. Little attention is paid to the characteristics of the information itself. Why should a

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upon without consulting an attorney.

NETWORK NEWS

Maryland Health Care Ethics Committee Network (MHECN)

MHECN's held its fall conference, "Spirituality, Religion, and the Role of Ethics Committees," on October 28, 2002. The conference, co-sponsored with Franklin Square Hospital and funded by a grant from the Foundation for Spirituality and Medicine, received very positive evaluations. Approximately 60 individuals attended the conference. On November 12, 2002, the Network held its Fall Journal Club meeting at Shady Grove Adventist Hospital. Two papers were featured: one summarized ethical issues related to care in the neonatal intensive care unit, and the other described end-of-life preferences among shelter-homeless individuals. The discussion was lively and thought-provoking. The next Journal Club meeting will be announced via email. Also, see the Calendar for details on MHECN's spring conference, "Clinical Informed Consent and Capacity: Law versus Ethics."

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Metropolitan Washing- ton Bioethics Network (MWBN)

The MWBN continues to promote regional ethics educational opportunities to its members through its partnership with Inova Fairfax Hospital in Virginia and the Clinical Bioethics Center at Georgetown University. In October, the Network held three sessions on ethics at a training program for court-appointed guardians. The sessions were sponsored by the D.C. Superior Court. A follow-up training session for all D.C. court-appointed guardians is being held May 21st, from 4:00-6:30 p.m. at the Moultrie Court House, 500 Indiana

Avenue, N.W., Washington, D.C. The Probate Division of the D.C. Superior Court is making such training mandatory for all attorney-guardians so that they are aware of all the many ethics issues that may face clients and prospective clients. Andrea Sloan, nurse-attorney in private practice and Matthew Kestenbaum, M.D., Medical Director of the Community Hospices of The Washington Home and Community Hospices, will be the featured panelists. Judge Christian will moderate. The topics will include Do Not Resuscitate Orders, artificial feeding and hydration, use of ventilators, and other related topics.

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Richmond Bioethics Consortium (RBC)

RBC continues to expand its educational offerings, programs, networking, and services to its member facility's ethics committees. The Fall 2002 Program, "Who Pays, Who Benefits, and Who Loses? The Promises, Perils, and Ethics of Consumer-Driven Health Care," provided a thoughtful exchange of experiences and ideas regarding ethical challenges for professionals in direct care, health policy and finance, and health care administration. In November 2002 the RBC held an Ethics Committee "Meeting of the Minds" at Children's Hospital, where representatives of seven area ethics committees shared their process for ethics consultation, membership, documentation, and function. Another similar meeting is scheduled for April 24 at 6:30 PM. The next RBC meeting will be held on March 20 at 6:30 PM.

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What Information Should Be Disclosed To Patients?

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physician decide to disclose certain information and not other information? Why should a patient want certain information and not other information? A challenging case illustrates the inadequacy of the currently used standards and will serve to demonstrate a different way of analyzing disclosure decisions that considers the characteristics of information.

The American Red Cross notified a hospital blood bank director that a unit of blood shipped to his hospital a year earlier and transfused to a patient came from an apparently healthy donor who subsequently developed Creutzfeldt-Jakob Disease (CJD). Because CJD has a long incubation period, the donor probably harbored the causative agent at the time of donation. The letter noted that the American Red Cross, the Centers for Disease Control, and the New York Blood Center "strongly discouraged" sharing this information with the recipient of the blood transfusion because there was no screening test, no treatment, and the information would cause the patient "tremendous stress." The letter also noted that representatives of the hemophilia community, a highly transfused group, disagreed with this position and at public meetings expressed their expectations that recipients of possibly tainted blood be notified.

CJD is a rare, rapidly progressive fatal brain disorder that has been transmitted to humans by hormones derived from cadaveric pituitary glands, corneal transplants, dura mater grafts, and reusable deep brain electrodes. A variant of CJD has been transmitted with the ingestion of beef and is popularly known as "mad cow disease."¹ The transmission of CJD by blood transfusion is theoretically possible but there have been no documented cases.² We might expect the increased use of blood products in recent decades to be associated with an increase in CJD if CJD were transmitted by blood; but that has not been the case. Confounding this reassuring data is CJD's long incubation period, which

can be decades; heavily transfused people may not survive long enough for us to observe manifestations of the disease. The rarity of CJD limits our ability to obtain a reliable number of observations and there is no laboratory test to determine whether the causative agent has been transmitted. It is not likely we will have a definitive answer to whether CJD is transmitted by blood in the near future.

There is reason for the blood bank director not to notify the recipient of the CJD blood. There is no proof that blood transmits the disease, there is no test similar to HIV testing that would indicate whether the agent has been transmitted, there is no treatment for CJD, and notification could be psychologically devastating to the recipient. However, CJD might be transmitted by

blood, the illness is horrendous, the patient might want this information, and although there is no treatment for CJD, it would be prudent for the recipient to know he should avoid donating any of his tissues or organs.

How should the blood bank director analyze this case? The traditional disclosure standards are not helpful. Decisions concerning the notification of CJD blood recipients are so unusual—and there are no clearly analogous situations—that no community professional standard exists. In several informal surveys, about half of the presumably reasonable people I questioned would want to be informed if they had received blood from someone who developed CJD and half would prefer they not receive this information.

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In his article, "What Information Should be Disclosed to Patients?," Dr. Steinberg discusses the three different disclosure standards that have been traditionally used in the health care setting. While Dr. Steinberg's analysis can be useful to health care providers faced with the difficult determination of whether to disclose certain information to a patient, statutes and common law in most jurisdictions specify which one of the three disclosure standards is applicable in the context of traditional informed consent.

Virtually all states have adopted either the professional standard or the objective patient standard. According to a relatively recent survey of state law, roughly half of the states have adopted each standard, though the physician or 'professional' standard has been adopted by the majority of these states. See Joan Krause, *Reconceptualizing Informed Consent in the Era of Health Care Cost Containment*, 85 Iowa L. Rev. 261, 314 (October 1999). The professional or "reasonable physician" standard examines what information the reasonable physician in the same or similar circumstances would have disclosed to the patient. Examples of states that have adopted this position include Colorado, Delaware, Florida, Idaho, Illinois, Kansas, Kentucky, Maine, Missouri, Nebraska, Nevada, New Hampshire, New York, North Carolina, Ohio, Tennessee and Virginia.

In jurisdictions adopting the objective "reasonable patient" standard, courts ask whether the physician disclosed information that a reasonable patient would consider material to his or her healthcare decision. In addition to Maryland, states adopting this standard include Alaska, California, Connecticut, Hawaii, Massachusetts, Mississippi, New Jersey, Pennsylvania, and South Dakota.

Very few states have adopted the subjective patient standard with respect to disclosure, but a few have adopted it in determining causation. In some states, e.g., New Jersey, a court will ask would the particular patient (rather than the objective patient) have declined consent if informed of all material risks. As Dr. Steinberg indicates, these standards may not be particularly helpful in the unique case scenario he describes, however, it is important for health care providers to understand, as a matter of law, that such standards do exist and differ from jurisdiction to jurisdiction.

What Information Should Be Disclosed To Patients?

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In the wake of a CJD scare in Canada involving the transfusion of albumin from a donor who subsequently developed CJD, 68 percent of presumably reasonable Alberta residents favored notification of recipients and 32 percent did not.³ Because some reasonable people favor notification and others do not, the reasonable-person standard is not helpful.

The subjective standard would be difficult to implement because the blood bank director could not call the patient a year after the transfusion without explaining the reason for the call - which would lead to notification of the patient independent of the patient's wishes. If there were a physician who knew the patient, that might to some degree obviate this problem.

Another approach to information disclosure discussions examines eight characteristics.⁴ Consideration of these factors may not make the blood bank director's decision easier, but they provide a useful framework for thinking about the problem.

Relevance is a threshold criterion. CJD is an infectious disease and its transmission by blood is theoretically possible; therefore information about the transfusion is relevant to the recipient. If the blood donor had glaucoma, that information would not be relevant because there is no reason to believe glaucoma can be transmitted by blood.

Probability is an important factor because an event that occurs with a probability of one in 10 thousand does not have the same claim on disclosure as an event that occurs with a probability of 10 percent. It is a reasonable guess that the probability of CJD transmission by blood transfusion is very low.

The significance of information is important because omitting insignificant information is less ethically troublesome than materially significant information. For example, an evanescent rash does not demand disclosure as strongly as heart or kidney failure. The factor of significance is high in this case because

CJD destroys the brain and is fatal.

The availability of interventions can in some instances trump all other factors. There is no diagnostic test for CJD and no treatment. The recipient of CJD blood would be well advised not to donate blood, a kidney, a lobe of liver or, when he dies, his corneas. Notification now might be advised so the patient can be alert to tests or treatments developed in the future. At this time the availability of CJD related interventions should be considered relatively low.

Does the patient have a subjective need for this information? Faced with the prospect of a fatal illness, even if the probability is low, some people might alter their lifestyle, take a long anticipated trip, or resolve a festering family dispute. We do not know the recipient in this case, therefore his subjective needs must be considered unknown.

The disclosure of information can cause harms. The knowledge that you have received blood from someone who developed an awful and ultimately fatal brain disease can cause anxiety and depression. Some Canadian recipients of CJD albumin were "scared silly every time they forgot a number or a key." If you inform a recipient of CJD blood, you may cause considerable harm.

Patient autonomy should be respected. If a patient has made it clear that he doesn't want certain types of information that wish should be respected. If a patient has indicated a desire for detailed information about his or her condition, even trivial details, to the extent possible those wishes should also be respected. Clinicians who routinely solicit information preferences from their patients are better equipped to gauge the factor of patient autonomy.

The decision-maker's perspective cannot be ignored. A transfusion service director who, in the wake of the AIDS crisis, promised full disclosure in all cases would be under self-imposed pressure to inform the CJD recipient. A decision maker director in a different professional culture that frowns on delivering bad news is likely to be more restrained. When the

disclosure decision is difficult, as in this case, my perspective is to err on the side of disclosure. That's why I would inform the recipient of CJD blood.

When there is a substantial probability of a significant future event and beneficial interventions are available, a patient who would want the relevant information and use it to modify his life without suffering mental turmoil should receive it. Of course, difficult cases will not be this straightforward. Information about some of the eight characteristics may be unknown or controversial and it may be unclear how to weigh contradicting factors, which differ qualitatively, one against the other. Despite these limitations, disclosure decisions are best made by including an analysis of the characteristics of the information in question rather than resorting to the flawed traditional professional, reasonable-person, and subjective standards. The identification of eight characteristics: relevance, probability, significance, availability of interventions, subjective needs, harms, autonomy and the decisionmaker's perspective will hopefully provide a framework for this analysis.

By David Steinberg, MD
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Footnotes

¹ Rhodes R., *Deadly Feasts: The Prion Controversy and the Public's Health*. New York Touchstone, 1998.

² Dodd RY, Sullivan MT., *Creutzfeldt-Jakob disease and transfusion safety: tilting at icebergs? Transfusion* 1998;38(3):221-3.

³ Sibbard B., *Features*. *Can Med Assoc J* 1998;159:829-31.

⁴ Steinberg D., *Informing a recipient of blood from a donor who developed Creutzfeldt-Jakob disease: the characteristics of information that warrant its disclosure*. *J Clin Ethics* 2001;12(2):134-40.

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INTERPRETATION OF HIPAA: CHALLENGES TO ETHICS COMMITTEES

A new emphasis on patient rights and confidentiality is coming as virtually every health care provider, health plan and health care clearinghouse in the United States readies itself for the April 14, 2003 compliance date of the Privacy regulations issued under the Health Insurance Portability and Accountability Act (HIPAA). Although the regulations will likely cause little change in the way ethics committees operate, the accompanying mandatory education of the "workforce" at each entity affected by the Rule will likely promote increased discussion by and with ethics committee members about what is meant by "privacy" and "confidentiality."

The authors of this article have spent the past eighteen months working on HIPAA implementation efforts at a local health system. During January and February 2003, an educational program was held to train and inform nearly 3,000 volunteer and paid team members of the Upper Chesapeake health care system and its medical staff. This article describes some of the confidentiality "myths" encountered and subsequent issues that may need to be addressed by our Ethics Committee as the organization moves to a culture of confidentiality in a healing and compassionate environment for patients and families.

The Challenge: Ethics Committee Access to HIPAA-Protected Information

The HIPAA regulations attempt to balance several new patient rights regarding control of access to protected (personally identifiable) health information or "PHI" with the operational reality that delivering good care, getting it paid for, and looking for

ways to do it better next time require wide access, use, and disclosure of that same information.

Ethics Committee members, when asked to consult about a particular case, need access to information about the patient's medical history, current condition, prognosis, treatment, goals, etc. in order to offer meaningful recommendations. This will be covered by the "treatment" provisions of HIPAA, which permit unfettered access to this information, even where the patient did not initiate the consultation.

Many committees also engage in retrospective reviews of prior consults for the education of committee members and as a quality check on the consultation process. This access should be covered by the provision of HIPAA that permits access to a patient's PHI for "health care operations," subject only to the restriction that the committee uses the "minimum necessary" information for a particular purpose.

Confidentiality Myths: "Statements" used to rationalize disclosure or non-disclosure

Myth #1: "EVERYBODY Does This" ***"I didn't give the patient's name"*** ***"But, s/he works here"***

Anyone who has spent five minutes working in a hospital or other health care facility knows that patient information is everywhere—so much so that those working in healthcare may develop casualness about how they disclose it, at least to one another. Ask two nurses who are discussing details of a patient that only one is actually taking care of and the three responses above will likely be offered. The collegial environment of healthcare often leads to a doctor and nurse sharing an interesting, perplexing, amusing or difficult patient encounter over lunch in the cafeteria. It is encouraged by the teaching process at most professional schools where the "case study" is a standard pedagogical technique. There is also a real need to "vent" the emotions aroused by involvement in troubling cases like

those involving abuse, violence or neglect.

The result is that the person who is most cautious about revealing so much as a patient's temperature to an unauthorized person outside the "workforce" will often talk freely with a co-worker, disclosing much more of his/her patient's PHI than is allowed by HIPAA. Unfortunately, there is no HIPAA provision that will sanction these discussions among those not caring for the patient outside of formal peer review, personnel policies, education or performance improvement activities.

Myth #2: "I didn't show her the actual record"

Another common misconception is that there is a distinction between PHI memorialized in a paper or electronic medical record and information that is passed verbally so that the latter is subject to different "rules." HIPAA, though, makes no such distinction.

Myth #3: "I'd like to tell you, but there are these new regulations" ***"We're no longer allowed to give information over the phone"*** ***"The new HIPAA Policy/Law prohibits me from telling you any further information"***

Misconceptions about HIPAA may also be used by those who are attempting to deal with increased restrictions on what information may be shared and the sometimes time-consuming and difficult responsibility of communicating with the family and friends of patients. HIPAA permits the sharing of PHI with those who, in the exercise of good professional judgment, are or will be involved in the patient's care so long as the patient has not expressly objected. Also, as noted above, HIPAA makes no distinction between the form of PHI.

Myth #4: "I'm sorry, that person isn't listed in our patient directory"

Presently, in Maryland, if you call a hospital to ask about your sister who had surgery yesterday, the facility can

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confirm her presence, tell you her location within the facility, and give a short description of her condition (good, poor, fair) without having asked your sister for permission to make such a disclosure. Providing such "directory information" freely changes significantly with the implementation of the HIPAA regulations.

Under HIPAA, patients will have a right to "opt out" of this virtual "directory" and remain protected from casual inquiries. This new "right" presents several challenges. First, there MUST be a change in the practice or habit of each person within the facility. Before speaking about Mr. Smith in room 303, they will have to determine if he is "in" or "out" of the directory. Second, most individuals do not want to lie, so healthcare staff need suggested language to use when communicating with the public.

Finally, members of the public are used to obtaining public information about their family and friends and may not respond cordially when it is withheld. A facility in Oklahoma began trialing its new HIPAA policies some months ago. The first consequence they noted was a lot of unhappy florists; the second was an equal number of unhappy "ex-directory" patients who didn't get their flowers. Patient and community education will take a while and needs to occur proactively at the time confidentiality status is determined.

A Role for Ethics Committees?

Shifts in attitudes and practice don't happen easily. There is a valuable role that ethics committees, as part of their patient advocacy role, can play in helping their institution make the cultural shifts associated with HIPAA. Education and support will work to minimize any adverse effects on patient rights from those who may use HIPAA as an excuse for limiting their responsibilities. At a minimum, committees should ensure that each of their members, particularly those from the community, are appropriately educated about what HIPAA does and doesn't require. This education needs to incorporate the same key concepts

and policies as the training provided to the organization's workforce.

Awareness of potential and actual situations will assist ethics committee members appropriately support decisions and confront myths associated with this major change in confidentiality and privacy rules. The culture of an organization is supported through these efforts and provides security to those involved with the processes and functions of the committee's activities. This is our challenge—are we prepared to perform our duty?

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HONORING DRIVER'S LICENSE DESIGNATION FOR ORGAN DONATION

The Transplant Resource Center of Maryland has recently changed how families of patients who are candidates for organ donation will be approached. Up until recently, families were permitted to make the choice about organ donation, regardless of whether the individual designated him/herself to be an organ donor via a donor card or driver's license. Now, an individual's designation about organ donation is recognized as his or her autonomous directive, and TRC will help guide family members to honor their loved one's wishes. Below is an ethical analysis supporting that decision from The Ethics Committee Transplant Resource Center of Maryland.¹

In the United States, the supply of organs and tissues from deceased donors is dependent upon two related ethical concepts: virtue and a respect for autonomy. The notion of organ and tissue donation as a "gift of life" is a societal call for donation that is seen as worthy of praise, salutary, and for which society as well as individuals ought to be grateful. Thus organ and tissue donation is a virtuous act along with other virtuous acts that good citizens may do that encourages a respect for life and community. Likewise our American culture also places considerable weight on the respect for personal autonomy. Respect for autonomy is a principle that posits that the moral community has an obligation to allow persons to live out their life plan, so long as those life plans do not hinder the freedom from harm for others. We have long recognized that a person's life plan can include certain desires even after death. We recognize that a person's desire for the distribution of personal assets extends after death and we also recognize that this is also the case for a person's desire for what is done with his/her body.

Indeed, current Federal and State law dealing with organ and tissue donation reflects these two ethical concepts. The Uniform Anatomical Gift Act of 1968, which has been adopted in some form by all 50 states, provides for organ and tissue donation with the provision of a donor card that, when signed by a person over the age of 18 and witnessed by two adults, becomes a legal instrument permitting physicians to remove organs and tissue after death. In 1984 the National Organ Transplant Act (NOTA), while not primarily regulatory, did provide funds for Organ Procurement Organizations and for the establishment of the National Organ Procurement and Transplantation Network. The network is designed to assist the OPO distribute organs within its geographical borders. In addition, the NOTA established a task force on organ transplantation which was charged with setting policy designed to increase the supply of donor organs and tissue. The task force stated that its goal was to increase the

value of social practices that enhance altruism and our sense of community. To achieve this goal the task force recommended that hospitals adopt policies requiring that next of kin be asked to consider donating the deceased organs.

The Omnibus Budget Reconciliation Act of 1986 took up this recommendation and mandated a "required request" policy for all hospitals participating in Medicare or Medicaid. This mandate required those hospitals to have written protocols for identifying potential donors and assuring that families of potential donors are made aware of the option of organ and tissue donation and their option to decline. The intent of this aspect of the act was to increase donation from those who otherwise had not, by the exercise of a donor card or driver's license, registered precedent autonomy for consent for organ and tissue donation. While the intention of the law was to increase organ/tissue donation through donor cards and driver's license designation as well as surrogate consent, it paradoxically may have had the opposite effect. A byproduct of the Act has been that it has made organ/tissue donor cards and driver's license designation less meaningful since many hospitals are no longer willing to rely solely on donor cards or driver's licenses as consent to procure the deceased's organs and tissue. The experience of many organ procurement organizations has been that family members, during the trauma of loss and grief, deny consent for organ/tissue procurement. Fearing bad public relations consequences and out of sensitivity to family grief, the organizations let the matter drop. While surrogates do have the right to refuse donation when the decedent has not exercised precedent autonomy through a donor card or driver's license, it is highly questionable morally and legally that they have that right when the decedent has exercised his/her autonomy. For a surrogate to deny the procuring of organs/tissues from a decedent who wished to be a donor is to violate the very notions of virtue and respect for autonomy which is the foundation for public policy and law.

Certain philosophical arguments have been made concerning whether autonomy is in effect after one has died. A distinction can be made between what is called "experiential interests" and "critical interests."² The former are those interests we have in experiencing which clearly we cannot have after death. The latter, in contrast, are those interests that are not to be denied after death but are to be understood as part of the life plan such as the distribution of an estate *and* what is done with the body after death. Just as a person would see their autonomy violated if their assets were not distributed as they wished after death, so too would she or he feel that a respect for autonomy was violated if their wishes about body disposal were not followed. As Robert M. Veatch has argued:

That duty of respect does not cease with the individual's death. The body is still the mortal remains of the individual, and his or her wishes deserve respect. Therefore, we can use the body for research, education, therapy, or transplantation only if that individual grants us permission, only if the body is made a gift to others. The reasoning is what philosophers would call *deontological*. Derived from the Greek word for "duty," the term is used to convey the idea that there are certain duties we owe to others regardless of the consequences. The ethical principle of respect for autonomy is one of the most profound and widely affirmed deontological duties in Western Culture. It is the foundation of the donation model. That model won the debate in the United States and most of the rest of the world. In the United States there could be no other solution.³

Veatch goes on to make the case that unless a surrogate can produce clear and convincing evidence that the deceased had changed her or his mind, that the OPO has a moral duty—not just a right—to follow the decedent's wishes to make a gift even over the

objections of family.⁴ While this stance may lead to confrontation, we can rely on the sensitivity and skill of our OPO personnel to handle such a situation. Higher orders of things are involved. If a person in an act of supererogation has made a "gift of life," we have a moral and legal obligation to honor that act. The same holds true with our obligation to honor an Advance Directive or uphold the Doctrine of Informed Consent. To violate an AD or informed consent should and often will result in both moral and legal sanction.

The William H. Amoss Organ and Tissue Donation Act of 1998 (MD) provides legal support for the relationship between virtue and autonomy. In addition to establishing a fund to increase citizen awareness about organ/tissue donation it also mandates reporting of all deaths within a hospital in order to assess the suitability of donation. It also stipulates that a person may designate him or herself as a donor through an Advance Directive/Living Will, an organ/tissue donor card or a donor designation on a Maryland Driver's License. According to the legal counsel of the Transplant Resource Center of Maryland in regard to the designation on the driver's license:

In interpreting these provisions [19-310(d), Subsection (j) of the Amoss Act], it is evident that the legislature intended the driver's license designation to constitute legal consent for organ, tissue and eye donation. The Amoss Act is fairly clear that where the decedent designates his consent to organ, tissue, and eye donation on his driver's license, the hospital and recovery agency are deemed to have consent and are not required to request the consent of the next of kin.⁵

Although the statute does not require it, counsel does advise giving weight to clear and convincing evidence of contrary intentions from family members. This is sound advice not only for public policy reasons, but also to assure that truly made autonomous decisions are honored.⁶

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The advancement of public recognition of our obligation to honor virtuous and autonomous acts should be a high priority educational mission of the Transplant Resource Center of Maryland in adopting a policy of honoring all legal designations for the consent of organ/tissue donation, including the designation on a Maryland driver's license. Anecdotal responses from sister OPOs in Virginia, Pennsylvania, and Colorado that honor all forms of legal consent have indicated that hospital personnel are uniformly enthusiastic about the policy. In addition, one OPO reported that a family that initially objected to donation, realized that honoring the loved one's wish was the right thing to do after more discussion. Again, the established skill and sensitivity of OPO staff along with a robust educational program should minimize potential conflicts.

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Footnotes

¹ TRC of Md Ethics Committee: Marion Borowiecki; Mark Ewing; Charlie Alexander; Karen Kennedy; Harry Congdon; Sharon Reynolds; Kimberly Miltenberger

² Ronald Dworkin, *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom* (New York: Vintage Books, 1994), pp. 201-04.

³ Robert M. Veatch, *Transplantation Ethics* (Washington, DC: Georgetown University Press, 2000) p. 147.

⁴ *Ibid.* p. 149.

⁵ Correspondence between Thomas V. Monahan, Jr, Esq and Mark J. Ewing, October 23, 2002, p.2.

⁶ *Ibid.* p. 3.

To participate in further discussion of these issues, join us at MHECN's June 2nd conference, "Clinical Informed Consent and Capacity: Law versus Ethics," where a panel will address the issues in greater detail. (See Calendar.)

Case Presentation

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee and an analysis of the ethical issues involved. Individuals are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information of patients and others in the case should only be provided with the permission of the individual. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to: Diane E. Hoffmann, Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201-1786 or dhoffman@law.umaryland.edu.

Case Study From The Maryland Nurses Association

Although this case did not go to an ethics committee, if your ethics committee were to get a call from a nurse in a similar situation, how would it respond?

A nurse on a women's surgical floor is caring for a patient who is 18 weeks pregnant who came in through the ER with abdominal pain. Appendicitis was ruled out, and the woman was admitted. When the nurse evaluated her, her pain was every 30 minutes, lasting for 10 seconds. Between these episodes she had no pain at all. The nurse called the physician, who was chief of obstetrics (OB), multiple times as the patient's pain episodes went from occurring every 30 minutes to every 20 minutes to every 15 minutes to every 10 minutes over a period of eight hours. The physician said he did not think the patient was in preterm labor, and even if she was, nothing would be

done to stop the labor, as the fetus would not be viable anyway. He ordered only extra strength Tylenol for her pain. After the sixth call from the nurse, the physician performed a vaginal exam and then requested a stat OB ultrasound, but told the patient he didn't think she was having contractions. The OB ultrasound showed a live fetus head down in the pelvic cavity. The physician repeated to the nurse that he didn't think the patient was in preterm labor and that if she was, nothing would be done to prevent it since they only attempt to intervene if the fetus is greater than 20 weeks. The patient later started bleeding and miscarried, at which point the physician gave her something stronger for pain. The infant was alive for a short time after birth—no OB nurses were present, no physician or OB staff, and no NICU staff. The nurse (who was not an OB nurse) was angry and frustrated with the substandard care she felt the patient received. Her supervisors told her there was no one else she could have gone to other than the attending physician involved, who was the chief of the department.

Comments From an Ethics Committee Chair

If this case came to our ethics committee, we would probably recommend an OB consultation first, perhaps with a perinatologist/high risk OB specialist, to clarify the latest standard of care guidelines. Regarding the professional conduct of the physician, it should not take six calls for the physician to respond—this is not very professional or caring behavior on his part. Generally these types of behaviors are reported up the chain of command, e.g., to department chairs or to the Vice President of Medical Affairs, Risk Manager, or even the CEO. All the committee can do is bring it to the appropriate person's attention for action. At our institution there are policies requiring that a pregnant patient in labor (term or

pre-term) be sent to the OB floor for evaluation by the OB staff. This would have taken the stress off the nurse in this case study, who was not familiar with OB procedures or the OB support staff. Either policies and procedures addressing this situation were not followed or they did not exist at this institution. If the latter is the case, the ethics committee should recommend to appropriate persons at the institution that policies, procedures, and guidelines be revised or created to assure that personnel in the hospital are able to provide the standard of care for all patients. In addition, there should be an identified chain of command through which staff can report unprofessional behavior by another staff member that puts a patient's care in serious jeopardy—either physically or emotionally.

Shahid Aziz, M.D.
Chair, Ethics Committee
Harbor Hospital

Comments From an Ethics Committee Vice- Chair

In our hospital, this particular situation would most likely have been referred by the ethics committee back to the interdisciplinary treatment team with a recommendation to either clarify the specifics of the existing treatment plan of care or to develop a complete treatment plan of care if one was lacking. This does not have to be prohibitively time-consuming but can take place expeditiously and at the bedside. What were the patient's pain scores and was there legitimate reason to withhold higher dosage of analgesic prior to delivery or miscarriage? After it was determined by ultrasound that there was a live fetus descending in the pelvic cavity, what preliminary preparations were made to care for the fetus, either still-birth or live birth? What were the patient's stated wishes? Why wasn't the patient transferred to a floor where staff had more experience caring for

women who miscarry? All of these questions should have been addressed by the interdisciplinary health care team prior to their occurrence, with consults to specialists as necessary.

If there existed the potential for conflict, perhaps a member of the ethics committee would have assisted in mediation. For example, did the conflict between the RN and the Attending originate from a difference in values related to treatment of the patient and/or treatment of the premature and non-viable baby? This case may also be appropriate for referral, after the fact, to the Performance Improvement or Quality Control Department. If there are not policies and procedures in place to support the delivery of quality care in circumstances such as these, this in itself needs to be addressed. One cannot be sure, given the limited information, as to why there was a lack of response on the part of the Attending. However, as with many hospitals, it appears that it would be appropriate for the VP of Medical Affairs to assist in mediating the situation. Our hospital's VP of Medical Affairs is also a member of the Medical Ethics Committee. No individual staff member, including the physician, should be placed in a position of isolation in the delivery of their care. This is truly one of the primary benefits of the interdisciplinary health care team: to render support to the physician in the decisions he or she has to make and to render support to other staff in the implementation of those decisions within the actual delivery of care.

The Rev. Robert E. Steinke, Ph.D.
Vice-Chair Medical Ethics Committee
Frederick Memorial Hospital

Comments Based on An Ethical Assessment Framework

Several ethical decision-making frameworks exist to help guide health care providers with difficult ethical issues. The Maryland Nurses Association created the Ethical Assessment Framework® (EAF) for this purpose. Here are the steps of the EAF:

1. Identify the concern/issue that may be an ethical problem
2. Gather relevant facts about the problem(s)
3. Determine if the problem is an ethical dilemma
4. Identify and clarify values, rights, and duties of patient, self and significant persons associated with the dilemma
5. Identify and use relevant interdisciplinary resources
6. Apply methods of ethical justification to assist in analyzing the dilemma
7. Propose actions/options
8. Consult guidelines from professional codes of ethics, if relevant
9. Prioritize the identified actions/options
10. Select an ethically justified action/option from those identified
11. Act upon/support the action/option selected
12. Evaluate the outcome

In a recent issue of *The Maryland Nurse* (a publication of the Maryland Nurses Association), the above case was analyzed using the EAF. Here we include Steps 4 and 6 of that analysis.

Cont. on page 10

4. Identify and Clarify Values, Rights, and Duties of Patient, Self, and Significant Persons Associated with the Dilemma/Issue

One can imagine what the patient valued: to maintain her pregnancy and protect her fetus, to be treated with care and respect, and to have her pain managed. In most cases the patient would value being informed about the medical facts, although it should be noted that this is not equally valued in all cultures (e.g., those in which women defer decision-making to a husband or another family member). The nurse valued patient autonomy and patient advocacy. The nurse's supervisor may have valued avoiding interdisciplinary conflicts and the time and energy involved in challenging a department chief's actions. Regarding the OB physician, perhaps he valued situations in which he could affect a positive medical outcome, but defined the latter narrowly. That is, perhaps he believed that whether or not the patient was in pre-term labor, there was nothing he could do for her medically, so this ended his obligation. Maybe he did not value the positive outcome that would have resulted in keeping the patient and nurse better informed and in better managing the patient's pain.

Most hospitals now post their own or the American Hospital Association's¹ version of the "Patient's Bill of Rights," which includes rights such as: to obtain considerate and respectful care; to obtain from physicians and other direct caregivers relevant, current, and understandable information concerning diagnosis, treatment, and prognosis; the opportunity to discuss and request information related to the specific procedures and/or treatments, including the medically reasonable alternatives and their accompanying risks and benefits; to be informed of hospital policies and practices that relate to patient care, treatment, and responsibilities, and to be informed of available resources for resolving disputes, grievances, and conflicts, such as ethics committees,

patient representatives, or other mechanisms available in the institution.

6. Apply Methods of Ethical Justification to Assist in Analyzing the Dilemma/Issue

Consequentialism: It seems that the outcome of miscarriage was inevitable in this case. However, the frustration and anger of the nurse and possible complicated bereavement of the patient because of how the case was mishandled could have been avoided. Thus, from a consequentialist perspective, the latter negative outcomes, because they were avoidable and were not balanced by benefits gained, are ethically unjustified.

Deontology: The physician appears blameworthy because he failed in his duty to respect and care for his patient based on standards of care. The nurse does not seem to share the same level of blame because the physician's actions apparently prevented her from fulfilling her obligation to advocate for her patient. More information is needed to determine whether other options were available to assist the nurse in advocating for her patient, such as going above the OB chief in lodging a complaint, calling for an ethics consult, or consulting with nursing colleagues in the OB department. In addition, administrators or supervisors have an obligation to provide a working environment that fosters ethical patient care, and may have breached those duties in this case.

Principlism: The principle of respecting individual autonomy was violated by the physician, who did not properly inform the patient of the medical facts of her impending miscarriage. Nonmaleficence (the principle of avoiding harm) was breached by the physician's dismissal of the patient's and nurse's needs for information, guidance, and support. The principle of beneficence was violated by the inattention to proper pain management and steps that could have been taken to minimize the emotional

and physical burdens of the patient's miscarriage.

Care: Reflecting upon the relationship between the *nurse and the patient*, the *nurse and the physician*, and the *nurse and her supervisors*, there are several breaches in the ethic of *care* in this case. The ethic of care requires us to withhold judgment until we get all of the facts and look at the case from multiple perspectives. It is possible that the physician was sleep-deprived or overwhelmed with other patients who took medical priority. Regardless, the interactions between those involved in this case fell short of the ideal, leading to substandard care and creating ill-feelings and regrets that might have been avoided if more attention had been paid to maintaining respectful, caring relationships among staff.

Virtue: The virtues of compassion, integrity, courage, and wisdom are relevant in this case. The physician appeared to lack compassion, wisdom, and integrity in his dismissal of the nurse's repeated requests to attend to the patient. That is, his actions compromised the patient's well-being as well as the physician's collegial relationship with the nurse. The nurse would have needed courage to challenge the OB chief and/or her supervisors—either while this case was unfolding or retrospectively, to avoid similar situations in the future.

Anita J. Tarzian, Ph.D., R.N.
Chair, Maryland Nurses Association's
Center for Ethics & Human Rights

Footnotes

¹ www.hospitalconnect.com/aha/about/pbillofrights.html, accessed December 8, 2002.

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CALENDAR OF EVENTS

March

March 25-26 "6th Annual Ethics Forum & End of Life Workshop," Georgetown University School of Nursing & Health Studies. Contact: reinertd@georgetown.edu or (202) 687-4853.

April

April 2 "The Ethics of Caring," Margaret Little, Ph.D., The Children's National Medical Center Annual Leiken Lecture, 8:00 am. (Free) Contact: <http://clinicalbioethics.georgetown.edu> or (202) 687-1122.

April 4-6 "Clinical Ethics Consultation: First International Assessment Summit," Cleveland, OH. For more information go to: www.clevelandclinicmeded.com/courses/ethics2003.htm.

April 10 "Technology, Memory, and the Age of Terror," Speaker: Eric Cohen, Technology & Society 2003 Lecture Series, Sponsored by the Ethics & Public Policy Center, Washington, D.C., 5:30 pm. (Free) Contact: Sarah Pentz (202) 408-0632, Sarah@eppc.org or www.EPCC.org.

April 11-13 "Bioethics in the First Person," ASBH Spring Meeting co-sponsored by Northeastern University's Feinberg School of Medicine, Chicago, IL. Contact: kmontgomery@nhu.edu or www.asbh.org.

April 25 "Attorneys General vs. Non-Profit Healthcare Directors: The Corporate Mission and the Public Good," Sponsored by the American Society of Law, Medicine & Ethics, Newark, NJ, Contact: www.aslme.org.

May

May 1 University of Maryland Medical Humanities Hour, "Abnormal Genes & Anti-Social Behavior," Speakers: Robert Wachbroit & David Wasserman, Shock Trauma Auditorium, University of Maryland Medical Center, Baltimore, MD, 5:00 pm. (Free)

May 1 "Squandered Trust: Professional Helping Relationships & Abuses of Power," Sponsored by Georgetown Center for Clinical Bioethics, Georgetown University, Contact: <http://clinicalbioethics.georgetown.edu/conferences/>.

May 22 "Biotechnology and the American Project," Speaker: Adam Wolfson, Technology & Society 2003 Lecture Series, Sponsored by the Ethics & Public Policy Center, Washington, D.C., 5:30 pm. (Free) Contact: Sarah Pentz at (202) 408-0632, Sarah@eppc.org or www.EPCC.org.

June

June 2 "Clinical Informed Consent and Capacity: Law versus Ethics," Conference sponsored by MHECN, a program of the University of Maryland School of Law, and Upper Chesapeake Hospital, Baltimore, MD. Contact: MHECN@law.umaryland.edu or (410) 706-4128.

June 3 "The Professional and Patient Relationship: Still Relevant in the New Millennium?," Ethics Forum, Inova Fairfax Hospital, Physicians Conference Center, Speaker: John Lantos, M.D., 5-8:00 pm. Contact: patricia.odonnell@inova.com, or (703) 321-2658.

June 3-8 Intensive Bioethics Course, Kennedy Institute of Ethics, Georgetown University, Washington, D.C., Contact: www.georgetown.edu/research/kie or (202) 687-8099.

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