

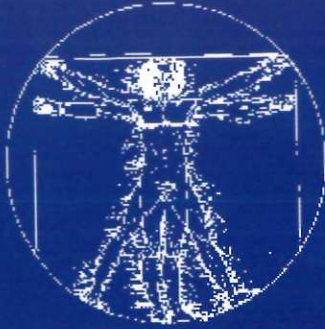
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 2001*

Mid-Atlantic Ethics Committee
Newsletter, Spring 2001

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MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

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 2001

ETHICS CONSULTANTS' EMOTIONAL PITFALLS

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Like scalpels, ethics consultants can do harm or good. The most likely cause of consultants unwittingly doing harm is their responding to deeply felt emotions of which they are unaware. Fear is, perhaps, the most powerful of emotions. The following examples involving fear show how emotions can alter what ethics consultants do. They include fear of defending minority views, of evoking fear in others, of losing friends, and of espousing unethical views.

Fear of Defending Marginal Views

The case of "Baby K," an infant born with anencephaly, illustrates the fear of defending "marginal views." Her mother wanted Baby K to receive all treatments possible and, as a result, Baby K survived for an unprecedented length of time. In public, nurses and doctors uniformly objected to Baby K's continued treatment. Some told me behind closed doors, however, that they agreed that Baby K should be treated, but wished these "doors" to remain closed, lest they seem disloyal and lose credibility with their colleagues.

A second example illustrating this fear took place when an incompetent patient was "using up" a hospital's

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Diane E. Hoffmann, JD, MS
Editor

blood supply. The staff in this case thought that the patient's treatment was futile, though if the patient stopped bleeding, he could have survived for several more years. The staff requested a consultation implicitly to have the ethics consultant convince the patient's family that the patient shouldn't have more blood.

The ethics consultant in this case could have, and possibly should have, told the staff that his pressuring family members to "comply" with the staff's

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to 20 copies)

Diane E. Hoffmann, JD, MS, Editor
Evan G. DeRenzo, PhD, Co-Editor
Nancy Zibron, MA, Layout Editor

Contributing Editors:

Elizabeth Bray, RN, JD
Co-Chair, Northern Virginia Health
Care Ethics Network

Brian H. Childs, PhD
Director, Ethics & Organizational
Development, Shore Health Systems

John C. Fletcher, PhD
Professor Emeritus University of Virginia,
Center for Biomedical Ethics

Jacqueline J Glover, PhD
Associate Director, Center for Health,
Ethics and Law, West Virginia Network of
Ethics Committees

Eugene C. Grochowski, PhD, MD, FACP
Associate Professor, The Johns Hopkins
University School of Medicine
& Bioethics Institute

Edmund G. Howe, MD, JD
Professor of Psychiatry, U.S.U.H.S.
Department of Psychiatry

Joan Lewis, Coordinator
Washington Metropolitan Bioethics
Network, D.C. Hospital Association

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MHECN Executive Director

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University of Maryland

Anita J. Tarzian, PhD, RN, MHECN
Education Chair & Research Associate

Jan Vinicky, PhD
Director, MedStar Center for Ethics,
Washington Hospital Center

Comments to:

aneil@law.umaryland.edu

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NETWORK NEWS

Maryland Health Care Ethics Committee Network (MHECN)

The Maryland Health Care Ethics Committee Network held its first Board meeting of the year on February 1, 2001. Elections took place without a change in the composition of Network officers. Diane Hoffmann continues as Chair, Eugene Grochowski as Vice-Chair, and Brian Childs as Secretary/Treasurer. Martha Knutson will continue as Chair of the Membership Committee and Anita Tarzian as Chair of the Education Committee.

The Network's Education Committee is planning for a June 15, 2001 full day conference to be co-sponsored by and held at Franklin Square Hospital. The conference title is "Two Topics in End-of-Life Care: African American Perspectives and Conflict Resolution." Dr. Annette Dula, EdD will be the keynote speaker covering issues on African-Americans' end-of-life preferences. In the afternoon, conference participants will have an opportunity for small group work on conflict resolution related to issues surrounding end-of-life decision-making in nursing homes, cases of futility and maternal/child conflicts. Brochures containing more detailed information will be mailed in April.

The Network is also planning to offer a Basics Ethics Education Course this fall on the Eastern Shore.

Metropolitan Washing- ton Bioethics Network (MWBN)

The Network's February 13th meeting was devoted to a review of the D.C. Superior Court Bioethics Visitors Program and the issues that the Court deals with in these matters. Andrea Sloan, R.N., Esq., led the program with colleagues Myrna Fawcett, Esq., Robert Gazzola, Esq. and Renee Fox, Esq. They shared key information about

guardians, conservators, responsible parties, representative payees, and other related individuals who can serve wards of the city. Speakers outlined the source and scope of authority of each and to whom each is accountable. They also provided details about the Bioethics Visitors Panel consultation and how volunteer Network members can become involved.

The D.C. Superior Court Bioethics Visitors Program is a unique service, available through the Probate Division, to assist with the identification of ethical issues in guardianship, conservatorship and related matters. Since 1996, Bioethics Visitors Panels have assisted the Court, offering consultation in matters ranging from appropriateness of certain family members serving as fiduciaries to questions regarding DNR orders and withdrawal of feeding tubes and ventilators. Volunteer Bioethics Visitor Panels have assisted with over 40 cases in a little more than four years.

Ms. Sloan explained that the Probate Judge usually decides when a Bioethics Visitors Panel would be helpful. At that point, the Judge appoints one of three individuals, John J. Lynch, M.D., Vera Mayer, Esq. or Ms. Sloan to be the Visitor and to work with two additional people to assess the ward and the bioethical issues in the case. Dr. Lynch, Ms. Mayer and Ms. Sloan have a group of approximately 30 volunteers from whom to choose to work with them. Typically, they select a multi-disciplinary group. None of the three panel members may have an affiliation with the institution or any other potential conflict of interest.

Mr. Gazzola said that it is not always the judge that requests the Bioethics Visitors Panel. He noted that as a Conservator of an individual needing a Guardian, he has requested such a consultation when the ward's medical condition warranted it. All three speakers indicated that in cases in which they were involved, the advice

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Ethics Consultants' Emotional Pitfalls

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belief was not appropriate. Alternatively, he could have "warned" the family that influencing them was his "ultimate design." However, if the consultant had responded in one of these ways, the staff might have strongly resented the consultant.

Fear of Evoking Fear in Others

Ethics consultants may evoke fear in careproviders by doing something that places careproviders at greater legal risk. For example, a consultant might suggest that a careprovider tell a patient about a possible mistake the careprovider may have made.¹ This could occur when a patient has lung cancer and a radiologist who initially views the patient's chest x-rays misses lesions which, on retrospective review, are visible 90% of the time.² Factually, in these instances, doctors missing these lesions may have been negligent or made a mistake. Legally, in such circumstances, patients have the right to sue.

Quality assurance personnel do not advise careproviders to tell patients about possible mistakes under these kinds of circumstances, though careproviders know better than patients when a patient could sue and possibly succeed. Rather, quality assurance personnel only advise careproviders to acknowledge their probable mistakes and, at these times, to apologize. Careproviders apologizing, paradoxically, makes it less likely that these patients will sue, because this apology enhances the patient/careprovider relationship. Still, truth telling may require that careproviders tell patients that they could sue, especially since they, more than patients, know whether a legal suit might be successful.

Ethics consultants choosing to raise the question of careproviders telling patients of mistakes and that they might sue and succeed should be prepared for a highly negative response (especially if the consultant suggests that a patient be told that the careprovider may *possibly* have made a mistake or have been negligent.) Moreover, the consultant's anticipation and fear of evoking such a

negative response may cause him or her to avoid discussing with the careprovider the option of disclosing medical mistakes, apologizing for them, and even perhaps informing the patient that (s)he can sue if the ethics consultant believes this is the right thing to do.

Fear of Losing Friends

Ethics consultants may also fear losing friends. Since they often work within the hospitals that employ them, if consultants oppose careproviders, aside from losing future consultations, they may lose the affection of care providers who are also their colleagues.

In a case with which I am familiar, an ethics committee believed that a patient's situation was "close to futile" since his benefit/burden ratio was equivocal. The committee "decided" that this patient could be treated if a specialist willing to do so could be found. A committee member then contacted specialists throughout the city, but none would agree to treat this patient. In light of the diversity of moral views on this question within the committee, this outcome was unlikely. An alternative explanation is that the specialists contacted all agreed not to treat this patient because this is what the specialists thought the individual calling them wanted them to say.

That physicians may "conspire" in this way is well known. The high likelihood of such conspiracy has been recognized by the courts in the context of informed consent and malpractice cases.^{3,4}

Ethics consultants cannot even share their views with impunity in an ethics committee. In another case of which I am aware, a patient was conscious in an ICU and could have survived there indefinitely. One ethics committee member stated his belief that this patient's ICU care "couldn't go on forever." He suggested that the patient's ICU treatments be stopped. Other members thereafter viewed this member differently.

Because of cases like this, I no longer ask others gathered together such questions as who among them has advance directives. Nor do I ask medical students in a group to indicate who among them believes that an infant

who is extremely bad off should live or die. The teaching gain of this "straw vote" is more than offset by the risk of potential long term damage to students' and staff members' interpersonal relationships.

Fear of Espousing Unethical Views

Ethics consultants may fear appearing "morally deficient." This might happen when they challenge the practice of respecting a patient's autonomy, such as in the following case.

A patient who was competent needed a heart operation to remain alive. His heart problem either "seeded" small infarcts to his brain or he was stressed by being in the ICU. Whatever the cause, his mental clarity decreased. When asked, he did not say, however, that he did not want the operation on his heart.

Although the surgery was scheduled and he had been medically "cleared," at the last moment, because he did not meet the most rigorous standards of "being competent," his heart surgery was canceled. His heart got worse before a guardian was appointed. The surgery could no longer be performed and he died.

This case exemplifies what some have referred to as patients dying with their "rights on." Ethics consultants may have difficulty challenging a psychiatrist who believes, in cases such as this one, that a patient lacks self-determining capacity. This judgment is, however, an ethical as well as a clinical decision. Consultants may feel deterred from speaking up in a case such as this because they fear that if they challenge the value of autonomy, they will be seen by others as "less moral."

Recognizing Problems and Rectifying Them

Numerous clues can signal that emotions may be "warping" an ethics committee's deliberations so that appropriate objective analyses cannot take place. One such clue is inconsistency of opinion. Another clue is simultaneous conversations. The fact that members interrupt others at some times, but not at others may not be coincidental. And persons may incon-

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sistently try to silence others by referring to an authority, as if a well-known ethicist's view, e.g. that of Professor Childress, should be the last word. That this "last resort" effort is used in some cases but not in others again may not be coincidental.

Ethics consultants can and should watch for these and other manifestations of emotions "taking over." If this occurs, they can utilize the following guidelines. First, they can clarify the agenda of providers when they are called in to consult on a case. Second, they can encourage all parties involved in a consultation to speak up and share their views.

The most common reason why ethics consultants' interventions may fail as a result of emotional factors is because all persons haven't spoken. As the prior analysis indicates, "these silences" can result from persons fearing anger when they express marginal views, fearing that they will lose friends, and fearing that they will be judged morally deficient.

Consultants can and should, therefore, pick up on a person's partial and non-verbal responses so that they can encourage the person to state what they were saying or thinking more fully or explicitly. Consultants can also ask persons who have not spoken what they think.

Having all persons speak, of course, takes time. Ethics consultants should be aware, therefore, that unless they can allow adequate time, the success of their consultations is likely to decrease.

Finally, consultants can and should "monitor" their own feelings. They should consider the possibility that any emotion they are feeling reflects at some level, conscious or unconscious, what others are feeling. This inference is based on the assumption that we all, at some level, have emotional responses that are more or less alike. By identifying one's own feelings and asking how they may have come to be, ethics consultants can recognize feelings that are not being recognized

or expressed by others. Rather than relying on others to express their views fully, consultants can take remedial measures by themselves to steer the discussion "back on the right track." They must first monitor their own emotions. If they recognize a distinct feeling which no one has expressed, they should express it themselves. Once the feeling has been articulated and the emotional intensity lessens, the consultant will know that the group is more likely to be on the "right track."

Edmund G. Howe, MD, JD
Professor of Psychiatry, U.S.U.H.S.
Department of Psychiatry

Endnotes:

- 1) Edmund G. Howe, "Possible Mistakes," *The Journal of Clinical Ethics* 8 (4): 323-328, Winter 1997.
- 2) J. R. Muhm, et al., "Lung Cancer Detected During a Screening Program Using Four Month Chest Radiographs," *Radiology* 148:609-615, 1983
- 3) *Canterbury v. Spence*, 464 F. 2d 772 (D.C. Cir 1972)
- 4) *Cobbs v. Grant*, 502 P. 2d 1 (Cal. 1972)
- 5) P.S. Ciechanowski, et al., "The Patient-Provider Relationship: Attachment Theory and Adherence to Treatment in Diabetes," *American Journal of Psychiatry* 158(1): 29-35 (2001).

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, 515 W. Lombard St., Baltimore, MD 21201-1786.

Case Study From A Virginia Hospital

Mr. O., a 94 year old nursing home resident with history of dementia for several years, was admitted to the CCU at a Virginia hospital with congestive heart failure. On admission, he was found to have respiratory distress and was intubated. Examination showed sub-optimal function of other organ systems including renal failure. Mr. O. had no living relatives and health care decisions were made by a court appointed guardian. This guardian gave permission for dialysis and Mr. O. had a central venous catheter placed and was dialyzed once. Kidney function gradually returned and Mr. O. was restored to his previous state of renal insufficiency without need for dialysis. Mr. O. was transferred to the Intermediate Care Unit (IMC) and remained there for several weeks. It was not possible to wean him from the respirator. He remained neurologically impaired and was maintained on tube feedings. Physicians discussed the placement of a tracheostomy and a gastrostomy tube. Nurses in the IMC requested an ethics consult to discuss futility of care. Dr. V., as the ethics consultant, attempted to contact the court appointed guardian and was unsuccessful. The attending physician was also unable to contact the guardian after numerous attempts. Dr. V. reviewed the chart and recommended that further efforts be made to contact the guardian since he was the only person authorized to speak for the patient. Finally the guardian was contacted. He insisted over the phone, without coming to see the patient, that he should have a tracheostomy and a gastrostomy. He said several years prior to admission, before Mr. O. became demented, Mr. O had said he wanted "everything done" in medical emergencies.

As the ethicist for this case how would you respond?

Comments From a Bioethicist

The story of Mr. O is a sad and all too common one. No plans have been made regarding medical decision-making for this gentleman as his health changed and, most likely, deteriorated over time. Mr. O is a 94 year old, demented (for several years), nursing home resident with no living relatives. His health is not—and has not been—good as is evidenced by the fact that he was admitted to the hospital with congestive heart failure (CHF), renal insufficiency and suboptimal function of other organ systems. Ideally at some point along the way—hopefully when Mr. O was still able to participate in decision-making—it would have occurred to someone to address advance care plans with or for Mr. O. But this didn't happen, and now we find Mr. O in his current situation.

Since it is not possible to change the past, we must consider how to proceed from this point on. Mr. O does have a court-appointed guardian. It is not clear exactly how involved this guardian has—or has not—been in Mr. O's life in the past. He appears to have limited information about Mr. O's previous wishes regarding medical treatment; however, this information is apparently quite old and of debatable validity. The guardian asserts that several years prior to admission, before Mr. O became demented, Mr. O stated (to whom and under what circumstances we don't know) that he wanted "everything done" in medical emergencies. It is questionable whether this alleged statement is a clear indication that given his current state, Mr. O would want continued aggressive interventions. Without additional information, it appears fair to say that we don't really know what Mr. O's wishes are.

Thus, it is the responsibility of those making decisions for Mr. O to make them on the basis of a "best interest" standard. Although the case history

does not give specific information about Mr. O's prognosis, it seems fair to assume from the information provided that the likelihood of a meaningful recovery to a state in which Mr. O would be able to participate in and enjoy his life is minimal at best. He is ventilator-dependent, neurologically impaired and has significant chronically-debilitating conditions including CHF and chronic renal insufficiency. If, in fact, further medical intervention—including a tracheostomy and a gastrostomy tube—cannot provide a meaningful benefit to Mr. O and is, instead, only serving to prolong the process of dying, then it would not seem to be in Mr. O's best interest to continue to provide it. What would appear to be in Mr. O's best interest would be the provision of palliative care in an attempt to make whatever time Mr. O has left as comfortable as possible.

Were I the ethicist in the case of Mr. O, my recommendation—for the reasons mentioned above—would be **not** to place the tracheostomy and gastrostomy tube, to discontinue all aggressive medical interventions, and to provide only those treatments which enhance Mr. O's comfort. I would further insist that Mr. O's guardian make himself available (preferably in person) to discuss these issues and Mr. O's further treatment with the care team. As Mr. O's appointed decision-maker, it is the guardian's responsibility to make the best decisions possible on Mr. O's behalf. In order to do that, he needs to have accurate medical information **and** he needs to consider what Mr. O's wishes were regarding health care or, if these are not known, what would be in Mr. O's best interest. The guardian does not appear to have done this to date thus calling his appropriateness as a surrogate decision-maker for Mr. O into serious question. If the guardian remains unavailable or unwilling to discuss the specifics of Mr. O's current situation (i.e., his extremely poor prognosis) with the care team, then it may become necessary to go back to the judge who appointed him and have the

judge either remind the guardian of his responsibility to the patient or even appoint another guardian. Mr. O is not able to speak for himself and needs someone to make decisions about what is best for him. If the guardian is unwilling or unable to do this, then someone else must. The health care team needs to bring the current guardian's lapse to the judge's attention so that appropriate measures can be taken.

Sadly, there is nothing that medicine can do at this point to cure Mr. O or return him to a level of meaningful function. However, we can do a great deal to enhance his comfort and minimize his ongoing suffering. Decisions about his ongoing care should be made for him by someone who understands this and who will strive to emphasize these goals. Mr. O deserves this.

Sue Edwards, PhD

Assistant Director, Center for Ethics
Washington Hospital Center

Comments From a Nurse Attorney

This case presents several related legal and ethical questions. They are addressed below.

What is the ethical duty of the health care provider when the fiduciary fails to act in accordance with his/her legal duties?

In VA Code Ann. §37.1-137.1, the duties of a guardian are defined.

"A guardian stands in a **fiduciary*** relationship to the incapacitated person for whom he was appointed guardian . . .

. . . A guardian shall maintain sufficient contact with the incapacitated person to know of his capabilities, limitations, needs, and opportunities. The guardian shall visit the incapacitated person as often as necessary.

A guardian, in making decisions, shall consider the expressed desires

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and personal values of the ward to the extent known, and shall otherwise act in the ward's best interest and exercise reasonable care, diligence and prudence."*

As a court-appointed fiduciary, the Guardian must answer to the court for his/her conduct. This Guardian was difficult to reach and refused to visit the patient. His information on Mr. O's wishes regarding medical treatment is reported to be based on a statement overheard several years ago. The facts do not indicate that the Guardian ever had discussions with Mr. O prior to his dementia or that the Guardian has since made reasonable inquiry into what Mr. O's wishes would be based on the deterioration of his medical condition. Health care providers cannot ethically allow the lack of diligence of any surrogate decision-maker to interfere with the care of the patient.

The Guardian's actions demonstrate some deficiencies in his/her fiduciary duties. Health care providers cannot permit such conduct when they believe that the needs of the Ward, Mr. O., are unmet. The hospital must insist that the Guardian review the case closely in light of the dramatic changes in the condition of the patient.

The health care provider should ask the Guardian whether or not he/she is prepared to make all necessary decisions, based on the best interests standard. The problem may be that the Guardian is unable and unwilling to make "life and death" decisions, in which case, the Guardian must be asked to resign or should be removed.

Legally, what can the health care provider do in such a situation?

Two legal solutions to the situation could be pursued. First, the health care provider can petition the Court to remove the present Guardian and appoint a successor. (In the District of Columbia, this proceeding can be initiated by a letter to the probate judge setting out the facts and asking for a hearing.) An order to appear at a

hearing on the issue will get the attention of the Guardian, especially if he/she is an attorney, and the issues can be presented to the Judge.

Second, if the Guardian resigns or is removed, Virginia also has a specific provision of Guardianship law at 37.1-134.21. (Effective until July 1, 2001) which provides for judicial authorization of the provision, withholding or withdrawal of treatment and detention of certain persons. Such an order will be made only where there is no legally authorized person available to give consent. So, if Mr. O's Guardian is removed or resigns, the Judge can conduct a hearing and make a decision in this matter.

An appropriate circuit court, or judge as defined in §37.1-1, "may authorize on behalf of an adult person, in accordance with this section, the provision, withholding or withdrawal of a specific treatment or course of treatment for a mental or physical disorder, if it finds upon clear and convincing evidence that (i) the person is either incapable of making an informed decision on his own behalf or is incapable of communicating such a decision due to a physical or mental disorder and (ii) the proposed action is in the best interest of the person."

Any person may request this authorization by petition. An evidentiary hearing will be held with notice to all interested parties and the Ward. Mr. O will be represented by counsel. The Court can maintain ongoing control of the case and require reports on changes in the condition of the Ward.

Does the Virginia health care provider have a duty to provide futile care?

The ethics committee should review the case in light of the now apparently permanent nature of Mr. O's deficits and the need for a permanent tracheostomy and gastrostomy tube placement. If the recommendation of the committee is that these procedures are appropriate and the Guardian has insisted and consented to them, the procedures should be carried out.

However, given Mr. O's age, the nature of his deficits and the proposed

treatments, the ethics committee might well recommend that aggressive medical treatments, including the proposed procedures, be withheld and/or withdrawn.

Several sections of the Virginia Code deal with the issue presented here.

At §54.1-2982, "Life-prolonging procedure" means any medical procedure, treatment or intervention which (i) utilizes mechanical or other artificial means to sustain, restore or supplant a spontaneous vital function, or is otherwise of such a nature as to afford a patient no reasonable expectation of recovery from a terminal condition, and (ii) when applied to a patient in a terminal condition, would serve only to prolong the dying process.

"Terminal condition" means a condition caused by injury, disease or illness from which, to a reasonable degree of medical probability a patient cannot recover and (i) the patient's death is imminent or (ii) the patient is in a persistent vegetative state.

Section 54.1-2990 specifies when medically unnecessary treatment is not required, it states that "nothing in this article shall be construed to require a physician to prescribe or render medical treatment to a patient that the physician determines to be medically or ethically inappropriate."

The Virginia statute and case law, however, provide contradictory direction to the physician which severely limits or curtails the ability to withhold or withdraw futile treatments.

How does the "14 day" rule affect the physician's right to refuse to provide inappropriate care?

Section 54.1-2990 specifies the procedure to be used when a physician refuses to comply with an advance directive or a designated person's treatment decision.

In such a case, "if the physician's determination is contrary to . . . the treatment decision of a person designated to make the decision . . . , the physician shall . . . inform the patient or the patient's designated decision-maker of such determination and the reasons for the determination. If the

conflict remains unresolved, the physician shall make a reasonable effort to transfer the patient to another physician who is willing to comply with the terms of the advance directive. **The physician shall provide the patient or his authorized decision-maker a reasonable time of not less than fourteen days to effect such transfer. During this period, the physician shall continue to provide any life-sustaining care to the patient which is reasonably available to such physician, as requested by the patient or his designated decision-maker.**"*

In addition to the Guardian's apparent failure to maintain current contact with the patient, the Guardian's statement that the decision to treat Mr. O is based on Mr. O's statement that he wanted everything done in medical emergencies. The current situation is not one of an emergent nature. The proposed procedures and ongoing treatment are of a chronic nature. The Guardian has not addressed the issue of Mr. O's wishes for chronic treatment or life-prolonging treatment as is being proposed.

The Virginia statutes state that medically or ethically inappropriate treatment is not required. As a practical matter, however, the statutes only authorize the physician to transfer the patient to another physician, (not to withhold or withdraw the care) when there is a conflict with a decision-maker. Moreover, the "14 day" rule, effectively requires two weeks of inappropriate treatment while the surrogate arranges for such transfer. The transfer to another physician does nothing to address the underlying question of the medical and ethical appropriateness of the treatment.

Furthermore, two well known cases from Virginia courts provide results that conflict with the statute.

In *In re Baby K*, 16 F.3d 590 (4th Cir.), cert. denied, 513 U.S. 825, 115 S. Ct. 91, 130 L. Ed. 2d 42 (1994), the court held that specifically, "to the extent this section [§54.1-2990, VA Code Ann.] exempts physicians from providing care they consider medically or ethically inappropriate, it directly

conflicts with the provisions of the Emergency Medical Treatment and Active Labor Act (42 U.S.C. '1395dd) that require stabilizing treatment to be provided; therefore, to the extent that this section applies to medical treatment decisions on behalf of infants and to the extent that this section exempts treating physicians in participating hospitals from providing care they consider medically or ethically inappropriate, it was preempted and did not allow the physicians treating Baby K to refuse to provide her with respiratory support."

Perhaps the one bright spot in Virginia is that since the Finn case, we know that political interference in such matters is not favored by the Courts.

In *Gilmore v. Finn*, 259 Va. 448, 527 S.E.2d 426 (2000), Virginia's governor filed two lawsuits to permanently prevent Michelle Finn from withdrawing nutrition and hydration from her husband, Hugh, who was in a persistent vegetative state. In a supportive "informal declaration" by twenty members of the Virginia General Assembly, the delegates asserted that food and water should not be denied where removal will cause death. The court found in favor of the wife. In denying the governor's request, the court found that Virginia's Health Care Decisions Act gave the wife the authority to make such decisions for her spouse and that such withdrawal was not a mercy killing or euthanasia.

Conclusion

When a fiduciary or surrogate decision-maker fails to perform his or her duties in making health care decisions for a patient, the health care providers have an ethical duty and legal remedies available to them which must be pursued. Such options will differ according to individual state law. The ethicist should be sure that legal counsel is consulted in this case as the various options are pursued.

Andrea J. Sloan, J. D., R.N.
Attorney in Private Practice
McLean, VA.

* Emphasis added.

MARYLAND ATTORNEY GENERAL'S NEW OPINION ON WITHDRAWAL OF FEEDING TUBES

In a recent legal opinion to the Secretary of Aging, the Attorney General provided guidance about the standards applicable to decisions to withhold or withdraw a feeding tube, particularly when a patient has advanced dementia. The opinion discussed the various decision-making methods available under the Maryland Health Care Decisions Act.

On a preliminary matter, the Attorney General pointed out that a health care provider has a legal duty to refrain from inserting a feeding tube so long as a patient can be fed by mouth "with reasonable efforts." The Attorney General explained that efforts to spoon feed become unreasonable when they are "so painstaking and time-consuming as to defy common sense" or when "the goal of achieving adequate nutritional intake by mouth is no longer realistically achievable." What is prohibited, the Attorney General wrote, is to resort to tube feeding for reasons unrelated to the patient's clinical situation, like higher levels of reimbursement.

Once the issue of tube feeding is presented clinically, the opinion noted, the Health Care Decisions Act authorizes tube feeding to be withheld or withdrawn on the basis of an instructional advance directive, after certification that the patient is in a terminal or end-stage condition or persistent vegetative state; by a health care agent, without certification of condition unless the advance directive appointing the agent requires it; or by a surrogate decision-maker, again after certification that the patient is in one of the three conditions noted above. In this regard, the opinion noted that advanced dementia meets the Act's definition of "end-stage condition."

The portion of the opinion that may be of greatest interest is its application of the Act's "medically ineffective treatment" provision to tube feeding. Under this provision, a patient's attending physician (with the concurrence of a consulting physician) may decline to provide a treatment that is ordinarily life-sustaining in nature if, in a particular case, the treatment would neither contribute to the health or comfort of the patient nor prevent the patient's impending death. The opinion pointed to recent studies suggesting that, in cases of advanced dementia, tube feeding might meet the Act's definition. While disclaiming any intention of using a legal opinion to state clinically relevant criteria for determining the medical ineffectiveness of feeding tubes, the opinion affirmed that a physician is authorized to reach this conclusion about the use of a feeding tube "based on the condition of the patient, in light of the physician's experience and pertinent information in the medical literature." It is noteworthy that, in an article published after the issuance of the opinion, a leading ethicist, after reviewing the literature, concluded that the benefits of tube feeding for patients with advanced dementia are "illusory," while the burdens are greater than many realize. Stephen G. Post, "Tube Feeding and Advanced Progressive Dementia," *Hastings Center Report* 31, no. 1 (2001): 36-42.

This opinion of the Attorney General, signed by Attorney General J. Joseph Curran, Jr. and Assistant Attorney General Jack Schwartz, was issued on November 16, 2000. It is available at <http://www.oag.state.md.us/Healthpol/index.htm>.

ETHICS COMMITTEES AND PAIN MANAGEMENT

An ethics consult is called to review a daughter's request that a Do Not Resuscitate (DNR) order be written for her mother, a 75 year old woman with dementia who was transferred to the hospital from a nursing home for treatment of sepsis. The daughter believes that her mother should be kept as comfortable as possible, and not undergo invasive procedures like cardio-pulmonary resuscitation. The ethics consult team focuses mostly on the issue of the DNR order. However, one member of the ethics consult team, picking up on various cues, asks the patient's daughter whether she believes the patient is currently experiencing pain. "Yes. I'm glad you brought that up!" the daughter exclaims. Another family member joins in—they tell of how at the nursing home the patient had been wincing and moaning as if she were in pain, particularly after the dressing was changed on the large wound on her sacrum. The nursing home staff had not addressed this pain, nor had the ICU staff at the hospital where the patient currently resided ("they said pain medication would interfere with her vital signs"). One of the suggestions, then, of the ethics consult team was that the staff should perform a thorough pain assessment (or perhaps, consult the pain team) and administer pain medications if needed so the patient would be as comfortable as possible. The family members were grateful that this was addressed and prioritized.

Pain management and ethics committees—what's the connection?

This case highlights several issues related to pain management and ethics committees. The first is that there is still a ways to go to ensure that pain

assessment is performed routinely in health care facilities. Although hospitals and other health care institutions have mechanisms in place to comply with the new Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) standards on pain management, continued vigilance and evaluation of these mechanisms is needed to ensure that they are providing the most effective pain management possible for all patients in pain. Ethics committee members should be a part of this process. They are often called upon to help family members and health care providers make decisions about what types of medical treatments to implement, withhold, or withdraw. Balancing the benefits and burdens of treatments involves assessing the degree of pain a patient may be experiencing, and identifying options for palliation of that pain (Rich, 2000). In addition, family members' perceptions of the patient's suffering should also be considered, especially when the patient is a child, a cognitively impaired adult, or someone close to death. The ethics consult team, ethics consultant, and/or ethics committee member helps promote the patient's good by advocating to ensure that pain has been adequately addressed. In this sense, attending to pain is a moral obligation of all members of the health care team, ethics committee members included. This may require requesting the consultation of a pain specialist if those taking care of the patient, or those involved in the ethics consult, do not have sufficient expertise to effectively assess and treat the patient's pain.

Pain in the cognitively impaired

In addition to highlighting the need for continued improvement and monitoring of current mechanisms to address pain management, the above case highlights the challenge of assessing pain in patients who are cognitively impaired. Although strategies have been developed to assist staff in assessing pain in cognitively impaired patients (e.g., various pain rating tools, behavior assessment, and obtaining input from

care providers and family), staff may not be aware of these strategies, or may erroneously assume that patients who are mentally impaired do not experience pain.

Pain in persons addicted to narcotics

Another area that ethics committee members and ethics consultants should be clued into is the mismanagement of pain in individuals who had or have an addiction to narcotics. Assumptions are often made that such individuals are merely drug-seeking and do not actually have pain. Yet, the incidence of individuals who feign that they have pain merely to get prescription pain medications is dwarfed by the incidence of undertreatment or inappropriate treatment of individuals who have a drug addictions history *and* have pain. The latter, who may or may not still be using street drugs, often need higher doses of pain medications for their pain to achieve relief—this does not mean that they are “drug-seeking.”

The examples given above are indicative of areas where health care professionals need continued education and mentoring in pain management. Targeting what ethics committee members should know, below are some myths about pain management, along with corresponding facts.

Myths and facts

1. Myth: Narcotics are only given to terminal cancer patients – they are not the drug of choice for chronic, non-terminal pain. **Fact:** Although some non-opioid medications have been effective in treating certain types of nerve-related pain, opioids such as oxycodone and its long-acting form “Oxycontin,” and morphine and its long-acting form MS Contin, and other opioids, may be needed to effectively manage chronic non-terminal pain. These opioids are often given in conjunction with other medications, such as non-steroidal anti-inflammatory drugs.

2. Myth: The risk of addiction to pain medications increases the longer one continues taking them. **Fact:** Although individuals become *physi-*

ologically dependent on prescribed narcotics taken for pain on a long-term basis (e.g., they will experience physical withdrawal symptoms if they abruptly stop taking them), only a small number, less than 1%, become psychologically addicted (e.g., take the narcotic for the “high,” not the pain relief).

3. Myth: It is likely that continued increasing of a patient’s dose of narcotics to relieve pain will cause fatal respiratory depression, although this is justified by the doctrine of double effect. **Fact:** Individuals develop a tolerance to the respiratory depressant effects of opioids rather quickly. If the dose of an opioid is increased in response to the symptoms of unrelieved pain, it is very rare that death is hastened. Studies have shown no difference in time to death of individuals who received high-dose morphine, or morphine after terminal ventilator withdrawal, than those receiving lower-dose morphine, or no morphine after ventilator withdrawal (Bercovitch, Waller, & Adunsky, 1999; Campbell, Bizek, & Thill, 1999; Thorns & Sykes, 2000).

4. Myth: If a physician writes excessive prescriptions for narcotics, this will trigger a review by the Federal Drug Enforcement Agency or the State Board of Physician Quality Assurance. **Fact:** Disciplinary or legal action for “overprescribing” opioids, although highly publicized, rarely occurs.

5. Myth: Women receive the same treatment for their pain as men. **Fact:** Studies have shown that, although women have a higher incidence of pain-related syndromes and report higher levels of pain than men, women’s pain is treated less aggressively than men’s pain, and women are more likely to have their pain reports attributed to their emotions (Hoffmann & Tarzian, 2001).

6. Myth: If patients have pain, they will ask for medication. **Fact:** Patients often do not tell health care professionals that they have pain—assumptions are often made that pain is a normal part of surgical recovery, or aging, and that all is being done that could be done, or that the health care

provider can tell when someone is in pain. Staff cannot assume a patient does not have pain simply because the patient has not complained of pain.

JCAHO’s pain management standards

A summary of JCAHO’s standards for treatment of pain are set forth below. Ethics committee members can do their part to keep health care facilities on track with compliance with these standards—not for the sake of compliance per se, but for the good of the patients served. Components of the new standards call upon health care facilities to:

- Recognize the right of patients to appropriate assessment and management of pain
 - Assess the existence of pain, and, if found, the qualities and intensity of pain in all patients
 - Assess pain initially and reassess after pain management interventions
 - Determine and assure staff competency in pain assessment and management, and address pain assessment and management in the orientation of all new staff
 - Establish policies and procedures which support the appropriate prescription or ordering of effective pain medications
 - Educate patients and their families about effective pain management
 - Address patient needs for symptom management in the discharge planning process.¹

Anita J. Tarzian, PhD, RN,
Education Chair & Research Associate
The Maryland Health Care Ethics
Committee Network

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Hoffmann, D.E. & Tarzian, A.J. (2001, in press). The girl who cried pain: A bias against women in the treatment of pain. *The Journal of Law, Medicine, & Ethics*.

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Endnote:

1) From "Joint commission focuses on pain management," August 3, 1999, news release @ www.jcaho.org/news/nb207.html, p. 1.

ETHICS NETWORKS FROM AROUND THE WORLD

In this issue we report on a Network not in the Mid-Atlantic region but still close-at-hand. Jacqueline Glover, Associate Director of the Center for Health, Ethics and Law at the University of West Virginia and Editor of the WVNEC Newsletter has provided the following information on the West Virginia Network.

The West Virginia Network of Ethics Committees (WVNEC) was founded in 1988 with the mission to educate health care professionals, institutions and the public about ethical issues in health care; to serve as a resource for them in analyzing ethical issues; and to assist health care institutions to start or strengthen ethics committees. The WVNEC newsletter, published quarterly, includes the following mission statement in each issue - *Improving patient care in West Virginia by promoting respect and compassion*. The WVNEC membership has recently voted to add Palliative Care to its mission. The WVNEC membership includes 65 institutions (40 hospitals, 16 nursing homes, 2 home health agencies and 7 hospices) and 32 individual members.

In addition to a quarterly newsletter, the WVNEC offers an annual educational symposium and biannual forums on current relevant ethical issues and a summer intensive course on ethics consultation. The WVNEC is governed by an advisory board consisting of six elected members. One member is from each of the following constituencies: hospitals, nursing homes, home care, and hospice plus two at-large members. The advisory board chooses the president, vice president, secretary and treasurer. The WVNEC is supported by the faculty and staff of the Center for Health Ethics and Law at West Virginia University and is housed at WVU's Robert C. Byrd Health Sciences Center in Morgantown, West Virginia.

The West Virginia legislature in 2000 passed the West Virginia Health Care Decisions Act that replaced their Natural Death Act, the Medical Power of Attorney Act and the Health Care Surrogate Act. The WVNEC and the Center for Health Ethics and Law were instrumental in the passage of this new health care legislation. This new law, which became effective on June 10, 2000, is comprehensive and eliminates the discrepancies and problems that existed among the old laws. Some 20 other states, including Maryland, have such comprehensive health care decisions acts. If you are interested in more information on West Virginia's health care decisions act go to www.wvethics.org. This is also a good place to find out more about WVNEC.

Network News

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provided by the Bioethics Visitors Panel was invaluable because the information provided to the Judge would not have otherwise been available.

Among the cases they cited was that of an individual who had been in St. Elizabeth's Hospital for forty years, and had had a prefrontal lobotomy. When his physical condition had deteriorated dramatically, the Guardian was asked about withdrawal of ventilator support. After the Bioethics Consultation, the Judge wrote a lengthy opinion regarding

substituted judgment and allowed the Guardian to make such a decision. In another case, after a Bioethics Visitors Panel report, a guardian was allowed to make the decision to stop feeding a 40-year old man who had been in a persistent vegetative state for eight years.

Ms. Sloan indicated that in recent meetings with the new Probate Judges, Kaye K. Christian and José López, they have indicated a serious interest in training their colleagues, especially for Judge-in-Chambers decisions, and in training guardians about their responsibilities under the law. Ms. Sloan said that additional meetings are being scheduled to plan these training sessions.

Virginia Healthcare Ethics Network (VHEN)

The Virginia Healthcare Ethics Network (VHEN) has been involved in the formation of a statewide organization to address end-of-life and palliative care in the state. The Virginia Palliative Care Partnership, formed in mid-December, includes the three academic health centers in the state, health care professionals, hospices, hospitals, nursing facilities, health care associations, and community groups. The Network is working to secure funding and has organized a steering committee and task forces to evaluate and improve care of the dying patient. Task forces will address public education, health professional education, policy at the state level, research and outcomes, support systems, and strategic planning for the group. The VHEN is excited to be involved in this project to improve care at the end of life in Virginia.

CALENDAR OF EVENTS

April

- 27-28 "Spirituality and Healing," Health Science Center, West Virginia University, Morgantown, WV. Co-sponsored by the Program for Integrative Medicine, School of Nursing, and School of Medicine. Fee - \$145, Friday \$95, Saturday \$50, drumming ceremony \$10. For further information call 304-293-3937 or cme@wvu.edu.
- 27-28 "Physician Assisted Dying: Assessing the State of the Debate" Minneapolis, Minnesota. Sponsored by the University of Minnesota's Center for Bioethics. Fee - \$100. For further information call 1-800-776-8636 or visit website at www.bioethics.umn.edu.

May

- 3 "7th Annual Faith, Ethics, and Healthcare Conference." Georgetown University Medical Center, Washington, DC. Sponsored by the Center for Clinical Bioethics. Fee of \$30 includes lunch. For further information contact Marti Patchell 202-687-1671 or patchelm@georgetown.edu.
- 4-5 "The Ethics of Managed Care: Professional Integrity and Patient Rights," Kansas City, Missouri. Sponsored by The University of Missouri-Columbia. Fee - physicians \$300 others \$200. For further information contact Elaine Rogers at 573-882-9973 or rogerse@health.missouri.edu
- 8 "Informed Consent in Cancer Clinical Trials: Practical Issues and Considerations" Howard University Cancer Center, Washington DC. 4:00 p.m. Co-sponsored by Howard University and Metropolitan Washington Bioethics Network. For further information contact Joan Lewis at 202-682-1581.
- 11 "Spirituality in Health Care: A Training Program for Professionals," University of Virginia, Charlottesville, Virginia. Sponsored by The Center for Biomedical Ethics. Fee - \$150. For further information call 804-924-5974.
- 21 "Ethical Issues in the Health Care of the Elderly: An Update," Morgantown, West Virginia. Sponsored by the West Virginia Network of Ethics Committees in conjunction with a week long conference of the West Virginia Health Care Association. For further information contact Linda McMillen at 877-209-8086 or lmcmillen@hsc.wvu.edu.

June

- 1-2 "Ethics Oversight at the Frontiers of Biomedical Research," Chicago, IL. Sponsored by University of Illinois at Chicago. For further information check webpage at www.researchethics.org or call 312-996-1175.
- 5-10 "Bioethics Beyond the Sound Bite: Intensive Bioethics Course XXVII." Sponsored by the Kennedy Institute of Ethics, Georgetown University, Washington, DC. Fee - \$1,400. For further information call 202-687-8099 or e-mail kicourse@georgetown.edu
- 15 "Two Topics in End-of-Life Care: African American Perspectives and Conflict Resolution," Franklin Square Hospital, Baltimore, MD. Co-sponsored by Maryland Health Care Ethics Committee Network and the Franklin Square Hospital Ethics Committee. For further information contact Anne O'Neil at 410-706-4457 or aoneil@law.umaryland.edu or Carol Miller at 443-777-7541 or carolmi@helix.org.

July

- 19-21 "Intensive Course in Palliative Care," Canaan Valley Resort and Conference Center, Davis, WV. Sponsored by the West Virginia Initiative to Improve End-of-Life Care. For further information call 304-293-7618.

