

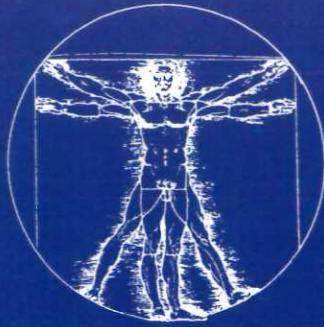
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 1997*

Mid-Atlantic Ethics Committee
Newsletter, Spring 1997

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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
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COMMON MISTAKES IN ETHICS CONSULTATIONS

This article is based on a presentation given by Edmund G. Howe, M.D., J.D. at the January 1997 meeting of the Washington Metropolitan Bioethics Network.

Ethics consultants often view themselves as offering only "recommendations." Yet, rightly or wrongly, careproviders may believe that if they violate these recommendations, they do so at their peril. For this reason, if ethics consultants' ethical leanings are flawed or biased, their interventions will be less than optimal.

In this article, I discuss three sources of errors ethics consultants may make and suggest how they may avoid them. Since persons in many areas of clinical care provide consultation, all of these persons subsequently are referred to as careproviders. A more extensive discussion of these errors can be found in two longer articles from which these comments are taken.^{1,2}

Erroneous Empirical Assumptions

Many ethical dilemmas involve careproviders making empirical inferences. A common example is careproviders making inferences regarding patients' capacity to take responsibility for themselves. The need for this inference is unequivocal when patients' legal competency is

Letter From the Editor

We have used this edition of the Newsletter to share with our readers the diversity of issues being considered by ethics committees. Our Calendar of Events seems to grow with each issue—it is filled with a wide variety of events covering nearly every aspect of the field of ethics. Our feature article, written by a psychiatrist, discusses common mistakes made in ethics consultations and the effect they can have on patients. Our case study explores an emotionally charged issue faced by a nursing home which involves an interpersonal relationship, moral beliefs and fear. We would be happy to hear your comments and hope that you will share with us information on your own diverse experiences with ethical issues.

Diane E. Hoffmann

open to question, but careproviders sometimes make this inference, and base their actions on it, when patients are less impaired. In such instances, making an accurate inference is critical.

A common error careproviders may make is to attribute a greater capacity for self-determination to patients than they

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NETWORK NEWS

Baltimore Area Ethics Committee Network (BAECN)

The Baltimore Area Ethics Network met in February to discuss the new JCAHO organizational ethics standards with Paul Schyve, M.D., Senior V.P. for Standards, JCAHO. No further programs have been finalized at this time. For further information about the February meeting or upcoming events, please contact Jack Syme, M.D. at (410) 368-3020.

Washington Metropolitan Bioethics Network (WMBN)

The Metropolitan Washington Bioethics Network is now an officially incorporated not-for-profit organization led by a Board of Directors. Its program planning for the 1997 calendar year is fully underway. In January, Randy Howe, M.D., J.D., presented the "Three Deadly Sins of Bioethics Consultation," a story-telling presentation that sparked a lively and extended discussion. The February meeting focused on the integration of clinical and organizational ethics, with Robert Olson, Ph.D., M.P.H., Principal with *meta-ethics*, as the program speaker. His presentation addressed definitions of organizational ethics, the connections between clinical and organizational ethics, the strategies for their implementation, the benefits thereof, and the kinds of resources available to health care institutions attempting to integrate clinical with organizational ethics.

The programs for the remainder of the year include a presentation on the subject of guardianships (tentatively scheduled for March 25), a two-day program titled "When Cure Is Not an Option," (April 11-12), a discussion of issues in organ donation and transplantation (May 13), a seminar on social justice topics (June), a program titled "The Last Mile of the Way: Ethical

Management of an Ethical Death" (fall), and a review and discussion of the Nazi German plans leading to the Holocaust as relevant to the current interest in assisted suicide (fall). For further information on any of these programs, consult the **Calendar of Events** at the end of this newsletter.

Virginia Bioethics Network (VBN)

The Virginia Bioethics Network will sponsor a series of four educational workshops throughout Virginia in the late spring and early summer. The workshop, "Reflections and Decisions: Ethics in Hospice Care," will be held in Northern Virginia, Bristol, Winchester and Richmond. The three-hour program will begin with an overview of the development of bioethics as a field. Discussion will then center on issues particular to hospice care, including confidentiality, physician-assisted suicide, withdrawal of feeding and/or hydration, and the ethics of pain management. On completion of the program, participants will be expected to: 1) discuss the basic principles of bioethics as it relates to hospice care, 2) be able to identify potential ethical issues in hospice care, 3) be able to identify bioethical issues unique to the home care setting, and 4) be able to discuss strategies for handling the unique issues encountered when caring for dying patients in the home.

Edward M. Spencer, M.D., Director of Outreach at the Center for Biomedical Ethics, University of Virginia, and the Reverend Jeanne Brenneis, Director of the Center for Bioethics, Hospice of Northern Virginia, will act as faculty for the workshop. The fee for the workshop is \$25 and Continuing Nursing Education credit has been requested. Further details will be announced in the next issue of *Bioethics Matters*, published by the Center for Biomedical Ethics, and brochures will be available in April. For further

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Common Mistakes

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actually have. In my own experience, for example, I struggled for months to find just the right dosage of the right drug for a patient who had manic depressive illness. She finally told me that she had never taken any of the medication I had prescribed. This is not uncommon among patients with manic depression, in part because they find it so difficult to give up the experience of their "high." Still, I felt I had responded in a highly judgmental manner. I believe now that my response was inappropriate for many reasons, but principally because I assumed that she had a capacity which she lacked.

Careproviders may be particularly prone to this error with patients who suffer from addictions. For example, careproviders may turn inebriated patients away from emergency rooms because they believe that these patients can control their drinking. In reality, this may be careproviders only opportunity to meaningfully intervene. Careproviders may also exclude patients from reentering a rehabilitation program after they have relapsed because they believe that this would reinforce their addictions. Or, careproviders may deny patients optimal medical treatments because they believe that these patients will continue to use alcohol or drugs making the treatments futile. These assumptions, however, may not be correct.

The error these and similar false assumptions have in common is the tendency to oversimplify. No less an authoritative body than the U.S. Supreme Court has made this error. In determining whether persons addicted to alcohol have or lack control, the court concluded, basically, that if they have control some of the time, they must have control all of the time.³ The court failed to consider that there might be more complex possibilities. For example, these patients may have acquired conditioned responses to external or internal cues that trigger overwhelming urges to drink. These patients' difficulties are compounded because they do not know that these conditioned responses exist.⁴

Understanding how careproviders make these errors is important because it can occur in a wide range of other contexts. As an example, a patient with cancer was discharged from the hospital and missed her follow-up appointment. Her doctor called and left a message on her answering machine. She never responded. Most likely, she was substantially demoralized. She might have responded in a different way if he had talked with her in person.

How can careproviders attempt to avoid such oversimplification, especially when the complexities which exist may be beyond that which they have imagined? First, they can ask patients questions. When careproviders must decide whether or not to prescribe large amounts of medication to patients who are depressed (i.e., a three-month regimen), some do so based on the reasoning that if these patients want to take their lives, they will do so no matter what the careprovider does. Some patients report, however, that if careproviders do not give them a larger amount, they will be less likely to take an overdose. These patients say that when they have the desire to take their life, although this desire seems overwhelming at the time, it is short-lived. Thus, if lethal amounts are not available, they will not die.

Second, even after hearing what patients report, careproviders may need to relate the patient's statement to their own experience in order to accept it. For example, when patients with addictions state that they lack control, careproviders may need to recall a time they felt overwhelmed by an emotion seemingly outside of their control. The experience of falling in love, for instance, seems outside of a person's control. It is in large part what makes this theme so popular in literature.

Unwarranted Moral Bias

Careproviders may also unwittingly respond to ethical dilemmas on the basis of personal moral bias. They may not know that this is occurring and may rationalize their initial bias using a logic that appears air tight. Since their view will then appear logical, they may believe that it followed from their

reasoning. Such bias actually precedes reasoning.

I am also guilty of this error. A patient who is a psychiatrist asked me to help him find a way to convince his girlfriend who had children to allow him to spend the night with her. I was familiar at the time with an unusual but sometimes singularly effective intervention called paradoxical therapy in which the therapist may suggest something that does not seem to make sense to the patient. This suggestion may cause the patient to see the problem in a new way or help the patient to shift priorities in order to find some way to respond to the therapist.

Using this approach, I told him to accept his girlfriend's decision and, if this didn't work out, to give me a call. He didn't call.

Later, I reflected on how strange it was that I had responded in this manner. Normally, I would have taken a conventional approach, such as asking him if there was a way he could respect her needs as well as his own. I suspected that I had felt a moral bias against his request but had not been aware of it at the time. The process of responding to a bias without knowing it and then rationalizing it is easier to identify in others than in oneself.

Another example involved a physician who argued against giving a patient with AIDS in his mid-thirties a trial of one of the new, sometimes most effective medications which recently have become available. It was clear from comments this physician had made in other cases that he believed he had some duty to protect society's resources. In this case, he argued against using a new drug solely on the basis of the patient's interest, arguing that the patient was much too ill to be likely to benefit.

The patient beseeched the physician to let him try it. When the physician's decision not to use the new drug was challenged by others, he added that it probably would not be effective because this patient was non-compliant. Previously the patient hadn't always taken his medications or taken them on

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Common Mistakes

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time. Prior to these new drugs becoming available, of course, the patient had had no hope.

The risk of responding to bias and then rationalizing it is illustrated by a careprovider's description of two highly similar patients he treated quite differently. One was a middle-aged woman who had cancer which, ultimately, was incurable but which may have responded significantly to chemotherapy. Her daughter, an adult, was devoted to her mother and pleaded with her mother's physician to try to convince her mother to prolong her life. This patient responded to her illness by becoming aggressive. She criticized the nurses and even reported one for chewing gum so loudly that she couldn't sleep. The nurses and, I suspect, her doctor disliked her. In response to the daughter's request, he said, "I've gone over all this with your mother once and she refused. There is no more I can do." He told the daughter that he believed approaching her mother again would violate her autonomy.

I was talking with this physician several months later about another patient he was treating. She, too, was middle-aged, had cancer, and had an adult daughter, but her prognosis was much worse. Also, her relationship with her daughter was much more distant.

This patient was, however, nice to everyone. The doctor told me he had tried many times to persuade her to accept chemotherapy, because this is what he would do for his mother. This patient, too, had refused. I asked him why he had tried so hard to persuade this patient, but not the other, to try chemotherapy, especially when the first one had a much better prognosis and relationship with her daughter. The physician looked stunned. He appreciated at that moment how his bias had determined his decision and that he had rationalized this decision to himself.

In each of these three cases careproviders could have "checked"

their behavior by attempting to discern whether they were acting inconsistently. In the case in which I was involved, I treated the patient inconsistently by using paradoxical therapy. The doctor treating the patient with AIDS was inconsistent because he saw the patient as being non-compliant even though the patient's request to let him try the new drug suggested that he would be as compliant as he could be. The physician treating the two patients with cancer treated them inconsistently by urging one, but not the other to try chemotherapy, despite the similar morally relevant features of their situations. When careproviders discern that they are acting inconsistently, they should presume that they may be acting on the basis of bias until they can determine otherwise.

Meeting Careproviders' Needs

The risk that careproviders may respond to their personal bias without knowing it is increased when their needs are at stake. I shall illustrate this circumstance with two examples: careproviders fearing that they will be sued and careproviders fearing that they will be censured by, and possibly, lose the affection of their colleagues.

An example in which careproviders may have responded to fear that they could be sued occurred when a patient who had a progressively worsening heart condition was scheduled to undergo cardiac surgery. This surgery was his only hope of survival.

In the ICU, because of his heart's condition or the environment, the patient sometimes became confused. Nonetheless, when asked if he wanted the surgery, he consistently responded that he did.

Just before the surgery, the patient signed the consent form. Another careprovider was asked to witness his signature. He refused because he thought that the patient was not sufficiently aware of what he was signing to be competent to give consent and that a guardian should be appointed to make this decision on the patient's behalf. Legally, the surgeons could have operated without the witness's signature, but they did not,

because they feared they could be sued.

It is worth noting, parenthetically, that the surgeons' rationale was not even legally sound. That is, the harm to the patient from the surgeons' not operating then was substantial and foreseeable. The patient's condition deteriorated rapidly until the surgery could not be performed. Legally, since the surgeons acted primarily to protect themselves and not the patient, their risk of being sued successfully was increased.

Although the patient died with his "rights on," as another commentator speaking of an analogous case said years ago,⁵ it was not the best outcome for the patient.

A case in which careproviders primarily responded to fear of their colleagues' censure and loss of affection involved a patient addicted to alcohol. The patient came to the hospital in a coma due to liver failure, and his careproviders believed that he would die. Since he was incompetent, his wife was asked whether she thought he would want CPR. She believed that he would not and his careproviders wrote a DNR order.

He survived and regained competence. He then revealed that he and his wife had not talked for years and that she was the last person he would want to make decisions on his behalf.

Even after he was discharged, the ethics consultants who had been involved in this case hadn't informed him that he could express this preference in an advance directive. I asked them, "How come?" They responded with incredulity, exclaiming that this was the last thing the *staff* would have wanted!

I must also confess guilt to making this error. When I asked "How come?" it had not occurred to me that his careproviders could have ensured that the patient's wishes were complied with by documenting his treatment preferences in his chart. That I had not considered this may have reflected my own bias or personal feelings of which I was unaware.

This possibility exemplifies the subtlety with which bias and fear can affect our ethical views. How then

might careproviders attempt to stop this from occurring?

One means is to pay attention to the intensity of careproviders' emotions when they discuss ethical issues. In the case above, the surgeons and person refusing to be a witness both were irate. Also, the ethics consultants expressing their incredulity were exceptionally excited when they responded. The intensity of these emotions may have reflected deeper underlying concerns on the part of the careproviders.

As I indicated, when careproviders encounter empirical possibilities different from those they previously have assumed, it may be necessary for them to take additional steps to truly believe their patients. Similarly, when careproviders have biases or their own needs are threatened, they may have to do more than merely recognize these influences to overcome them. They may have to experience sufficient empathy to enable them to overcome their bias or personal need. This may require that careproviders seek out someone more knowledgeable about certain kinds of patients or involve themselves more directly with their patients.

Yet, it may be just as important in some instances for careproviders to appreciate how their patients are different from themselves. The severe depression of patients who want to commit suicide may, for instance, differ qualitatively from the severe depression people commonly experience after a profound loss, such as that of a spouse. An addict's urge to use alcohol and drugs may differ qualitatively from the experience of persons who are not addicted.

In some cases, careproviders must pursue two paradoxical goals, simultaneously: acquiring empathy by finding ways in which they can identify with their patients, and acquiring understanding by appreciating how their patients may be different from themselves. While difficult, this may allow careproviders to make progress which otherwise would not be possible. In many contexts, patients may find it

difficult to imagine that their life could be meaningful again. Careproviders struggling to imagine how their patients may be different while simultaneously identifying with them may be experiencing a challenge similar to what their patients are facing. As a result, they may have an exceptional ability to acquire empathy for these patients.

by Edmund G. Howe, M.D., J.D.
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1. E.G. Howe, "The Three Deadly Sins of Ethics Consultation," *The Journal of Clinical Ethics* 7:99-108, 1996.
2. E.G. Howe, "Deadly Sins, Continued: Treating Patients with Addictions," *The Journal of Clinical Ethics* 7: 195-204, 1996.
3. *Powell v. Texas*, 392 U.S.514 (1968).
4. M.Keller, "On the Loss of Control Phenomenon in Alcoholism," *British Journal of Addiction* 67: 153-166, 1972.
5. D.Treffert, "Dying with Their Rights On," *The American Journal of Psychiatry* 130: 1041, 1973.

Case Presentation

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee and how the committee resolved it. 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: Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201-1786.

Case Study From a Nursing Home in Maryland

The patient is a 42 year old, C-5 quadriplegic residing in a nursing home. He is totally dependent on others for all activities of daily living and is very much into controlling how that care will be delivered. The resident came to this nursing home from another nursing home where he had established a friendship with a 50 year old woman with a disabling muscular disease. At their request, she relocated to the same nursing home and became his roommate. After several weeks, they began to talk to the staff about their wanting to be placed naked in bed together and then be left alone for a few hours. There were certain staff members who opposed this on moral grounds. The nursing home was concerned about safety issues since the two people involved did not have control over their motor skills. If one were to fall off the bed or become wedged between the side rail and mattress, there was potential for injury. The couple refused to consider placing the mattress on the floor and a double bed was out of the question because they did not actually want to sleep together all the time. Complicating the situation was the fact that the man was still legally married despite the fact he had not had contact with his wife for over 15 years.

Certain staff also voiced concern about the union because, in their judgment, the man was mentally abusive to the woman. The couple's request did not seem to stem from a true desire to have a loving, physical relationship, but to force the nursing home staff to comply with their request. The whole situation was very emotionally charged on both sides. The couple involved refused any type of sexual counseling or outside intervention. They were insistent that they had the right to do as they pleased and it was the nursing home's obligation to

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fulfill this right exactly as they demanded.

The nursing home staff felt they had the right *not* to be forced to comply with something they morally objected to, and that could be considered illegal since he would be committing adultery. The nursing home administration was concerned with safety and liability issues, as well as the possible scandal that could ensue should the community at large discover that the nursing home had been a party to this. The couple involved felt it was nobody's business but their own and the nursing home should find a way to accommodate their request without discussion or delay.

This case was turned over to the nursing home ethics committee.

Outcome

The nursing home ethics committee decided that the resident would have to get a divorce before the nursing home could comply. Even though adultery was not a prosecutable crime, the ethics committee considered it against the law. Therefore, the staff could not assist in an illegal act. Once a divorce was obtained, the nursing home would pay for an outside consultant to assist in the actual physical act. No staff member would be required to accommodate the couple if he/she did not want to be involved.

The problem was that the man could not obtain a divorce without the assistance of his sister who couldn't seem to find the time to process the paperwork. While this was being worked out, the man said he no longer wanted to room with the woman and was not interested in pursuing a relationship.

Case Discussion: Comments From a Nursing Home Administrator

Administrators of nursing facilities often find themselves in a quandary regarding the rights of an individual resident versus and the rights of other individuals, and versus legal responsibilities. No case is crystal clear, and judgements must be made.

Quite often when a "situation" develops, it is clouded by interpersonal relationships, emotions, moral beliefs and fear. Getting down to the basic issues takes some detective work. Separating fact from emotion is the first task of the administrator.

Most nursing facilities work hard to have policies in place that help to prevent conflict. Outside resources are often called on to help when conflict occurs. Ethics committees bring multiple perspectives to discussion of important issues.

Although the couple are apparently "two consenting adults" capable of making their own decisions, they are not able to carry out their own wishes. In this case, the residents had demanded to be placed naked in bed together and left alone. The facility (perhaps before considering the legality of the act) proposed ways to accomplish this. The couple refused these accommodations and other attempts to help the them. While there are rights given to each resident by law such as the right to make choices about aspects of life important to him or her, the residents must recognize that there are certain limitations imposed by residence in a nursing facility. These limitations reflect the responsibility accepted by the facility for the welfare of the resident, and the dynamics of living in a group situation. While nursing facilities work to be as "home-like" as possible, by nature nursing facilities are not "like home". Strict regulations impact almost every aspect of daily life.

Staff no doubt recognized how significant the need for control would

be in a 42 year old man totally dependent on others for his care. Such situations often result in "battles of will," where the resident may make unreasonable demands just to show his power to get a response, and staff may resist the most reasonable of requests to show "who is in charge." Confrontation can become the standard dynamic of interaction. No one wins. Consultation with a psychiatrist or psychologist might have been helpful to help the resident deal with his own physical limitations. Since the resident refused outside intervention, it might have been helpful for the staff to have consultation as they planned the resident's care.

The couple's demands were morally offensive to some staff members. While the staff must understand that they may not impose their moral values on others, the facility should not ask staff to participate in actions that compromise their moral or religious beliefs. This can often be accommodated by finding a willing staff person, or as proposed in this case, bringing someone in from the outside.

The facility has the responsibility to assure the safety of each resident. These judgments can become very complex, deciding what may or not be safe under certain circumstances. The facility will usually err on the side of caution. In some situations, residents might be asked to sign a document accepting responsibility for their actions, but in this case residents could not sign, and probably would not have agreed to involve their responsible parties. There is also some question as to how much liability can be waived in such a situation. Participation of a lawyer would have been essential in making those judgments.

The description of this case implies that there were difficult interactions with the resident before this specific incident, and the ombudsman could have been helpful both before and during this specific incident. An objective third party can often help to defuse the emotional tension surrounding the demands of the residents. A chaplain or visiting clergy can sometimes advocate for residents as well.

The ethics committee determined that the most significant issue at hand was the legality of the request, and was prepared to grant the couple's wish when that concern was eliminated. The ethics committee's decision probably would not have satisfied the resident had he continued to pursue the relationship. The facility may have wanted to assist him in finding an advocate to facilitate his divorce, as well as obtain a consultant to assist the resident to carry out his wishes.

I have found it helpful to:

- Have written facility policies that are made known to prospective residents before admission to clarify expectations and avoid problems after admission. This becomes particularly important when the prospective resident may have a lifestyle quite different from other residents, as when a much younger resident is admitted to a facility whose programs are designed to meet the needs of elderly residents. Our "marketing" instincts often prompt us to paint optimistic pictures of life in the facility, but we should be careful to be honest and open about what the prospective resident may experience and what he might reasonably expect.

- Encourage staff to closely monitor resident progress so that problems are identified early, and interventions can be put in place. The sooner a difficult issue is addressed, the more likely a positive outcome can be achieved. Tough situations rarely "go away" as in this case. This should include early discussion with the ethics committee when a potential ethical problem has surfaced, rather than waiting until a crisis occurs.

- Rather than attempting to resolve "symptoms," look beneath those symptoms to identify more basic issues that need to be addressed. A conflict situation might appear to be isolated, and staff may miss the messages contained in the interaction. Multidisciplinary care planning meetings are good opportunities to look for "trends" and "messages" in residents' actions so that the staff can work to understand and address the real needs, wants and desires of the resident.

- Have regular, structured staff education to prepare staff to deal with difficult situations and understand their roles and responsibilities. Nursing facilities are stressful work environments - most residents and families have multiple needs. Residents have longer lengths of stay than in acute care settings. Staff is called on not only to be technically competent but to relate effectively over long periods of time. It is not uncommon for relationships with staff to become primary for residents who do not have close family or friends. Education and supportive counseling for staff can help them to maximize their interactions with residents and families, and anticipate developing problems.

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Case Discussion: Comments From a Staff Attorney

The issue of residents wanting to have sex or having sex in a nursing home is always a charged issue. The general, if unspoken, feeling is that it is somehow unseemly for older people to have an interest in sex or to express such an interest. In this case, the residents are not old, but middle-aged and disabled. A similar discomfort stigmatizes disabled people.

A whole variety of reasons is put forward to oppose honoring these residents' request to be placed in bed together—it's immoral, the man is married to another woman, what if one of them is injured, he's mentally abusive. These concerns are not totally without merit; there is *some* valid point behind each of them.

A facility, for example, is legally responsible for the physical safety of its residents and needs to take actions to prevent placing its residents in dangerous situations. Similarly, a facility's responsibility to assure that

residents function at their highest practicable psychological level would require the facility to take steps to prevent one resident from mentally abusing another. If the man were married to another woman and had a form of dementia that made him incapable of understanding that he was acting in a sexual way towards a woman who was not his wife, and if this behavior was not the pattern of *his* lifetime, that would be another case. The facility would then be responsible to help him behave as he would behave if he understood what he was doing and could control his behavior. Finally, a staff member having personal moral objections to placing the couple together because the man was married to another has the right to be excused from assisting the couple, under the rationale of the Patient Self-Determination Act.

But there is nothing in the facts presented here to suggest that either resident is mentally incapable of understanding what is happening or of affirmatively choosing what he/she wants. The facts state only that two residents relocated together to the facility, share the room (the facility should be commended for allowing unmarried people to share a room), and now want to be placed in bed together sometimes and to be left alone for a few hours. These facts suggest a relationship of some duration between two consenting adults who are mentally capable of making choices and decisions. There are strengths in this relationship and positive factors in the couple's ability to make choices that the facility needs to nurture and support, not challenge in a power struggle. The fact that the couple is unable to *exercise* their choices without assistance should not be permitted to diminish their right to choose and to have their choices respected. Unfortunately, the stubbornness of the couple to have their wishes respected without further delay only intensifies resistance on the facility's side.

The facility needs to accommodate the couple's choices to the extent

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Case Discussion

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possible. In AIDS units, facilities have been able to accommodate residents' need and desire for privacy in sexual matters with the facility's need to perform medical and nursing functions in an institutional setting. In a negotiated compromise in one facility, residents agreed to refrain from sexual activity during certain agreed-upon hours when nursing and medical procedures were performed and staff agreed to respect residents' closed doors during other hours. A similar accommodation is necessary here.

The facility needs to accommodate the couple's autonomy and decision-making while promoting their safety to the extent possible—e.g., the facility needs to assure that the couple can reach the call bell when they are in bed together. But even if an unsafe condition were created, the facility needs to respect the couple's right to make choices, (even choices that the facility considers poor choices), to take some risks, and to reject medical advice.

Whether the relationship this couple has is a relationship that the staff approves of and would choose for themselves is not the point. Residents have the legal right under federal law to make choices about matters that are important to them and to have those choices respected. Facility staff may not paternalistically substitute their judgments for the judgments and choices of competent adults.

Finally, the facts in this case do not seem particularly difficult. The residents appear to be competent adults making decisions about personal matters. The facility staff is putting up unnecessary roadblocks and refusing to treat them as competent adults. Referring the "case" to the ethics committee seems inappropriate and unnecessary.

by Toby S. Edelman, J.D.

National Senior Citizens Law Center
Washington, D.C.

MARYLAND ATTORNEY GENERAL BEGINS PROJECT ON CARE OF THE DYING

In January of this year, the Office of Maryland Attorney General J. Joseph Curran, Jr. began a project on the care of the dying intended to identify and eliminate legal barriers to effective pain relief and other responses to the needs of terminally ill patients.

Announcement of the project coincided with the start of hearings by the Supreme Court of two cases in which terminally ill patients and their doctors challenged state law prohibiting physician-assisted suicide. Observers feel that the assisted suicide issue will divide the country as much as the abortion issue, and Curran conceived the project as a response to this inevitable polarization. Whatever the Supreme Court's decision, Curran says that the current system of caring for the terminally ill is inadequate and needs to be reevaluated and reformed.

Curran points to evidence that shows that in caring for the dying, pain is often not adequately controlled and patient wishes about the intensity of medical interventions are sometimes not heeded. He says, "...dying people do suffer needlessly. One major study of hospital intensive care units found that of those patients who died, half had moderate or severe pain during most of their last three days of life. Other studies show that although 95 percent of cancer patients could get relief from their pain with advanced pain management methods, nearly half do not get adequate pain relief. For these patients, assisted suicide is not the answer. It is humane, patient-centered care."

He adds that pain management is not the only problem. When patients do not want high-tech medical intervention at the end of life, studies show that doctors often fail to understand or carry out the patient's decision. Planning tools like living wills and other advance medical

directives too often do not achieve in practice their goal of honoring patient choice.

Curran has opposed physician-assisted suicide as a solution to these problems and has joined 18 other states in urging the Supreme Court to allow the states to decide the issue as a policy matter, and not to impose physician-assisted suicide as a federal mandate.

Specifically the "Care of the Dying" project will:

- examine legislation, such as laws on prescription abuse that are rightly aimed at controlling diversions of drugs for illegal use, to determine if they have the unintended effect of making doctors afraid to treat pain aggressively.

- insist that health maintenance organizations and others who provide managed care give priority to pain relief and comfort care.

- make sure that no regulatory barriers stand in the way of hospitals, nursing homes and other health care facilities that want to provide hospice-type care and consider how state law might create financial incentives for facilities to respond fully to the needs of the dying.

- reexamine Maryland's law on living wills and other advance directives to determine if they can be made more usable by patients and health care providers alike.

Assistant Attorney General Jack Schwartz, Chief Counsel for Opinions and Advice, is in charge of the project and will consult with patient advocates, health care providers, hospital and other facility administrators and state officials prior to Curran's issuance of legislative and other policy recommendations.

Curran says, "The status quo is unacceptable. So is a future dominated by bitter debate over assisted suicide. That debate is important, but it must not be allowed to block the common effort toward a shared goal: excellent end-of-life care."

Network News

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information, please call (804) 924-5974.

In November 1996, the Center for Biomedical Ethics at the University of Virginia sponsored a two-day conference, "Responding to the JCAHO Organization Ethics Standard: A Workshop." This workshop was intended to help health care organizations, particularly hospitals and nursing homes, understand the JCAHO's new Standards for Patient Rights and Ethics and develop response strategies appropriate for the individual health care organization. The conference featured a talk by Paul Schyve, M.D., Senior V.P. for Standards at the JCAHO, titled "What Is the JCAHO Trying to Do?" and a response thereto by Thomas A. Massaro, M.D., Ph.D., Chief of Staff of the University of Virginia Hospital, Director of Medical Affairs at the U.Va. Medical Center and Associate Dean for Clinical Affairs at the U.Va. School of Medicine. The transcripts of their talks are reprinted in the January 1997 issue of *Bioethics Matters*, a newsletter published by the Center for Biomedical Ethics. For a copy of the newsletter, call (804) 982-3978.

The Center for Biomedical Ethics is also sponsoring through its Outreach

Programs the following educational programs in long-term care: "Medical and Legal Perspectives on Ethical Decisionmaking in Long-Term Care" (February 18 in Richmond, VA) and "Creating a Work Environment that Fosters Ethical Decisionmaking in Long-Term Care" (May 29 in Roanoke, VA). For information on educational programs in long-term care offered by the Center, contact Jessica Waugh, M.A., at (804) 353-3209.

West Virginia Network of Ethics Committees (WVNEC)

The West Virginia Network of Ethics Committees has a full schedule of programs planned for this spring. The March 12 Ethics Grand Rounds at the University of West Virginia at Morgantown will present "Ethics throughout the System: Honoring Advance Directives from the Nursing Home to the ER to the SICU?," a program that will be available for viewing over MDTV. On May 16, the WVNEC will present its Tenth Annual Symposium, titled "Moving Beyond 'There's Nothing More We Can Do'

to Providing Quality Care at the End of Life." Featured speakers include Decline Walsh, M.D., the Director of the Palliative Care Service at the Cleveland Clinic Foundation, William F. May, Ph.D., The Cary M. Maguire Professor of Ethics at Southern Methodist University, and Maureen Haralabatos, R.N., Clinical Director and Nurse Practitioner for the Palliative Care Service at Stony Brook University Medical Center. This symposium will feature workshops for the Network's newly formed special interest groups for hospitals, nursing homes, hospices, and home health care agencies.

As for the fall schedule of events, the WVNEC on November 12 presents the Wilhelm S. Albrink Memorial Lecture-ship in Bioethics, which will feature Hilde Lindemann Nelson, Ph.D., Director of the Center for Applied and Professional Ethics at the University of Tennessee-Knoxville, speaking on "The Patient in the Family: An Ethics of Medicine and Families." The WVNEC will also host a fall forum on developing standards for ethics committee functions. For dates and registration information, contact Cindy Jamison at (304) 293-7618.

CALENDAR OF EVENTS

MARCH

- 11 Georgetown University Center for Clinical Bioethics, Bioethics Colloquium. "Physician-Assisted Suicide," Daniel P. Sulmasy, O.F.M., M.D., Ph.D., Director of the Center for Clinical Bioethics and Assistant Professor of Medicine, Georgetown University Medical Center. 5:00-6:45 p.m. (presentation begins at 5:30 p.m.), at the Warwick Evans Room, Building D, Georgetown University Medical Center, Washington, D.C. For information, contact Stacy Schultz at (202) 687-1122, fax (202) 687-8089.
- 8-12 Georgetown University Kennedy Institute of Ethics, Advanced Bioethics Course. "Ethical Challenges in Managed Care." At the Kennedy Institute of Ethics, Georgetown University, Washington, D.C. Tuition is \$1,050; reduced tuition is available to some graduate students, and some partial scholarships are available to those without institutional funding. Continuing education credits are available. For information, contact the Course Coordinator at (202) 687-6771, fax (202) 687-8089, e-mail KICOURSE@gunet.georgetown.edu.
- 12 University of West Virginia Center for Health Ethics, Ethics Grand Rounds. "Ethics Throughout the System: Honoring Advance Directives from the Nursing Home to the ER to the SICU?" 12:00 noon, at the Addition

Auditorium, Robert C. Byrd Health Sciences Center, University of W.Va., Morgantown, WV. For information, contact Cindy Jamison at (304) 293-7618, fax (304) 293-7442, or *e-mail* cjamison@wvuvphs1.hsc.wvu.edu.

- 13 University of Maryland Medical System, Medical Humanities Hour. "Rethinking the Right to Reproduce," Bonnie Steinbock, Ph.D., Dept. of Philosophy, State University of New York at Albany. 4:30 - 5:30 p.m., at the Shock Trauma Auditorium, University of Maryland Hospital, Baltimore, MD. For information, call (410) 706-6250.
- 14-15 American Medical Association, Sesquicentennial Conference. "Ethics and American Medicine: An Interdisciplinary Conference of Physicians, Bioethicists, and Historians." To be held in Philadelphia, PA. For information, contact Renee Allison at (312) 464-5875, fax (312) 464-5843.
- 22 Mount Washington Pediatric Hospital, Inc., Conference. "Obtaining Good Decisions for Dying Children," co-sponsored by the Mt. Washington Pediatric Health System, the Bioethics Institute of Johns Hopkins University, and the Center for Values and Service of Loyola College. 8:30 a.m. - 4:30 p.m., at Knott Hall, Room 202, Loyola College, Baltimore, MD. Registration fee is \$40 (includes lunch); registration deadline is March 12. For further information, contact Mary Costello at (410) 578-8600 ext. 237, or Pam Klima at (410) 578-8600 ext. 367 (registration contact).
- 25 Metropolitan Washington Bioethics Network, Meeting. "Ethical Issues in Guardianships," Vera Mayer, Senior Advocate, Iona Senior Services. 4:00 - 6:00 p.m. (tentative), location to be announced. For information, contact Joan Lewis at (202) 682-1581, fax (202) 371-8151.

APRIL

- 10 The Ethics Institute, "Physician-Assisted Suicide: Progress or Peril," Timothy E. Quill, M.D., Professor of Medicine and Psychiatry, University of Rochester School of Medicine and Dentistry, 8:00 p.m. at Alumnae Hall Auditorium, Cedar Crest College, Allentown, Pennsylvania. For information or registration materials, call (610)-740-3790.
- 11 The Ethics Institute, "Dying to Die: Constitutional Dimensions of Physician-Assisted Suicide," George J. Annas, J.D., M.P.H., Professor and Chair of Health Law Department, Boston University School of Public Health and "Faithfulness in the Face of Death," Allen D. Verhey, Ph.D., Chair, Professor of Religion, Hope College, Michigan, 8:30 a.m. - 12:00 noon at Alumnae Hall Auditorium, Cedar Crest College, Allentown, Pennsylvania. For more information or registration materials, call (610)-740-3790.
- 11 Georgetown University Center for Clinical Bioethics, Bioethics Colloquium. "Mental Health and Managed Care," Stephen A. Green, M.D., Clinical Professor of Psychiatry, Georgetown University Medical Center. 5:00-6:45 p.m. (presentation begins at 5:30 p.m.), at the Warwick Evans Room, Building D, Georgetown University Medical Center, Washington, D.C. For information, contact Stacy Schultz at (202) 687-1122, fax (202) 687-8089.
- 11-12 Metropolitan Washington Bioethics Network, Conference. "When Cure Is Not an Option," Kathy Brenneman, M.D., and others. Sponsored in collaboration with the Washington Area Geriatric Education Center Consortium, the Washington Hospital Center, and the American Geriatrics Society. 4:00 - 6:00 p.m. (tentative), at the National 4-H Center, Chevy Chase, MD. For information, contact Joan Lewis at (202) 682-1581, fax (202) 371-8151.
- 17 University of Maryland Medical System, Medical Humanities Hour. "Rationing Health Care: Why? How?," Alfred Sommer, M.D., M.H.S., Dean of the Johns Hopkins School of Hygiene and Public Health, Baltimore. 4:30 - 5:30 p.m., at the Shock Trauma Auditorium, University of Maryland Hospital, Baltimore, MD. For information, contact Dr. Jack Syme at (410) 706-6250.

MAY

- 1 & 8 Virginia Bioethics Network, Workshop. "Reflections and Decisions: Ethics in Hospice Care," Edward M. Spencer, M.D., Director of Outreach, Center for Biomedical Ethics, University of Virginia, and Rev. Jeanne Brenneis,

Director, Center for Bioethics, Hospice of Northern Virginia. May 1: Time: TBA, at Hospice of Northern Virginia, Falls Church, VA. May 8: Time: TBA, at Camelot Health & Rehabilitation, Harrisburg, VA. For information or to register, contact the Center for Medical Bioethics at (804) 982-3978.

- 11 Georgetown University Center for Clinical Bioethics, Bioethics Colloquium. "20th Century Visions of Reproductive Technology," Susan Squier, Ph.D., Brill Professor of English and Women's Studies, Penn State University. 5:00-6:45 p.m. (presentation begins at 5:30 p.m.), at the Warwick Evans Room, Building D, Georgetown University Medical Center, Washington, D.C. For information, contact Stacy Schultz at (202) 687-1122, fax (202) 687-8089.
- 13 Metropolitan Washington Bioethics Network, Meeting. "Issues in Organ Donation and Transplantation," Cheri McKenzie and others. 4:00 - 6:00 p.m. (tentative), at the Washington Regional Transplant Consortium, Falls Church, VA. For information, contact Joan Lewis at (202) 682-1581, fax (202) 371-8151.
- 16 West Virginia Network of Ethics Committees, Tenth Annual Symposium. "Moving Beyond 'There's Nothing More We Can Do' to Providing Quality Care at the End of Life," Decline Walsh, M.D., Director of the Palliative Care Service, Cleveland Clinic Foundation; William F. May, Ph.D., Cary M. McGuire Professor of Ethics, Southern Methodist University; and Maureen Haralabatos, R.N., Clinical Director and Nurse Practitioner, Palliative Care Service, Stony Brook University Medical Center. Time TBA, at the Robert C. Byrd Health Sciences Center, University of W.Va., Morgantown, WV. For information, contact Cindy Jamison at (304) 293-7618, fax (304) 293-7442, or *e-mail* cjamison@wvuvphs1.hsc.wvu.edu.
- 28 University of Maryland Law and Health Care Program, Conference. "Conducting Research on Cognitively Impaired Patients." Westminster Hall, Speakers and Time TBA. For information, contact L&HCP office at (410) 706-3378 or (410) 706-7239.
- 29 University of Virginia Center for Biomedical Ethics, Workshop. "Creating a Work Environment that Fosters Ethical Decision-Making in Long-Term Care," Janet McDowell, Ph.D. Sponsored in collaboration with the Virginia Association of Non-Profit Homes for the Aging. 10:00 - 11:00 a.m., at the Hotel Roanoke, Roanoke, VA. For information, contact Jessica Waugh at (804) 353-3209, fax (804) 828-7438, *email* [net%"jwaugh@gems.vcu.edu"](mailto:jwaugh@gems.vcu.edu).

JUNE

- 7-12 Georgetown University Kennedy Institute of Ethics, Intensive Bioethics Course. "Contemporary Challenges in Health Care Ethics." At the Kennedy Institute of Ethics, Georgetown University, Washington, D.C. Tuition is \$1,350; reduced tuition is available to some graduate students, and some partial scholarships are available to those without institutional funding. Continuing education credits are available. For information, contact the Course Coordinator at (202) 687-6771, fax (202) 687-8089, *e-mail* KICOURSE@gunet.georgetown.edu.
- 12-15 Georgetown University Medical Center, Center for Clinical Bioethics, Conference. "Catholic Identity in Health Care: Public Responsibility and the Culture of Profit." Conference topics include *Catholic Health Care and Profit*, *Managed Care and Christian Ethics*, *Institutional Integrity and Moral Pluralism*, *The Role of Ethics Committees*, *Mergers and Partnerships: Cooperation Revisited*, and *The Common Good and Social Responsibility*. To be held in Washington, D.C. For information or to register, contact Stacy Schultz at (202) 687-1122, fax (202) 687-8955, *e-mail* ccb@medlib.georgetown.edu.
- 12-19 Virginia Bioethics Network, Workshop. "Reflections and Decisions: Ethics in Hospice Care," Edward M. Spencer, M.D., Director of Outreach, Center for Biomedical Ethics, University of Virginia, and Rev. Jeanne Brenneis, Director, Center for Bioethics, Hospice of Northern Virginia. June 12: Time TBA, at Bristol Regional Medical Center, Bristol, Va. June 19: Time TBA, at Masonic Home of Virginia, Richmond, VA. For information or to register, contact the Center for Biomedical Ethics at (804) 924-5974.

