

Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 2005*

Mid-Atlantic Ethics Committee
Newsletter, Summer 2005

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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

Summer 2005

THE CONTINUUM OF CONSCIOUSNESS—IMPLICATIONS FOR HEALTHCARE DECISION MAKING

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Questions about how aggressively lifesaving measures should be implemented often rest on the quality of life of the patient. A key component of quality of life evaluations is the ability of the individual at some point in the future to have “meaningful interactions” with others. Minimum ingredients of being able to socially interact include possessing awareness of oneself and others, some working memory, and the ability to communicate, all qualities of *consciousness*. For many people, decisions about withholding or withdrawing life-sustaining treatments for a loved one who has suffered significant brain injury hinge on the likelihood that the person will regain consciousness. What’s often not understood is that consciousness is a continuum, with whole brain death on one end, normal levels of arousal and awareness on the other, and various other states in between. The concept of consciousness was at the core of debates over whether Theresa Schiavo’s feeding tube should have been discontinued—was she *really* in an irreversible vegetative state, or could she have been in a “minimally conscious state” in which patients are severely cognitively impaired but have some awareness? To make matters worse, the press has routinely interchanged terms like “persistent vegetative state,” “minimally conscious state,” coma, and

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

Diane E. Hoffmann, JD, MS
Editor

“brain dead,” contributing to the overall confusion.

Consensus among experts on definitions of these states, along with new research in brain physiology, has brought some clarity and raised new questions (see Definitions). For example, a *diagnosis of vegetative state* is made when a person loses certain bodily functions (like control over bowel and bladder), retains other bodily functions (like breathing and sleep-wake cycles), and shows no purposeful behavior that would indicate awareness of himself or his environment. A vegetative state is

**The Mid-Atlantic Ethics Committee
Newsletter**

is published three times per year by the
**Maryland Health Care Ethics
Committee Network**
Law & Health Care Program
University of Maryland School of Law

**500 West Baltimore Street
Baltimore, MD 21201
410-706-7191**

Individual Subscriptions/\$35 per year
Institutional Subscriptions/\$90 per year
(up to 20 copies)

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NETWORK NEWS

MARYLAND HEALTH CARE ETHICS COMMITTEE NETWORK (MHECN)

On June 28th, MHECN sponsored a one-day basic ethics course (*Healthcare Ethics in Action*) at Franklin Square Hospital Center. The course/conference, aimed at providing ethics committee members with an overview of basic concepts in bioethics, was co-sponsored by Franklin Square Hospital Center and the Health Facilities Association of Maryland. MHECN will host a similar basic ethics conference every other year for new ethics committee members as well as those interested in a refresher course on basic bioethics concepts and skills. This Fall, MHECN is planning a conference that will focus on Maryland's new Patient's Plan of Care Form, which goes into effect in October, 2005. Look for upcoming announcements about the date, time, and details of that conference.

For more information about MHECN, contact MHECN Program Coordinator: Anita J. Tarzian, PhD, RN at (410) 706-4457, ore-mail: MHECN@law.umaryland.edu.

THE METROPOLITAN WASHINGTON BIOETHICS NETWORK (MWBN)

MWBN continues its relationship with the Probate Division of the D.C. Superior Court.

For more information about MWBN, contact Joan Lewis, Executive Director, 202-895-9408, jlewis@iona.org.

RICHMOND BIOETHICS CONSORTIUM (RBC)

On August 1st, RBC held a panel discussion about the Theresa Schiavo case. The Consortium is also sponsoring an educational course this fall for its members. RBC continues implementing its high school science teacher grant program, which involves helping local high school science teachers to produce and implement a science unit that involves bioethics.

For more information about RBC, contact Gloria Taylor, RN, MA, CPTC, RBC President, taylorgj@unos.org.

SAVE THE DATES

*The University of Maryland School of Law's
Center for Dispute Resolution (CDRUM)
and*

Law & Health Care Program

*invite you to attend a two part
Medical Malpractice Conference*

September 23, 2005

**The New Medical Malpractice Legislation:
Issues, Implementation & Impact**

October 28, 2005

**Beyond the New Medical Malpractice Legislation:
New Opportunities, Creative Solutions, and Best Practices for
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The Continuum of Consciousness

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referred to as “persistent” or “permanent” based on the *prognosis* of irreversibility. Like other medical prognoses, it is based on medical probabilities of recovery. With traumatic brain injury, vegetative state is considered irreversible after 12 months, and with non-traumatic brain injury, after 3 months. Some people emerge out of a vegetative state into a minimally conscious state (MCS), in which they still have very limited ability to think and communicate, but they demonstrate some evidence of self-awareness and purposeful movements (Giacino & Whyte, 2005).

Use of more sophisticated brain scans and tests like functional magnetic resonance imaging (fMRI), positron emission tomography (PET), and somatosensory evoked potentials (SSEPs) hold out hope for more accurately diagnosing absence of consciousness and predicting its irreversibility. For example, in one case, a 26 year old woman in a vegetative state for four months after developing acute disseminated encephalomyelitis showed spontaneous eye opening and tracking, but no reliable demonstrations of purposeful limb or eye movements, which could have indicated that she was in a MCS. Menon and colleagues (1998) obtained PET images both while the woman was shown digital photographs of familiar faces and while she was shown scrambled images of the same photographs that no longer resembled faces. PET images showed certain areas of the woman’s brain associated with visual perception and cognition were activated while she was being shown the familiar faces. This woman eventually emerged from the vegetative state and was able to verbalize and clearly recognize faces.

A contrary finding was revealed in the case of a woman who was in a vegetative state for 20 years. She lacked evidence of purposeful movements or the ability to follow commands, but would intelligibly verbalize single words every 24 to 72 hours. Intelligible speech is one criterion for the diagnosis of MCS. Based on interpretation of PET scans, Schiff and colleagues (2002) concluded that these verbalizations were remnants of the formerly integrated speech circuitry in her brain that were randomly, rather than

intentionally, firing to produce the spoken words. Other studies revealed similar findings, that the part of the brain responsible for perceiving and responding to a given stimulus is disconnected and nonfunctioning in patients in PVS. Such a patient might reflexively respond to a pin prick by flinching, but would not have awareness of the sensation or a conscious response to it—he or she would not be *experiencing pain* (Laureys, et al., 2002).

However, brain testing cannot yet accurately measure volitional response, which is necessary to distinguish between PVS, MCS, and locked-in syndrome. The current gold standard for diagnosis remains repeated and thorough behavioral assessments. Andrews, et al. (1996) estimated that up to 40% of patients diagnosed as being in a vegetative state in referring institutions were found to be in a MCS when examined at specialized referral centers. There are several reasons for this disturbingly high estimate, including that volitional responses may be infrequent and thus require a large set of observations, and there may be confounding impairments that interfere with the patient’s ability to demonstrate volitional response (e.g., paralysis, speech dysfunction, hearing or visual loss) (Giacino & White, 2005). Steps to minimize errors in assessing disorders of consciousness include using multisensory stimuli to prompt behavioral responses, giving commands within the patient’s physical capability, eliciting observations of family members or staff participating in the patient’s daily care, and using systematic observation procedures and standardized rating tools when possible. Particular care must be taken when assessing a child to use assessment procedures that are appropriate to the child’s age and developmental level (Giacino, et al., 2002).

These developments raise interesting questions. For one, if persons in PVS don’t experience pain and suffering because they lack conscious awareness of painful stimuli, does the same apply to infants? Not long ago, infants were not medicated for potentially painful procedures because they were not thought to experience pain. Is the infant’s *developing* consciousness different from the irreversible unconsciousness of the

patient in PVS who cannot experience pain? And what about the patient in MCS who is unlikely to progress beyond the most rudimentary levels of conscious awareness—if this person formerly documented that (s)he would not want to be kept alive if in PVS, would this also apply to MCS? Again, distinctions between a patient’s current level of functioning and potential future functioning seem important to those making such decisions (for themselves in the future or for a loved one). Emerging potential treatments for disorders of consciousness (e.g., pharmacologic interventions, sensory stimulation, hyperbaric oxygen therapy, and deep-brain stimulation) lack research evidence showing their efficacy in facilitating recovery of consciousness in patients in a coma or vegetative state. As a result, we must struggle with the existing ambiguities. Joseph Fins, who has conducted research on MCS, aptly summed up the challenge:

If we hope to help patients and families make the tough choices following brain injury, we will need to embrace the ambiguity that goes along with long courses of recovery and questions about altered selves. These decisions will be more challenging than decisions to remove life support in the face of overwhelming sepsis or pursue treatment in the face of widely metastatic cancer. We will also need to demand diagnostic honesty and precision. In discussing diagnoses with families we will need to strike a balance between realism and hope. The objective must be to bring greater attention to the minimally conscious patient without engendering expectations for the permanently unconscious (Fins, 2005, p. 24).

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DEFINITIONS

Brain dead: Irreversible cessation of all function of the brain—both the higher cognitive centers (responsible for thinking and perceiving) and the brain stem (responsible for regulating body functions). Confirmed by tests showing no brain activity (e.g., EEG, brain scan, angiography). In the U.S., a person who is brain dead is considered legally dead.

Coma: Loss of function of both the cortex and the reticular system in the brain. There is no evidence of sleep-wake cycles on EEG, the patient has no spontaneous or stimulus-induced eye-opening, and cannot follow commands, make purposeful movements, or speak intelligibly. Coma rarely lasts longer than 2-4 weeks and is followed either by vegetative state (VS) or recovery of consciousness.

Locked-in syndrome: A condition in which corticospinal injury has produced quadriplegia in which a patient has no ability to make any purposeful movements other than in the eyes, and retains conscious awareness. Communication may be established through eye or eyelid movements.

Minimally conscious state: A condition of severely altered consciousness in which a patient demonstrates minimal but definite behavioral evidence of self or environmental awareness on a sustained basis, including at least one of the following: following simple commands, gestural or verbal yes/no responses, intelligible speech, or purposeful behavior. Near the upper boundary of functioning, patients in MCS may say words or phrases and gesture, and may show evidence of memory and attention. They are considered to have “emerged” from MCS only when they can reliably and consistently communicate.

Vegetative state: A *diagnosis* based on the PRESENCE OF: recovery of reticular system sufficient to sustain basic functions such as breathing, spontaneous eye-opening with evidence of sleep-wake cycles on EEG, bowel and bladder incontinence, cranial-nerve and spinal reflexes; and the ABSENCE OF: awareness of self or the environment, ability to interact with others, sustained, reproducible, purposeful, or voluntary behavioral responses to multi-sensory stimuli; and evidence of language comprehension or expression.

Persistent vegetative state: A *prognosis* of the likelihood of a patient in a VS recovering consciousness based on the cause of brain injury (traumatic or nontraumatic) and the length of time the person has been in the VS. With traumatic brain injury, VS is considered irreversible after 12 months, and with nontraumatic brain injury, after 3 months. This prognosis is based on statistical probability of recovery. Based on recent studies, researchers have questioned whether rare cases of late recovery from PVS (i.e., after many years) really involved patients in a *minimally conscious state* (MCS) who were misdiagnosed. The rare individuals who have emerged from PVS almost always remained in a MCS.

Permanent vegetative state: An alternative to the term “persistent vegetative state” that denotes the *prognosis* of irreversible VS.

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EDUCATION AND CONSULTATION

Education, consultation, and policy review and development—these are the most widely recognized roles of healthcare ethics committees. The first two dominate the work of most ethics committees. Yet, a review of the literature on healthcare ethics committees yields more articles about consultation than education. Is this because ethics committees spend most of their time doing consults? Research doesn't support this assumption. A 1997 survey of Maryland healthcare ethics committees revealed that an average of 2.87 consults were conducted per 100 hospital beds that year (Hoffmann, Tarzian & O'Neil, 2000). That's not a lot of consults to keep a committee busy. Has the number of ethics consults per institution increased since 1997? Perhaps.

But that raises yet another question: Should the goal of ethics committees be to increase their number of consults? Some ethics committees have established different goals, such as fostering ethics knowledge and skills among staff. Without relying too heavily on the ethics committee or consultants, staff could then more adeptly resolve ethical conflicts in their daily practice. While more complicated ethical conflicts and dilemmas should be referred to the ethics committee, there are basic ethics issues that might be defined as "ethics standards of care;" that is, the basics about ethical decision-making and conflict resolution that all health care professionals *should* know about. Some ethics committees see their role as working toward the goal of all professionals at their institution being proficient in these "basic ethics standards." Others expand that scope to include patients, family members, or members of the larger community in their educational efforts.

... the goal of ethics *consultation* may not be just to resolve individual conflicts or dilemmas, but to provide an opportunity for learning and moral reflection in an otherwise fast-paced health care facility, what Margaret Urban Walker referred to as a "moral space."

So, how do these committees implement the task of educating staff or others? Here are a number of ways:

- Ethics rounds – having a member of the ethics committee round in the ICU or other areas of the hospital to help identify and raise awareness of ethical issues
- Ethics Grand rounds – hosting lectures on ethics topics or case studies
- Ethics training courses or workshops – either holding in-house workshops or sponsoring staff to attend external courses or workshops
- Newsletters – writing and distributing institutional newsletters highlighting the work of the ethics committee
- Incorporating ethical language & concepts into patient meetings
- Sending e-mail to all staff to present or discuss an ethics case
- Being more inclusive about whom to include in ethics consults, to expand educational opportunities for all

The last bullet presents a provocative idea: that the goal of ethics *consultation* may not be just to resolve individual conflicts or dilemmas, but to provide an opportunity for learning and moral

reflection in an otherwise fast-paced health care facility, what Margaret Urban Walker referred to as a "moral space." Some health care professionals are reluctant to request ethics consults. They may feel that ethics consultations take too much time, or that they overly complicate a patient's care by adding yet more people to those already involved. They may feel that they are just as able as the ethics consultant(s) to resolve patient care issues that have ethical dimensions. But if ethics consultation is framed as an opportunity to expand the opportunity to learn from difficult cases, and to "protect moral space" in an institution, perhaps education and consultation can co-exist harmoniously as worthy goals of any ethics committee. To that end, it's unclear whether facility-wide ethics education would lead to *fewer* consults as a result of increased independence in ethical reasoning abilities among staff, or *more* consults, as a result of increased awareness of ethical issues and the need to dialogue about them.

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PERSONHOOD

The concept of personhood was formed in response to basic philosophical questions like, “When does human life begin?” and “Who has moral standing in society?” Technology has pushed the limits of the debate by its ability to both create and extend life, raising the question of whether the embryo, fetus, and patient in a persistent vegetative state should be afforded the same moral worth, rights, and protections as other human beings. Most scholars generally agree that a living, organic being of human origin is a *human* being. Meaning, it is not a giraffe being, it is not a drosophila being, it is a *human* being. Moreover, this being comes into existence once gametes fuse. The debate about abortion, euthanasia and the like has turned to whether existing as a human being means existing simultaneously as a *person*. There are two approaches to this question about what it means to be a person, what we will call the “cognitive criteria” standard and the “human-beings-as-persons” standard. The latter holds that human beings, regardless of their cognitive capacity or stage of development, are persons with inalienable and extrinsic rights that deserve protection (Spitzer, 2000). The cognitive criteria standard holds that being human is necessary but not sufficient for being a *person*, and that persons have a unique moral status that confers rights to them that are not owed to non-persons.¹ According to the second view, criteria for personhood include awareness of oneself over time (i.e., of a lived past and anticipated future), the cognitive capacity to reason and to act freely, and the ability to communicate through verbal or nonverbal language (Beauchamp, 1999).²

There are problems with maintaining either view. Starting with the cognitive criteria standard, this view explains why the autonomy of the pregnant woman who has decided to end a pregnancy trumps the interest of the fetus. The woman, as a person, has rights, including

the right to make decisions about whether to gestate a fetus and deliver a baby. The fetus, as a non-person, has no such right. But what about the newborn who is no longer gestating in the womb? Such a newborn is not a person according to the cognitive criteria version of personhood—newborns have no self-awareness and cannot reason. The same criteria that justify abortion should apply for infanticide, and yet infanticide remains almost universally condemned. Thus, the cognitive criteria version of personhood can’t answer why abortion can be morally justified but not infanticide.

Esposing the human-being-as-person standard carries with it its own set of problems. If every human life, from the moment of conception, is a human person, then embryos are persons. As such, they deserve the same rights and protections as other incarnated persons. This is a basic argument against abortion, equating the destruction of human embryos or fetuses as morally equivalent to killing a living person. Yet, among those who share this view, one rarely sees the same moral outrage over a homeless person who freezes to death on the street as that encountered when a leftover embryo is destroyed. That is, some who hold this view do not display behaviors that parallel their alleged reverence for *all* persons—born and pre-born. For example, they oppose abortion, but do not demand social policy reform to eliminate cultural and social influences that perpetuate the need for abortion. This apparent hypocrisy leaves them vulnerable to criticism.

The human-beings-as-persons standard of personhood advocates for humans (born and pre-born) who cannot speak for themselves, but offers little guidance about when it is ethically acceptable to forego life-prolonging interventions for humans who are unable to voice their own preferences. The cognitive criteria standard of personhood provides a framework for deciding under

what set of circumstances life-sustaining treatments could be withheld or withdrawn (e.g., for those in a persistent vegetative state or minimally conscious state, when personhood is lost), but risks devaluing lives of humans who are severely cognitively impaired. Perceived obligations of the principle of *respect for persons* may influence how one sides on this issue. Some may think that protecting vulnerable individuals who can’t make decisions for themselves requires a uniform pro-life stance, whereas others may be apt to apply a mindful benefits-burdens calculation in deciding matters of life and death for such individuals. Whether these individuals are *persons*, and how that should factor in the decision-making, is the point in question.

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Endnotes

¹ Some would say humanness is not required, but there is currently inconclusive evidence that any species other than humans possess self-awareness and the capacity to reason.

² Beauchamp also introduced the concept of “moral personhood,” attributed to those who are capable of making moral judgments about right and wrong actions, and who have motives that can be judged morally (p. 315).

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. Readers 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 about patients and others in the case should only be provided with the permission of the patient. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to MHECN@law.umaryland.edu, or MHECN, the Law & Health Care Program, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201.

CASE STUDY FROM A MARYLAND HOSPICE

Mr. Bracken is a 72 year old man who was diagnosed two years ago with lung cancer that has recently spread to the liver and bone. While in the hospital to treat his shortness of breath and control his pain, he makes it known that he does not want further attempts at curative therapy. Rather, he would like to be kept as comfortable as possible and return home to his apartment, where he has lived alone for the past eight years. Mr. Bracken is described by staff as eccentric, stubborn, and “fiercely independent.” He appears distrustful of strangers, at times to the point of seeming paranoid, but his physician evaluates him as being cognitively intact and capable of making his own end-of-life decisions. It’s explained to him that to go home to his apartment, he will need assistance with his daily needs and medical (palliative) care, and that home hospice can provide this. After much encouragement (he thinks he can manage on his own), he agrees to the hospice referral. When the hospice liaison interviews him in the hospital, she explains that hospice typically requires that a caregiver be present in

the home. Mr. Bracken explains that he will be fine in his apartment—his neighbor is available if he needs help, he has everything he needs by his bedside, he can make it to the bathroom and front door, and Meals-On-Wheels brings a daily meal to him. He insists he be allowed to continue living on his own. He has limited other support systems, being estranged from his family. He maintains minimal contact with a daughter who lives in another city, about 120 miles away. He is admitted to the home hospice program, and a nurse, Ms. Tracey, is assigned. Despite coming up with a creative plan of care to allow Mr. Bracken to live on his own, after a couple of weeks after Mr. Bracken is admitted to home hospice, Ms. Tracey and the hospice home health aide assigned to care for him have several causes for concern about Mr. Bracken’s safety. He continues to smoke cigarettes, despite being on oxygen (he insists he turns the oxygen off and smokes away from the oxygen tank). He sometimes forgets to take all the medications in the pre-dosed medicine box prepared by the nurse. And apparently, due to increasing weakness, he uses a rolling office chair to get back and forth from his bed to the front door and bathroom. Roaches and rodents are visible. Nevertheless, he insists that he be allowed to stay where he is comfortable and refuses to consider transfer to a group home or inpatient hospice facility. The nurse consults the hospice ethics committee about how far to go in respecting Mr. Bracken’s autonomy.

RESPONSE FROM A HOSPICE MEDICAL DIRECTOR

*“It’s all about me” –
Dying, dignity, and the
limits of autonomy*

A couple of years ago, a patient walked into my office with the words, “I can’t breathe

anymore.” Two hours later, we had a tentative diagnosis of lung cancer; by that evening, we had pathologic confirmation.

The patient – elderly, independent, and as ‘ornery’ as our Mr. Bracken – was adamant in his refusal of any curative treatment. “Make me breathe better, and I’ll be happy.” His symptoms were relatively easy to treat – low-dose steroids, sublingual morphine as needed, and an inhaler.

What was impossible to treat was his rapid functional decline. He left his home of almost 50 years, moved in with a cousin, and continued to deteriorate. Our hospice service saw him from the outset of his diagnosis, and his primary nurse and social worker expressed similar concerns to those voiced by Mr. Bracken’s team – the cousin (technically the ‘caregiver’) was rarely home, and when he was home, he was often drunk. The patient took his medicines haphazardly, eventually stopped bathing, and after a few weeks, never left the confines of his bedroom. With a tremendous amount of coaxing (which bordered on coercion), he accepted a move to a group home “where he would be safer.” Two days later, the group home director called 911 when she found the patient unconscious, with an empty bottle of morphine by the bed.

Before we could intervene, the patient was intubated in the emergency department (the anxious triage nurse pointed out that she was told that this was an attempted suicide), and was admitted to intensive care.

An estranged daughter, the hospice nurse, the hospice social worker, the ICU attending, and I gathered to discuss options. He was, at this point, well-ventilated, and stable, but incapable of maintaining a level of consciousness that would protect his airway. The intensivist suggested he be given ‘some narcan, to wake him up and ask him what he wants to do.’ The hospice nurse almost screamed her objection. The social worker suggested he be maintained on the ventilator until his level of consciousness improved, and that he

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CASE PRESENTATION

then be transferred to a nursing home, 'because he's going to need more supervision.' The daughter was baffled by the discussion – "If you'd ever really known my dad, you should have seen this coming – I'd just let him go." We eventually decided to extubate him, transfer him to our inpatient palliative care unit, and 'take our chances.' He died about 4 hours after extubation, quietly, without any further medical interventions.

My patient's case – as messy as it is – is one possible ending to the choices facing Mr. Bracken and his team. But I'd like to point out several salient features:

- 'Autonomy' – at least as it's commonly used in the ethics literature – is a remarkably brittle foundation on which to construct a theory of action. It cracks (often, with little effort), can be slippery, and one person's autonomy can often seem like another's prison (as my intensivist colleague later commented to me, 'I'm not in the habit of aiding suicides.')
- The law – again, as currently derived – is also less than satisfying. The duly designated proxy in this case – the estranged daughter – might be legally empowered to make a decision (which is precisely what hospital counsel told us when we consulted them), but her attitude was more one of resignation (and some irritation at getting dragged into 'another one of Dad's messes'). She was clearly not the thoughtful 'substitute judge' that we read about in the ethics literature.
- The hospice nurse was – appropriately, I think – horrified at the idea of waking up a terminally ill patient to his pain, dyspnea, and fear 'just so that we can all feel better about ourselves.'
- The hospice social worker pointed out that one of the principles of a 'good

hospice death' was that it be "safe, and dying of an overdose in a group home is hardly 'safe'."

The decision we reached was, essentially, one of exclusion – we each said what we wouldn't be willing to accept (or, better, what we each thought, from our professional and personal perspectives, was ethically *unacceptable*). But none of us had a clean, satisfying course of action. The patient solved potential future problems by dying (rather than regaining consciousness, and thereby forcing us, once again, to decide the question of disposition).

Finally, though, what Mr. Bracken's case misses – as did the case above – is the complexity, context, texture, and sheer chaos of human behavior. My sense is that Mr. Bracken would be willing to accept all of the potential possibilities for an 'unsafe' and untidy death that continuing to live alone might entail. And I might even be willing to accept his decision – as long as he could answer for me the same question that the group home director asked of me after I told her about the resident's death: "I guess that's nice for him, but who's going to clean up the mess? Everybody's upset here. I don't think my residents are going to let me take in another hospice patient if they're just going to kill themselves."

The only person I might consider completely autonomous, in the end, is a hermit, with no family, no relation, and no community memory of his existence. I don't know if such a person has ever actually existed in history. For the rest of us – including the Mr. Brackens' of this world – every decision we make, even if it's ultimately 'about me,' has its own life and afterlife, long after we're gone.

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RESPONSE FROM A HOSPICE ADMINISTRATOR

This case is as common as it is problematic. It is the rare hospice Interdisciplinary Team (IDT) Meeting without discussion of a patient sharing some elements in Mr. Bracken's story. Easy answers are even rarer, but a first approach to resolving them is to distinguish between the effect of patients' choices upon themselves and the effect of their choices upon others. Mr. Bracken's smoking puts his neighbors at risk.

As an apartment dweller, Mr. Bracken has neighbors adjacent to his walls. While we might defend his right to choose living in a potentially unsafe but comfortingly familiar environment over moving to a less personally appealing but safer place, we are not justified in allowing him to jeopardize his neighbors' safety.

If Mr. Bracken forgets to take his medications even when they are in a pre-dosed medicine box by his bed, chances are high that he will forget to turn off his oxygen before smoking. In his increasingly weakened state, it's also reasonable to assume that he will at some time smoke in bed. The tanks would be nearby. Furthermore, his medications probably will make him more somnolent. This increases risk of fire from cigarette ashes on bedclothes. He could also easily fall from his rolling desk chair with a lit cigarette in his fingers. Even if Ms. Tracey could elicit a promise to stop smoking from Mr. Bracken, it would be naïve to think he would keep it.

State and federal regulations, as well as professional standards, prohibit the staff from disclosing information about Mr. Bracken's condition to them without his explicit permission. Furthermore, even if the staff did ignore those rules and inform the landlord or other tenants it would be unreasonable to expect others to vacate their homes or assume risk of fire.

Suppose Mr. Bracken lived alone in a trailer in the middle of a large soybean field? Even then the staff should consider the risk taken by fire responders. A twenty five year old could die trying to save Mr. Bracken.

It is not clear from the case as presented if either his daughter or neighbor has been designated Mr. Bracken's "primary caregiver" or if he has given permission to the hospice to share with them protected health information. If not, the staff should encourage Mr. Bracken to give such permission and speak with at least one of them about the implications of his choices. At the very least they could cut off his supply of cigarettes. Mr. Bracken might have a right to refuse relocation but no one is obligated to provide him with cigarettes.

Given his "ornery" personality, his formal designation of a health care agent is as unlikely as it is desirable; however the staff should encourage Mr. Bracken to make such a designation if the other person is willing to accept it. If Mr. Bracken refuses to allow staff to communicate with either his daughter or neighbor and if the cigarette supply is not cut off, the hospice should report the situation to Adult Protective Services or the appropriate local authority.

The hospice should also report Mr. Bracken's home conditions and the hospice's risk assessment to the physician ordering care for Mr. Bracken. Even if there is little evidence of decline in mental capacity, the hospice care plan should reflect plans to repeat the earlier evaluation at some time. The Medical Director or hospice physician might also visit Mr. Bracken periodically and communicate findings to the attending physician.

Often Meals on Wheels volunteers observe risks and report them to the health care agency connected to that program. Fear about breaking HIPAA rules has silenced some of the communication that used to flow more easily among health care organizations

but the hospice might explore the legal ramifications of communicating with the local agency.

Mr. Bracken's condition will continue to worsen. He will be less able to eat unassisted, to administer his own medications, toilet, answer the door, and answer the phone. If Mr. Bracken is still at home when he becomes bed bound, at some point the visiting staff and volunteers might be unable to leave him. Therefore the care plan should include a provision to increase volunteer services, ideally around the clock. Realistically, however, it is the rare volunteer who can take many hours in a dirty, roach infested apartment. The patient's condition might also warrant a few days of continuous care if nursing is needed for eight or more hours a day. Given the danger to others of his smoking, hospice staff should remove matches from Mr. Bracken's reach.

As staff members deepen their relationship with Mr. Bracken, they should continually encourage him to move to the hospice residence or to a nursing facility. He is most likely eligible for Medicaid, which would pay for his room and board at a nursing facility. Hospice personnel can continue to visit and care for him in his new home.

When patients are hospitalized or in a nursing facility the range of their choices is so severely limited and the power of staff and physicians to influence patients is so great that we must put great emphasis on defending patient autonomy. When patients are at home and especially when they are alone at home, their choices are much broader and the consequences of their choices go well beyond the effect on others of a patient in an institution.

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INTERACTIVE CONSENT SOFTWARE

Florida Hospital Orlando became the first hospital in the country to use new interactive informed consent software for surgical patients. The software program uses audio, streaming video, animation, and touch screens to walk patients through planned surgical treatments (to date, cardiac patients undergoing angioplasty, catheterization, and stenting). The program explains the nature, indications, complications, equipment, risks, and alternatives of a planned surgical procedure, and then tests the patient's level of understanding.

Scott Pollak, MD, the Florida Hospital cardiologist who helped develop the software, explained, "These days, many patients are taking a more proactive approach to their own healthcare. They often search the internet and other medical sources for information about their condition and treatment. The interactive informed consent tool will ensure patients get thorough and accurate information right in the hospital setting."

The interactive consent software is played on a special touch screen that allows patients to stop, rewind, and review the presentation. It is mounted on a cart that rolls up to the patient's bedside. The patient takes a test at the end of each section. The doctor then receives a printout indicating the patient's score and any questions he or she might have, which helps the physician target the informed consent discussion to the patient's needs. If the software proves to be a success, it will be developed for other procedures as well. Dr. Kerry Schwartz, a cardiologist who works with Pollack, predicts such success, stating, "Overall, a more informed patient, who is actively involved in his or her health care, be it preventive or therapeutic, will do better in the long run. This interactive process will greatly enhance this involvement."

For more information about the software, go to <http://www.floridahospitalmedicalnews.com/news-Cardiology-id143.html>.

LEGISLATIVE UPDATE

Federal Legislation

Pain Care Policy Act of 2005 (House Bill 1020)

The National Pain Care Policy Act of 2005 is currently before the House Health Subcommittee. This bill would prompt a White House Conference on Pain Care and a national public awareness campaign. It would also require military health care facilities and veterans health care facilities to provide more extensive pain care. Managed health care plans offering Medicare Advantage plans would be required to include appropriate pain treatment. For more information, please visit www.painfoundation.org.

Maryland Legislation

Senate Bills 718 and 321 Hospitals-HIV Testing–Consent and Public Safety Workers

This new legislation adds public safety workers to the list of individuals whose exposure to the bodily fluids of a hospital

patient (or patient prior to hospital admission) triggers an HIV test of that patient, even without his or her consent. Previously, the testing was limited to exposure of health care providers and first responders. Public safety workers are defined in the legislation as career or volunteer members of a fire, rescue, or emergency medical services department, company, squad, or auxiliary; any law enforcement officer; or the State Fire Marshal or a sworn member of the Fire Marshal's office. These bills were both signed by Governor Ehrlich on May 10, 2005.

House Bill 565 Hospitals–Bone Marrow Donation

Hospitals that offer bone marrow transplant services are now required to allow individuals to donate bone marrow if the physician agrees that the donation will benefit the donee without undue risk to the donor. This bill was signed into law by Governor Ehrlich on May 10, 2005.

Senate Bill 247–Health Care Decision Making Forms–Health Insurance Portability and Accountability Act–Personal Representatives

Clarifying the effect of the federal Health Insurance Portability and Accountability Act (HIPAA) on advance directives, this bill amends the Health Care Decisions Act and states that a health care agent is a personal representative and may receive protected health information to aid in making informed decisions regarding an individual's health care. This bill was signed into law by Governor Ehrlich on April 26, 2005.

Failed Maryland Legislation

Legislation to create a Maryland Stem cell research Fund offering grants and loans to public and private entities of the state to support embryonic stem cell research failed to pass during the session. In addition, legislation that would have required increased reporting requirements from clinical trial sponsors, as well as change the requirements for institutional review boards, failed to pass.

MEDICAL DECISIONS ACT NOT TIME

On May 20th, Gov. Robert Ehrlich vetoed Senate Bill 796, the Medical Decisions Act of 2005 after its passage by the Maryland General Assembly. The bill would have allowed domestic partners residing in Maryland to register in a state-maintained Life Partnership Registry. Life partners would then be ensured visitation rights in medical emergencies and enjoy the same rights afforded married couples on issues of medical decisions. Gov. Ehrlich acknowledged a need to protect unmarried couples but ultimately concluded that their rights should be addressed by creating “a central directory of advance directives and related legal documents” instead of defining a new category of legal relationship that “could lead to the erosion of the sanctity of

traditional marriage as already codified in Maryland law.” Equality Maryland, the state's largest gay and lesbian rights organization, responded stating that the majority of rights contained within the now defeated bill “cannot be accomplished through an advance directive, power of attorney or last will and testament.” The organization accuses Gov. Ehrlich of bowing to political pressure despite the fact that the bill expansively defined life partnership and explicitly avoided the issue of same-sex marriage. Gov. Ehrlich pledged to work with the General Assembly on future legislation to address these health care concerns.

Under current law, if a decisionally-incapable person is diagnosed as being terminally ill, in an end-stage condition, or

a persistent vegetative state, an unmarried partner who has not been appointed as the patient's health care agent has the least priority in the hierarchy of surrogate decision-makers. She or he can sign an affidavit attesting to having an intimate relationship with the patient and knowing his or her end-of-life wishes, but the patient's parent, adult child, or sibling will be consulted first. This becomes especially problematic when a patient who has AIDS and is gay has kept these facts from his family, preferring that they not be told. Yet, in order to make medical decisions for the patient, the surrogate must be told the reality of his medical situation. Ethically, the partner may be the one most appropriate to make decisions on behalf of such a patient, but legally, the family takes precedence.

CALENDAR OF EVENTS

SEPTEMBER

- 22-24** The 'E' Word: The Role of Emotion in Health Care. The 5th Annual Quandaries in Health Care conference, the Given Institute of the University of Colorado, Aspen, CO. For more information, contact Mary Lou Wallace at 303-315-5096
- 23** The New Medical Malpractice Legislation: Issues, Implementation & Impact, conference sponsored by University of Maryland School of Law Center for Dispute Resolution (CDRUM) and Law & Health Care Program. For more information, visit www.law.umaryland.edu/conferences.asp, or contact Toby Treem at 410-706-6228
- 23** The Changing Healthcare Landscape: Ethical Choices, Scientific Promises, and the Quality of Life, conference sponsored by New Jersey Health Decisions, New Jersey Law Center, New Brunswick, NJ. For more information, contact njhd@verizon.net, or call 973-857-5552

OCTOBER

- 14** Ethics Across the Lifespan in Life-Limiting Illness, Sponsored by Capital Hospice Institute for Education and Leadership, Fairfax County Government Center, Fairfax, VA. For more information, visit www.capitalhospice.org/healthcare/educational
- 17- 20** International Health Care Ethics Colloquium, Georgetown University, Washington, DC. Topics include: Methods in Bioethics, Moral Pedagogy, Clinical Ethics, Organizational Ethics, and Research Ethics. October 18th is a one day Symposium on Culture and Ethics. For more information, visit <http://clinicalbioethics.georgetown.edu> or call 202-687-1122
- 20** David Flood, PhD, "Transplant Donor-Recipient Relationship: Being informed from urban legends, fiction, film and medical ethics." Medical Humanities Hour lecture, Shock Trauma Auditorium, University of Maryland Medical Center, 22 S. Greene Street, Baltimore. 4-5 PM. For more information, contact hsilverm@medicine.umaryland.edu
- 20-23** Suffering and Justice, Annual Meeting of the American Society for Bioethics & Humanities. Omni Shoreham Hotel, Washington, D.C. Includes a Clinical Ethics Consultation pre-conference workshop on October 20. For more information, visit <http://www.asbh.org>
- 21** Mourning Through the Lens of Various Faith Traditions, Sponsored by Capital Hospice Institute for Education and Leadership, Fairfax County Government Center, Fairfax, VA. For more information, visit www.capitalhospice.org/healthcare/educational
- 28** Beyond the New Medical Malpractice Legislation, conference sponsored by University of Maryland School of Law Center for Dispute Resolution (CDRUM) and Law & Health Care Program. For more information, visit www.law.umaryland.edu/conferences.asp, or contact Toby Treem at 410-706-6228

NOVEMBER

- 7-9** Improving Care for Those Experiencing Life-Limiting Illness. Seventh Annual Josefina Magno Conference Series, sponsored by Capital Hospice. Falls Church, VA. For more information, visit <http://www.capitalhospice.org/healthcare/educational/Seminars.asp>
- 10** Eric Cassell, MD, "The nature of suffering applied to the whole patient." The Dr. & Mrs. Howard B. Mays Lectureship in the History of Medicine and Ethics (Medical Humanities Hour lecture), Shock Trauma Auditorium, University of Maryland Medical Center, 22 S. Greene St., Baltimore. 4-5 PM. For more information, contact hsilverm@medicine.umaryland.edu

DECEMBER

- 1** Joseph A. Carrese, MD, MPH, "Examining ethical issues at the interface of different cultural systems." Medical Humanities Hour lecture, Shock Trauma Auditorium, University of Maryland Medical Center, 22 S. Greene St., Baltimore. 4-5PM. For more information, contact hsilverm@medicine.umaryland.edu

