

Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Mid-Atlantic Ethics Committee
Newsletter, Summer 2010

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MID-ATLANTIC ETHICS COMMITTEE

NEWSLETTER

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

Summer 2010

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BIOETHICS THROUGH A DISABILITY LENS

Currently, most requests for clinical ethics consultation involve end-of-life issues. Should a feeding tube or ventilator be withdrawn from a dying person? Should a do-not-attempt-resuscitation order be written without the patient's or surrogate's consent? Should a neonatal intensive care unit team oblige a parent's request to keep a severely impaired neonate alive on maximum life support despite probable mortality? Since the field of bioethics arose to address dilemmas associated with emerging life-prolonging medical technologies, it's not surprising that clinical ethics focuses predominantly on end-of-life decision-making. But this has engendered widespread feelings of distrust among disability rights activists toward clinical ethics consultants and the health care providers they advise, whom they view as being wholly ignorant of disability rights and the social model of disability.*

In a session at the conference "Disability, Health Care & Ethics—What Really Matters" on April 28th, co-sponsored by Maryland Healthcare Ethics Committee Network (MHECN) and Kennedy Krieger Institute, I explored the origins of this distrust as it relates to end-of-life care. There is some commonality between hospice/end-of-life care and disability rights advocacy—both value holistic care centered on maximizing an individual's quality of life; when possible, in a home-based setting. But the ultimate fear of many hospice patients is dying alone and in pain or other distress, whereas the very real fear of many persons with a dis-

ability is dying too soon at the hands of health care workers who do not see the worth in prolonging their lives, and the associated burdens and costs. Research studies have corroborated the latter. Non-disabled persons and health care providers are more likely to rate the quality of life of persons with disabilities as poor, while individuals who have a disability rate their own quality of life as good or better (Bach & Tilton, 1994; Gerhart, et al., 1994; Lule et al., 2009). Reasons that persons with disabilities sometimes rate their quality of life as poor often have more to do with others' negative attitudes toward them, and barriers that exclude them from meaningful work and social activities, than to their mental or physical impairment(s). The unemployment rate of 66% among persons with disabilities—unchanged for over twenty years—is just one example of rampant disability discrimination.

In 1991, Leonard Kriegel made the argument on behalf of the disability community:

"Our complaint against society is not that it ignores our presence but that it ignores our reality, our sense of ourselves as humans brave enough to capture our destinies against odds that are formidable. Here is where the cripple and society war with each other. If we were satisfied to be held up for compassion, to be infantilized on telethons, we would discover that this America has a great deal of time for us, a great deal of room for us

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. Each issue includes a feature article, a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing, or related disciplines.

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is not intended to provide legal advice
or opinion and should not be acted
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Bioethics

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in a heart open to praise for its own generosity. ... In literature ... [and] on television as bathetic as the stream of smiling children paraded before our eyes as if their palsy were Jerry Lewis's reason for living, what we invariably discover is that our true selves, our own inner lives, have been auctioned off so that we can be palatable rather than real. We can serve the world as victim or demon, the object of its charity or its terror. But the only thing we can be certain of is that the world would prefer to turn a blind eye and a deaf ear to our real selves—and that it will do precisely that until we impose those selves on the world.” (pp. 65-66).

Kaufert and Koch (2003) present an example of how disability bias influences end-of-life care in describing a case involving a man with amyotrophic lateral sclerosis (ALS) who opted for a tracheotomy and portable ventilator to prolong his life. After the man's wife

died, he made repeated requests that his ventilator be stopped. The principle of respect for patient autonomy was used to justify complying with his wishes. The health care team believed the man knew that stopping the ventilator would cause his death, and that he was freely choosing to die. They saw their role basically as following a dying man's request and palliating his suffering. Kaufert and Koch, however, suggest that this man may have chosen to die not based on an informed, autonomous wish, but because he was depressed at his wife's recent death, and fearful of living in an institution due to the lack of a home caregiver to help with his daily physical needs. Instead of simply complying with his wish to stop life support, Kaufert and Koch argue that health care providers were obligated to address this man's grief over his wife's death and lack of home support, present options for social and community services to allow him to remain in his home, and arrange for him to meet with other long-time

The Maryland Healthcare Ethics Committee Network (MHECN) is a membership organization, established by the Law and Health Care Program at the University of Maryland School of Law. The purpose of MHECN is to facilitate and enhance ethical reflection in all aspects of decision making in health care settings by supporting and providing informational and educational resources to ethics committees serving health care institutions in the state of Maryland. The Network works to achieve this goal by:

- Serving as a resource to ethics committees as they investigate ethical dilemmas within their institution and as they strive to assist their institution to act consistently with its mission statement;
- Fostering communication and information sharing among Network members;
- Providing educational programs for ethics committee members, other healthcare providers, and members of the general public on ethical issues in health care; and
- Conducting research to improve the functioning of ethics committees and ultimately the care of patients in Maryland.

ventilator users. They cite David Jayne to portray the mainstream view that prolonging the life of patients with ALS causes undue burden not only on the patient, but on others caring for the patient. As Jayne stated, looking back on his decision to have tracheotomy surgery to allow for long-term ventilator use:

“My now ex-wife told me how selfish I was for wanting to live. That my young children had suffered enough and it would cause them only more pain. It was a sickening sense of abandonment. I have absolutely no doubt if I did not have the ability to communicate my desires the [tracheotomy] surgery would not have taken place.” (Jayne, 2005)

Discriminatory attitudes about the quality of life of a person who breathes with a ventilator need to be challenged—whether for a person with ALS or a spinal cord injury. Not doing so reveals a disability bias that Kaufert and Koch point out is pervasive among health care professionals.

Similarly, Johnson (2006) compares how most health care providers and bioethicists viewed the Terri Schiavo case as an end-of-life case, whereas disability rights groups like Not Dead Yet viewed it as a disability rights case. The former cited evidence supporting withdrawing Ms. Schiavo’s feeding tube to include that she would never recover from her persistent vegetative state (PVS), that her g-tube feedings were a medical treatment that was delaying her death, that she did not want to be kept alive in her condition, and that the burdens of keeping her alive with the feedings outweighed any benefits (Goodman, 2006).

Disability rights advocates such as ADAPT (American Disabled for Attendant Programs Today), The ARC of the United States, and Not Dead Yet

asserted that because PVS is often misdiagnosed, one should err on the assumption that a person may have some level of consciousness, even if the person cannot communicate. They highlighted that there was no hard evidence of Terri Schiavo’s wishes, and that even if she had completed a living will, advance directives are inherently disability-biased (see Derbyshire & Levy, July 2010). Advance directives require people to state preferences for life-prolonging treatments they might want in the future, but studies show that able-bodied persons often change their minds about their preferences for life-prolonging treatments when they become disabled. Most people with disabilities do not view wheelchairs, ventilators, and feeding tubes as medical devices—rather, they view them as empowering adaptive devices. And they take issue with the assumption many make that if an individual cannot recover from an impairment—such as PVS—this may justify withholding or withdrawing hydration, nutrition, or other life support measures (Johnson, 2006).

So, how can we health care providers and clinical ethicists better address disability rights issues? For one, we can increase our knowledge and awareness of disability perspectives. Disability blogs are a good way to start (see Box above). We can ensure that there is adequate representation of disability perspectives on our ethics committees by including members with knowledge about the social and medical models of disability, the history of disability rights advocacy, and state resources for persons with physi-

DISABILITY BLOGS

Bad Cripple

<http://badcripple.blogspot.com/>

Disability News

<http://www.patriciaebauer.com/>

Disability Studies, Temple University

<http://disstud.blogspot.com/>

Life with a Severely Disabled Child

<http://severedisabilitykid.blogspot.com/>

Media dis&dat

<http://media-dis-n-dat.blogspot.com/>

Mysteries and Questions Surrounding the Ashley X Case

<http://huahima.wordpress.com/>

Planet of the Blind

<http://www.planet-of-the-blind.com/>

What Sorts of People

<http://whatsortsofpeople.wordpress.com/>

cal and mental disabilities. We can support hiring policies that welcome disability activists, independent living center organizers, and persons with disabilities. And we can examine our own fears and emotions surrounding death and disability that may influence how we approach ethical decision-making in health care. As Johnson (2006) wrote:

“... Most people resist looking too closely at the kinds of issues that await us when we lose the ability to communicate. We do not like thinking about disability any more than we like thinking about death or end of life issues. We do not like facing the reality of incapacitated lives. If only we could achieve a willingness to raise the veil of denial about the shadow-world of brain damage and decision-making, it might serve as a legacy from the Terri Schiavo ordeal.”

With health care reform underway, and the prevalence of disability rising,

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CURVES: A MNEMONIC FOR DETERMINING MEDICAL DECISION-MAKING CAPACITY AND PROVIDING EMERGENCY TREATMENT IN THE ACUTE SETTING

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The evaluation of medical decision-making capacity and provision of emergency treatment in the acute setting may present a significant challenge for both physicians-in-training and attending physicians. Although absolutely essential to the proper care of patients, recalling criteria for decision-making capacity may prove difficult during a medical emergency. Furthermore, emergencies present a particularly challenging situation for assessing decision-making capacity, as altered mental status is frequently a confounding factor. Stakes may be high, with the absence or delay of treatment quickly leading to loss of life or limb. In addition, discord with regard to determination of decision-making capacity may be commonplace among medical staff despite access to the same clinical information and laboratory data. In an emergency, therefore, it becomes imperative that decision-making capacity be assessed in an efficient manner. Although several tools exist that can assist in the evaluation for capacity (Dunn, et al., 2006; Grisso, et al., 1997), they frequently prove cumbersome, time consuming, and difficult to perform in an acute care setting. Of equal importance to determining capacity are recognition of a true medical emergency and recollection of the criteria required to provide emergency treatment in the absence of explicit informed consent. This article presents two

cases that illustrate the need for quick assessment of decision-making capacity and the criteria for emergency treatment. It then provides and demonstrates the use of a mnemonic (CURVES: Choose and Communicate, Understand, Reason, Value, Emergency, Surrogate) that addresses the abilities a patient must possess in order to have adequate decision-making capacity, as well as when emergency treatment can be provided without patient consent.

Clinical Cases

Case 1

Ms. S. is an 84-year-old woman with a history of severe chronic obstructive pulmonary disease (COPD). She presents with a 1-week history of progressively worsening shortness of breath, cough, increase in clear sputum production, and wheezing. On examination, the patient appears in extremis. Her respiratory rate is 28, and she is using accessory musculature to breathe. There are diffuse, quiet wheezes in her lungs bilaterally, with an ominous lack of air movement. An arterial blood gas reveals a markedly decompensated respiratory acidosis, and the overall picture appears consistent with a life-threatening COPD exacerbation. Hospital admission with either noninvasive positive pressure ventilation, intubation, and/or comfort care measures are presented to the patient as the possible responses to her

situation. However, the patient states “I want to die at home. Please, let me go home.”

The doctors involved are faced with the following questions: Should the patient be discharged home, with the knowledge that this will likely result in her death? Does this patient have adequate capacity to make this decision?

Case 2

Mr. M. is a 53-year-old morbidly obese man who was admitted for suspected obesity hypoventilation syndrome and obstructive sleep apnea. The on-call physician is called to his bedside emergently, after he was found unresponsive to verbal and noxious stimuli. Arterial blood gas reveals a combination of hypoxia and decompensated respiratory acidosis. On lung examination, there is a complete lack of respiratory effort, and there are no breath sounds. The patient is ventilated with a bag-valve mask at maximal supplemental oxygen, and he partially arouses, but remains groggy. Respiratory effort is somewhat restored, to a rate of 6 breaths/min. Bedside oximetry increases to 89%. However, the patient’s head begins to bob, and it appears that he will soon lose consciousness. Anesthesia is paged for a stat intubation.

Two minutes pass, and anesthesia arrives. The patient has become more awake and is looking around the room. His pulse oximeter is now

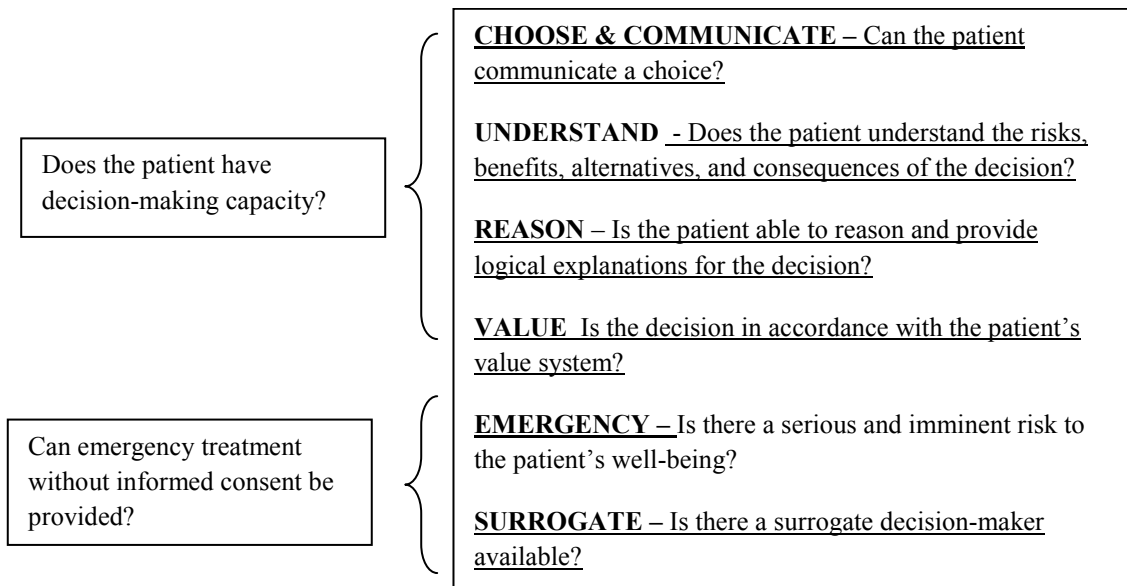


Fig. 1

reading 93%, although respirations remain shallow and infrequent. Given his significant respiratory acidosis, the medical team prepares for intubation. At this time, the patient shouts “I don’t want a tube! No tube!”

The doctors involved are faced with the following questions: Should this patient be intubated? Does he have the capacity to decide his course of therapy?

The CURVES Mnemonic

We propose a mnemonic, CURVES (Choose and Communicate, Understand, Reason, Value, Emergency, Surrogate), to aid in the evaluation of decision-making capacity in an emergency. (Fig 1).

- **C – Choose and Communicate.** Patients must be able to choose from among the options before them. Furthermore, their choice must be made without coercion or manipulation, although appropriate persuasion is permitted (Beauchamp & Childress, 2001). Each patient must be able to communicate his or her preferences, whether

verbally, in writing, or through the use of signals

- **U – Understand.** The patient must understand the relevant risks, benefits, alternatives, and consequences of any planned intervention or course of action. The following questions may be helpful in assessing the patient’s degree of understanding:
 - o “In your own words, please tell me about what we’ve just discussed, regarding your current illness and the decisions we need to make.”
 - o “What do you think will happen if you receive (or do not receive) the intervention?”
 - o “What do you understand to be the alternative(s) to the recommended plan?”
- **R – Reason.** The patient must be able to reason and provide adequate explanations for accepting or declining each intervention.
- **V – Value.** The patient’s decision should be consistent with his or her value system.

Physicians should strive to be aware of and understand the patient’s values, and they must also be aware that patient values and goals may change with time. The following question may be helpful in determining the degree to which the patient’s values are playing a prominent role in the decision being made:

- o “How did you reach your decision to accept (or reject) the intervention, and what is guiding your thinking about this?”

If the patient lacks the ability to choose and communicate, understand, reason, or act consistently with his/her values (to a degree consistent with the benefits and risks of the decision), adequate decision-making capacity is not present. In such cases, the physician must next determine if emergency treatment should be rendered, provided that two additional requirements are met (American College of Legal Medicine, 2007; Dunn, et al., 2006; Grisso, et al., 1997).

CURVES

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- **E – Emergency.** A true emergency exists; that is, there is serious and imminent risk to life or limb.
- **S – Surrogate.** No surrogate decision maker or legal document detailing the patient's desires is immediately available, and there is no time to obtain an ethics consultation.

When both of these conditions are present in the context of lack of medical decision-making capacity, a physician may intervene without explicit informed consent, as long as the proposed intervention would be acceptable to a reasonable person or to the patient if they were able to speak for themselves. It is important to note that such an action does not occur in the complete absence of consent; rather, the physician is operating under the presumption of implied consent (Derse, 2005).

Next we return to the cases and use the CURVES mnemonic to work through them and arrive at a plan of action.

Case 1: Refusal of Hospital Admission in a Life-Threatening COPD Exacerbation

Ms. S. is found to be alert, oriented, and vocal. The different courses of action that may be taken (noninvasive positive pressure ventilation, intubation, and medically-supported comfort care measures) are presented to her, and she is able to repeat each option, using her own words. She states, "I don't want a mask or tube. I don't want any machines. I just want to die in my own home." She voices understanding that leaving the hospital would result in worsened breathing and possibly death. The patient's adult children, who were eventually found in the Emergency Department waiting room, corroborate both the reasoning process and her decision as consistent

with previously stated preferences and values.

Ms. S. should be allowed to return home, even if that means she will die there.

Case 2: Refusal of Intubation in Hypercapnic Respiratory Failure

Mr. M. is able to slowly recite his name, birth date, and location. He explains his refusal of intubation by stating: "I just don't want it." He mumbles when asked to repeat, in his own words, the risks, benefits, or alternatives to intubation. He cannot explain the consequences of his refusal. Review of the patient's admission note reveals that he previously desired intubation, if medically necessary. No surrogate decision-makers are immediately available.

Emergency treatment in the absence of informed consent should be provided, and Mr. M. should be intubated.

Summary

The process of approaching and evaluating decision-making capacity in the emergency setting may be facilitated by recalling our proposed mnemonic, CURVES. The physician assesses decision-making capacity by determining the patient's ability to: Choose and Communicate a course of action; Understand the intervention's risks, benefits, alternatives, and consequences; Reason and provide logical explanations for the choice; and apply his or her Values to the decision. If these functional abilities are intact, then under most circumstances, the patient's preferences should be honored. If any of these functional abilities are lacking, and the patient is deemed not to have adequate decision-making capacity, then the physician must determine if a true Emergency exists and assess availability of a

Surrogate decision maker. If an emergency situation is present and a surrogate cannot be found in a timely manner, then emergency treatment may be provided for a medical condition warranting intervention.

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PATIENTS WITHOUT PROXIES: WHAT'S HAPPENING IN OTHER STATES?

Cynthia Griggins, PhD, MA is co-director of the Clinical Ethics Service at University Hospitals in Case Medical Center, Cleveland, Ohio. She summarizes here a hospital protocol she helped develop to make medical decisions for seriously ill (but not necessarily terminally ill) patients who do not have an available surrogate decision-maker.

For some time we at Case Western Reserve Hospital have been aware of a growing number of unfortunate patients who arrive at our teaching hospital, incapacitated and requiring complex medical care, but without anyone to serve as a surrogate decision-maker. These patients are sometimes elderly nursing home residents who have outlived all relatives. Often they are homeless mentally ill individuals who long ago lost all ties to families or friends. Other times they are isolated “loners” brought to the hospital by a neighbor or acquaintance who is concerned but who lacks either moral or legal authority to make decisions for the patient. The patient requires care for which consent is necessary. It might be aggressive care

in an ICU, a major surgery, an amputation, or referral to hospice care, but search for family turns up no one.

Decision-making is clear if the situation is a true emergency: assume consent and act to save life or limb. It is also relatively clear if there is ample time before a decision has to be made: approach the court and request that a guardian be appointed. However, getting a guardian takes six to eight weeks in our urban county, making this approach untenable most of the time. Even if it were possible to wait, it would be cruel, costly, and unethical to allow a patient to go untreated for that length of time, just as it would be unethical to wait until the patient’s condition worsened to the point of an emergency, thus allowing physicians

to act without formal consent. Moreover, our overworked probate court has neither the time nor the resources to appoint “emergency guardians” to make medical decisions.

Disturbed by the inconsistent manner in which decisions were being made for these “patients without proxies (PWP),” our hospital ethics committee decided to develop a protocol. We began with several assumptions. First, we felt that placing the burden of decision-making on treating physicians posed an unacceptable conflict of interest and could lead to unwanted outcomes. An individual physician’s bias can cause her to either overtreat or undertreat a seriously ill patient. Fear of lawsuits can result in defensive

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CASE WESTERN'S MODEL AND MARYLAND LAW

The problem of “patients without proxies” has troubled clinicians and policy makers for years. See, for example, Karp N. and Wood E., “Incapacitated and Alone: Healthcare Decision Making for Unbefriended Older People,” *Human Rights*, Volume 31, no. 2 (2004), 20-24. Case Western’s innovative approach should be seen as a promising pilot study.

Hospitals in Maryland that might want to adopt Case Western’s model should be aware, however, of differences in the legal context between Ohio and Maryland. The Case Western approach was initiated in part because delays of many weeks in guardianships compromised quality care. If, by contrast, the circuit court

in a Maryland county responds in a timely way to petitions for emergency guardianship, a hospital in that county may have no need for an interim informed consent mechanism.

But suppose that a Maryland hospital, like Case Western, sometimes is troubled by delays in guardianship. Before adopting Case Western’s approach, a Maryland hospital should seek advice from its counsel about how such a role for ethics committee members fits within the framework of Maryland law. In effect, ethics committee members would serve as surrogates who are not authorized as such in the Health Care Decisions Act (HCDA). Although neither the HCDA nor other law explicitly prohibits clinician reliance on such an informed con-

sent mechanism, one effect would be loss of the immunity granted by the HCDA. Of course, the absence of immunity does not equate to liability, and I myself doubt that most cases of interim decision making for an unbefriended patient pose any real risk of liability for the clinicians who accept the informed consent or refusal of the ethics committee members. Nevertheless, other lawyers may not agree. Consequently, a Maryland hospital should proceed cautiously before emulating Case Western’s approach.

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Patients Without Proxies

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medicine rather than decisions made in the patient's best interest. Alternatively, without someone to advocate for the patient, a physician may fail to offer reasonable options or may withdraw treatment too soon. Second, we believed that decisions for PWP should not be made by employees of the hospital. Again, conflict of interest was our main concern, but we also believed that a lay person's viewpoint was needed to challenge and counter-balance the medically-based thinking of the treatment team. Finally, we were committed to transparency and accountability. Decisions for PWP and the process by which they were made should be open and readily available to examination by anyone who raised legitimate questions.

With the help of the hospital attorneys, we researched our state law to determine whether there were any statutes to guide us or limit us in our planning. State laws vary in providing guidelines for making decisions for patients without proxies; our own is silent on the matter. After checking with the local probate court, adult protection agencies, and adult guardianship programs (who all declined to take on the task of decision-making for hospitalized patients and gave us their blessing), we received the hospital administration's approval to proceed.

Our own PWP protocol is built on a model first proposed by the Veterans Affairs (VA), with some modifications. A small subgroup of the hospital's ethics committee was formed, consisting of community members who would be readily accessible (within 24 hours) for decision-making. These individuals, usually not medically-trained, but versed in ethical decision-making, do not work for the hospital. Currently

the subcommittee consists of several professors, psychologists, lawyers, and a music teacher with some training in bioethics.

The protocol states that the ethics consultant on call and a social worker be notified as soon as it is suspected that a seriously ill and incapacitated patient may lack a surrogate. The social worker, with the assistance of the ethics consultant, launches an aggressive search for family, following all possible leads. They contact nursing homes, neighbors, landlords, local police, relevant service agencies, and anyone who may know the patient, asking not only about relatives, but also about the patient's history, lifestyle, values, and quality of life, gathering information and preparing for later discussions of what might be in the patient's best interests. For example, nursing home staff may tell us that despite her dementia, a patient has been relatively active and content in the nursing home, suggesting that a return to baseline might be a desirable goal. Or a neighbor may tell us that a patient has become increasingly withdrawn and invalid since his wife's death, and has repeatedly stated that he would not want to live in a nursing home or be kept alive in a severely disabled condition.

The intensive search for relatives is extremely important. It has been successful with about 40% of patients first thought to lack proxies. Not only has it been a relief to staff to find surrogate decision-makers, but it also has been gratifying when we have been able to re-unite estranged family members who then provide support for an isolated patient. The search has, however, turned up relatives who refuse to act as surrogates, in which case we still

invite them to participate in decision-making to the extent that they feel comfortable.

When it becomes clear that no surrogate can be found, and a major medical decision must be made for the incapacitated patient, the ethics consultant then convenes the PWP committee. The consultant guides them in reviewing the chart and briefs them on background information that has been gathered regarding the patient's lifestyle, values, and quality of life prior to hospitalization. The committee members are encouraged to meet the patient, and to whatever extent possible, communicate with her. The committee and ethics consultant then meet with the medical team (i.e., the attending physician, appropriate consultants, social work, nursing, etc.), who present the patient's medical condition, and various treatment options, with risks, benefits, and long-term prognosis articulated as much as possible. The committee then discusses the various alternatives (including comfort care), focusing not only on short term demands and benefits, but also on long-term quality of life. They then make a recommendation to the medical team regarding which treatment plan they believe is in the patient's best interest. Usually this process is accomplished in a single meeting of one to two hours, although occasionally a patient's changing medical status requires multiple meetings and communications. The ethics consultant records all deliberations and recommendations in the patient's medical record.

Because the PWP committee does not have the legal standing of a proper surrogate, their recommendation is just that—a recommendation. As always,

the ultimate decision to deliver any treatment, such as a surgery, chemotherapy, or even CPR, lies with the attending physician. However, in over 90% of our cases, the physician has agreed with the committee's recommendation. Should the attending physician disagree (or if the PWP committee has not been able to reach a consensus among themselves), the case is presented to an emergency meeting of the full ethics committee. If full consensus still cannot be reached, the protocol dictates that the Chief Medical Officer (CMO) should make the final decision on the treatment of the patient. Although several cases have gone to the full ethics committee, we have never needed to call upon the CMO to decide a case.

The hospital administration and attorneys approved our protocol, and we have now used it for about 70 cases over a period of five years (though only about 50% have required that the PWP committee be convened). Our experience with the protocol has been extremely positive. We have made recommendations regarding code status, surgeries, amputations, tracheostomies and PEG tubes, dialysis, and chemotherapy. Sometimes we have recommended aggressive treatments; other times we have rejected them and recommended comfort care. For those patients who are expected to live, we have recommended rehab and nursing home placement and guardianship for future decision-making. For those who are not expected to live, we have rec-

ommended palliative care or hospice.

For further information on designing a PWP protocol, see Hyun, I, Griggins, C, Weiss, M, Robbins, D, Robichaud, A and Daly, B. "When patients do not have a proxy: A Procedure for medical decision making when there is no one to speak for the patient." *The Journal of Clinical Ethics*, Volume 17, no. 4 (2006), 323-330. You can also contact me directly: Cynthia.griggins@uh-hospitals.org

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University Hospitals Case Medical Center.

FOCUS: EDUCATING ETHICS COMMITTEE MEMBERS

Looking for ideas on how to educate ethics committee members at your facility? The American Society for Bioethics and Humanities (ASBH) has published an Education Guide to help. In addition to general content about clinical ethics and ethics consultation services, the Guide includes the following content domains, along with learning objectives and suggested exercises and readings related to each content domain:

Core Ethical Issues Involving Adult Patients

- Decision-Making Capacity
- Informed Consent

- Surrogate Decision Making
- Advance Care Planning and Advance Directives
- End-of-Life Decision-Making
- Privacy and Confidentiality
- Pregnancy and Perinatal Issues
- Dealing with "Difficult" Patients: Professional and Institutional Responses
- Negotiating Difference and Accounting for Context

Core Ethical Issues Involving Minors

- General Framework for Minors and Decision-Making
- Ethical Issues Involving Newborns & Critically Ill Infants and Children

- Ethical Issues Involving Chronically Ill Infants,
- Children and Adolescents
- Ethical Issues Involving Adolescents

An Education Guide order form is available at <http://www.asbh.org>. The cost is \$20 (\$15 for ASBH members).

CASE PRESENTATION

One of the regular features of this 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, Law & Health Care Program, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201.

This Case and the following Commentaries are reprinted from the Fall 1994 issue of the MAEC Newsletter

CASE FROM A VIRGINIA HOSPITAL

A 58 year old white male, residing in a local homeless shelter, exhibited suicidal ideations and tendencies, and was brought to the hospital psychiatric center for evaluation, and subsequently, was involuntarily admitted. The patient did not have any family or significant others. He was not compliant, although not violent. Having suicidal ideations, as well as indications of several suicidal attempts, the court found the patient to be incompetent. The hospital sought guardianship to assist in the decision making process with regard to his treatment.

After a medical workup, authorized by the guardian and the hospital, physicians discovered that the patient

had terminal colon cancer. They also determined that a powerful regimen of chemotherapy might lengthen the patient's life by twelve to eighteen months. Unfortunately, this medication is known to cause significant nausea and vomiting, in addition to other severe side effects. The patient refused the medication, but was forced to receive this treatment against his will. The patient became delusional, insisting that it was the chemotherapy that was causing his cancer.

The nursing staff, physicians, and guardian sought assistance from the hospital ethics committee for advice in the determination and evaluation of ethical treatment options. Some of the questions put before this committee included: Is it reasonable to discontinue treatment that may preserve life, although at a significantly reduced quality of life? If so, does the patient's desire to discontinue treatment carry any weight given the court's adjudication of his incompetency, his suicidal ideations and his delusional state?

COMMENTS FROM AN ATTORNEY

This case raises both substantive and procedural issues with respect to the appropriate role of the institution's ethics committee. In addition, the case illustrates what many in the field know all too well: it is generally better to deal with most bioethical issues at the earliest opportunity, than to wait and do so later.

The Initial Decision to Treat

Since this case concerns the propriety of reversing a course of treatment which was consented to,

not by, but on behalf of, the patient, a decision to withdraw treatment should be made on the same basis as was the initial authorization. Therefore, a discussion about the reasonableness of a decision to discontinue chemotherapy and what weight, if any, should be accorded the patient's refusal, must include an analysis of the initial decision to commence the chemotherapeutic regimen. Understanding that initial decision is of vital importance and the ethics committee must, consequently, explore this issue.

The forced administration of chemotherapy is assumed to have been authorized by the patient's guardian. Inasmuch as many chemotherapy regimens may involve experimental treatment, the importance of obtaining valid informed consent to such treatment cannot be overlooked. Presumably, the Committee will discover that the guardian considered the risks and benefits to the patient from receiving chemotherapy and concluded that the benefits outweighed the risks, including the risk of foregoing treatment. Hopefully, the Committee will also determine that the guardian specifically concluded that the known adverse side effects of treatment (as well as the unknown risks) were outweighed by the benefits associated with a possible increase in the patient's life by 12 to 18 months. One must wonder, however, whether the patient, in a lucid interval would concur in such assessment and arrive at the same decision. A related issue is whether the court order establishing the guardianship contemplated and enabled decisions of this magnitude or whether the court intended only for the guardian to make decisions with regard to the patient's mental health

treatment. If the latter, it makes sense to go back to court to enlarge the surrogate's power in consideration of the patient's condition.

The Decision to Discontinue Treatment

Taking up the questions of the reasonableness of discontinuing treatment and whether to accord any weight to the patient's apparent desire to forego treatment, two responses come to mind. Assuming that the guardian acted within the scope of the court's guardianship appointment and in accordance with the patient's best interests and gave valid and effective informed consent to commence the chemotherapy regimen, it seems not only unreasonable, but inappropriate, to discontinue a potentially life lengthening course of treatment. The autonomy of this patient has been surrendered to the legally designated surrogate decision maker, the guardian. It makes no sense to attribute decisional weight to the patient's protestations because such objections are not viewed as emanating from a rational thought process. Indeed, if a decision were to be made to discontinue chemotherapy without the guardian's consent, what would be the source of authority for any such decision. In this context, therefore, the ethics committee can only confirm that informed consent to treatment was obtained.

Best Interest of the Patient

On the other hand, this case may be viewed as one in which the surrogate decision maker—the guardian—appears (to the treatment team) not to be acting in the patient's best interests and to the extent the patient's preferences are at all discernible, the

treatment decision appears to be at odds with such preferences. In this situation, it seems appropriate for the ethics committee to become involved and explore whether the guardian's decision making is centered on the patient's best interests. It seems unreasonable, however, for the Committee to go beyond this role by attempting to insert itself as the decision maker on the question of discontinuing treatment or the arbiter between the guardian and an incompetent ward. Assuming the Committee has not been legally empowered to wrest decision making power from the patient or the patient's surrogate, the Committee should not affect a change in the treatment course without the assent of the guardian. As an attorney, I would be quite uncomfortable with giving any ethics committee that much rope.

If, after reviewing the facts, it is evident to the Committee that the guardian is not acting in the patient's best interests, it would be appropriate to challenge the guardian on this issue. If the guardian is unwilling to reassess his or her decision making, the matter can always be brought before the court—the source of the guardian's authority. Notwithstanding the patient's evident desire to discontinue treatment, and without a court order, it would be unreasonable for the ethics committee (or the hospital for that matter) to discontinue treatment authorized by the guardian. Nothing in the facts presented indicate that the guardian's authority to speak for the patient has been curtailed or revoked.

If the guardian is willing to reassess the decision to commence chemotherapy, he or she should be encouraged to ascertain, as much as

possible, the patient's basic values and preferences. Failing an ability to do that, I would recommend that the guardian talk, not only to medical oncologists, but also to cancer patients currently undergoing treatment, who are willing to share their story, so that the guardian can have a better appreciation for how a rational patient responds to the core question: is the adversity of chemotherapy worth the expected benefit?

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COMMENTS FROM A PHYSICIAN & ETHICS COMMITTEE CHAIR

The central question in this case is whether the ethics committee and the guardian, acting on behalf of an incompetent patient, lacking advance directives, must adopt a vitalist principle: prolong life at any cost. This case is especially difficult as the patient appears to reject life, given his repeated attempts at suicide. Here, the committee must not only wrestle with the general problems of applying a substituted judgment or best interest test, but also with the choice of whether to accept a mentally ill patient's assessment that life is not worth living, or to explicitly override his wishes.

The Question of Competency

The courts deem suicidal patients incompetent on the assumption that their feelings reflect irrational and profound depression — sane persons would not choose to take their own lives. In general, from the legal

Case Presentation

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perspective, no consideration is given to the possible causes of the patient's feelings, nor to the likelihood that the patient will ever achieve a condition in which such feelings were not present. Further, the state's interest in life per se is thought to justify paternalistic intervention when a patient represents a danger to himself (Childress, 1991; Greenberg, 1991). While, ethically, incompetence based on suicidality does not necessarily reflect generalized incapacity to make any and all medical decisions (Buchanan & Brock, 1989), in this case, the patient's mental state directly affects a decision regarding life-lengthening chemotherapy. To the extent that his suicidal tendencies are irrational, his capacity to decide is impaired. In these circumstances, the committee should not support the patient's refusal of chemotherapy, nor, using a best interest assessment, consider the patient's apparent lack of desire to live. Given the absence of a pre-suicidal reference point, recommending chemotherapy seems the path of least resistance, as well as, consistent with the ethical commitment to treat and to prolong life.

Best Interest of the Patient

Best interest judgments are inherently problematic in our American environment, which is so heavily weighted toward respect for individual preference, however idiosyncratic (Gutheil & Appelbaum, 1983). Absent adequate information about an individual's general values or specific preferences, one must ask what a "reasonable person" would do in similar circumstances (Canterbury v. Spence, 1972). One model for such decision making proposes a "community standard", invoking

as the reference group the patient population served by a particular facility (Emanuel & Emanuel, 1993). While an attractive concept, this idea raises questions about how to identify the appropriate reference population. Hospitals typically do not serve homogeneous patient groups. Our own institution cares for incompetent, isolated individuals of many ethnic extractions, and socioeconomic or educational backgrounds. In this case, would the majority of patients in the hospital, to which this patient was involuntarily committed, share his values and experience?

The patient's social situation might also lead conscientious committee members to mistrust their own capacity to make a best interest judgment on his behalf. A committee of reasonably healthy, socially and economically comfortable individuals may realize that it is too easy for them to accept a homeless, deluded man's assessment of his life as not worth living. To offset these social biases and to avoid discriminating against this vulnerable man, the committee might, therefore, recommend treatment. When this concern is coupled with a mistrust of suicidality as a competent expression of will, the committee's safest moral course is to choose treatment which prolongs life, however compromised.

Another fact, which favors compelled treatment, is that the patient is homeless. This makes it unlikely that he is insured. As a result, even comfort care, through a home or in-patient hospice, may be unavailable. By insisting on treatment, the committee may believe it is ensuring the patient's access to pain relief and comfort measures that he might otherwise not receive.

Recommending chemotherapy

will, however, only temporarily solve the committee's and the clinicians' dilemma. This man's condition will continue to deteriorate, necessitating rescue efforts which are more and more invasive, with increasingly lower probabilities of success. As a result, prior to the patient's death, the committee will continue to face questions about how much therapy he should be forced to undergo.

A Mental Health Treatment Approach

One alternative is for the committee to recommend coercive treatment with the goal of enhancing the patient's capacity to make a decision (thereby enhancing his autonomy), rather than for the beneficent purpose of cancer treatment (Buchanan & Brock, 1989). Using this approach, a vigorous trial of therapy, for both his delusional state and his depression, would precede a decision regarding chemotherapy. If he responds to treatment, a more reasonable discussion of cancer therapy will then be possible. Further, when such patients are in remission from their mental illness, they can be encouraged to enact advance directives in which they might consent to re-hospitalization and treatment during future relapses (Buchanan & Brock, 1989). In this case, an advance directive would assist clinicians in both the management of the patient's mental illness, and his cancer treatment.

In some locales, it might be possible to ameliorate the patient's social situation, for instance, his homelessness, reducing his suicidal thoughts. However, rational decision making for all patients is expected to take into consideration the reality of their familial and economic situation

as they contemplate treatment. Ethics do not require the removal of all the burdens that might make this man unhappy or that lead him to refuse treatment, but only to mitigate, insofar as possible, demonstrably irrational ideation about his illness, its treatment, and its potential impact on his future.

What if the patient does become capable of understanding his disease, its prognosis and the implications of treatment, is no longer delusional, demonstrates capacity to decide, but remains pessimistic, even suicidal, despite an appropriate course of treatment? At this point, the committee must consider that the patient's emotional state is a fixed condition of his life. If no social or medical intervention is able to reverse it, his hopelessness may not be morally different than one patient's irremediable pain or another's fear of future disability. If the latter's decisions about medical treatment are respected, then it seems only equitable to afford the same respect to the choices of this patient.

But what if psychiatric treatment fails to resolve the patient's delusions and/or inability to understand his condition and options? What if adequate psychiatric treatment cannot be enforced legally? In these circumstances, the committee should not recommend chemotherapy.

If he were not homeless, nor had a history of suicidality, but was rather an irreversibly incompetent, fifty-eight year old white male, without advance directives or identifiable surrogates, would we feel obliged to choose chemotherapy on his behalf? Here, the Saikewicz case provides insight (*Superintendent of Belchertown State School v.*

Saikewicz, 1977). Joseph Saikewicz, at fifty-seven, had never been competent due to mental retardation, just as the patient in this case has no discoverable competent past. Similarly, Mr. Saikewicz faced treatment for cancer. The decision in the Saikewicz case, based on compassion for the potential sufferer, was to forego treatment. Likewise, in the case of our fifty-eight year old homeless man, neither our misgivings about psychiatric illness and suicidality, nor our collective responsibility for this man's homelessness should interfere with compassionate decision making. The ethics committee should, therefore, recommend comfort care for this patient, rejecting burdensome efforts to prolong his life, which this patient cannot comprehend.

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Bioethics

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now is a good time for health care providers, ethics committee members, bioethicists, policy makers, and disability rights advocates to join forces and identify common goals and how to achieve them.

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*The social model of disability views the main causes of disability as being rooted in people's negative attitudes toward persons with physical and mental impairments, and programs that keep persons with disabilities living in institutions, unemployed, and isolated from meaningful work and social life. The medical model views disability as being caused merely by the physical or mental impairments themselves—impairments that can

and should be treated or cured.

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CALENDAR OF EVENTS

SEPTEMBER

- 17** (12:30 - 2:00 PM) Complete Lives in the Balance. Guest Lecture Series at the Hoffberger Center for Professional Ethics. Samuel Kerstein, Associate Professor of Philosophy at University of Maryland College Park, will examine the foundations of Kantian Ethics. Student Center Bogomolny Room, University of Baltimore, 1420 N. Charles St., Baltimore, MD. For more information, visit <http://www.ubalt.edu/template.cfm?page=3339>.
- 18-19** Moral Distress in Health Care Symposium. Coast Plaza Hotel & Suites, 1763 Comox Street, Vancouver, BC. For more information, visit <http://www.nursing.ubc.ca/IPONS/>.
- 21** The Science, Ethics and Politics of Vaccine Mandates. Sponsored by the Center for Bioethics of the University of Pennsylvania, The Children's Hospital of Philadelphia, The University of Pennsylvania Health System, and the Society for Health Care Epidemiology of America. BRB Auditorium, 421 Curie Boulevard, Philadelphia, PA. To pre-register, contact Janice Pringle at jpringle@mail.med.upenn.edu or call 215-898-7136.

OCTOBER

Sept. 30 -

- Oct. 2** A Need to Confess? Writing About the Healthcare Experience. 8TH Annual Quandaries in Health Care Conference. The Given Institute of the University of Colorado, Aspen, Colorado. For more information, visit http://www.coloradobioethics.org/calendar_home.html.
- 3** Ethics of Invasive Brain Testing: Limits and Responsibilities. 19th International Cleveland Clinic Epilepsy Symposia. Cleveland, OH. For more information, visit <http://www.ccf.org/neuroethics> (click on NeuroEthics Symposia)
- 15-16** Open Hearts, Open Minds and Fair Minded Words: A Conference on Life and Choice in the Abortion Debate. Princeton University, Princeton, NJ. For more information, visit <http://nohiddenmagenta.wordpress.com/2010/02/14/open-hearts-open-minds-and-fair-minded-words/>, or contact Kim Girman at kgirman@princeton.edu.
- 21-24** Health and Community. The 12th Annual Meeting of the American Society for Bioethics & Humanities (ASBH). Hilton San Diego Bayfront Hotel, San Diego, CA. For more information, visit <http://www.asbh.org>.

NOVEMBER

- TBA** End-of-life decision-making and Maryland Law - A Community Forum. Morning conference and afternoon roundtable discussions of Maryland's Health Care Decisions Act, focusing on issues related to withholding or withdrawing medically ineffective treatment. Baltimore, MD. Check MHECN's website for more details at <http://www.law.umaryland.edu/mhecn> (click on Conferences).
- 19** (12:30 – 2 p.m.) Negative Duties and the New Harms. Guest Lecture Series at the Hoffberger Center for Professional Ethics. Judith Lichtenberg, Professor of Philosophy at Georgetown University, will speak about the challenges of justice and charity in a diverse society. Business Center Room 003, University of Baltimore, 1420 N. Charles St., Baltimore, MD. For more information, visit <http://www.ubalt.edu/template.cfm?page=3339>.
- 19** New York's 2010 Family Health Care Decisions Act and its Impact at the Hospitalized Patient's Bedside. 2010 AMBI Clinical Ethics Conference sponsored by Albany Medical College, Albany, NY. For more information, visit <http://www.amc.edu/academic/bioethics/index.html>.

DECEMBER

- 3-4** Transforming Humanity: Fantasy? Dream? Nightmare? Sponsored by the Penn Center for Bioethics, and the Penn Center for Neuroscience & Society. For more information, contact John Schook at jshook@centerforinquiry.net, 716-636-4869.

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