

Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Mid-Atlantic Ethics Committee
Newsletter, Spring 2007

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MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

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

Spring 2007

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

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DISABILITY AND SLIPPERY SLOPES

Ashley is a nine year old girl who, as an infant, developed static encephalopathy with global deficits. She currently functions at about the level of a 3 month old with severe physical and mental deficits. She cannot move on her own, and is cared for at home by her parents. When Ashley entered a growth spurt and started developing secondary sexual characteristics about three years ago, her parents began exploring options that eventually were realized in what they call "the Ashley treatment." To address the concern that Ashley would not understand the pain and discomfort of monthly menstrual periods, her uterus was removed. To avoid the discomfort of large breasts (more so because her wheelchair straps cross over her chest, and because hormonal treatments that were part of the "treatment" would enhance breast development), her breast buds were surgically removed. Lastly, to keep her from growing so that her parents and other caregivers could more easily transport her, she received a 2-1/2 year course of high dose estrogen, which fused the growth plates in her bones. As described on the blog where Ashley's parents explain their choices for Ashley, keeping Ashley smaller means she "can continue to delight [in] being held in our arms and will be taken on trips more frequently and will have more exposure to activities and social gatherings." See <http://ashleytreatment.spaces.live.com/>.

The recent debate surrounding the "Ashley X" case provides an opportunity to shine the light on disability, how it is

defined and its role in surrogate decision-making. Reactions across the globe swept through the media after Douglas Diekema, chair of the ethics committee that reviewed Ashley's case at Children's Hospital and Regional Medical Center in Seattle, co-authored a paper about "the Ashley treatment" (Gunther & Diekema, 2006). Charges that the Ashley treatment was unethical fell into two general categories: (1) the harms to Ashley outweighed the benefits, and (2) the precedent contributes to a larger disability bias in society that undermines the rights and flourishing potential of persons with disabilities. The ethics committee deliberated on, and ultimately rejected, #1. While those involved in the ethics case consultation expressed concerns related to #2 (Clarren, 2007), their ethical analysis stayed focused on Ashley.

In considering the degree to which an ethics committee might consider implications for society or "slippery slope" arguments when deliberating on a case like Ashley's, it might be helpful to review how this case fits within the greater "disability rights" discourse. Outrage among some disability rights advocates that Ashley's body was medically modified to make it easier to take care of her (even if this was not the parents' primary reason for doing so) touched a nerve among those who have fought against the "medical model" of disability. In this view, those who cannot attain "species-normal" functioning (e.g., seeing, hearing, ambulating, etc.) are considered disabled. Attempts are made to normalize their functioning to the extent possible by surgical repair, rehabilitation,

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or opinion and should not be acted
upon without consulting an attorney.**

NETWORK NEWS

MARYLAND HEALTH CARE ETHICS COMMITTEE NETWORK (MHECN)

On January 30th, MHECN sponsored a symposium at GBMC on *Money & Medicine: Bedside Ethics of the Medical Marketplace*. See article in this issue, p. 4, for more information about the event. On July 26th, MHECN is sponsoring a one-day education conference, *Ethics Committees in Action*, for ethics committee members. See Calendar for details, and check our website for updated information: www.law.umaryland.edu/mhecn.

Contact MHECN at (410) 706-4457; or e-mail MHECN Program Coordinator, Anita Tarzian, PhD, RN, at MHECN@law.umaryland.edu.

METROPOLITAN WASHINGTON BIOETHICS NETWORK (MWBN)

After serving as Executive Director of the Metropolitan Washington Bioethics Network for 16 years, Joan Lewis is stepping down from that position. A new Director has not been identified to date.

RICHMOND BIOETHICS CONSORTIUM (RBC)

RBC partnered with the Department of Veterans Affairs Employee Education System and the Mid-Atlantic Health Care Network to present the course, "Mediation Skills for Ethics Consultants" on May 30, 2007. RBC holds its elections this spring.

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

Disability and Slippery Slopes Cont. from page 1

or use of adaptive aids. (In Ashley's case, the medical and surgical interventions even went beyond attempts to "normalize" Ashley—they would keep her size and appearance closer to her 3 month old stage of development rather than her chronological age, something that many disability rights activists find morally unjustifiable.) The question about what is "normal" and thus what constitutes a "disability" is influenced by cultural norms and currently available medical technology, and has its own body of literature (see Vehmas, 2004).

In contrast, the "social model" of disability views the problem being not with the individual who is impaired, but with the society that oppresses, stigmatizes, and isolates that individual. For example, a woman who is paralyzed may ambulate with a wheelchair, but only becomes disabled when she must rely on others to open a door or help maneuver a curb due to lack of ramped curbs and doors that automatically open. According to the social model, we should strive to remove attitudinal and structural barriers that prevent all people from participating in society to the best of their abilities (see <http://www.disabilityisnatural.com/>). We should do this in a way that maximizes individual autonomy and dignity.

Unfortunately, there is a strong tendency for able-bodied/minded persons ("abled-persons") to judge the quality of life of disabled persons as inferior. History has shown that such attitudes can lead to blatant rights violations, ranging from involuntary sterilization of women who are thought to be intellectually impaired to eugenic killings. Disability advocates are mindful of this history when they react to societal endorsement of practices such as prenatal screening for genetic diseases. The implication that parents could abort a fetus to avoid having a "disabled child" is (according to some disability activists) dangerously close to the conclusion drawn by Hitler's ranks that people with disabilities are better off dead.

Interestingly, the social model of disability originated from individuals with *physical* disabilities who advocated removing attitudinal and physical barriers

that preclude acceptance of persons with impairments into mainstream society (McClimens, 2003). While the same model is used to promote rights of persons with intellectual disabilities (e.g., mental retardation), some contend that the social model is biased against those with intellectual impairments. Other models have emerged, such as the “People First” movement, which endorses accommodating the needs of those with physical or intellectual impairments by focusing on their abilities rather than their impairments and seeing them as valued persons first and foremost. However, even within this movement, there is an assumption that disabled persons have some level of cognitive capacity. The beliefs posted on one state’s “People First” website (<http://www.peoplefirstofillinois.org/index.html>) unwittingly reflect this assumption:

- We believe every person should go to a regular school
- We believe that people have a right to speak for themselves and make their own decisions
- We believe everyone should have the opportunity to live in the community and to have REAL jobs for REAL pay.

For people like Ashley who are so impaired (in her case, both cognitively and physically) that making her own decisions is an impossibility, one must question whether the disability rights discourse is excluding people like her, or whether using the term “disabled” to describe her is a misnomer. Advocating for Ashley’s “rights” as a disabled person seems to be a misread of the principle of “respect for persons,” which requires that persons who can make their own decisions be allowed to do so (within certain limits), and that persons who cannot make their own decisions be protected from harm. For people in the latter category who never had and will never have decision-making ability (like Ashley), others must make decisions for them based on a best interest standard, not based on an autonomy claim. It is understandable that those who are disabled and who *have* decision-making capacity feel threatened and frustrated by others’ false assumptions about their rights, worth, and abilities. However, projecting such frustrations onto all impaired persons leads to fuzzy logic. Gregory Liptak, a pediatrician who works with children who are developmentally disabled, illustrated

this tendency when commenting on Ashley’s case: “What they did to this child takes away her personhood. She’s a human being and with that comes all the same rights as you or I have to experience normal

deliberation. But perhaps this is the price we have to pay for the choices we now have at hand. Our love of enhancement technologies and high-tech medicine that seeks to overcome human

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development and sexual pleasure” (Clarren, 2007). Liptak’s comment resonates for many disability rights advocates, but doesn’t apply to Ashley, who cannot experience consensual sexual pleasure.

The focus of the Clarren article was that the process by which the ethics committee reached consensus in Ashley’s case was over-simplified, and that there were more divergent views among members than was presented to the press. Clarren cites pediatrician bioethicist Chris Feudtner as saying, “This lack of an auditable record [of how the ethics committee deliberated] leaves any internal dissension or debate squelched from view, leaving the sense this was an easy decision for the committee to make, when that may not have been the case.” The implication is that the committee should have considered the potential impact on others with disabilities, and not restricted their debate to Ashley alone. Feudtner is quoted as saying, “Some child, somewhere, with much less severe mental disability than Ashley, will get this treatment. It will happen and there needs to be more people standing up and saying this will have side effects we didn’t anticipate.” An internet blogger presented an alternative view: “It’s time that doctors, and advocates for the disabled, and the general public, started to recognize that we can’t base treatment for one person on what might happen to others. People deserve to be treated in a way that is best for them, not in a way that is best for someone with some other level of disability” (“jebldmm,” 2007).

On one hand, including slippery slope arguments when deliberating in an individual case consultation seems unfair to the patient and family, who should be the primary focus of the

limitations is at odds with the reality that medical technology is actually increasing disability prevalence in society. Neonatal intensive care units and trauma centers are saving lives while creating infants with a full range of physical and cognitive impairments, and adults with brain damage from head trauma. At the same time, there is a tendency among abled-persons to want to maintain control and avoid “devastating outcomes” of being alive without a perceived “good quality of life.” Research has shown that abled-persons underrate the quality of life of others who have physical and cognitive impairments, and are poor predictors of their own future preferences, were they to become impaired. Such biases threaten the fairness of health care decisions made on behalf of a patient when disability is at issue.

So, we are left with several puzzles and challenges. We need to include in our ethics case consultations marginalized voices like those of persons with disabilities, who are too often ignored, inappropriately infantilized, or devalued by mainstream society. But the voices of disabled persons who can communicate with us may not accurately represent those who can never speak for themselves. Caregivers of persons who have limited or no decision-making potential should be part of the conversation. And how do we address slippery slopes when our main obligation is to the individual in front of us? Mairs (1996, p. 120) wrote, “People who act on principle are likely to sacrifice the individual for the agenda, which is frequently shaped by their own, often

Cont. on page 5

CONFERENCE EXPLORES COST, MEDICINE AND ETHICS CONSULTS

The issue of health care cost has been a taboo subject in the patient-provider encounter. This may be because health care providers believe cost should not influence health care treatment decisions, or because they do not know how to broach the topic with patients. Yet, cost concerns have a real impact on patients, families, and institutions. To address the issue of cost in more depth, MHECN co-sponsored the symposium, "Money & Medicine: Bedside Ethics of the Medical Marketplace," at the Greater Baltimore Medical Center on January 30, 2006.

Speakers delivered remarks on the issue of costs in decisions to withhold or withdraw life sustaining treatment after attendees acted as an ethics committee in considering a case in which the cost of medical treatment may have influenced decisions made at the bedside. The case involved a man with end-stage lung cancer who requested that he remain on a ventilator through his death to avoid suffocating. His physician agreed, but an ICU attending later decided that ventilatory support was inappropriate for its intended purpose of achieving a peaceful death. That physician decided to discontinue the ventilator without mentioning to the patient's family that the cost of the patient's stay in the ICU had exceeded the patient's insurance coverage for it, so that the hospital stood to minimize its financial losses if the patient died sooner rather than later. The question posed to the "audience as ethics committee" was, should cost be a consideration in the ethics committee's deliberation on the case, and if so, how?

When thinking of conflicts over health care costs, we often think of situations where health care providers or institutions are looking after their own financial interests. But keeping a patient alive can have significant financial implications for the patient and his or her family. For example, a stay in the ICU for just a week can cost thousands of dollars, pushing some uninsured patients into bankruptcy. Marion Danis, Head of the Section on

Ethics & Health Policy in the Department of Clinical Bioethics at the National Institutes of Health, gave sobering statistics about the societal and personal costs associated with end of life care for cancer patients in the U.S., including the facts that: 1) bedside rationing does occur; 2) medical care costs have risen dramatically; and 3) patients and families are paying an increasing proportion of those costs. Danis identified ways that physicians currently ration at the bedside, both implicitly and explicitly. Most physicians currently do not discuss the financial implications of health care decisions with patients or family members, perhaps due to lack of communications expertise in this area and a shared belief that physicians do not and should not consider cost in making treatment recommendations. Danis believes physicians should inform themselves about the impact of cost on medical care, and that they should develop the expertise to discuss not only the potential benefits and risks of a procedure or treatment but also its costs. She explored the potential impact of such disclosure on patient care.

Fairness, Danis suggested, might be enhanced through such disclosures by prompting physicians to consider cost in justifying their decisions for choosing one treatment over another (for example, ordering an expensive lab test that may not improve clinical outcomes for the patient). A more consistent practice of financial disclosure might also protect against discriminatory practices in which rationing decisions are unfairly targeted toward only certain patients.

Danis further suggested that provider-patient trust could be enhanced if patients were told directly about rationing decisions and the basis for them, rather than finding out later from a source other than the patient's physician. For example, even though the ICU attending in the case study may have correctly concluded that a ventilator is an inappropriate palliative intervention to avoid suffocating while

dying, the patient's family may perceive that the decision was motivated by cost if they discover that the hospital stands to financially benefit from the ventilator withdrawal. Informing the family of the financial facts along with the palliative standard of care to achieve a peaceful death, Danis contends, may help to preserve trust and empower patients and families to make informed choices. For example, in the case study, if the patient's continued stay in the ICU was no longer covered by insurance, the hospital might bill the patient (or his estate) for unreimbursed costs of treatment. If the physician who offered continued ventilator support had explained this to the patient, along with the full range of palliative care options, the patient may have made different choices. Furthermore, explicit discussions of medical finances may enhance patient well-being by identifying sources of financial stress and providing information, reassurance, or referral to assist patients with financing their medical care.

Danis suggested that ethics consultants recognize the influence of bedside rationing (both implicit and explicit), that they model discussions about financial conflict, and that they advocate proactive conversations about how patients and families cope with financial issues. Symposium attendees debated the pros and cons of having physicians take on this additional duty, given their poor performance communicating with patients about end-of-life care.

Rebecca Elon, Associate Professor of Medicine at Johns Hopkins University School of Medicine and Clinical Associate Professor of Medicine at the University of Maryland School of Medicine, explored the prevalence and types of bedside rationing and their influence on the practice of medicine. One example of a common bedside rationing device is the use of clinical practice guidelines. There is also price-based rationing (limiting access to a drug

or treatment based on price), insurance-based rationing (traditional indemnity or managed care), and individual clinical judgment (for example, giving a less expensive clot-dissolving agent to a stroke patient admitted to the emergency department). Elon explored the conundrum that bedside rationing is unavoidable if Americans want to control health care costs, but that it may come (ironically) at a price. Because current approaches to bedside rationing are often invisible and unacknowledged, there is a risk of discriminatory rationing and threats to provider-patient trust. Devising more ethically just ways of rationing health care resources without damaging trust or violating the physician's duty to advocate for the patient is the challenge that lies ahead.

Diane Hoffmann, Professor of Law and Director of the Law & Health Care Program at the University of Maryland School of Law, spoke on "Costs, Benefits and Medical Futility – Policy Approaches to Limiting Health Care at the Margins." Hoffmann argued that costs, to the extent that they play a role in health care decision making at the margins, should not be a matter for clinicians at the bedside but rather should be a result of policy debates at the state or national level. While health care providers and institutions are important actors in these cases, decisions made at the bedside are more likely to be subject to claims of bias and discrimination. Therefore, any decision to incorporate costs into the treatment equation should be a result of considered deliberation by elected officials who can take into account the voices of the numerous stakeholders concerned about this issue. She also cautioned that in the medical futility context, cost is really only an issue when there is some benefit to continued treatment. If there clearly is no benefit, there should be no need to consider costs. The problem, she asserted, is that often there is not agreement on whether there is any benefit. Patients or their family members often think there is some

benefit when health care providers do not. Once we begin to balance benefits and costs, or allow health care providers to do so, we start down a slippery slope and also quickly intrude on the legal authority of the patient's family members to make decisions based on the patient's best interest, i.e., whether the benefits of a proposed treatment outweigh the burden. While burdens can include costs, it is the patient's family, not the physician, who decides how much weight to give them. The intractability of defining medical futility has led to a view that policies should focus on process not substantive criteria as a way to resolve conflicts over futile care.

Hoffmann discussed one state that had adopted a process approach to resolving these conflicts. The Texas Advance Directives Act includes a procedure for resolving disagreements about treatment decisions "at the margins." The law provides that in cases where families wish to continue medical treatment but the physician decides that continued treatment is "medically inappropriate" (a term which the law does not define), an ethics committee is authorized to review the physician's decision. If the committee affirms the decision of the physician and no alternative provider can be found to treat the patient within ten days, the patient's life sustaining treatment can be withheld or withdrawn over the objections of the patient and/or his family members. Despite the statutory procedure, a number of cases decided under the law have been criticized because of the perception that cost, or the fact that the patient was uninsured, was a factor. Hoffmann discussed how one might improve upon the Texas statute by designing a process that is perceived as fairer by third party observers.

At the end of Hoffmann's presentation, attendees discussed the benefits and drawbacks of the Texas statute. By a show of hands, the majority of attendees opposed it, however, a significant minority felt that it was a good law, striking the right balance between patient/family and health care provider concerns about medically futile care.

deeply buried, presuppositions about what constitutes an acceptable life." Ironically, one could argue that basing an objection to "the Ashley treatment" on potential harm to less-disabled individuals does just what Mairs, a disability rights advocate, bemoans—sacrifices Ashley for the disability rights agenda. Surely that can't be the right course. I suspect the answer lies somewhere in between. The potential impact on others of a particular medical treatment decision should not be the primary focus of an ethics case consultation. But it should be a consideration somewhere in the process, particularly when deliberating on precedent-setting cases where unexplored personal biases may create blind spots that warrant careful reflection before coming to consensus and communicating recommendations to the public.

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References

- Clarren, R. (February 9, 2007). Behind the Pillow Angel. http://www.salon.com/news/feature/2007/02/09/pillow_angel.
- Gunther DF, Diekema DS. (2006). Attenuating growth in children with profound developmental disability: a new approach to an old dilemma. *Arch Pediatr Adolesc Med.* 160(10):1013-7.
- "jebldmm" (February 8, 2007). It's so much easier to do nothing. http://letters.salon.com/news/feature/2007/02/09/pillow_angel/view/?show=ec.
- Mairs, N. (1996). *Waist-High in the World: A Life Among the Nondisabled*. Boston: Beacon.
- McClimens, A. (2003). The organization of difference: People with intellectual disabilities and the social model of disability. *Mental Retardation* 41(1), 35-46.
- Vehmas, S. (2004). Ethical analysis of the concept of disability. *Mental Retardation* 42(3), 209-222.

ADDRESSING THE “JUDGMENT TRANCE:” WHY ETHICS CME'S SHOULD BE REQUIRED FOR PSYCHIATRISTS

You have 20 years of clinical experience under your belt. You feel that you know your strengths, weaknesses, and limits. You’ve come to believe that the therapeutic relationship is the key “medically active ingredient” in treatment. So, you start to think that it is the most important thing to develop, enhance and preserve in your work with patients. You are treating a new patient who believes that much can be learned from you; not just your knowledge but the way you live your life. You respond. You share stories about your life: your marriage, your struggles parenting your child, your experiences in college. The patient really resonates. This encourages you to start sharing more vulnerable stories – episodes that have much in common with the patient’s experience. You find yourself sharing how a professor in college crossed some lines with you, got too close, actually seduced you. The patient feels your pain, because it’s similar. Next session, you get a gift from the patient. It’s food. The patient invites you to share the food. You need no further reflection, after 20 years, than to check in with your own feelings. It feels right. Develop the relationship, don’t allow the patient to feel rejection. You prepare your coffee table to share the repast. The next session is a beautiful day, you move out to the balcony together and share food again. Feels right. Next session, another gorgeous day, and the park across the street seems like an inviting therapeutic environment. So you move the session out there, it’s like having a class outdoors on a beautiful day in college – no harm done. The following session, you get up in the morning, see the weather is fine again, know that it’s a hot day, so that morning you dress in something more comfortable and casual for outdoors. It’s slightly more revealing, but it feels comfortable, and that’s important. Towards the end of that session, after eating, coffee feels right, so you and the patient swing by the cafe for a cup. The therapeutic relationship is deepening, the patient is trusting you more and more. You’re getting to material that

has never been reached before. You are feeling very effective, the sensation of a senior therapist, at ease in your complex art. You find yourself looking forward to these sessions. In fact, you start to make sure that there is nobody else scheduled immediately after this patient’s hour, so you can linger a bit longer over coffee. It helps to move the session to the last one of the day. You are increasingly aware that you are treating a truly remarkable person, and feel fortunate for the serendipity of being matched up by referral and chance. Indeed, you feel that your years of experience permit you to try stretching, taking slight extensions of conventional technique, bending technical rules that are really designed more for beginners, to help structure their introductory years in the ill-defined and elusively broad art of therapy. Like training wheels, you sense there is a point where typical conventions are oversimplified and even unnecessary. This isn’t something you can or even need to talk about with any colleague. They probably wouldn’t understand. They have to be here, in this *particular* therapeutic relationship, to really get it. Only you can get it. It took 20 years, but you’re really feeling you are starting to get it.

And so it goes: the slow procession of feelings, rationalizations, and instincts which propel you down a self-determined, well meaning, and increasingly self-deluded path. You drift further and further “off-the-reservation,” a satisfying journey which, one day, ends in surprise, when you are being interviewed by the Maryland Board of Physicians about this case. Where did you go wrong? Did you ever know you had?

For the last few years, as Chairman of the Clinical Ethics Committee for Sheppard Pratt Health Systems, I have been called upon widely to give lectures on topics in Medical Ethics, with a specific focus on ethical issues in mental healthcare. The audiences are almost always social workers and psychologists; rarely, if ever, is there a psychiatrist in the audience. Why is this? It turns out that for some years, both of these professions have

required not just continuing education credits to renew their licenses to practice, but specifically, 3 credits yearly in ethics. In contrast to our fellow mental health professionals, though we are required to have yearly credits to renew our licenses as physicians, there are no specific requirements for psychiatrists to take courses in any particular area, let alone ethics.

I want to argue that a requirement in ethics training for physicians in general, psychiatrists in particular, should be implemented, in parallel with the already established requirements of social workers and psychologists. Historically, physicians were long resistant to the idea of medical ethics as an important clinical discipline. There was a sense that it belonged in a course in philosophy departments or at special “think tanks” like the Hastings Center for Bioethics in New York, but not in hospitals, on rounds, or in grand rounds. However, that recalcitrance has gradually eroded, partly with the help of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) which, over the last decade, has started to require that hospitals have an Ethics Committee, which could be consulted by staff or patients. Even prior to this, the federal government instituted the requirement of an Institutional Review Board (IRB) to review any protocol for human experimentation for ethical soundness.

One need not look past the headlines to observe that we live in times of great ethical confusion and misbehavior in many professions. My own work with ethics consultations in health care systems and on the Maryland Psychiatric Society (MPS) Peer Review committee has revealed to me that there is indeed considerable ethical confusion and misadventure (both knowingly and unknowingly) among psychiatrists.

Systematic ways of thinking through moral conundrums do exist and have been developed in the formal field of Medical Ethics. These processes are not

necessarily merely a matter of following one's intuition. Indeed, I have seen "clinical intuition" lead many a psychiatrist astray in this domain. The ever increasing pressure to make decisions quickly, to spend less time with patients and less time in consultation with colleagues, have all combined to increase the chance of clinical behavior that is not just substandard, but frankly, unethical.

It turns out that considerable thought, writing, and discussion has been taking place in the field of medical ethics over the last few decades, which is keeping up with developments. Issues that have challenged ethical thinking are evolving. Such issues as the ethics of relating to managed care organizations, doctor/patient boundaries, and patients refusing treatment are some examples of issues about which thinking has been rapidly evolving in systematic ethical analysis. Critical thinking about these areas is advancing, much as neuroscience and pharmacology are advancing. Yet there is little opportunity to avail oneself of training in these matters. Indeed, the demands of more concrete and procedural knowledge, such as psychopharmacology, can be seductive and can lead one away from the "softer" topics when considering how to spend precious CME hours.

Moreover, there are not many CME hours out there for ethical training of psychiatrists. I recently had an opportunity to give an hour lecture on a CME closed-circuit TV and web cast program. Though asked for more, it was impossible for the producers to find underwriters for more ethics broadcasts. In contrast, underwriters (read: pharmaceutical companies) were standing in line to sponsor programs on treatments of illnesses with pharmacotherapy.

The fact is that mandating continuing education in ethics for social work and psychology produced a market for such courses, and suddenly, they were commonly available. In my experience, they are eagerly attended, not simply because they are mandated. Attendees seem to find this training of immediate value to common practice conundrums. These seminars actually help to raise basic awareness of when one is actually on ethically controversial ground – a basic

awareness that, though fundamental, is often lacking. It is one thing to know how to skate on thin ice; it is another thing entirely to learn how to recognize that the ice is getting thin.

More than any other kind of healing professional, therapists and psychiatrists are often soloists. What we do is, by necessity, very private. Typically, we are utterly alone with our patients. This makes us vulnerable to creating a hermetically sealed zone in which our clinical judgment is deployed, without being readily accessible to feedback from other authoritative colleagues or sources. My work on the MPS Peer Review Committee demonstrates to me the kind of "judgment trance" that can be fostered, in which progressive rationalizations can lead to a subtle, gradual drift away from standard ethical practice. Unfortunately, it is often left to the patient or family member to ring the alarm bell, signaling that the psychiatrist is "off-the-reservation." One need only read the report of sanctions by the Maryland

Board of Physicians to see that psychiatrists are overly-represented in that roll call of dishonor.

I submit that this is not surprising, considering the nature of psychiatric work. That means that psychiatry has a particular need for ethical education to cultivate a more robust and effective ethical self-monitoring.

This is the reason that I think it is time for psychiatrists to join the good sense of their colleagues, the social workers and psychologists, and require mandatory continuing education in one particular area – ethics. The zeitgeist of our increasingly ethically confused society calls for it, the virtue of humility in the face of a complex clinical art calls for it, and last (and least) – our malpractice attorneys call for it.

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“VALUE” MNEMONIC IMPROVES ICU END-OF-LIFE COMMUNICATION

Researchers found that when the following mnemonic device was used in a family conference to discuss end-of-life treatment decisions for a patient nearing death, family members were more likely to feel heard and supported, and were more likely to concur with a decision to forgo life-sustaining treatment, than were family members who participated in a family conference in which the mnemonic was *not* used.

V = VALUE what family members say

A = ACKNOWLEDGE their emotions

L = LISTEN

U = UNDERSTAND the patient as a person by asking questions

E = ELICIT questions from family members

Lautrette, A., et al. (2007). A communication strategy and brochure for relatives of patients dying in the ICU. *The New England Journal of Medicine*, 365:469-478.

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—LIFE-SAVING SURGERY AGAINST PATIENT'S WISHES

In this issue, we present an actual case that was recently featured in a New York Times article.

Dr. Michael E. DeBakey, a previously healthy 97 year old cardiac surgeon, suffered a dissecting aortic aneurysm, a condition for which he himself devised the surgical repair. Fearing that surgery for a man his age would leave him severely mentally or physically impaired, he opted to accept his impending death. Over the next few weeks, he was cared for at home with conservative measures to prevent aortic rupture, an unlikely outcome without surgery. He periodically went to the hospital for imaging tests to measure the aneurysm's size. It grew from 5.2 to 6.6 cm over a 3 week period, and about 2 weeks later, was up to 7.5 cm.

Eventually, he agreed to hospitalization. At this point, his kidneys had failed, and there were signs that the aneurysm was leaking. A do-not-resuscitate order was written, and a note written in his chart

stating that he did not want surgery to correct the dissection. He told his physician and long-time colleague both that it was "time for nature to take its course," but also that the doctors had to "do what they need to do." He then became unresponsive. His family insisted that the doctors operate, as it was his only hope of surviving. They reasoned that he would want what they want. The surgeons who knew him well thought they should operate, but the anesthesiologists were reluctant to go against his prior stated wishes, particularly since he was a poor surgical risk due to advanced age. An ethics consult was called.

Source: "The Man on the Table was 97 but He Devised the Surgery," by Lawrence K. Altman, *New York Times*, December 25, 2006.

COMMENTS FROM A CLINICAL ETHICIST

While the specific details of Dr. DeBakey's case are unique, the issues the case raises for ethics consultants and hospital ethics committees are not. Beneficence is at play, as surgery will provide the best, if not only, chance to repair the aneurysm. Non-maleficence, on the other hand, might compel a physician not to provide a risky surgery that could severely harm an elderly patient. While these are important considerations, neither seems to provide absolute guidance. A patient in his or her 90's may be otherwise healthy and able to tolerate surgery, thus justice (as fairness) could also be an important consideration, in ensuring that a patient would not be denied a potentially curative treatment based on age alone. At the same time, respect for patient autonomy would support a capacitated patient's right to refuse a potentially beneficial treatment. Since the patient's wishes are somewhat unclear and in dispute in the case at hand, issues and questions about patient autonomy

provide the crux of the ethical dilemma posed in the DeBakey case.

The main questions that the ethics committee must consider upon being consulted are whether or not surgery in this situation would be against the true wishes of the patient, and whether the family members are acting as appropriate surrogate decision makers at this point in time. Since the patient initially decided to remain at home and not undergo surgery upon diagnosis, some clinicians involved, such as the anesthesiologists who reportedly raised questions in this case, felt that proceeding with surgery at this point in time may not be consistent with the patient's wishes. On the other hand, at the time of the ethics consult, the patient had recently consented to hospitalization after spending a number of weeks at home, which may reflect a shift in his preferences for treatment of the aneurysm. In examining whether this shift is significant and representative of a true shift in the patient's preferences for treatment, it is natural to turn to the patient's most recent statements of his preferences. However, the patient's statements about nature taking its course and doctors doing what they have to do can be interpreted as rather contradictory. Thus, an ethics committee needs to seek further guidance as to what exactly the patient meant by these statements in the situation as it currently stands.

The natural people to whom a healthcare team and/or ethics committee would turn to clarify a patient's statements about his or her wishes would be a patient's family members. Additionally, the patient's spouse would be the legally authorized surrogate decision maker in the state of Texas absent a properly executed medical power of attorney. Ethics committee members must always be careful to assess whether a surrogate decision maker is appropriately using substituted judgment to make decisions as to what the patient would have wanted in a particular situation. If a surrogate decision maker seems to clearly be imposing their own wishes on a patient, contrary to a patient's known wishes, the ethics consultant/committee

members have a responsibility to raise this concern. Surrogate decision making can be a very emotional process, and having an ethicist or ethics committee to actively help a surrogate think through how to appropriately make decisions on behalf of an incapacitated patient may be very helpful to the surrogate, and very helpful in achieving an ethically sound outcome.

When, in a case such as DeBakey's, it is difficult to ascertain the patient's actual wishes, and it is also difficult for some members of the team to have complete confidence in family members' assessments of the patient's wishes, should ethicists and committee members feel comfortable in trusting the family to lead the decision making process? Tia Powell has observed that family members are very often the best-suited individuals to engage in empathetic communication that helps find a patient's "voice" when a patient is incapacitated, as family members have intimate knowledge of the patient and his or her personality. Family members know their loved ones in a complex way that a healthcare provider usually does not, and this knowledge of a person's manner of making complex decisions can be invaluable when the patient's wishes are truly unclear.

In this case, I would recommend that the ethics committee and healthcare team engage family members in an active way as partners in medical decision-making to determine why they believe the patient would desire surgery now when he explicitly rejected surgery a number of weeks before. Knowing what they know about the patient and how he thinks, were his directives to his physicians at his diagnosis likely based on his condition at the time or were they absolute? Would he have changed his mind given his worsening condition? Does allowing nature to take its course mean rejecting treatment options altogether to this particular patient, or only not attempting resuscitation if the patient were to arrest? All of these are legitimate questions which the family may be able to answer from the patient's perspective much better than a physician, nurse, or other provider.

While the patient seems to have strongly rejected a surgical intervention

in the past, the team and the ethics committee must be aware that patients are allowed to change their minds. If the committee feels after this exploration with the family that the patient likely would have changed his mind in recent days given his condition, or that his seemingly conflicting statements most likely do not represent an outright rejection of surgery, then the surgery would be ethically justified. At the same time, individual professionals may still be uncomfortable proceeding given the controversy in the case, and this hesitancy should also be honored by allowing these providers to remove themselves from involvement in the case.

Finally, both the professionals involved as providers and the members of the hospital ethics committee must be cognizant of their own biases and conflicts in a situation such as this. In Dr. DeBakey's case, many staff members at his hospital through the years may have come to have a personal relationship with him. On one hand, these personal relationships could be valuable in assessing what his wishes likely would have been and whether or not the family was honoring those wishes. On the other hand, this could also serve to cloud the judgment of some professionals. The key is to be aware of personal relationships an ethics consultant or committee member might have with the subject of an ethics consultation, and try to ascertain how this is influencing the recommendations being made. If at all possible, ethicists and committee members with personal connections to a patient or a situation being brought forward for ethics consultation should not be involved in the formulation of ethical recommendations.

While Dr. DeBakey's particular case leaves many questions, it also helps us think about potential answers. Being prepared in advance for encountering situations with similar ethical issues can help ethics consultants and committee members function much more effectively to bring about ethically sound resolutions.

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References

Altman, L. "The Man on the Table was 97, but He Devised the Surgery," *New York Times*, December 25, 2006, p. A1.

Powell, T. (2005). Voice: Cognitive Impairment and Medical Decision Making, *Journal of Clinical Ethics*, 16:4, 303-313.

COMMENTS FROM A BIOETHICIST

One of the issues that first comes to mind after reading a case like this is the complexity of respecting a patient's autonomous wishes when such wishes appear to change over time. Adding to the complexity in this particular case is the fact that the patient became incompetent to make an autonomous decision after he had given contradictory statements shortly before he lost consciousness. At stake here then are both the authenticity of the patient's wishes and the standards of surrogate decision-making. An additional complicating factor in this scenario is the background and the celebrity of the patient at stake – a famous cardiothoracic surgeon whose very specialty was the exact surgery he was subjected to. In this response, I will try to explore the several pieces that make this such a fascinating and essentially educational ethical puzzle.

First, let us look at the issue of authenticity of this patient's wishes. When this patient, retired cardiothoracic surgeon Dr. DeBakey, was first diagnosed with his potentially life-threatening aortic aneurysm, he consciously chose to adopt a "watchful-waiting" strategy. The progression of his disease was closely monitored, but essentially left untreated, as per the patient's clearly stated preferences. Knowing that he could and probably would eventually

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die if the aneurysm would burst, he appeared to accept this fate. Considering his wealth of knowledge and experience in this area, his decision would have to be regarded as well-informed and voluntary. When the aneurysm had progressed to a dangerously large size and had started to cause kidney problems, however, he did allow himself to be hospitalized for treatment. This could be interpreted as a change of mind about his treatment plans. Key questions here are if DeBakey did indeed autonomously revoke his prior decision and if that was authentic for him. As Beauchamp and Childress state, deciding whether particular actions are autonomous may depend, in part, on whether they are in character or out of character. As a life-long surgeon, inventor of one of the more invasive and dramatic surgical interventions, it certainly seemed in character for DeBakey to choose surgery over palliative care. Even stronger, the previous decision *not* to operate may have seemed out of character to his family members. Perhaps this explains why the family, as his surrogate decision-makers, felt that DeBakey, a surgeon himself, would have wanted surgery.

The fact that a DNR order was written still does not preclude a preference for surgical intervention, as it specifically refers to life-saving measures in case of an emergency, such as sudden cardiac arrest. Performing an essentially non-emergency procedure, namely, repairing the aneurysm *before* it burst, would not be considered resuscitation. Being so well-known at his hospital, DeBakey's celebrity and reputation as a dedicated surgeon obviously contributed to the general opinion that he would have wanted to undergo surgery—except for the anesthesiologists, both the treating surgeons and the family agreed that this was the best decision at that time. Once the decision to treat was made, the surgical team followed through with every measure necessary even in the course of (to be expected) complications and the need for temporary mechanical ventilation, and despite the advanced age of the patient. While not every nonagenarian would necessarily be offered this intense treatment for a variety

of possible reasons, the chosen course of action did seem appropriate and consistent in this case, especially considering the eventual positive outcome. Had DeBakey become fully and indefinitely dependent on mechanical ventilation or other life-supporting measures, then the surrogate decision-makers could have reconsidered the situation at that point. Fortunately, they did not have to make such a life-and-death decision.

This brings us back to the issue of surrogate decision-making. As Beauchamp and Childress explain, in current biomedical ethics an ordered set of standards for surrogate decision-making is favored, running from (1) autonomously executed advance directives, to (2) substituted judgment, to (3) best interests. The first two are, according to Beauchamp and Childress, essentially identical, as they both are founded in pure respect for autonomy. They go on to state that in absence of reliable traces of wishes, surrogate decision-makers should adhere only to the best interest standard. In this case, there were quite contradictory statements and documents to guide the surrogate decision-making process. First, there was the note in the chart that DeBakey did not want surgical correction of his aortic dissection. This appears to be a sufficiently clear and ethically binding written advance directive, to be respected by the family as surrogates. (Whether it was *legally* binding would depend on whether it was witnessed in accordance with Texas law.)

What complicated the surrogate decision-making process were the statements made by DeBakey before he lost consciousness, that "...doctors had to do what they need to do." This was interpreted by the family as an acceptance of the need for surgery as somewhat of an inescapable medical fact. Whether this was a correct interpretation, only DeBakey himself can attest to. In light of these seemingly contradictory patient's wishes, the surrogates should have adhered to the best interest standard instead. When doing so, surrogates should consider the

formerly autonomous patient's preferences, values and perspectives only as far as they affect interpretations of quality of life, direct benefit, and the like. How these considerations would have influenced the family in their decision-making process is only a guess from my part, but quite possibly they would have come to the same conclusion when we take direct benefit and values into account. The only argument that could be used to choose to forgo surgery and to "...let nature take its course..." is the consideration of the prospective quality of life. An active, take-charge personality like DeBakey arguably could have ended up being quite unhappy in a dependent state (e.g., bed-ridden) if that would have been the outcome. Luckily, erring on the side of active surgical intervention turned out well in this case, and illustrates that even for a seemingly moribund 97-year old, an aggressive approach may still be warranted.

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References

- Altman, L. "The Man on the Table was 97, but He Devised the Surgery," *New York Times*, December 25, 2006, p. A1.
- Beauchamp, T.L. and Childress, J.F. (2001). *"Principles of Biomedical Ethics"* 5th Ed. Oxford University Press, Inc. Chapter 3: "Respect for Autonomy."

Update

Dr. DeBakey survived the surgery and is currently participating in patient rounds, ambulating in a wheelchair. He is happy the doctors saved his life, and surmises that he was "in denial" when he refused the surgery.

CALENDAR OF EVENTS

JUNE

May 31

–June 1 Doing Health Care Ethics, A workshop on clinical and organizational ethics. Sponsored by the Georgetown University Center for Clinical Bioethics, Georgetown University, Washington, DC. Visit <http://clinicalbioethics.georgetown.edu/> or e-mail seamanm@georgetown.edu for more information.

4-9 Intensive Bioethics Course, sponsored by the Kennedy Institute of Ethics, Georgetown, Washington, DC. For more information, visit <http://kennedyinstitute.georgetown.edu/>.

20-22 “What is needed to do ethics well?” Sponsored by Sentara Center for Healthcare Ethics. Marriott City Center, Newport News, Virginia. Contact Julia West at (757) 388-4263, jmwest@sentara.com.

21-22 Bridges to Latino Health: Si Se Puede! Sponsored by the Loyola University Chicago Public Health Action Project, Chicago, IL. Visit <http://bioethics.lumc.edu>.

JULY

13-14 Pediatric Bioethics Conference, sponsored by the Seattle Children’s Treuman Katz Center for Pediatric Bioethics. Bell Harbor International Conference Center, Seattle, Washington. Contact angel.latterell@seattlechildrens.org for more information.

26 Ethics Committees in Action. Sponsored by MHECN and the Beacon Institute. Bon Secour Spiritual Center, Marriotsville, MD. Visit www.law.umaryland.edu/mhecn, or e-mail MHECN@law.umaryland.edu.

AUGUST

6 Summer Seminar in Health Care Ethics, sponsored by the University of Washington, Seattle, Washington. For more information, contact mms23@u.washington.edu.

SEPTEMBER

18 Stem cell research: Are we ready for clinical trials? Speaker: David Magnus, PhD, Director, Stanford Center for Biomedical Ethics, Stanford University. Sponsored by the University of Pennsylvania’s Center for Bioethics. 3401 Market St., Ste. 321, Philadelphia, PA. RSVP to clinksca@mail.med.upenn.edu or call (215) 898-7136.

