

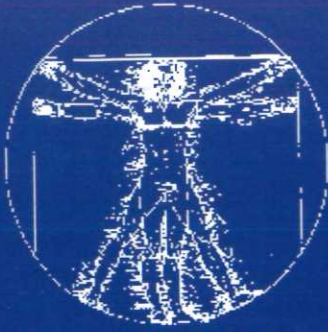
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 2000*

Mid-Atlantic Ethics Committee
Newsletter, Spring 2000

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MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
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MILLENNIAL REFLECTIONS ON THE BURDENS AND BENEFITS OF TECHNOLOGY

It seems appropriate, in this first newsletter of the year 2000, to reflect on technology and its place in the dialogue about healthcare and ethics. Historically, “progress” has been measured in part by a society’s degree of technological innovation. However, throughout this century, prognostications of life in the year 2000 and beyond often included visions of technology replacing many human functions and even trumping human emotions. This reveals the kind of love-hate relationship we have with technology—we strive to create it, we measure success with it, and at the same time we fear its power to diminish or extinguish our humanity. Is technological progress an inherent good? By what ways do we weigh the benefits and burdens of technological innovation?

In his book *Why Things Bite Back: Technology and the Revenge of Unintended Consequences*,¹ Edward Tenner writes of what he calls “revenge effects” of technological innovation. A revenge effect is not the same as a side effect or a trade-off—it is an unforeseen negative consequence of applied technology. For example, computers and the internet have transformed the “civilized” world, but not without a

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price. Consistent computer use can cause eye strain, neck and back pain, and carpal tunnel syndrome. Costs to train and educate employees and students and to maintain computers and protect them from cyber viruses and system crashes are creating growing disparities between those who can afford state-of-the-art computer technology and those who can’t. Moreover, while technology is often envisioned as a time-

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NETWORK NEWS

Maryland Health Care Ethics Committee Network (MHECN)

MHECN continues to move ahead with its goal of serving the needs of ethics committees throughout Maryland. On January 24th the first Board meeting was held and officers were elected. Diane Hoffmann, JD, MS will serve as Chair of the Executive Board, Eugene Growchowski, PhD, MD as Vice-Chair, and Brian Childs, PhD, as Secretary/Treasurer. Martha Knudson, JD will serve as Chair of the Membership Committee and Anita Tarzian, PHD, RN will chair the Education Committee.

Goals for the coming year include: continue to seek funding, increase membership, establish the Network on a sound business foundation, and provide educational programs to the ethics community in Maryland including an ongoing basic course in bioethics for interested members.

The first educational program for this year will be held at Harbor Hospital on June 1st. The program will be a follow-up to the lively discussion started at the Annual Meeting with an interactive interchange between ethicists, legal experts, healthcare providers, and the Maryland bioethics community. Dinner will be provided. A recent ER segment about dying and advanced directives will be presented followed by an open discussion of questions such as: What level of capacity is needed to revoke an advanced directive? How do we best show respect for patients with diminished capacity who revoke their advanced directive? This should be a provocative evening. Look for registration brochures in April.

Metropolitan Washington Bioethics Network (MWBN)

The MWBN continues its thought-provoking speakers program in April. See this issue's Calendar for April's

talk. Contact Joan Lewis at 202-289-4923 or jlewis@dcha.org for more information. The Network in collaboration with the DC Partnership to Improve End-of-Life Care is involved in a work group on revising the Guardianship statute and the Health Care Decisions law in the District to give full decision-making powers to court-appointed guardians. At present, the court-appointed guardians have limited decision-making authority unless they go back to court (in some cases repeated returns to court are necessary). For example, most guardians will not agree to a do not resuscitate order unless they receive a specific order from the judge.

This same working group is also attempting to revise the current Advanced Directive form used in the area (legal in all three jurisdictions—DC, MD, VA) to enhance its "usability." The work group plans to add a section encouraging individuals to "express in their own words" what they value and what they would want in the event of a serious illness, and to add a section that will deal with long-term progressive illnesses/conditions such as Alzheimer's, where patients might want to express their wishes based on level of functioning, not a specific diagnosis.

Much of this work has been informed by the Network's consultation program with the DC Superior Court, which is an ongoing service provided by Network members. At the present time, the Network is consulting on about 15-20 cases a year, providing information to the probate court regarding bioethics issues in guardianship proceedings. Various educational activities for judges and guardians-attorneys are in the early planning stages.

Northern Virginia Ethics Network (NVEN)

A new group of those interested in bioethics is beginning to meet in Northern Virginia under the leadership of John Fletcher, PhD. Twenty-five people

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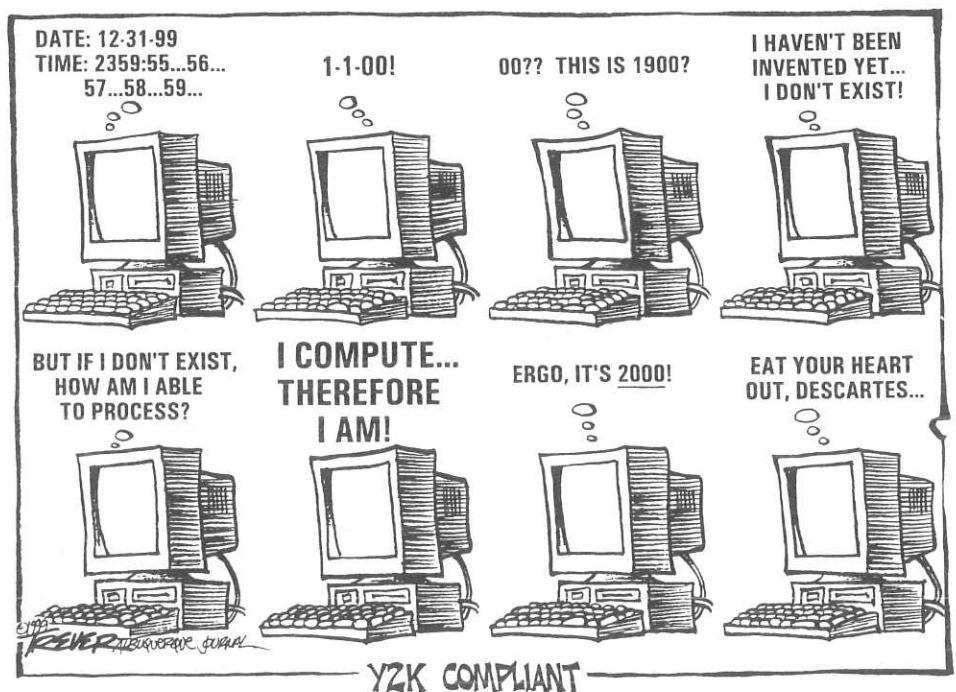
Millennial Reflections
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saver, the advent of computer e-mail and faxing tends to increase time demands on an individual by decreasing communication turn-around-time. Where you once had a few days to send a requested document by mail (now referred to as "snail mail," reflecting our bias toward instantaneous communication), you may now send it by e-mail attachment or by fax the same day you receive the request! Tenner expounds on these and other areas of technology where revenge effects can be seen, including environmental disasters, proliferation of animal and vegetable pests, and increased iatrogenic morbidity and mortality in healthcare facilities. There is an interrelationship among many of these revenge effects. For example, technological innovation allowed for cars to travel at higher speeds. Faster cars led to more physical injuries from car accidents. This in part helped refine trauma centers and trauma medicine, which caused both a dramatic increase in survival from head injuries and also a substantial increase in persons with head injury-related disabilities.

Although we might agree on one common goal in medicine being to minimize harms and maximize goods, it is challenging to exhaustively identify all possible goods and harms that a new technology brings, especially when we're trying to consider benefits and harms both to individuals and to society at large. The creators of CPR foresaw both its beneficial and harmful potential, and cautioned future clinicians to restrict its use to individuals with sudden cardiac failure who could be recovered. Despite that admonition, its use became widespread as a default intervention for any hospitalized patient whose heart stopped beating or who stopped breathing. This then led to the creation of Do Not Resuscitate (DNR) orders, which have not been without their own revenge effects (e.g., confusion over their interpretation, perceptions that patients with DNR orders get less vigilant care, privacy concerns regarding how to identify patients with a DNR, etc.)

Ironically, it has been shown that good health is associated with the results of nonmedical technological change (e.g., improved sanitation, an improved economy, better education, and a cleaner environment) more so than with scientific medicine. Nevertheless, one of the defining features of this century has been modern medicine's commitment to medical progress, which has predominantly focused on disease identification and cure, and treatment of severe injuries or traumas. Medical science has been less responsive to the chronic health concerns that are increasing in prevalence. While chronic health problems require a more holistic

several reasons for this, including the strong belief among many that good healthcare requires implementing medical technology, the expectation in this society that disease can either be cured or that illness can be localized and identified,³ and financial motives that make it necessary to use medical equipment to recoup purchasing costs through reimbursement. Availability of medical technology sometimes dictates its use more so than need per se. For instance, most individuals state that if they suffered from a terminal illness, they would prefer to die at home rather than in the hospital. Moreover, it has been shown that hospitals are not very



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treatment approach, the revenge effects of medical progress include a move away from caring for the person as a whole to treating specific body organs or systems, and increased distance between the patient and the provider. Along with the many successes that medical progress boasts, Tenner mentions several other revenge effects of some medical treatments, including increased disability, suffering, and even death.²

The example of CPR underscores the tendency for medical technology, once introduced, to become the standard of care—even if lower-tech approaches produce the same outcomes. There are

good providers of end-of-life palliative care. Yet, one study showed that the strongest determinant of whether a terminally ill individual dies in a hospital is if (s)he lives in an area where there are available hospital beds.⁴

How do we prevent medical technology from becoming the tail that wags the dog? Well, just as the sinking of the *Titanic* inspired the formation of the International Ice Patrol,⁵ revenge effects in medicine require increased monitoring and vigilance. Tenner writes, "Chronic problems almost by definition demand maintenance rather than

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solution; while the need for vigilance and care becomes itself a chronic irritation.”⁶ Healthcare facilities have multiple checks in place to avoid medication errors, equipment failures, and other mishaps. Health maintenance and screening procedures have grown in complexity and cost over the past few decades (see article on Genetic Testing in this issue). The end result of these revenge effects is the need for *more* technology and *increased* maintenance, which requires *more*, not less, human work to function. So much for technology replacing humans.

Although technology-induced revenge effects abound, Tenner also acknowledges the existence of what he calls, for the lack of a better phrase, “reverse revenge effects,” which refer to unintended good that results from implementation of some new forms of technology. For example, medical technology produced the ability to resuscitate severely low birthweight neonates, and to artificially ventilate, hydrate, dialyze and feed individuals who would otherwise have died. This created ethical dilemmas of deciding when certain technologies should be withheld or withdrawn. One response to this was the formation of ethics committees to help sort through these ethical issues.

An example of a reverse revenge effect is the formation of an ethics committee that promotes ethical reflection, deliberation, and decision-making for committee members, staff and the community, which is beneficial for all those involved. That is, a society whose members are able to identify the moral issues and discuss them intelligently and compassionately will be more likely to take better care of themselves and each other. However, not all ethics committees fall in this category, and those that are poorly run may be worse than having no ethics committee at all. A definite red flag is raised if ethics committee members do not actively contribute to ethical discussion, debate, and deliberation but

feign consensus, and decisions are really made by a committee chair or subgroup. Whether your ethics committee represents an antidote to, or an example of, revenge effects of healthcare technology depends on the honest, open, and active involvement of its members.

Ideally, technological innovation in healthcare should neither cause us to bury our heads in the sand, nor to embrace that technology wholeheartedly without putting time into substantive ethical reflection. We face future advances in medical technology that range from exciting/promising to troubling/disturbing. I hope we will take a proactive stance to help ensure that technologic innovation in medicine contributes to the goal of improving health without sacrificing core values. In order for this to happen, we must take the time to become fully informed, to harness the creative energy necessary to imagine all possible burdens and benefits that new technology may bring, to engage in meaningful dialogue about these issues, and to act in accordance with agreed-upon values and goals. Protecting a place for ethical reflection and discussion in healthcare institutions is one corrective to counter the increasingly complex revenge effects of modern medical technology.

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PUBLIC HEARING ON THE OVERSIGHT OF GENETIC TESTING

On January 27 a public hearing was held in Baltimore to obtain public input on the oversight of genetic testing. This public hearing was one of several mechanisms by which the Secretary’s Advisory Committee on Genetic Testing (SACGT) gathered information about genetic testing oversight in the U.S. Various members of a panel described their experiences with genetic testing. One panelist told of a woman who had her fetus tested for Huntington’s disease, which is fatal during middle to late adulthood, and for which there is no cure or treatment. The woman’s husband didn’t want to know if the fetus tested positive. It did. The woman had the pregnancy terminated, and told her husband she had a miscarriage. Later they divorced, in part because of the wife’s burden of keeping her secret. Another panelist described how she had herself tested for Huntington’s disease after watching her mother die from it. After undergoing a thorough 8-month protocol that included pre- and post-test genetic counseling, she learned that she had a copy of the mutant gene, although she is currently without symptoms. She was then fired from her job because the company she worked for was self-insured and those in charge believed her medical care would be too costly (despite there being no known treatment or cure for this disease). Her fiancé broke off their engagement, and she experienced other types of alienation after learning the results of her genetic test. Still, she is grateful for the knowledge and the process by which she was counseled. These are some of the personal stories that were shared at this meeting. In addition, scientists and others involved in policy making addressed various issues related to oversight of genetic testing.

Francis Collins, Director of the National Center for Human Genome Research, referred to the “double edged helix” of the genetic revolution—that it has the potential for tremendous good along with the potential for tremendous

¹ E. Tenner (1996). *Why Things Bite Back: Technology and the Revenge of Unintended Consequences*. New York: Vintage Books.

² Full text of the Institute of Medicine’s report on medical mistakes [L.T. Kohn, J.M. Corrigan, & M.S. Donaldson (Eds.) (2000). *To Err is Human*. Washington, DC: National Academy Press] is available online at books.nap.edu/books/0309068371/html.

³ See Tenner, pp. 39-44.

⁴ See R.S. Pritchard, E.S. Fisher, J.M. Teno, S.M. Sharp, D.J. Reding, W.A. Knaus, J.E. Wennberg, & J. Lynn for the SUPPORT Investigators (1998). *Influence of patient preferences and local health system characteristics on the place of death*. *JAGS*, 46, 1242-1250.

⁵ See Tenner, p.330.

⁶ *Ibid*, p. xii

harm. He acknowledged that most morbidity and mortality is from common diseases that tend to run in families, but for which there are many genes at work which are relatively weak in expression. These genes, combined with environmental triggers, cause the disease to express itself. There are anywhere from five to 50 or more genetic flaws in each of us—some may never encounter the environmental triggers needed to create disease, or a combination of flaws may need to be present, or we may die of something else before the disease expresses itself. Within the next ten years, we will know much more about these genetic flaws and disease propensities. The question is, do we want to know? In some instances, yes. For example, if we could identify those at risk for colon cancer through genetic testing, those individuals could be screened with colonoscopies, and the cost of mass population colonoscopy screening could be avoided while preventing mortality through early detection. However, genetic testing for diseases that do not have successful treatment (like Alzheimer's) may simply put individuals at risk for increased stigmatization and discrimination, not to mention psychological distress. Dr. Collins stressed that we shouldn't have to wait for a crisis to pass legislation protecting against genetic discrimination.

Currently, there are six main reasons for genetic testing: (1) to confirm a suspected clinical diagnosis, (2) to detect a carrier for a recessive disease, like Tay Sach's, (3) to make a prenatal diagnosis, like Down's syndrome or spina bifida, (4) to screen newborns for certain treatable conditions, like sickle-cell disease, (5) to test healthy individuals for disease susceptibility, like hemochromatosis, and (6) to predict responsiveness to therapy, such as which drug will work best for a given individual. Dr. Collins pointed to the fifth reason as the one with the greatest growth potential and the cause for greatest concern. Will individuals who carry certain genes that make them more likely to contract specific diseases be turned down from jobs, fired, or denied insurance coverage? If genes are

identified that predispose individuals to certain types of behavior, could this mean that human freedom to act responsibly is limited by genetic inheritance? These are the types of questions that arise when genetic testing is discussed.

Genetic screening is a specific application of genetic testing. Reasons for genetic screening include treating or managing disease, providing information for making reproductive decisions, preventing onset or manifestation of disease, and doing research. Dr. Robert Murray from Howard University compared reasons for the success of Tay Sachs screening and the initial failure of the sickle-cell screening programs. This had to do with educational levels and socioeconomic status of the targeted groups, levels of trust with the medical community, degree of voluntariness of the screenings, and the nature of the diseases being screened. Dr. Murray mentioned five principles that should guide genetic screening programs, based on other published guidelines: confidentiality of test results, fully informed consent, prior education of the community, accuracy of test results, and pre- and post-test counseling. Ensuring accuracy and reliability of test results (clinical validity) was mentioned as an important component of any genetic testing oversight initiative. Clinical utility (the clinical usefulness of genetic information obtained) is also important.

For example, if you are told you have twice the risk of acquiring a disorder based on the results of a genetic test, but this means your risk is only increased from 1% to 2%, the test may be clinically valid but not clinically useful.

Andrew Imparato, President of the American Association of People with Disabilities, cautioned that genetic testing can be used to stigmatize and discriminate against people with disabilities. Mr. Imparato called for moving from the medical model (which views disability as an illness requiring medical treatment) to the social/civil rights model, in which people with a disability are viewed as a minority group and experience discrimination. In the social model, disability is recognized as a normal part of the human experience—one that we should strive harder to recognize and accommodate instead of finding more ways to ignore or eliminate. Mr. Imparato asked, why do we routinely screen for Down's Syndrome and spina bifida? How are couples counseled? What assumptions are made about the quality of life of the baby born with Down's Syndrome, or the experience of the family? Too often parents are not provided with enough information about the implications of having a child with a particular genetic disorder, even though clinicians believe they are giving genetic information so

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LAST ACTS UPDATES ITS WEBSITE

Last Acts, a national coalition to improve care and caring at the end of life, has recently updated its Web site. The updated site is a comprehensive resource center with news, facts, books, music, quotes, and program initiatives related to end-of-life care. In addition to improved, easier navigation and more content and tools, recent additions include:

- ◆ Tomorrow's Tools – a thought-provoking discussion forum on how information technology is and could be used in care at the end of life
- ◆ In the News – review of articles on end-of-life issues from newspapers, magazines and journals to help you stay on top of events and opinions shaping the public's view

Visit www.lastacts.org and see for yourself!

the parents can make “a more informed choice.” Mr. Imparato pointed out that information can sometimes do more harm than good. For example, genetic testing that shows a predisposition toward bipolar disorder might be useful in that parents could more closely watch their child for signs of the disorder. But is that an appropriate trade-off in light of the strong potential to discriminate against individuals with such disorders? Couldn't parents monitor their children anyway, without such a test?

Mary Davidson, Director of the Alliance of Genetic Support Groups, underscored that one can't answer the question “Are you for or against genetic testing?” with a “yes” or “no” answer. One's answer depends on the nature of the condition, the accuracy of the test, its clinical usefulness, the values and beliefs of the individual being tested, and his or her family's values and beliefs. Dr. David Satcher, Assistant Secretary for Health and Human Services and the U.S. Surgeon General, identified three areas that need attention when discussing genetic testing: (1) that genetic tests should only be available for use in clinical practice when they demonstrate reliable accuracy, (2) rigorous continuous quality assurance practices need to be in place regarding the *process* of genetic testing and genetic counseling, and (3) health care providers and the public need to be educated about whether, when, and how to recommend or use genetic testing.

What type of oversight for genetic testing would best address these issues? Should it be marketplace driven? Practice guidelines and professional standards? Government regulation? Consensus was that mandatory government regulation would be too burdensome and unnecessary—rather, current mechanisms for oversight should be extended, or a new oversight mechanism could be formed (an interagency review board that would include several government agencies, or a consortium of government, private, and professional organizations). Some who testified thought oversight should not place a higher burden on genetic tests per se, that not all genetic risks are the same. For example, the procedure that uses

genetic testing to determine the predictive effectiveness of a particular drug seems more analogous to an allergy test and carries a lower risk burden. A representative of the American Association of Clinical Chemistry thought there should be no distinction between genetic and nongenetic testing, that *all* laboratory testing should have equally rigorous oversight. Another individual thought the FDA system of classifying scheduled drugs (like narcotics) provides an appropriate model for overseeing genetic tests, which could be classified according to risk categories.

For a summary of SACGT's report, visit their website at www.edc.org/sacgt2/summary.

Case Presentation

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee and how the committee resolved it. Individuals are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information of patients and others in the case should only be provided with the permission of the individual. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to: Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201-1786.

Case Study From A Maryland Hospital Center

The patient is a sixty year old man who was transferred to the intensive care unit at a Maryland hospital from another hospital. He has a long history of cirrhosis of the liver with episodic

admissions to the hospital for complications thereof including encephalopathy, infection, bleeding and others. On this occasion he is admitted with jaundice, edema, worsening encephalopathy, possible sepsis and obtundation. He requires intubation for respiratory support. The health care team implements a treatment plan that results in initial stabilization of the patient. The patient has executed an advanced directive and has appointed his long term girlfriend as his agent. She has had close involvement with the patient and his care for an extended period of time and understands his underlying disease and its complications. There is no other family or other individuals involved in decision making for the patient. The health care team and the patient's agent discuss goals of therapy. The patient has taken an aggressive approach to his care and treatment and according to the agent would continue to want aggressive care if he could speak for himself. He has been evaluated for a possible liver transplant in the past but felt not to be a candidate. The team and the agent agree to continue the current treatment and to assess closely the patient's response and need for reevaluation of his treatment plan. The agent and the healthcare team, however, disagree about the patient's code status. The team suggests to the agent that a DNR (do not resuscitate) order would be appropriate in this setting since if the patient should arrest despite his treatment a resuscitation attempt would be futile and likely result in pain and suffering for the patient. Despite prolonged discussion the agent declines to consider further a DNR order. The treating physician consults the Patient Care Advisory Committee since he is contemplating placing a DNR order in the chart over the objections of the patient's agent with the feeling that it would represent futile care.

Response From a Physician

One can look at this case from at least three perspectives: an example of the problems with advanced directives, a case of futility, or a case of failure to communicate.

Advanced Directives: An Imperfect Device

In one sense this case is a perfect example of the need for a durable power of attorney for health care. The patient has no family members and wants his girlfriend to make decisions for him when he has lost the capacity to do so. Since she has no legal standing to participate in his health-care decisions, he has appointed her his health-care agent. When the patient loses capacity, she can participate in the patient's medical decision-making process in the same way that the patient would have participated if he had capacity.

Furthermore, this woman appears to have knowledge of the patient's wishes or at least knows a lot about the patient's past choices. Regardless of her knowledge of the patient's wishes, the patient presumably trusted her to make appropriate decisions for him.

An agent can be impeached if the agent is clearly acting contrary to the patient's best interests and to the patient's wishes. That does not appear to be the case here. She asserts that the patient has chosen aggressive treatment in the past and she wants to continue aggressive treatment. There is no evidence of secondary gain in keeping the patient alive. She does not continue to get his Medicare benefits (the patient is only sixty) nor does she assert any inability to let go because of guilt or other unresolved emotional ties. On the other hand, one could argue that the patient's past desires to seek aggressive treatment were based on his perspective of a reasonably good prognosis and that the situation has now changed; in the new situation, the patient would not choose aggressive treatment because the prognosis is now so poor.

So why, you may ask, if the patient has a durable power of attorney and the

agent is acting in the patient's best interest, is there a conflict? There is a conflict because the physician disagrees with the agent over the writing of a DNR order. The physician is asserting his moral agency by claiming that attempting to resuscitate this patient is futile and will likely cause unnecessary pain and suffering for the patient. Presumably, if the patient had the capacity to make his own decisions, but was otherwise similarly situated, the physician would continue to insist on writing a DNR order. Thus, this is not a failure of the advanced directive so much as it is an unrealistic expectation that advanced directives will solve all the ethical problems. Shared decision making must still take place between two moral persons. Each person, the physician and the agent, has values that must be respected. The physician is not a hired gun who must do whatever the patient or agent wants and the patient or agent is not a passive participant who simply agrees to the physician's recommendations.

Futility

The claim of futility requires careful scrutiny. If it is dismissed too easily, it denies the moral agency of health-care providers; however, if it is accepted too readily, it gives physicians the power to override the wishes of patients, agents or surrogates any time the physician disagrees with them. In an analysis of a claim of futility two things must be considered. First, one must consider whether the problem is a disagreement over the goals of therapy rather than whether the goals can be reached. For example, tube feeding a patient in a persistent vegetative state (PVS) is not futile treatment because the tube feeding will in fact provide nutrition and hydration; however, the care givers may believe that keeping someone alive in a PVS is not a proper goal of medicine. The case report states that the goals of therapy have been discussed, but I suspect that the current level of treatment was discussed and agreed upon but not the goals that this treatment was expected to achieve. Is the goal of therapy that the patient leave the hospital alive? Is this goal achievable?

Or is the goal to keep the patient alive as long as possible? Is this an acceptable goal of medical therapy?

Second, one must distinguish between absolute physiologic futility and low probability of success. For example, a patient, who has a failing heart in the ICU on full life support with high dose pressor agents, a ventilator with 100% oxygen, and antiarrhythmic agents, develops ventricular fibrillation. Since the patient is already getting a resuscitation, except for the chest compressions, the chance that his heart can be returned to a normal rhythm is nonexistent. The patient in this case is not similarly situated. If he suffers a monitored cardiac arrest, he has a chance of being resuscitated, albeit a small chance. So an attempt at resuscitation is not futile *per se*. However, the resuscitation may be futile in the sense that the overall goals of therapy cannot be achieved by even a successful resuscitation attempt. Also, if the odds of success are very small, then we often label such an attempt futile, but this is mistaken unless we take into account the goals of therapy and how likely one is able to attain those goals. If it is highly unlikely that the patient can leave the hospital alive, then a small chance of successful resuscitation seems inappropriate to attempt. On the other hand, if a patient has a life-threatening acute illness that can successfully be treated, then even a small chance of a successful resuscitation may be appropriate to attempt.

When balancing the benefits and burdens of treatment, the probability of success of the treatment as well as whether the patient will suffer because of the treatment are important considerations; however, when considering DNR orders, the patient may suffer only if the resuscitation attempt is successful. Patients in full arrest are unconscious and are not capable of feeling pain. If the arrest is only partially effective and the patient's heart rhythm is restored but the patient suffers permanent brain damage, the patient may suffer considerably. The patient may also suffer if he

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Case Discussion

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survives with rib fractures. Thus, it is contradictory to argue both from futility and from pain and suffering of the patient with respect to DNR orders. If it is futile to attempt resuscitation, then the patient will not survive and thus will not suffer.

Failure to Communicate

Often, a conflict over futility is the result of a failure to communicate. Two areas of communication failure have already been cited. The first had to do with the surrogate's argument that the patient wanted aggressive therapy in the past and so he would want aggressive therapy now. It should be pointed out to the agent that because of the change in prognosis, the patient may now reach a different conclusion. Second, a discussion of the goals of therapy might have resolved the conflict or at least clarified the conflict. Such discussions should begin by asking the agent about her understanding of the patient's medical problems. This allows the physician to correct any misunderstanding and allows further discussion to take place with a similar understanding of the medical indications. Further discussion should proceed with the acknowledgment that both the physician and the agent want to do what is best for the patient and to do what the patient would have wanted—of course, within limits of good medical practice. This establishes a common ground. This approach will often resolve many such conflicts, but unfortunately not all.

If the conflict cannot be resolved, then the physician may have to transfer the care of the patient to another attending physician. In this case, such a transfer may not be easy to arrange. In the meantime, the physician should not write the DNR order unless he believes that a resuscitation attempt is physiologically futile. There are two reasons for this recommendation: First, the physician may be bound by Maryland law to follow this course (*see* adjoining discussion). Second, a futile attempt at resuscitation is not the worst thing that could be done to this patient. In fact

keeping this patient on a ventilator for months with no hope of the patient ever leaving the hospital alive is certainly a much bigger ethical problem than one failed attempt at resuscitation. This brings us back to the importance of communicating clearly about long term goals of therapy.

Eugene C. Grochowski, PhD,
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Associate Professor
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Response From a Maryland Attorney

Of government regulation, Dr. Johnson observed, “good cannot be complete, it can only be predominant.” Which is to say, a law like the Maryland Health Care Decisions Act can do some good by providing a sensible legal context for difficult clinical and moral issues. Even when the law is clear, however, as it is in this case, invoking the law too quickly forfeits the greater good that can be achieved through a genuinely collaborative process of care planning.

First I shall try to justify the claim that the law, as applied to this case, yields a decisive answer about the authority to enter the disputed DNR order. Assuming that the patient's advanced directive tracked the model in the Health Care Decisions Act, the patient's girlfriend, acting as his agent, has broad authority to “consent to the provision, withholding, or withdrawal of health care, including, in appropriate circumstances, life-sustaining procedures.” The term “life-sustaining procedures” includes cardiopulmonary resuscitation. (Sec. 5-601(m)(2) of the Health-General Article, Maryland Code.) Therefore, as a general matter, it is for the agent to decide on the course of care were the patient to suffer a cardiac or respiratory arrest—that is, whether CPR should be attempted or whether a DNR order should be entered so that comfort care measures instead of

CPR would follow an arrest. Yet, a health care agent's decisional authority is not absolute. Physicians are protected under section 5-611(b) of the Act from being “requir[ed] . . . to prescribe or render medically ineffective treatment.” CPR can be deemed a medically ineffective treatment if it would not “prevent the impending death of the [patient].” Sec. 5-601(n)(2).

In this case, the health care team has concluded that, “if the patient should arrest . . . a resuscitation attempt would be futile . . .” The chameleon-like word “futile” is not used in the Health Care Decisions Act. Perhaps the care team judges CPR to be “futile” because, even if it successfully restored circulation and averted impending death, the patient's residual quality of life would be very poor. If that is their basis for recommending a DNR order, they should enter the order only if they are able to gain the agent's concurrence. If, however, “futile” means that even temporarily successful CPR would not avert an active dying process, then CPR in this case fits within the Act's definition of “medically ineffective treatment.” Accordingly, if the patient's attending physician, with the concurrence of a second physician, so certified, then the attending physician would have the legal authority to enter a DNR order despite the agent's objection. (Sec. 5-611(b)(2). The family would then be provided with a written statement of this decision and an offer of assistance with transferring the patient to another physician and institution if so desired. A detailed discussion about a physician's authority to enter a DNR order may be found in a recent letter of advice, available on the Attorney General's web site, www.oag.state.md.us; follow the link to “Health Policy.”

Yet, the legally authorized entry of a DNR order over a health care agent's (or surrogate's) objection should be a last resort. Although the case summary refers to “prolonged discussion,” is the agent really clear about what the clinical situation would be after an arrest? Does she incorrectly equate DNR status with an abandonment of care? Does she view agreeing to a DNR order as the equivalent of signing the

patient's death warrant? Has she been offered social work or pastoral care services? The patient care advisory committee should encourage a redoubling of efforts to have the patient's code status be decided collaboratively rather than by force of law.

Jack Schwartz, JD
Director of Health Policy
Office of the Attorney General
State of Maryland

DHEP RESPONDS TO NEEDS OF HEALTHCARE COMMUNITY

From the Center for Biomedical Ethics,
University of Virginia Website

Ten years ago a new innovative program called Developing Hospital Ethics Programs (DHEP) was initiated at the Center for Biomedical Ethics at the University of Virginia under the direction of Dr. Edward Spencer. The program's goal is to help participating healthcare organizations initiate or substantially strengthen their overall ethics program.

DHEP is continuously modified so that it continues to reflect the latest thinking concerning the pertinent issues, the focus, and the important mechanisms inherent in the operation of an effective healthcare ethics program.

The next DHEP session is scheduled for April 24 - April 28, 2000. This session introduces three separate educational tracks, one of which will be chosen by each participant depending on the needs and interest of the participating institutions. The first three days of the session will be common to each track and will be attended by all participants. The education during these three days will concentrate on an overview of clinical ethics in healthcare organizations today, on important changes in healthcare law, and on issues of importance for today's health care providers, both professional and institutional.

During the final two days of DHEP the clinical ethics track, under the direction of John C. Fletcher, PhD, former Director of the Center, and Robert Boyle, MD, Director of the UVA Ethics Consultation Service, will focus on clinical ethics issues including mediation, practice in mock consultations, and discussion of cases from participating institutions. The research ethics track, under the direction of Jonathan Moreno, PhD, Director of the Center, and Paul Lombardo, JD, PhD, Director of Mental Health Law Training, Institute of Law Psychiatry and Public Policy, will concentrate on an up-to-date analysis of human research ethics issues and on practical issues associated with initiation and strengthening of local IRBs (Institutional Review Boards). Ann Mills, MBA, Associate Director of Outreach Programs and Edward M. Spencer, MD, Director of Outreach Programs and course director for DHEP, will direct the organization ethics track which will focus on the meaning and important aspects of the rapidly developing field of healthcare organization ethics.

Each track will provide ample time for discussion of pertinent issues associated with that particular aspect of healthcare ethics. Registration fee is \$1500/person. The fee covers tuition, all educational materials, registration for continuing education credits, and all breakfasts, lunches, plus two evening meals. Please contact Ann Mills at 804 982-3978 (e-mail amh2r@virginia.edu) if you have questions or wish to register.

HOSPITALS ADOPT NON-HEART-BEATING ORGAN DONATION POLICIES

As we approach National Organ and Tissue Donor Awareness Week (April 16-22), we are reminded that about

62,000 people presently are waiting for an organ, and 4,000 Americans died last year before they could get one. Each day about 57 people receive an organ transplant, but another 13 people on the waiting list die because not enough organs are available.¹ Campaigns to increase the number of potential organ donors have succeeded, although there is still a need to increase this pool, particularly among ethnic minorities. Recently, several hospitals have made available an additional option for organ donation. Individuals who are imminently dying but not brain dead may donate their organs through a process referred to as "non-heart-beating organ donation" (NHBOD).

Dr. Michael Devita, chair of the ethics committee at UPMC Presbyterian Hospital at the University of Pittsburgh, spoke at Johns Hopkins Hospital on February 23 about the process of creating a hospital policy for NHBOD at UPMC. The emphasis was on *process*, as it took over 20 revisions of the policy during its three year formulation. Drafting such a policy included weighing the harms and benefits to donors and recipients, such as administration of drugs that help preserve organ quality but may adversely affect the patient. Regitine, for example, was considered unnecessary, even though it could be beneficial for organ retrieval, while heparin was included because it was not considered to be measurably harmful to the patient in the time frames during which NHBOD takes place. In UPMC's protocol, patients who are candidates for NHBOD (i.e., those who meet imminent death criteria) are identified, consent is obtained from a family member or health care agent, an ethics consult is requested to provide a third party review (to ensure that consent was free and informed and to help protect the interests of the donor and family), an arterial catheter is placed in the patient before the procedure and heparin infusion begins, the patient is taken to the operating room, where life support is withdrawn, death is pronounced two minutes after heart rate and respiration stop, and the organs

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Hospitals Adopt Non-Heart-Beating Organ Donation Policies

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are then procured. Family members can stay with the patient during and after life support withdrawal. If they choose to stay with their loved one's body after death is pronounced, operating room staff wait until the family members leave before initiating organ retrieval.

By far, the biggest hurdle in implementing this policy and protocol at UPMC has been resistance from the operating room (OR) staff. This led to several meetings being held with the OR staff in which they vented and discussed their concerns. As a result, a "care committee" for NHBOD was formed, with two OR staff members joining the ethics committee. Because of the attention to process, a positive by-product of this effort has been education of staff about ethical issues related to NHBOD, and consensus building.

Questions that remain about NHBOD include: Is the expenditure of effort worth

the number of organs that are obtained through this process? Does the practice of NHBOD risk spreading myths that organ harvesting takes priority over patient survival, and could this negatively affect the number of willing organ donors? What are the short- and long-term psychological effects on family members whose loved one undergoes NHBOD? In what ways can family members be best informed about and supported through the process? How does NHBOD affect staff members? Are there rituals that could help family members and staff experience this somewhat new, albeit selfless, way of dying that would minimize emotional distress to those involved and support the grief process of loved ones? These questions speak to the need for continued discussion and evaluation of NHBOD.

Johns Hopkins hospital recently became the first hospital in Maryland to approve a policy for NHBOD. Their policy, like UPMC's, includes the provision that an ethics consult is called for each NHBOD candidate "whose

surrogate has signed a consent." It is expected that other hospitals will be discussing and drafting NHBOD policies in the near future.

¹ For more information, visit www.unos.org/Newsroom/critdata.

Network News

Cont. from page 2

attended the first meeting. A second meeting will be held on May 5, 2000 in Clifton, VA. The purpose of the group is two-fold: 1) To be of service to one another's institutions and programs with education and training and 2) to meet quarterly to discuss issues and needs. The group welcomes anyone interested to attend the May meeting. For further information contact John Fletcher at jcf4x@virginia.edu.

CALENDAR OF EVENTS

April

- 18 "Clinical Ethics, Part II - Assisted Suicide and Euthanasia," Daniel Davis, Ph.D., Georgetown Medical Center, LA2-4 Preclinical Science Building, 10 AM - 12:00 noon. For more information call (202) 687-8999.
- 19 "Current Issues in Health Care," by Congressman Ben Cardin, University of Maryland, School of Law, Baltimore, MD, 12:00 noon - 2:00 p.m. Sponsored by the Student Health Law Organization and the School of Law, Law and Health Care Program. For further information contact Jayson Slotnik at jslotnik@aol.com.
- 24 - 28 "Developing Hospital Ethics Programs," Charlottesville, VA. Sponsored by the Center for Biomedical Ethics, University of Virginia. Fee \$1,500. For further information contact Ann Mills at 804 982-3978 or amh2r@virginia.edu. (See article on page 9.)
- 25 "Clinical Ethics, Part II - Justice and Fairness in Health Care," Edmund D. Pellegrino, MD, Georgetown Medical Center, LA2-4 Preclinical Science Building, 10 AM - 12 noon. For more information call (202) 687-8999.

- 25 "Research Ethics for Basic Scientists," Lauren Cobbs, MD & Sorrell Schwartz, Ph.D., Georgetown Medical Center, 8 AM - 10 AM. Call Dr. Cobbs, (202) 687-5473 for more information.
- 26 "Living with Grief: Children, Adolescents and Loss," Johns Hopkins Hospital, Hurd Hall, 1:00 PM - 4:30 PM. Teleconference and post-conference discussion and panel focusing on ways to help children and adolescents cope with loss, grief, and bereavement. Moderated by Cokie Roberts, sponsored by the Hospice Foundation of America. For more information visit www.hospicefoundation.org.

May

- 3 - 5 "Protection of Human Subjects: The Myth of Privacy and Confidentiality Explored," Tampa, Florida. Sponsored by the Office for Protection from Research Risks, NIH. For further information call (301) 435-5648 or dr20a@nih.gov.
- 12 "Sharpening your Ethics Consultation Skills: An Update of Difficult Cases and Issues," Days Inn Conference Center, Flatwoods, WV. Fee WVNEC members \$75.00; others \$90.00. Sponsored by The West Virginian Network of Ethics Committees. For further information call WVNEC at (304) 293-7618 or lmcmillen@hsc.wvu.edu.

June

- 1 "I don't want to die today,': Complexities of Advanced Directives," Harbor Hospital, Baltimore, MD, 6:00 - 9:00 p.m. Sponsored by the Maryland Healthcare Ethics Committee Network and Harbor Hospital. For further information contact Anne O'Neil at (410) 547-8452 or aoneil@law.umaryland.edu.
- 5 "Race, Ethics, and Research," by Dorothy E. Roberts, Attorney and Professor at Northwestern University School of Law, 4:00 - 5:30 p.m. Sponsored by Johns Hopkins Hospital Medical Ethics Committee and Consultation Service. For further information contact Sharon Mears at 410-955-0620.
- 6 - 11 "New Century, New Challenges: Intensive Bioethics Course XXVI," Georgetown University, Washington, D.C. Sponsored by the Kennedy Institute of Ethics. Fee \$1350. For further information call (202) 687-8099 or kicourse@gunet.georgetown.edu.
- 22 - 23 "Nursing Excellence in Palliative Care," Days Inn Conference Center, Flatwoods, WV. Sponsored by: West Virginia Initiative to Improve End-of Life Care, the Claude Worthington Benedum Foundation, and the West Virginia University School of Nursing. Fee \$150.00. For further information call (877) 209-8086 or cjamison@hsc.wvu.edu.

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