

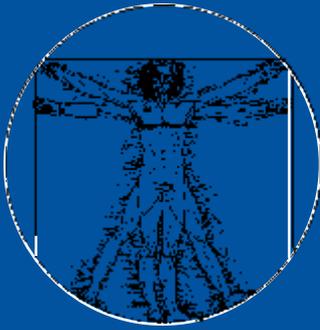
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 2004*

Mid-Atlantic Ethics Committee
Newsletter, Fall 2004

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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

Fall 2004

THE ROLE OF ETHICS COMMITTEES IN ALLOCATING SCARCE MEDICAL RESOURCES

Inside this issue:

The Role of Ethics Committees in Allocating Scarce Medical Resources	1
Network News	2
EMS/DNR Orders	4
Deconstructing "Do-Not-Resuscitate" Orders	5
Philosophy Corner—Focus on 'Autonomy'	6
Skill Building in Ethics Case Consultation	7
Case Presentation:	
Case Study from a Maryland Emergency Room	8
Response from an Emergency Room Physician	8
Response from a Jehovah's Witness Lawyer	9
Calendar of Events	11

Faced with a potential crisis, in late October the Centers for Disease Control (CDC) appointed a permanent ethics panel to help it think through who should receive priority in the allocation of the scarce supply of the flu vaccine and how it should deal with future epidemics. According to a *New York Times* article, this was the “first time in its history” that the CDC had created such an entity.¹ Perhaps it is a sign of the emerging legitimacy of public health ethics.² Although ethics panels at the national level are not new, their use in the area of public health is a recent development. Prior and existing national ethics commissions have dealt with questions of life sustaining treatment, stem cell research, cloning, research on the decisionally impaired, and new reproductive technologies, but they have not generally addressed the thorny issues created by public health problems. Arguably, one of the most challenging of these is the allocation of scarce medical supplies and services during a potential public health crisis.

While most institutional ethics committees deal with health care treatment issues that raise ethical principles of autonomy, beneficence, or nonmaleficence, they deal less frequently with issues of distributive justice. These latter issues are more likely to arise

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

for policy makers at the local, state or national level when decisions need to be made about rationing scarce resources. But the situation with the distribution of the flu vaccine may have required hospitals, nursing homes, and possibly their ethics committees, to make some difficult rationing decisions.

CDC Allocation Criteria

On Oct. 5th when Chiron Corporation announced that none of its influenza vaccine would be available for distribution in the U.S. for the 2004-05 flu season, the CDC announced its

NETWORK NEWS

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The information in this newsletter
is not intended to provide legal advice
or opinion and should not be acted
upon without consulting an attorney.

MARYLAND HEALTH CARE ETHICS COMMITTEE NETWORK (MHECN)

Recently, MHECN distributed its member resource binder to MHECN institutional members. The binder includes resources for ethics committee members, including relevant Maryland legislation, previous newsletter case studies, and video, website, and bibliographic resources. The binder will be a living resource, intended to house MHECN newsletters and future mailed additions.

Educational Programs

On November 17, 2004 MHECN sponsored a conference on DNR issues at Charlestown Retirement Community in Catonsville, MD (see p. 5 for highlights of the conference).

In Summer 2005 MHECN is planning a basic ethics education conference. Stay tuned for more details.

Contact MHECN at (410) 706-4457;
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The Role of Ethics Committees Cont. from page 1

plans to limit the remaining supply of the vaccine to adults 65 years of age and older, children 6 to 23 months of age, individuals with certain chronic illnesses, pregnant women, residents of nursing homes and children on chronic aspirin therapy. In addition, it recommended the vaccine for individuals who might spread the flu to high-risk individuals, including household contacts of infants under 6 months of age and health care workers providing direct patient care.³

In early November the CDC developed a second allocation plan for distribution

THE METROPOLITAN WASHINGTON BIOETHICS NETWORK

The Metropolitan Washington Bioethics Network co-sponsored Georgetown University's Bioethics Colloquium on November 11, 2004. Edmund Pellegrino, MD, Member of the International Bioethics Committee of UNESCO, spoke on "UNESCO's International Bioethics Committee: The Quest for Universal Norms of Bioethics."

MWBN also continues its guardian training sessions with the D.C. Superior Court Probate Division.

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of the remaining doses of the vaccine to the states based on 1) the number of high-priority individuals in the state, 2) the number of doses the state had already received and 3) the state's unmet needs. Each state was then to distribute its allocation to its high priority groups.⁴

The Need for Additional Guidance

While the CDC made it clear that the vaccines should only be given to the very young, the very old, and the chronically ill, state and local health authorities, concerned that they might not have sufficient supplies to cover everyone in

these categories, asked for additional guidance as to who should receive priority within this group. This was the case in southeastern Pennsylvania. On November 30th, the front page headline in the *Philadelphia Inquirer* was "Healthy seniors asked to forgo flu shots." According to the article, healthy seniors in southeast Philadelphia were asked to skip the flu shot this season to make sure there would be sufficient supply for the elderly with significant health problems. The proposal was made by the Delaware Valley Healthcare Council, which was responding to concerns that the federal guidelines had not been specific enough, especially to help nursing homes make tough decisions as to how to allocate the vaccine between residents and workers and among residents.⁵ In other states, public health authorities asked for guidance as to whether to send the vaccines to nursing homes or pediatricians' offices.

Ethical Approaches to Distributive Justice

Allocation decisions put into play issues about who is most in "need" or most deserving or who can most "benefit" from the limited service or treatment. An ethics panel may be helpful in making recommendations under such circumstances. Beauchamp and Childress have articulated a number of approaches to distributive justice. These include egalitarian, libertarian and utilitarian theories.⁶ Much debate in the field focuses on which of these approaches should have priority. Under an egalitarian approach we would give everyone an equal share or an equal opportunity. In the context of the flu vaccine this might mean the young would have priority over the old as they deserve an equal opportunity at life; the elderly have had their opportunity. John Arras, a member of the CDC ethics panel and a professor of bioethics at the University of Virginia characterizes this as the "fair innings approach" in which "people are supposed to get a certain number of fair innings in a life time."

A libertarian approach would be

to allocate the vaccine according to free market exchanges or the ability to pay. While this may be an appropriate allocation mechanism for many goods and services, it seems ill suited to health care supplies that can influence who lives and dies. There were reports in the press about hospitals receiving offers from "greedy wholesalers eager to supply them with flu shots for \$800 when a shot should cost about \$10."⁷ Even if hospitals or individuals were willing to pay this amount, it seems unfair that only those who could afford to pay such high prices would have access to the scarce good.

Utilitarian theories focus on distribution that will achieve the best outcomes or greatest good but leave us to debate how to define those concepts. Does it mean to distribute the vaccine in a way that will: 1) prevent those who are most at risk of contracting the flu from acquiring it; 2) save society the most money (i.e., give it to those who would cost society the most if they contracted the flu); 3) result in the greatest number of additional years of life (or "quality-adjusted life years") for those who receive it; or 4) result in the greatest number of lives saved of individuals who are most productive, wise or compassionate? These are all possible utilitarian approaches.

The Role of Ethics Panels and Committees

While an ethics panel may help public health authorities think through these approaches by articulating them and helping apply them to various scenarios, such panels should not be the scapegoats when "wrong" decisions are made. The ultimate decision-makers must be those who are accountable to the public. If they are to rely on the recommendations of ethics panels, they should ensure that such panels not only include experts in the field of bioethics but also include a broad representation of views on what constitutes the public good so that our public officials are not hemmed in by a particular philosophy or parochial perspective. On the institutional level, ethics committees must also be viewed

as fair and impartial bodies with both expertise and representation from the community the institution serves. For either a national panel or a local ethics committee to have any credibility it must be viewed as fair, knowledgeable and representative.

Notes

¹Gardiner Harris, "U.S. Creates Ethics Panel On Priority for Flu Shots," *New York Times* (Oct. 28, 2004) at A14.

²See Nancy E. Kass, "Public Health Ethics: From Foundations and Frameworks to Justice and Global Public Health," *32 J. of Law, Med. & Ethics* 232 (2004).

³Testimony of Dr. Julie Louise Gerberding, Director, CDC, before the House Energy and Commerce Committee, Subcommittee on Health (Nov. 18, 2004). Available at <http://energycommerce.house.gov/108/Hearings/11182004hearing1404/Gerberding2254>.

⁴"CDC and States Announce Plan to Distribute 10.3 Million Flu Shots Nationwide; Public Health Officials Call Allocation Fair and Aimed at Most Vulnerable Americans," CDC Press Release (Nov. 9, 2004) available at <http://www.cdc.gov/od/oc/media/pressrel/r041109.htm>.

⁵See Marian Uhlman & Virginia A. Smith, "Healthy seniors asked to forgo flu shots," *The Philadelphia Inquirer*, (Nov. 30, 2004) at 1.

⁶See Tom. L. Beauchamp & James F. Children, *Principles of Biomedical Ethics*, 3d edition (1989).

⁷Arthur L. Caplan, "Flu Shot shortage poses public health disaster," at <http://www.bioethics.net/articles.php?viewCat=2&articleId=70>.

Cont. on page 3

EMS/DNR ORDERS

On September 21, Samantha Freed, a third year law student and research assistant for MHECN, spoke with paramedics at the Woodbine Fire Department about Do-Not-Resuscitate (DNR) orders in the pre-hospital (outpatient) setting. This article is based on excerpts from Freed's presentation.

Paramedics may recognize several types of EMS (emergency medical services)/DNR Orders as valid. These include:

- An original or copy of the Maryland EMS/DNR and Medical Care Order Form

- Another state's EMS/DNR form presented in Maryland

- A Maryland EMS/DNR Bracelet insert

- A Medic Alert EMS/DNR Bracelet or Necklace

- An oral EMS/DNR Order provided by an on-line, EMS medical command and control physician

- An oral EMS/DNR Order provided by a physician who is physically present on the scene with the patient and the EMS personnel in the outpatient setting¹

EMS personnel in the pre-hospital setting may **NOT** acknowledge the following forms of a DNR order:

- An advance directive **without** an EMS/DNR Order

- Facility-specific DNR orders

- Physician's notes in medical records or prescription pad orders

- DNR stickers

- An oral request from someone other than a physician

- An oral order from an attending physician who is not on-site

- Any other device or instrument not listed as acceptable in the MIEMSS protocols²

The Maryland EMS/DNR and Medical Care Order form was created to eliminate the burden on EMS personnel trying to decipher whether they may follow a DNR Order provided by a patient's family member. The EMS/DNR Order form takes the second-guessing out of a situation which is already hectic, and where every minute is vital to life. For example, if paramedics are presented with an advance directive barring resuscitation attempts, but there is no EMS/DNR Order Form, family members can very persuasively insist that the paramedic follow the advance directive (that is, not try to resuscitate the patient). But in this situation, EMS personnel are obligated to try to resuscitate the patient. Paramedics have so little time to evaluate the situation and act appropriately, it is not practical to ask them to interpret documents that vary in form and content. This is also the reason that the EMS/DNR Order must be in a particular form.³

Consider the following scenario: Two paramedics arrive on-scene to find a 92 year old woman unconscious. Her son does not present any documents but hands the phone to one of the paramedics. There is a voice on the other line that states "I am this woman's physician and I have in front of me papers signed by the patient that say she does not want any attempts at resuscitation." Because the physician is not on-scene, this is not a valid EMS/DNR Order. However, if the paramedics in the scenario received orders from an on-line, EMS medical command and control physician not to attempt resuscitation, then the paramedics could refrain from attempting to resuscitate the patient.⁴

Paramedics are put in a difficult situation when nursing home residents have not discussed DNR orders with their care providers, especially involving transport between a nursing home and emergency room. Local paramedics can play a role in educating facilities they work with about the Maryland EMS/DNR and Medical Care Order form.

This is especially true for nursing homes, since paramedics are often called to transport nursing home residents to the hospital or other health care settings.

EMS/DNR orders may also apply to children. The Maryland Code authorizes EMS to follow the Maryland EMS/DNR and Medical Care Order form "pertaining to adult patients in the outpatient setting."⁵ The Attorney General has written an advice letter about this provision and its application to minors.⁶ Although the Maryland Code refers only to adult patients, EMS personnel are authorized to follow the Order form with respect to minor children if a parent or legal guardian has consented.

Notes

¹ The Maryland Medical Protocols for Emergency Medical Service Providers. Effective July 1, 2004. Maryland Institute for Emergency Medical Services Systems, available at <http://miemss.umaryland.edu/Protocol2004Update.pdf>, pp. 139-40.

² *Id.*

³ See Md. Health Gen. Code Ann. §5-608(c)(1) (2004).

⁴ See Md. Health Gen. Code Ann. §5-608(c)(2)-(3) (2004).

⁵ See Md. Health Gen. Code Ann. §5-608(a)(1) (2004).

⁶ For the full text of attorney general opinions and letters of advice related to EMS/DNR orders, visit <http://www.oag.state.md.us/Healthpol/legal.htm>.

If you or your organization is interested in having Ms. Freed give a presentation on EMS/DNR Orders in the pre-hospital setting, you may contact her at MHECN by e-mail at mhec@law.umaryland.edu or phone 410-706-4457. For a copy of the EMS/DNR Medical Care Order form, visit www.miemss.umaryland.edu/DNRorderform.pdf.

DECONSTRUCTING "DO-NOT-RESUSCITATE" ORDERS

On Wednesday, November 17, 2004, MHECN co-sponsored the conference, "Still Hazy After All These Years—DNR Orders: Problems and Solutions," at Charlestown Retirement Community in Catonsville, MD. Other sponsors included Erickson Retirement Communities, St. Agnes Hospital, and the Health Facilities Association of Maryland.

The morning began with a provocative keynote address by Glenn Treisman, a physician in the Department of Psychiatry and Behavioral Sciences at Johns Hopkins Hospital. Dr. Treisman spoke about "Unintended Consequences of DNR Orders." These include health care providers (HCPs) too readily giving up on treatments that can enhance the quality of or prolong a patient's life merely because a DNR order is present. Treisman has little faith in the ability of generic end-of-life wishes expressed in living will documents to effectively guide a physician's decisions about whether to withhold attempts at CPR. Furthermore, since withholding CPR attempts through the writing of a DNR order carries these other "unintended consequences" that are not in the patient's best interests, Treisman believes that DNR orders should be approached with caution. A better method of providing patient-centered end-of-life care, Treisman asserts, is for the physician to have a relationship with the patient and make decisions that are informed by that relationship. If a prior relationship has not been formed, Treisman believes that in many cases, a physician's judgment of the incapacitated patient's best interest should trump the patient's living will instructions. Attendees challenged this view by arguing that a relationship-centered model is out of touch with how medicine is practiced today, that favoring trials of life-saving or life-prolonging technology (LPT) and discontinuing them if they don't achieve the intended goal is at odds with the greater reluctance many HCPs have to withdrawing LPT, and that a physician's judgment of what's in a patient's best interest can be biased toward that physician's own moral beliefs or risk-averse practices.

Gene Grochowski, an associate professor of Medicine at Johns Hopkins University School of Medicine and the Berman Bioethics Institute, gave a similarly cautionary address about DNAR (Dr. Grochowski prefers the term DNAR—"Do Not Attempt Resuscitation") orders ("Unsuccessful CPR is Not the Problem, and a DNAR Order is Not the Solution"). According to Grochowski, DNAR orders can stifle conversation about end of life (EOL) care because they are seen as the solution. Moreover, they create confusion regarding what interventions are permitted to prevent an arrest. Grochowski also believes that health care providers go to illogical extremes by describing graphic details of cracked ribs and violent cardiac shocks to encourage dying patients to agree to a DNAR order (i.e., if you need CPR attempts, you can't feel pain; you wouldn't "experience" the "violent" CPR attempts). He thinks it's not the CPR attempts that most patients fear, but the possibility of surviving in a highly impaired, technology-dependent state. The latter can be avoided by being clear about the goals of LPT and physicians taking the initiative to withdraw LPT if the intended goals have not been achieved. Grochowski doesn't advocate that physicians discuss a DNAR order initially with sick inpatients they've never met before. Rather, he advises that physicians ask the patient who the physician should talk to if the patient can't make decisions him/herself. This opens the door to a more in-depth conversation after some rapport has been established, or, if the patient loses mental capacity, identifies a surrogate decision-maker.

As part of a panel session, Glenna Earle (a nurse at Upper Chesapeake Medical Center-UCMC), Kevin Lynch (a physician at UCMC) and Martha Ann (Marty) Knutson (Legal Compliance Officer at Upper Chesapeake Health) addressed institution-wide problems with DNR orders. UCMC created a "Resuscitation Status" policy and a "Resuscitation Status Order" (a pink sheet for easy chart visibility that documents: 1) the patient's decision-making capacity; 2) with whom resuscitation status was discussed; 3) the content of the discussion; 4) reasons for the resuscitation status; 5) whether or

not to attempt full or limited CPR; 6) the signature of the physician; and, 7) if applicable, physician certifications of futility). Ms. Earle and Dr. Lynch discussed their successes and challenges in implementing the policy and form, and educating staff members, patients, and families about it.

Marty Knutson then discussed "Futility, Liability, and other Legal Aspects of Foregoing CPR Attempts," including the Maryland legal case, *Wright v. Hopkins*, "good faith" immunity, legislation allowing emergency treatment (such as CPR attempts) without consent, a patient's right to have his or her EOL wishes honored (including refusals of CPR attempts), and issues related to medical futility of CPR attempts.

Philip Panzarella, MD, MPH of Franklin Square Hospital and Rev. Dr. Bob Steinke, of Frederick Memorial Hospital presented an interactive session demonstrating appropriate and inappropriate communication related to DNR orders. They used video clips from the End of Life/Palliative Education Resource Center (EPERC) to illustrate their points. See www.eperc.mcw.edu. Kelly Niles, MPA, at the Center for Aging Studies at UMBC and two residents from the Charlestown Retirement Community then spoke about the "Consumer-Directed Model" in which consumers make their own health care choices, with implications for EOL care.

Concurrent sessions included how to proceed when a physician refuses to write medical orders (such as a DNR order) that are consistent with a patient's wishes; discussing DNR in special settings (the neonatal intensive care unit, the operating room, and hospice); discussing DNR orders with religious- or culturally-based vitalists and ethnic minorities; and an open table discussion of legal issues surrounding DNR orders and the Patient's Plan of Care Form that is being drafted by the Maryland Attorney General's Office.

If you have ideas for future MHECN conferences, or would like to co-sponsor a conference, please e-mail us at MHECN@law.umaryland.edu, or call (410) 706-4457.

PHILOSOPHY CORNER – FOCUS ON ‘AUTONOMY’

Enlightenment is the release of human beings from their self-incurred tutelage. Tutelage is the inability to use one's own reason without direction from someone else. This tutelage is self-incurred when its cause does not lie in the lack of reason, but in the lack of resolution and courage to use it without direction from someone else. Sapere aude! Have courage to use your own reason!—that is the motto of the enlightenment.

What is Enlightenment? Immanuel Kant, 1784

Autonomy comes from the Greek words *autos* ('self') and *nomos* ('law'), evoking the concept of "self-governance" or "self-determination." It is the cornerstone of the Enlightenment period, when reason was embraced as the key to progress in science, politics, and the moral life. The philosophical origins of the Enlightenment are often attributed to a group of French philosophers who challenged the public's deference to organized religion and political monarchy, which were responsible for such atrocities as the Christian Crusades in the middle ages, and the burning of 'witches' in the 17th century. Instead, the Enlightenment philosophers promoted the concepts of critical thinking, education reform, political democracy, and rational moral conduct. Rene Descartes (1596 – 1650) was one such philosopher. Known for his contributions to mathematics and to what later developed as the field of neuroscience, Descartes pursued fundamental questions about the relationship between external "reality" and how we perceive it. He explored connections between the mind in the form of thoughts, the brain and nervous system, and the "soul," raising questions about whether "true knowledge" exists independent of the human mind, and proposing a systematic method of seeking objective knowledge (the scientific method). Enlightenment thinkers believed that

human beings have free will, and that free will is exercised through rational thought. Ironically, recent discoveries in the fields of genetics and neuroscience, borne out of the groundwork laid by the post-Enlightenment's scientific enterprise, question the existence of free will. Yet, autonomy requires free will—despite competition from our genetic predispositions, deciding which actions are moral and choosing to implement them assumes that we are free to do so.

Immanuel Kant (1724 – 1804), another influential Enlightenment philosopher, is most closely associated with the concept of self-determination. Kant was an "idealist" in that he believed individual knowledge did not represent an external reality; rather, it was constructed by human minds taking in information and actively making sense of it. According to Kant, a truly moral person must transcend the passive acceptance of rules and norms handed down by his or her culture or religion and actively determine himself or herself what is right or wrong.¹⁻³ Kant accorded more worth to rational duty-based acts than those motivated by emotions like compassion or love. Emotions can be inconsistent and illogical, whereas applied reason aimed at the right target (i.e., not solely at mundane desires like accumulation of material possessions or power for the sake of having it) more reliably leads to a citizenry that takes others' perspectives fairly into account. An example of a reason-based mechanism that could assist one's autonomous reasoning is Kant's 'categorical imperative': "Act only on that maxim which you can at the same time will to be a universal law."⁴ For example, if you come up with your own rule, such as, "I must never lie to my patients," you would test the validity of this rule by asking whether every rational health care provider could accept it.

Critics of Kantian ethics point to its emphasis on reasoning ability as a significant flaw in that it favors individualism and excludes those with impaired or absent reasoning abilities. However, Kant viewed the application of individual autonomy as being embedded within community in that it requires taking others' considerations into account, and treating others (particularly

vulnerable persons unable to reason on their own) "as an end withal and never as a means merely."⁴ The broader Kantian principle of "respect for persons" reflects this dual obligation: to promote individual self-determination, and to protect persons who are not rational agents by promoting their well-being and preventing them from being harmed. These concepts were formalized in the well-known text, "Principles of Biomedical Ethics,"⁵ by Beauchamp and Childress, who included the Kantian principle of *respect for persons* along with the principles of *beneficence*, *non-maleficence*, and *justice*, which were adapted from W.D. Ross's⁶ work. This principled approach was first introduced to the broader biomedical community in the 1970's after the publication of *Ethical Principles and Guidelines for the Protection of Human Subjects of Research* (commonly known as *The Belmont Report*)⁷. For several reasons, a focus on autonomy has dominated the principled approach in Western bioethics, and has recently been challenged as overly individualistic.⁸⁻⁹ Perhaps this is because of the tendency to interpret autonomy in the context of individual rights (things owed to a person), rather than Kant's conception of autonomy as a commitment to using reason to guide moral actions. As Bramann summarized:

It is the faculty of reason that most powerfully connects human beings with each other, and which turns a merely natural society into a human community. In a society where all people base their important judgments on reason, where everybody makes an honest attempt to see things also from other people's point of view, there will not be many unsolvable disagreements. It is only where people are ruled by their unacknowledged drives and unexamined passions that consensus and cooperation eludes them.¹

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SKILL BUILDING IN ETHICS CASE CONSULTATION

In 1998 MHECN conducted a survey of ethics committee members in Maryland and found that over 60% of ethics committee members had no prior ethics education. One of the three tasks performed by ethics committees is ethics consultation (along with education and policy review).

Ethics committee members who participate in ethics consultation should receive basic training in this area, but often don't. One resource that has recently been made available to the public is the Neiswanger Institute's web page, "Skill Building in Ethics Case Consultation," at http://www.meddean.luc.edu/depts/bioethics/ECE_index.htm. Power Point presentations with voiceover narration provide an overview of ethics case consultation in the U.S. (by Kayan Parsi, JD, PhD) and how to conduct and evaluate an ethics consultation (by Mark Kuczewski, PhD). There are also links to video clips of four simulated ethics case consultations showing student

consultants doing their best to mediate an ethical conflict. An accompanying evaluation template can be used to rate what you think the consultants did well and what needs improvement. These are excellent resources that your committee can use at an educational portion of a meeting or as a training tool for members involved in case consultation.

Other approaches to increasing basic ethics education include short-term courses or workshops, such as the week-long Georgetown Basic Ethics Education course. MHECN has sponsored basic ethics education for ethics committees, including a multi-class series at GBMC and Kennedy Krieger hospitals. Also, MHECN is planning a basic ethics education course for Summer 2005 (specific date to be announced). Take advantage of these resources!



*Simulated ethics consult video link.
Photo courtesy of the Neiswanger Institute
for Bioethics & Health Policy.
See <http://bioethics.lumc.edu>.*

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. Individuals are both encouraged to comment on the case or analysis and to submit other cases with which their ethics committee has dealt. In all cases, identifying information about 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: Diane E. Hoffmann, Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201, or dhoffman@law.umaryland.edu.

CASE STUDY FROM A MARYLAND EMERGENCY ROOM

Mrs. Daniels is a 75 year old woman with a history of dementia who is brought to the emergency room (ER) from a nursing home with a severe gastrointestinal bleed. Her records from the nursing home state that she is a Jehovah's Witness and does not want a blood transfusion under any circumstances. There is no appointed health care agent and no one in her record identified to make medical decisions for her. Mrs. Daniels gave verbal consent for transport to the hospital to treat her symptoms (weakness, vomiting blood, black stools, lightheaded, low blood pressure when arising, fast heart rate, and shortness of breath). When she arrived she was alert and knew her name, where she was, and what month it was, but she didn't know the year or exact day. When asked about her religion, Mrs. Daniels could only recall that she did go

to church. The physician explains to her that she is bleeding from her stomach and will die if she does not receive a blood transfusion. Upon hearing this, Mrs. Daniels tells the physician she wants the blood transfusion if not having it means she will die. Shortly after, her adult children arrive and vehemently refuse for her to be transfused with blood products. They insist that Mrs. Daniels doesn't know what she is asking, due to her dementia. They believe she would not have asked for the blood transfusion if she did not have dementia. Unable to obtain synthetic blood products, Mrs. Daniels is given intravenous fluids and medications that temporarily stabilize her. However, after her children leave, Mrs. Daniels' condition worsens—she vomits large amounts of bright blood, and becomes increasingly short of breath and dizzy. Questioned again about a blood transfusion, she repeats, "I don't want to die." The physician decides to give the blood transfusion. However, after one unit of blood is given, Mrs. Daniels' heart stops, she receives an unsuccessful attempt at cardiopulmonary resuscitation (CPR), and dies. Upon returning, the family members see the empty blood bag hanging from their mother's arm and become angry and distraught that their mother will be eternally shunned from their kingdom.

RESPONSE FROM AN EMERGENCY ROOM PHYSICIAN

The physician in this case faced a true ethical dilemma. He wanted to respect Mrs. Daniels' autonomy, but how? Should he comply with her prior stated wishes not to receive blood transfusions, or go against them by accepting her request for a transfusion as a credible change of mind? Giving her one or more immediate blood transfusions had the potential to save her physical life while going against a religious prohibition she held when not demented. One might first ask, did Mrs. Daniels have the capacity

to give informed consent for a blood transfusion? Consent is not legally or ethically valid when a patient who gives it lacks the capacity to understand the consequences of her choice. The family would likely argue such was the case here—that their mother lacked the ability to consent to a transfusion. Some might be inclined to infer that since no family member had been legally appointed to act in the patient's stead, Mrs. Daniels had decisional capacity prior to this admission. However, it is important to separate the concepts of 'mental competency' (a legal judgment based on global mental capacity, often assessed as part of a guardianship proceeding) and decisional capacity (the ability to communicate a particular choice and understand the consequences of that choice). The fact that Mrs. Daniels had consented to be transferred to the hospital could provide some evidence that she could make specific decisions about her health and that she wanted treatment for this particular life-threatening condition. The physician believed that Mrs. Daniels understood the gravity of the situation she faced—that death was inevitable without a transfusion. She appeared fearful of dying, and articulated a wish to avoid this, even if it meant receiving a transfusion.

Is the fact that dementia occluded Mrs. Daniels' memory of her religious convictions relevant to her request for the transfusion? If one were to defer to her medical records, which stated no blood transfusions in accordance with her religious beliefs, one would not proceed to transfuse her. Yet, how is one to know, had she been able to remember her religious convictions, if she still would have chosen the blood transfusion? Is it possible that Mrs. Daniels abandoned those convictions and prior stated wishes surrounding blood transfusions in order to save her own life? Many times patients are brought to emergency rooms with living wills ruling out use of life support technology that they then ask for. The health care providers abide by the [capacitated] patient's current decision, effectively nullifying his or her living

will. All patients have the right to change their minds concerning their medical treatment. Where does autonomy dictate that the physician err in this case—on the side of believing Mrs. Daniel's plea to avoid death or on the side of abiding by her prior stated wishes?

A physician guided by the beneficence principle for this patient would do what (s) he thinks best promotes the patient's well-being, but well-being can be defined by spiritual as well as physiologic outcomes. The dilemma in this case is that it is uncertain which one should have priority. Clearly, ethical principles don't always point to a definitive course of action. Based on the need for a rapid response with no prior relationship with Mrs. Daniels or her family, the physician decided to err on the side of avoiding death and giving the transfusion. However, not acting more immediately achieved the unfortunate outcome of death after a blood transfusion. One could argue that the physician breached an ethical duty to inform the family that a blood treatment was going to be administered as per the patient's request. However, their absence when the patient was critically unstable precluded such a conversation between the physician and family. Moreover, the fact that the patient requested the blood transfusion when the family members were absent raises the possibility that the patient felt pressured by the family to refuse the transfusion, and the physician may have felt an obligation to protect the patient from any possible family pressure. The issue of family or ecclesial pressure has been discussed by Muramoto.¹

Although ethics is distinct from law, physicians must act within the confines of the law when delivering patient care. Regarding the physician's legal liability, he could be open to liability for wrongful death caused by delaying the blood transfusion, or battery (i.e., giving the transfusion against the patient's prior stated wishes). However, these outcomes are unlikely given the lack of clarity regarding the patient's wishes. The Maryland Health Care Decisions Act (§5-607) allows for emergency medical treatment for a patient who is incapable of making an informed decision if an

authorized surrogate is not immediately available and the attending physician determines that "there is a substantial risk of death or immediate and serious harm to the patient," and "with a reasonable degree of medical certainty, the life or health of the patient would be affected adversely by delaying treatment to obtain consent." In this case, however, it was unclear whether the patient was incapable of making a decision. Moreover, if she were clearly decisionally incapable, the physician would have likely complied with her prior stated wishes and not given her the transfusion. What's unique to this case is that the patient may have been decisionally capable of consenting to a blood transfusion, but there wasn't time to find out. With a child, judges have determined in the past that parents' religious values cannot be used to withhold life-saving medical treatment. Conversely, this patient is an adult but one with limited autonomy (the extent of which is in question) due to her dementia. There is legal precedent for an appointed proxy deciding against a blood transfusion for a mentally incapacitated Jehovah's Witness adult. In that case, the appointed surrogate was also a Jehovah's Witness.¹ However, in this case there was not time to seek a court order (which raises the question—if there were time, would the physician have been obligated to do so?).

The Jehovah's Witness (JW) community might contend that it's rare for a card-carrying JW believer to rationally change her mind about receiving blood; that her core belief in eternal salvation trumps any momentary lapse of faith, fear, or cognitive impairment that might underlie a request for blood products. Yet, perhaps the professional autonomy of the physician also deserves respect. That is, for many reasons, Mrs. Daniels' physician is more concerned about mis-identifying the rare exception (i.e., letting an unwilling JW patient die unnecessarily), than about violating a JW patient's religious prohibition. Were the physician of the JW faith, he might think differently. The difficulty faced by emergency physicians daily is that they must make life and death decisions with little time to weigh psychological and

spiritual variables. There was not time for a court hearing or ethics consultation on the patient's mental capacity in this scenario. I would argue that it's too much to ask this physician to disregard his patient's request for blood transfusions without more conclusive information about whether her request was valid. However, this patient should have been treated sooner and with more blood to be of benefit. Unfortunately, this is a case of too little, too late.

Eva C. Dickinson, M.D.
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Note

1. Muramoto, O. (1998). *Bioethics of the refusal of blood by Jehovah Witnesses: Part 1. Should bioethical deliberation consider dissident views?* *Journal of Clinical Ethics*, 24(4), 230-239.

RESPONSE FROM A JEHOVAH'S WITNESS LAWYER

One of the fundamental principles of modern medicine is that patients have the right to control what is done to their own bodies. This principle, more formally known as the doctrine of bodily self-determination, places obligations on both patients and their doctors. Patients have an obligation to make their wishes known, especially if they strongly object to certain types of medical treatment on the basis of their religious or personal beliefs. As a corollary, doctors have an obligation to obtain their patients' informed consent before administering any type of medical treatment or procedure.

In the case study, the patient is described as a 75-year-old woman with a history of dementia who was brought to an emergency room from a nursing home with a severe gastrointestinal bleed. She is also described as having records at the nursing home that list her as one of Jehovah's Witnesses. These records state that she would refuse blood transfusions under any circumstances. Her treating

Cont. on page 10

physician feels that she needs blood transfusions and apparently the patient has given consent, but the consent is not clear.

The first question facing ER personnel is whether or not the patient has sufficient decision-making capacity to make medical decisions for herself. If she has capacity and is able to clearly express her wishes, her decision should be respected and no further inquiry is needed.

However, in this case, the patient's history of dementia, her answers to certain basic questions, and her lack of clarity on the issue of whether she would consent to blood transfusions compared to her prior expressed wishes has called into question her capacity. This means that the records maintained by the nursing home have become exceptionally important. In many cases, Jehovah's Witnesses have executed statutorily valid advance directives that: 1) clearly indicate their refusal of blood transfusions; 2) state their wishes concerning procedures involving the use of their own blood; and, 3) state their wishes concerning end-of-life matters. These documents, commonly known as a "DPA-card" in the Witness community, are statutorily valid in all 50 states and the District of Columbia, and can be relied on as a legal expression of the person's wishes.

The nursing home should be contacted to determine whether or not the records they maintain on the patient include a "DPA-card" or a similar advance directive. Again, if such a document exists, whether or not a health care agent has been appointed, the patient's wishes are clear. This document is controlling, notwithstanding the wishes of other family members or even the treating physician. For example, in the case *In re Duran*, the Pennsylvania appellate court upheld a Witness patient's refusal of blood as recorded in her Pennsylvania health-care power of attorney over the objections of her non-Witness spouse.¹

Assuming no such document exists, the physician should seek direction from

the court as to how to proceed. While the exact procedure to do so varies from state to state, an important principle in these types of cases is that doctors should not be placed in the position of becoming adversaries of their patients. As the Supreme Court of Florida explained in a case involving a Jehovah's Witness patient and blood transfusions, "a health care provider must not be forced into the awkward position of having to argue zealously against the interest of its own patient."² Therefore, the Florida court directed that the state's attorney must be contacted by hospitals or physicians when there is a dispute about patient care. While this procedure is arguably more cumbersome for the physician than approaching the court directly, it actually serves to insulate the doctor and hospital from liability by removing them one step from the legal proceedings.

In this case, there was a window of time to commence legal proceedings after the patient was admitted once the patient's relatives arrived and the potential conflict was identified. The patient was stabilized for a period of time while she was given intravenous fluids and other medications. Arguably, the state's attorney and the judge could have been contacted during this time period, presented with the facts, and asked for a decision. In most courts, a judge is available 24 hours a day to handle these types of emergencies.

In the event there is insufficient time for a judicial determination to be made, the physician must use his best judgment in rendering medical care. Of course, there are potential consequences for proceeding without clear direction from the patient or direction from the court. If blood is given, the foremost of these consequences is a potential lawsuit for battery. This is particularly true when, as the case study suggests here, the patient's family is adamant about the patient's refusal and is upset about the transfusion.

As this case study demonstrates,

patients should be encouraged to execute advance directives to avoid foreseeable conflicts in their healthcare. This is particularly true when it comes to patients who refuse treatment on the basis of their religious beliefs.

Finally, Jehovah's Witnesses do not believe that they will be 'eternally shunned from the kingdom' for receiving an involuntary blood transfusion. Nonetheless, even involuntary transfusions are viewed as a violation of one's body and result in many of the same emotions and feelings of spiritual worthlessness experienced by rape victims. Hopefully, by discussing these matters in advance, these types of physician/patient conflicts will be minimized to the benefit of all parties involved.

Adam G. Linett
Associate General Counsel
Watchtower Bible and Tract Society of
New York, Inc.
Legal Department

Notes

¹ *In Re Duran*, 769 A.2d 497 (Pa. Super. Ct. 2001).

² *In Re Dubreuil*, 629 So. 2d 819, 823 (Fla. 1993).

We welcome comments to this case study, including how cases such as this are handled at your institution. Please e-mail your comments to MHECN@law.umaryland.edu.

CALENDAR OF EVENTS

January

- 31 12:00PM-1:30PM (free) Human genetic databases: Towards an international frame work. Bernice Elger, Ph.D., The Emanuel & Robert Hart Lecture Series, University Of Pennsylvania Center For Bioethics, 3401 Market Street, Suite 320, Philadelphia, PA. For more information, visit <http://www.bioethics.upenn.edu/>.

February

- 10 7:00 PM Leon Wieseltier, Literary Editor, The New Republic. United States Holocaust Memorial Museum Insight Lecture Series on the exhibit *Deadly Medicine: Creating the Master Race*. Admission is free, but seating is limited. For reservations call 202-488-0407. The *Deadly Medicine* exhibit runs through October 16th, 2005, and will be open before and following the program. Doors open at 6 p.m.
- 14-18 Becoming an Ethics Consultant (intensive training course). St. Francis Medical Center, Honolulu, Hawaii. Speakers include: Howard Brody, MD, PhD, Jing Jih Chin, MD, Lawrence J. Schneiderman, MD and others. For more information visit <http://www.bioethicshawaii.org> or contact Jan Miyamoto, telephone 808-547-6050; e-mail: janm@sfhs-hi.org.
- 24 4:00 PM-5:00 PM (free) Andrea Kalfaglou, PhD, Reproductive Genetic Engineering Technologies: Hope and Fears for Our Genetic Future, University of Maryland Medical Center Medical Humanities Hour. Shock Trauma Auditorium. Contact: hsilverm@medicine.umaryland.edu.
- 25-26 Western Regional Bioethics Conference, sponsored by the Arizona State University Bioethics Club, Bioethics Program at Arizona State University, Tempe, AZ. Contact: Ryan Childers at wrbc@asu.edu or 480-965-8627, or visit <http://lifesciences.asu.edu/bioethics/wrbc/>.

March

- 3-4 3:00 PM-4:00 PM Catholic Health Care Ethics: Foundations and Applications. Sponsored by the Catholic Health Association of the United States and the Neiswanger Institute for Bioethics and Health Policy, Loyola University, Chicago, Stritch School of Medicine, Chicago, IL. Visit www.bioethics/umc.edu/.
- 8 12:00PM-1:30PM (free) Barbara Coombs Lee, JD, RN (title of talk to be announced), The Emanuel & Robert Hart Lecture Series, University Of Pennsylvania Center For Bioethics, 3401 Market Street, Suite 320, Philadelphia, PA. For more information visit <http://www.bioethics.upenn.edu/>.
- 5-12 Humanistic Medicine, Self-Care and the Art of Life Well-Practiced. The 35th Annual Conference of The Society for Humanism in Medicine, The Keystone Resort and Conference Center, Keystone, Colorado. For more information, visit: <http://www.humanisminmedicine.org> or e-mail Ann Colston Wentz, MD, at annewentz@humanisminmedicine.org.
- 11 In the Nation's Compelling Interest: Eliminating Racial and Ethnic Disparities in Health Status (Conference), University of Maryland School of Law, Baltimore, MD. Contact Lu Ann Marshall, 410-706-4128, lmarschal@law.umaryland.edu.
- 17 7:00 PM Leon Kass, MD, University of Chicago. United States Holocaust Memorial Museum Insight Lecture Series on the exhibit *Deadly Medicine: Creating the Master Race* (see February listing above for contact information).

April

- 7-9 The Ethics of Bioethics, a Conference co-sponsored by The American Society of Bioethics and Humanities and the Albany Medical College/Graduate College of Union University Bioethics Program. The Albany Medical College and the Inn at College Park of Union College. Abstracts accepted through February 15. For more information visit <http://www.bioethics.union.edu>, or contact Ann Nolte at bioethics@union.edu, 518-388-8045.

