

Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 2006*

Mid-Atlantic Ethics Committee
Newsletter, Fall 2006-Winter 2007

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MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

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

Fall 2006-Winter 2007

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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

CHOOSING PATERNALISM?

Autonomy, at least in the context of our framework for patient decision making, is under siege. The attack is coming from at least two quarters. Some believe that patients have taken the autonomy model too far, demanding certain treatments that physicians would not recommend. This has occurred in legal cases like *Wanglie*,¹ *Gilgunn*,² and *Baby K*³ where physicians believed that continued life-sustaining treatment for the patient was "futile," or medically inappropriate, and patients or their family members demanded continued treatment. But, it also occurs in other medical settings, for example, where pregnant women demand c-sections or assertive parents demand an antibiotic for their child's sore throat. The second onslaught comes from a wholly different perspective, that patients are uncomfortable making complex medical treatment decisions for themselves, especially when their choices are fraught with uncertainty. These patients, or their family members, are overwhelmed by the information and the responsibility.

Most attention in the bioethical and medical literature has focused on the first of these assaults; I want to focus on the latter. There is considerable support for the view

that patients who are ill and fragile may not want to make their own treatment decisions. In his book, *The Practice of Autonomy: Patients, Doctors and Medical Decisions*,⁴ law Professor Carl Schneider amasses considerable data on this point. For example, he cites a study by Ende et al.,⁵ who presented 312 patients in a primary care clinic with a series of vignettes representing various levels of illness severity and asked them in each scenario, on a scale from 0 to 100, to indicate their desire for making their own treatment decision. The mean score for the study population was 33.2, indicating that patient preferences for decision making were quite weak. In addition, they found that as patients were asked to consider increasingly severe illnesses and as they got older their desire to make decisions themselves declined.

Schneider also presents data that patients are willing to cede some of their autonomy when they are incompetent, even if they have expressed preferences for or against various forms of treatment. He cites the work of Sehgal and colleagues⁶ who asked 150 dialysis patients "how much leeway their physician and surrogate should have to override

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NETWORK NEWS

The Mid-Atlantic Ethics Committee Newsletter

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Diane E. Hoffmann, JD, MS, Editor
Anita J. Tarzian, PhD, RN, Co-Editor
Lu Ann Marshall, BS, Layout Editor

Contributing Editors:

Elizabeth Bray, RN, JD
Co-Chair, Northern Virginia Health Care
Ethics Network

Brian H. Childs, PhD
Director, Ethics & Organizational
Development, Shore Health Systems

Evan DeRenzo, PhD
Ethics Consultant, Center for Ethics,
Washington Hospital Center

Edmund G. Howe, MD, JD
Professor of Psychiatry, U.S.U.H.S.
Department of Psychiatry

Joan Lewis, Executive Director
IONA Senior Services
Washington, DC

Laurie Lyckholm, MD
Asst. Professor of Internal Medicine and
Professor of Bioethics and Humanities,
Virginia Commonwealth School
of Medicine

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

Ian Shenk, MD
Bioethics Network, Fairfax Hospital

Henry Silverman, MD, MA,
Professor of Medicine,
University of Maryland

Comments to:
MHECN@law.umaryland.edu

**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)

MHECN is sponsoring a
panel discussion and
dinner,
*Money & Medicine: Bedside Ethics
of the Medical Marketplace*, from
4:30 p.m. to 7:15 p.m., at Greater
Baltimore Medical Center on January
30, 2007. This symposium will
provide an opportunity for health
care providers and ethics committee
members to explore the topic of
health care cost as it relates to an
individual clinical case. Speakers
include Marion Danis, MD; Rebecca
Elon, MD; MPH, Diane Hoffmann,
JD, MS; and Jack Schwartz, JD.

MHECN will offer its biannual
basic ethics education conference
for health care ethics committee
members in the summer of 2007,
most likely in June. This will be a
one-day conference geared toward
health care ethics committee
members.

MHECN is pleased to announce
that the Johns Hopkins Berman
Institute of Bioethics (formerly
the Phoebe R. Berman Bioethics
Institute at Johns Hopkins) has joined
MHECN as an affiliate member.
We welcome their support and
involvement.

Contact MHECN at (410) 706-4457;
e-mail: MHECN@law.umaryland.edu.

MHECN Program Coordinator:
Anita J. Tarzian, PhD, RN.

THE METROPOLITAN WASHINGTON BIOETHICS NETWORK (MWBN)

MWBN members took
advantage of several local
ethics educational
opportunities at Georgetown
recently. It continues its guardian
training sessions with the D.C.
Superior Court Probate Division.

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

RICHMOND BIOETHICS CONSORTIUM (RBC)

At the VAST (Virginia
Association of Science
Teachers) conference
in November, RBC presented
information about a grant project
to encourage science teachers
to address bioethical issues in
their classrooms. RBC is offering
\$500 "classroom mini-grants" for
biology and life sciences teachers
to introduce the topic of bioethics
to students in grades 6-12. RBC
recently generated new mission and
vision statements as a result of its
strategic planning process.

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

[their] advance directive if overriding were in [their] best interests.” The patients varied greatly in their responses: 39% said “no leeway;” 19% said “a little leeway;” 11% said “a lot of leeway” and 31% said “complete leeway.”

Articles confirming this perspective have also appeared in the popular press. A little over a year ago, a *New York Times* article, entitled “Awash in Information, Patients Face a Lonely, Uncertain Road,”⁷ described the anguish and abandonment patients feel when forced to make difficult medical decisions. The article described the case of a 39 year old patient with ovarian cancer that had metastasized to her liver. She was asked to decide whether to undergo a novel chemotherapy regimen about which five oncologists disagreed. When she asked her doctor what she should do he said he didn’t know, that she would have to make the decision based on her own values. The patient,

“bald, tumor-ridden and exhausted from chemotherapy was reeling. ‘I’m not a doctor!’ she shouted, ‘I’m a criminal defense lawyer! How am I supposed to know?’” The story illustrates the frustration, anxiety, and loneliness of being a “modern patient” attempting to cope with medical uncertainty.

When patients are competent, ideally they and their physicians engage in shared decision-making, where there is give and take between both and neither the autonomy nor the paternalism model dominates. However, once a patient lacks competency, the opportunity for shared decision-making may be gone (at least as between the patient and the physician). In those circumstances, how should we respond?

If we are persuaded by the studies and anecdotes indicating that at least some portion of our population is not comfortable with the “autonomy model,” should we change our legal

framework for health care decision making, in particular our framework for making decisions about life-sustaining treatment for patients lacking decision-making capacity?

Certainly, we cannot abandon autonomy; for many people the autonomy model is still sacrosanct. Rather, we need a model that allows for flexibility – for both autonomy and paternalism. There are, however, obstacles to choosing paternalism once a patient lacks decision-making capacity. One reaction would be to give patients an option to “undermine” their own autonomy, i.e., to autonomously choose paternalism. At least one state, Alabama, has made it easier for patients to give up some autonomy by modifying the state’s advance directive form to allow patients to indicate whether they want their wishes strictly followed or prefer that their proxy do what he or she thinks is best, even if it means doing something different from what the patient has specified in the form.⁸ The Maryland legislature recently made a similar change to its advance directive form.⁹

Another response would be to make it easier for patients to appoint their physician as their health care agent. Many states actually prohibit this, arguably due to concerns about physician paternalism and possible conflicts of interest.¹⁰ Ironically, these laws replace physician paternalism with state paternalism.¹¹ In New York, for example, health care proxy instructions provide that you can appoint your physician as your proxy but then he/she cannot also be your treating physician.¹² In Maryland, a physician can be appointed as a health care agent

MARYLAND PATIENTS GIVEN ADVANCE DIRECTIVE FLEXIBILITY

During the 2006 Legislative Session, the Maryland General Assembly passed several amendments to the Health Care Decisions Act. Among those changes was a provision in the advance directive form allowing patients to specify how strictly they want their stated preferences followed. The model form includes a provision allowing the individual completing the form to choose one of the following options:

1. I realize I cannot foresee everything that might happen after I can no longer decide for myself. My stated preferences are meant to guide whoever is making decisions on my behalf and my health care providers, but I authorize them to be flexible in applying these statements if they feel that doing so would be in my best interest.
2. I realize I cannot foresee everything that might happen after I can no longer decide for myself. Still, I want whoever is making decisions on my behalf and my health care providers to follow my stated preferences exactly as written, even if they think that some alternative is better.

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CLINICAL CANCER RESEARCH: CAN THE PHASE I TRIAL EVER BE ETHICAL?

Although MHECN does not focus specifically on research ethics, there may be times when a physician is put in the role of advising a patient as to whether he or she should enroll in a Phase I clinical trial. This article, by Laurie Lyckholm, an Associate Professor and Program Director of Hematology/Oncology and Palliative Medicine at Virginia Commonwealth University School of Medicine, explores this topic and provides a helpful framework for physicians confronted with this question.

I am not a classical philosopher by trade or training, but a medical oncologist and medical school professor who trained in clinical medical ethics. One of the most compelling reasons for such training, which was not regularly offered in medical school in the 1980's, was to be able to ethically navigate my patients and myself through the complex challenges that arise when enrolling a patient with cancer in a clinical trial.

It is helpful to understand that there are four phases of clinical trials, each with its own particular set of ethical challenges. But the Phase I trial is most vexing to a host of bioethicists and researchers alike.

Phase I cancer therapy trials involve the use of an experimental agent or experimental use of conventional agents, or a combination of the two. These trials are aimed at cancers that have become resistant to conventional agents, or those for which there is minimal effective treatment or cure, such as advanced melanoma, and cancers of the kidney, liver/gall bladder, and brain, among others.

The experimental agents have had some success in preclinical, usually animal experiments, so they are now being tried in humans. The chance they will shrink or at least stabilize the cancer is somewhere between 5 and 40%.

The primary goal of the Phase I trial is to test the experimental agent for side effects and dose limiting toxicity, with efficacy against the cancer a distant secondary goal. Phase I trials are not limited to cancer research, and the same principles may be generally applied when researching other diseases.

It is the closest one gets to the patient being, as many of mine have correctly said, "a guinea pig." Despite the fact that patients, or subjects, as they are called when they enter a clinical trial, are told that the goal is not therapeutic, surveys have shown that many patients believe the reason they are participating in the Phase I trial is to cure their cancer.

Testing new therapies on patients to see how toxic they are ... does that sound ethical? It has not been that long since the Tuskegee Syphilis Study, Willowbrook hepatitis experiments or the atrocities performed in the name of science by the Nazis during WWII. Safeguards, beginning with the Belmont Report and the Nuremberg Code, and creation of institutional review boards with oversight of the protection of human subjects, have been placed to prevent such practices from ever occurring again. With those protections, toxicities are monitored very closely during Phase I trials, not only since that is the focus of the study, but also as a way to protect the patient from undue harm. Patients who are

considered too vulnerable, such as those who are mentally challenged, prisoners, and others, are excluded from the studies. And consent forms are extensive and written to make sure that potential study subjects receive the most comprehensive information possible (which may actually be a drawback, in the form of information overload).

Those who feel that phase I studies may be conducted ethically use two main arguments; one, that if patients give their consent, after being informed extensively of the risks, benefits and the purpose of the trial, then it is their autonomous decision to do so. Secondly, it is arguably ethical to offer possible treatments that may slow the cancer and may also advance the science of cancer treatment overall. Toxicity and study outcomes are carefully monitored, and the study is discontinued if there is excess toxicity or excess mortality attributable to the agents being studied.

On the con side, there are arguments that informed consent is not really possible in these circumstances because the patients are vulnerable and desperate, frightened by the specter of advancing disease. In addition, the complex nature of both the study designs and the treatment itself does not allow for full understanding by most patients, even with the most thorough disclosure. After all, thorough disclosure does not equal thorough understanding.

There are also competing interests for the physician-scientist—the patient under his or her care and that of scientific as well as personal professional advancement. The conflict between patient care and

Cont. on page 10

IS YOUR ETHICS COMMITTEE COMPETENT TO CONSULT? WHAT ARE BENCHMARKS OF SUCCESS?

According to the American Society for Bioethics and Humanities' *Core Competencies for Health Care Ethics Consultation* (1998), at least one person in your facility's ethics committee (EC) should have advanced expertise in each of these areas:

- Moral reasoning and ethical theory
- Common bioethical issues and concepts
- Health care systems
- Clinical context
- Local health care organization's policies, including those on:
 - ✦ Advance Directives
 - ✦ Organ Donation
 - ✦ Goals of Care
 - ✦ Patients with Long Term Stays
 - ✦ Patient Consent
 - ✦ Ethics Committee Access
 - ✦ HIV Testing
 - ✦ Interdisciplinary Collegiality
 - ✦ Reproductive Services
- Cultural and religious beliefs of those served by the facility
- Relevant codes of ethics and professional conduct guidelines
- Relevant health law

In addition, Anita Catlin, DNSc, FNP, FAAN, Ethics Consultant and Associate Professor of Nursing at Sonoma State University in California, recommends the

following benchmarks to measure the competence of your committee (Catlin, 2006, p. 9):

- Ethics should be proactive, not reactive. The EC should work to create or improve policy that might mitigate continual response to individual dilemmas.
- The outcomes of the ethics committee should be translated into demonstrable outcomes.
- The EC has representation from all constituencies in the hospital, with co-chairs representing the largest facility constituency (e.g., nursing).
- The EC is well trained by a leader in ethics who has received formal ethics education.
- EC members are known to facility staff, are trained in consultation, and are available for immediate discussions of minor issues, and can call for a full committee consultation when needed.
- There is a standard recorded format for the ethics consultation. The form is kept and used for data collection, trend identification, and educational purposes.
- Members of the facility know how to contact the EC, and do so. There are materials available on the units for reference.
- Ethics rounds are made on the various shifts. There is an ethics training binder on every unit.
- Members of the EC belong to and attend the annual meeting of the American Society for

Bioethics and Humanities. Each member has a copy of the Core Competencies for Health Care Ethics Consultation.

- Members of the EC receive and read health care ethics journals, such as the *Journal of Clinical Ethics*; the *Hastings Center Report*, *HEC Forum*, or the *Cambridge Quarterly of Healthcare Ethics*.
- Physician members have received End-of-Life Physician Education Consortium (EPEC), or comparable, training.
- Nurse members have received End-of-Life Nursing Education Consortium (ELNEC), or comparable, training.
- Members of the staff are aware of the Nursing and Medical Codes of Ethics and Patient's Bill of Rights, and care is delivered accordingly.

References:

Catlin, A. (2006), Plan to Bring Ethics Committee to Magnet Standards, Submitted to Kaiser Santa Rosa Organization, Santa Rosa, California, September 15, 2006.

American Society of Bioethics and Humanities (1998), *Core Competencies for Health Care Ethics Consultation*. Glenview, Illinois: American Society of Bioethics and Humanities. Order online at www.asbh.org.

American Medical Association (AMA) Council on Ethical and Judicial Affairs (2006), *Code of Medical Ethics 2006-2007: Current Opinions with Annotations* (Code of Medical Ethics). American Medical Association.

American Nurses Association (2001), *Nursing Code of Ethics with Interpretive Statements*.

FOCUS ON THE CENTER FOR ETHICS AT THE WASHINGTON HOSPITAL CENTER

The Center for Ethics at the Washington Hospital Center, founded by Dr. John Lynch, is credited with being one of the oldest hospital ethics programs in the country. It evolved from an ethics committee established in 1982 to a program housed in the Hospital's Department of Pastoral Care, and then developed into a separate department in 1992. Its current director is Nneka Mokwunye, a PhD candidate at Howard University. Two other bioethicists on staff are Evan DeRenzo, PhD and Daria Grayer, MA. Dr. Lynch is still an active member of the Center and is the current Chair of the Hospital's ethics committee.

The Center provides consultations in clinical and research practice, and also coordinates continuing education programs in bioethics, develops and critiques institutional hospital policy, and develops and implements independent research on biomedical issues. The Center runs a 35-member bioethics committee that has three subcommittees: policy, education, and consultation. A new venture for the Center is the publication of *The Journal of Everyday Clinical Ethics*. The *Journal* is scheduled to be released January 2007. (For further details on submissions please email ethics@medstar.net.)

The Center's mission is to "develop, promote and maintain the highest standards in ethical knowledge and awareness in all aspects of clinical practice." In October, as part of its own education mission, the Center hosted a *Bioethics Awareness Week* (October 16-20, 2006). Events included opportunities to meet the members of the ethics committee and discuss bioethics topics such as medical futility; an advance directive fair and information seminar; women's awareness workshops; "breakfast with bioethics" to discuss clinical ethics case studies; and "ask the ethicist" sessions where staff and community members could bring their own ethical issues for clarification or discussion. During the advance directive fair the Center staff assisted over 150 participants in completing advance directives and disseminated numerous information packets for participants to give to their family members and friends.

The week long educational program included a focus on HIV awareness and prevention specifically on disclosure of HIV positive mothers to their partners. The goal was to help these mothers obtain the necessary assistance for protecting their babies from HIV

transmission. "Breakfast with Bioethics" and "Ask the Ethicist" sessions were a time for staff to ask any questions they had about these issues, in particular. The ability to discuss one-on-one with the bioethicists gave the staff a mechanism to release any moral distress they were feeling and find comfort in knowing that their concerns were being addressed.

The Center will be holding *Bioethics Awareness Week* annually.

Has YOUR facility instituted a special program or educational endeavor in bioethics that you would like to share? Let us know by emailing us at MHECN@law.umaryland.edu, or calling (410) 706-4457.

CASE PRESENTATION

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee and an analysis of the ethical issues involved. Readers are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information about patients and others in the case should only be provided with the permission of the patient. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to MHECN@law.umaryland.edu, or MHECN, the Law & Health Care Program, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201.

CASE STUDY FROM A D.C. HOSPITAL

Ms. Casey is a 32 year old woman who delivered a full term infant at a D.C. hospital. As she is HIV positive, the team begins teaching her about the antiretroviral regimen her infant will be sent home with. Ms. Casey discloses to her physician that her husband does not know that she is HIV positive, and she does not intend to tell him. There is reason to believe that Ms. Casey does not intend to give her infant the antiretroviral drugs prescribed, and may not be taking antiretrovirals herself, for fear her husband will find out about her HIV status. The

physician tries to convince Ms. Casey of the importance of taking antiretroviral medications and of telling her husband about her HIV status, but she is adamantly opposed to doing so. She tells the physician and nurse involved in her care that if someone informs her husband about her HIV status, she will sue for privacy violation. The nurse requests an ethics consult. She is concerned about the rights of the husband and the welfare of her patient's infant.

RESPONSE FROM A BIOETHICIST AND ETHICS CONSULTANT

The ethical dilemma of this case rests on the collision of the principles of autonomy, beneficence, and nonmaleficence. These principles are at play in the following ways:

- the autonomy of the mother to request that her HIV status remain private and confidential,
- the autonomy of the father to have any relevant information that directly relates to his well being presented to him,
- beneficence towards the mother to protect her from the negative consequences of her HIV status being divulged,
- beneficence towards the father by allowing him to protect himself from any further exposure to HIV,
- beneficence towards any other person who the father may infect if he is HIV positive, due to not knowing his own HIV status,
- beneficence towards the baby in providing necessary medical interventions to prevent HIV infection,
- nonmaleficence to the mother by avoiding harm that would ensue if her privacy and confidentiality were violated if her HIV status were to be disclosed,
- nonmaleficence to the father by avoiding harm that might ensue if he were not informed about his wife's HIV status and his own risk of being infected, and
- nonmaleficence toward the baby by preventing HIV transmission through preventive treatments, which is less likely to happen if both parents are not informed of the medical appropriateness of the antiretroviral drugs for prevention of transmission.

It is the ethical duty of the hospital to provide appropriate care for its patients. In this case, the baby and the mother are both patients of the hospital. In an effort to protect the baby, the physicians have the ethical duty to inform both parents of the risks of exposure to HIV and the therapies needed to minimize or eliminate transmission. If, in having

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CASE PRESENTATION

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this conversation, the father deduces that the HIV exposure comes from his wife, then that it is a side effect of the informed consent process.

Ethically, there is a strong argument that the patient has a moral obligation to inform her husband about her HIV status. The physician can do his or her best to convince the patient to do so. However, opinions differ about whether a physician's primary duty is to protect the patient-provider relationship by not breaching a patient's trust (i.e., by informing a sexual partner about positive HIV status), or to protect a third party who may be at risk of harm. For example, some argue that more harm may come by requiring physicians to breach patient confidence in such situations, since this may erode patient-provider trust and lead to patients avoiding medical care.

While clinicians are obligated to warn others of known direct harms (for example, a homicidal patient divulges a plan to his psychologist to kill his girlfriend, as in the famous Tarasoff case), there are differing opinions about whether or not

divulging a positive HIV status to a current or former sexual partner constitutes direct harm. States have different laws about clinician disclosures in such situations. In the District of Columbia (D.C.), the physician cannot inform the patient's husband that he has been exposed to HIV or suggest that he be tested and protect himself from further exposure. (In contrast, Maryland law allows, but does not obligate, a physician to make such a disclosure.) However, D.C. law allows the physician to inform a child's father of all relevant information regarding the welfare of the child, and this supersedes the right of the mother to keep her HIV status private.

The physician should inform the mother that relevant information to provide appropriate care for the baby (including the need for ART medication to prevent HIV transmission) will be shared with her husband. Once the baby is born, all information relevant to provide appropriate treatment for the baby must be divulged to both parents. The mother may sue the hospital

for violating her right to privacy. That is a price the hospital has to pay to fulfill its ethical obligation to provide adequate care to the baby, which in this case trumps the obligation to protect the mother's privacy regarding her HIV status. As the ethics consultant for the case, my recommendation would be to inform the mother that the health care team will provide all relevant medical information about the care of the infant to both parents, and the baby will not be discharged until this conversation has taken place and there is agreement to follow the regimen to minimize HIV transmission. I would have social services continue to follow the case and child protective services keep an eye on the situation to make sure the baby is getting the necessary treatments.

*Nneka Mokwunye
Ph.D. Candidate, M.A.
Director, Center for Ethics
Washington Hospital Center*

EDUCATIONAL OPPORTUNITY! 3-Class Ethics Course at INOVA Health System, Falls Church, VA

Thursday, February 8, 2007
Ethics in Everyday Clinical Practice

Wednesday, April 11, 2007
Current Controversies in Healthcare Ethics

Friday, May 11, 2007
Ethical & Psychosocial Management of the Patient and Family Identified as Difficult

For more information, contact Patti O'Donnell, PhD, Director, Center for Ethics, Inova Health System at 703-321-2658 (phone) or patricia.odonnell@inova.com.
To register, call Inova Teleservices at 703-205-8384.

CASE PRESENTATION

RESPONSE FROM A NURSE ATTORNEY

This case is about the welfare of the child. The mother's statements have given rise to a reasonable probability that the child will not get the necessary medications and that universal precautions will not be observed. Immediate and life-threatening harm to the child is likely.

If I were hospital counsel I would call the Emergency Judge and Petition for the appointment of a Temporary Guardian of the Child. I would allege parental neglect. An immediate hearing on the Emergency Petition would be scheduled at the hospital. The parents would attend the hearing during which only the child's medical status would be discussed. Any available lab values or other information about the child which would justify the need for the antiviral regimen would be revealed. The doctors may ultimately just state that they have reason to believe the child has had a significant HIV exposure. The husband is likely to deduce the source of the child's need for antiretrovirals without being directly told that the wife is HIV positive. If he should ask outright, the hospital staff could suggest that he discuss this with his wife.

After the disclosure of the child's status (and most likely the mother's HIV positive status), there may be no need for further

court intervention. The mother or father may agree to administer the medications. If the mother is uncooperative and continues to resist medicating the child, taking her own medications and observing universal precautions, I am confident that a D.C. judge would appoint a Guardian of the child and order the antiretroviral treatment on a *parens patriae* theory. The husband/father could be appointed depending on his conduct at the hearing. The judge might order ongoing intervention by a child welfare agency. In any event, this family is going to need a lot of support and ongoing monitoring once the child's medical status is revealed.

An emergency Petition is exactly the action I have taken in several cases in which the parent of a minor child/infant has refused blood transfusions for religious reasons. In those cases the parents had an arguably valid reason for refusing the treatment. Here, the mother's reason is somewhat understandable, but is secondary to considerations of the child's welfare. If she is concerned about domestic violence or abandonment of financial support by the spouse, the wife should be offered access to any available resources. The husband will discover her HIV positive status sooner or later. This information is best

delivered in the relative safety of the hospital with readily available information and support for the family.

The father of the child has a right to know about the child's medical status and a right to protect himself. The hospital has an ethical duty to advise him of the child's medical status and the need to use universal precautions when caring for the child, both for the child's welfare as well as his own. Unless the hospital provides this information to both parents, the child cannot be safely discharged.

The hospital risks the wife's lawsuit for invasion of privacy. However, this risk is far less than the risk to both the welfare of the child and the husband. The child is likely to sustain harm if deprived of reasonable medical treatment and could sue the hospital. The hospital has no rational basis to permit withholding of information about the child's medical needs from the father. One parent has no greater rights to control this information than the other parent, assuming there are no questions about paternity.

*Andrea Sloan, R.N., Esq.
Private Practice*

Choosing Paternalism?

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but only if he/she is not the owner, operator, or employee of a health care facility where the patient is receiving care, unless the physician would also qualify as a surrogate decision-maker under the law.¹³ Whether or not we should loosen our laws to allow for this option raises normative questions about whether physicians should be given the authority to both treat and act as agent.

Unfortunately, our current framework for health care decision making seems to be one in which we expect that one size will fit all. In the 1960s, we rejected the paternalism model and adopted autonomy. Perhaps, at least in the context of decision-making for patients who lack capacity, we need a scheme that allows for both — permitting the patient to choose autonomy *or* paternalism.

Endnotes

¹ *In re* Conservatorship of Wanglie, No. PX-91-283 (Minn. Dict. Ct.

Hennepin Co., June 28, 1991).

² *Gilgunn v. Mass. Gen. Hosp.*, No. 92-4820 (Mass. Super. Ct., Apr. 21, 1995).

³ *In re* Baby “K”, 16 F.3d 590 (4th Cir. 1994).

⁴ CARL E. SCHNEIDER, *THE PRACTICE OF AUTONOMY: PATIENTS, DOCTORS, AND MEDICAL DECISIONS* (1998).

⁵ *Id.* at 36 (citing Jack Ende et al., *Measuring Patients’ Desire for Autonomy: Decision Making and Information-Seeking Preferences Among Medical Patients*, 4 J. GEN. INTERNAL MED. 23 (1989)).

⁶ *Id.* at 42 (citing Ashwini Sehgal et al., *How Strictly Do Dialysis Patients Want Their Advance Directives Followed?*, 267 J. AM. MED. ASS’N 59 (1992)).

⁷ Jan Hoffman, *Awash in Information, Patients Face a Lonely, Uncertain Road*, N.Y. TIMES, Aug. 14, 2005, § 1, at 1.

⁸ ALA. CODE § 22-8A-4(h) (LexisNexis Supp. 2005).

⁹ S. 369, 2006 Leg., 421st Sess. (Md. 2006). The Department of Veterans Affairs is also revising its Advance Directive Form to include a provision that would allow patients to specify how strictly they want their preferences followed. Personal communication from the VHA National Center for Ethics in Health Care, March 31, 2006.

¹⁰ See Arti Rai, Mark Siegler, & John Lantos, *The Physician as a Health Care Proxy*, HASTINGS CTR. REP., Sept./Oct. 1999, at 14.

¹¹ *Id.* at 16.

¹² N.Y. PUB. HEALTH LAW § 2980(3)(c) (McKinney 2002).

¹³ MD HEALTH GEN Code Ann § 5-602(b)(2) (2006).

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Clinical Cancer Research

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the advancement of knowledge is one that I personally find daunting at times, as I find it difficult to tell a patient that they will be “used” to evaluate toxicity and dose limitations; however Phase I trials have resulted in effective treatments and wondrous advances in cancer care. The bottom line, however, is that the person in front of me is, and will always be, front-and-center my primary interest.

So, how can this dilemma be resolved? The first premise must be that there is no way around it: Phase I trials must be performed in order to make cancer treatment advances for the next generation. There must

be a paradigm change that informed consent is not the ethical litmus test of the Phase I trial. There is no one true ethical rationalization for the Phase I trial, but rather a simple set of criteria that, if followed, will assist in rendering ethical the Phase I trial: (1) those designing and administering the study do so as carefully as possible so as to minimize harm and maximize efficacy; (2) those providing care and information for the study subject do their very best to inform them that they are being studied for side effects and toxicity primarily, and that the likelihood of their cancer responding to the treatment is less than 50%, with cure nearly impossible; (3) patients

with advanced cancer must be informed of the alternative to clinical trials, which is supportive care that may translate to better quality of life, and they must be told clearly that they have a choice in the matter. Finally, the physician-scientists must try to resolve their conflicts of interest in favor of the person in front of them—their patient.

*Laurie Lyckholm, M.D.
Associate Professor and
Program Director
Hematology/Oncology and
Palliative Medicine
Virginia Commonwealth University
School of Medicine*

CALENDAR OF EVENTS

JANUARY

- 8 **(9:00 a.m.)** Current Challenges in Research Ethics. Sponsored by the SouthEastern Pennsylvania Consortium for Higher Education. Speaker: Arthur Caplan, Ph.D. Holy Family University, 9801 Frankford Ave., Philadelphia, PA. Contact: (215) 572-8543, or register online at www.sepche.org.
- 23 **(7:00 p.m. – 9:00 p.m.) (free)** Why You Should Care About Research on Humans in Developing Countries. Speaker Nancy Kass, Sc.D. Sponsored by the Johns Hopkins Berman Bioethics Institute, “Grounds for Discussion.” Evergreen Coffee House at 501 West Cold Spring Lane, Baltimore. For more information on this event, please visit www.hopkinsmedicine.org/bioethics/events/GrandRounds.pdf, or contact Stephanie Davis at stdavis@jhsp.edu or 410-516-8570. RSVP Requested.
- 25 **12 Noon (free)** Grand Rounds: Bioethics, Genetic Testing and Genomic Medicine. Sponsored by the Shady Grove Adventist Hospital Ethics Committee. Oak Room, Weinschel Education Center, Shady Grove Adventist Hospital, Rockville, MD. Contact: paul@vannice.com.
- 26 **(8:00 a.m. – 4:30 p.m.)** The Future of Hospital Ethics. The Orange Tree Golf Resort, 10601 N. 56th St., Scottsdale, AZ. Contact: 602-445-4356, e-mail edservices@azhha.org, or visit www.azhha.org/public/education and click on “Program Calendar.”
- 30 **(4:30 p.m. – 7:15 p.m.)** Money and Medicine: Bedside Ethics of the Medical Marketplace. Co-sponsored by the Maryland Health Care Ethics Committee Network at the University of Maryland School of Law, the Health Facilities Association of Maryland, and Med-Chi. Greater Baltimore Medical Center (GBMC), Towson, Maryland. For more information, visit www.law.umaryland.edu/mhecncn, call Lu Ann Marshall at (410) 706-4128, or MHECN at (410) 706-4457, e-mail MHECN@law.umaryland.edu.

FEBRUARY

- 2 **(7:30 a.m.)** Giving and Receiving Bad News, The Sister Margaret James Lecture. Speaker Rhonda Fishel, MD. St. Agnes Hospital, 900 Caton Avenue, Baltimore, MD. Registration and breakfast at 7:00 a.m. in the Alagia Auditorium. Lecture at 7:30 a.m. RSVP to Carol Webb at 410-368-3412 by February 1.
- 21 **(7:00 p.m. – 8:00 p.m., reception to follow)** “Medicare Matters: Is a Social Contract Possible in Health Care?” Christine K. Cassell, MD, MACP. The Fourth Annual John Collins Harvey Lectureship, Leavey Conference Center, Georgetown University. Contact and RSVP: 202-687-

