

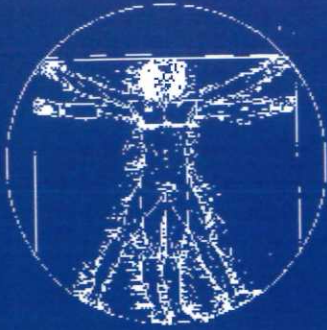
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 2001*

Mid-Atlantic Ethics Committee
Newsletter, Fall-Winter 2001

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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-Winter 2001

PRE-IMPLANTATION GENETIC TESTING: A DEBATE NOT WORTH HAVING

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Pre-implantation genetic diagnosis (PGD) is an in vitro fertilization (IVF) technique currently used by couples whose children are at risk for a genetic disorder. Gender selection may play a role when the disorder involves a sex-linked gene. A recent controversy ensued when John Robertson, the ethics committee chair of the American Society of Reproductive Medicine (ASRM), was quoted as saying in a letter to a fertility specialist that "it is sometimes acceptable for couples to choose the sex of their children by selecting either male or female embryos and discarding the rest" (Reuters Health, 9/28). The Executive Director of the ASRM later pointed out that Robertson was quoted out of context, and that his statement was not a ruling of the ethics committee or the position of the society. The issue of PGD being used to allow couples undergoing IVF to select the gender of their child has come before local ethics committees, whether those affiliated with fertility clinics, with hospitals that provide reproductive technology, or in health care facilities that use this debate as an exercise in ethical analysis. Dr. Evan DeRenzo gives her impressions here about having such a debate in an ethics committee forum.

The Mid-Atlantic Ethics Committee Newsletter is a publication of the University of Maryland School of Law's Law & Health Care Program and is distributed in cooperation with the Maryland Health Care Ethics Committee Network. 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

Ethics committees that spend their valuable time debating the ethics of using PGD for gender selection are either significantly confused or misguided. The most fundamental reason for confusion is that few persons are sufficiently trained in ethical analysis to be able to avoid the conceptual error that there is a moral difference between something someone thinks will produce good (i.e. pleasure) for him or herself (or immediate family) and a moral (i.e.,

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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.

NETWORK NEWS

Maryland Health Care Ethics Committee Network (MHECN)

MHECN has had a busy Fall. On September 8th the Network held a one-day basic healthcare ethics workshop at Shore Memorial Hospital in Easton. Recently, the Network received funding from the Foundation for Spirituality and Medicine to hold a conference next Spring entitled "Spirituality, Healthcare, and the Role of the Ethics Committee." Details about the conference will be available early in 2002. On November 15th MHECN held its annual business meeting and celebrated its third year since its reorganization with a dinner meeting at North Arundel Hospital. Jack Schwarz, Director of Health Policy at the Maryland Office of the Attorney General, gave a stimulating talk entitled, "Legal Dim Sum," about an assortment of legal/ethical issues including advance directives, feeding tubes, decisional capacity, pain control and research. Board elections were postponed until a change in the by-laws can be discussed and voted on by a quorum of the membership at a special meeting to be called in January.

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Metropolitan Washington Bioethics Network (MWBN)

The Metropolitan Washington Bioethics Network was invited by Sister Carol Taylor, Director of the Center for Clinical Bioethics, to participate with the Center, the Jesuit Community, and the Department of Philosophy at Georgetown University on a program held on October 29th entitled, "Stem Cell Research: Science, Religion and Ethics in Dialogue." Sister Carol moderated the program. The speaker was Kevin T. Fitzgerald, SJ, PhD, the

Dr. David Lauler, Chair of Catholic Health Care Ethics at the Center. Respondents were LeRoy Walters, PhD, the Joseph P. Kennedy, Sr. Professor of Christian Ethics at the Kennedy Institute of Ethics at Georgetown and Roberto Dell'Oro, PhD, Assistant Research Professor and Senior Research Scholar at the Center. They discussed the issue of stem cell research from a number of perspectives, including the concept: "Is 'scientific good' good for society?"

In January, the MWBN is hoping to have a joint meeting with the Northern Virginia Healthcare Ethics Network. The date is likely to be on January 18th or January 25th. The purpose of the joint meeting is to provide an opportunity for the two groups to network and to determine how they might work together in 2002.

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Richmond Bioethics Consortium (RBC)

The RBC will sponsor three full-day workshops in Spring 2002 for current and prospective ethics committee members. "Orientation to Ethical Decision Making: A Series of Workshops" will be held at the McGuire VAMC, 8:00 a.m. to 4:30 p.m. on April 19, May 3, and May 17, 2002. Topics to be addressed will include the history of the bioethics movement, ethical theories, privacy and confidentiality, determining decision-making capacity, informed consent, forgoing life-sustaining treatment, death and dying, pediatric and reproductive issues, genetics, research, organizational ethics, and ethics consultation. RBC encourages member institutions to send participants from their institutions. Individual members are also invited to attend.

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Pre-Implantation Genetic Testing Cont. from page 1

social) good. Making this error is understandable in that the average ethics committee rarely starts off its monthly discussions with an explicit review of the origins of Western ethics. Ethics committee chairpersons don't usually remind committee members that the Greeks sat around together attempting to understand what it takes to create the good life rather than how to feel good.

The time that committees should be spending on pedagogical preparation is easily preempted when the committee's agenda is to discuss such technologically mind-boggling, whiz-bang, scientific advances as pre-implantation genetic testing. Couple this general lack of erudition with

everyone's gut reaction that babies are good and loving the baby you have is even better, and one arrives at the kind of discussions heard today in hospital ethics committees about whether or not to offer pre-implantation genetic testing for gender selection.

Now, it is certainly true that the advent of pre-implantation genetic testing is a wonderful technology, if used appropriately. Such appropriate use occurs when parents, who have already borne a child with a genetically identifiable disorder that results unequivocally in a slow, painful, premature death, take advantage of the technique. Since there can be little argument offered for the position that medical technology ought to be employed to reduce pain and suffering, applying pre-implantation genetic testing to assure that another child not have to go through such suffering is an ethics no-brainer. This is not merely pre-implantation genetic testing, it is pre-implantation genetic diagnosis, which makes for a big moral difference.

To leap from such a case, however, to the position that it is morally accept-

able to offer pre-implantation genetic testing for the purposes of gender selection is a leap over the edge of logical moral argumentation. On what moral justification might such a position rest? What are we diagnosing?

From a Utilitarian perspective, the potential consequences of having parents select their baby's gender runs a high risk of producing imbalances in the natural bell curve distribution between the genders. Even when motive appears reasonably virtuous (the happy family of perfect gender off-

“Given the kinds and numbers of health care services that persons already really, really, really need . . . , we certainly should not be using precious health care resources to produce designer families.”

spring balance), letting parents choose, rather than letting gender distribution occur without technologic intervention, could ultimately result in all sorts of social harms (e.g., not enough of one gender or the other to perpetuate the species is a nice starting point).

One is hard pressed to imagine anything but a rejection on deontologic grounds. One could never meet the categorical imperative with, “One should always be allowed to select the gender of one's baby.” And why not? Because there are bound to be occasions in which gender preference would be a result of a disregard for the dignity of each human.

From a virtue ethics perspective, no matter how loud the protestations, one could never be sure the motive for the gender selection was virtuous. Although we might find the goal of ‘family gender balance’ morally blameless, there will be others who seek to bear one gender or another for morally unacceptable reasons. The history of female infanticide bears witness to the harms of discrimination.

The notion of justice as the fair distribution of benefits and burdens

across members of a society also requires declining to establish a policy that would permit pre-implantation genetic testing for gender selection. Given the kinds and numbers of health care services that persons already *really, really, really* need that we do not offer, we certainly should not be using precious health care resources to produce designer families.

Finally, back to the fundamentals of ethical analysis. There is no sustainable ethical argument that is grounded in self-interest. True, for the most part, babies are a gift to society. True, babies are intrinsically good and should be appreciated for their inherent dignity as human creatures. True, loving babies is good for society. Loving babies sets the stage for the growth of the babies into productive, contributing adults and for the survival of the species. But just

because some parents might want to select the gender of their child does not translate into a coherent moral argument for providing pre-implantation genetic selection services, regardless of the truths about the good loved babies bring to a society.

Rather, there is really no respectable argument that can be mounted in favor of a policy that permits pre-implantation genetic testing for purposes of gender selection. So why would an ethics committee waste time considering such a policy?

Unfortunately, most ethics committees simply do not take the time for self-education in the basics of ethical analysis that would prevent discussions with such confused thinking. When education in introductory philosophy is suggested, ethics committee members roll their eyes. But because of this core informational void, committees waste time talking about things that sound like they are ethical arguments but are not. They are simply illogical, meandering and time-wasting conversations about issues that have ethical implications, such as the possibility of setting

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LEGAL BRIEFS

Children as Research Subjects: *Grimes v. Kennedy Krieger Institute, Inc.*

On August 16, 2001, the Maryland Court of Appeals shocked researchers who conduct investigational studies involving children and the institutions that sponsor them when it held that, "in Maryland, a parent . . . cannot consent to the participation of a child or other person on legal disability in nontherapeutic research or other studies in which there is any risk of injury or damage to the health of the subject." In such cases, according to the Court, "parental consent, no matter how informed, is insufficient." The legal world was equally shocked because the Court ruled on this issue *sua sponte*; that is, without prompting or the request of the parties in the case.

Two separate lawsuits were brought against Kennedy Krieger, an internationally known pediatric treatment and research facility, by the parents of two children involved in a study of the effectiveness of different lead paint abatement techniques. The cases filed in Baltimore City Circuit Court claimed that the mothers of the children allegedly harmed by their participation in the study were not properly or timely informed by Kennedy Krieger of the risks to their children or of elevated levels of lead in their children's blood or their homes. The Circuit Court dismissed both cases on summary judgment, stating that Kennedy Krieger had no legal obligation to make houses safe or to notify the families about the dangers they faced because Kennedy Krieger was not a landlord and never promised to provide medical care.

The Circuit Court rulings were appealed to the Court of Appeals. The plaintiffs merely wanted the Court to order that trials be conducted to determine whether Kennedy Krieger was negligent in the way it conducted the studies with respect to Ericka Grimes and Myron Higgins and breached its duty of care to the children. The Court of Appeals remanded the case for trial, but extended its opinion to admonish the

research methods of Kennedy Krieger and accuse the Johns Hopkins University Institutional Review Board (which reviewed the protocol) of protecting the interests of the researchers at the expense of children by instructing the researchers to circumvent federal regulations designed to protect children participating in nontherapeutic research. In its scathing opinion, the Court compared the actions of Kennedy Krieger to those of the Tuskegee Syphilis Study, the intentional exposure of soldiers and Navajo miners to radiation, the secret administration of LSD to soldiers, the injection of chronically ill patients with cancer cells without their consent, the typhoid experiment conducted by the Nazis at Buchenwald, and the use of "plague bombs" by the Japanese military in World War II. Following its comparisons, the Court stated that

[i]t is clear to [the] Court that the scientific and medical communities cannot be permitted to assume sole authority to determine ultimately what is right and appropriate in respect to research projects involving young children free of the limitations and consequences of the application of Maryland law.

Moreover, the Court noted its belief that Institutional Review Boards are, primarily, "in-house organs" and cannot be trusted to be sufficiently objective to protect the interests of children and determine the ethicality of the experiments they review.

The holding of the case—that parental consent is not sufficient for nontherapeutic research that poses any health risk to the child—aroused great concern among researchers in Maryland. According to numerous medical institutions and associations that reviewed the opinion, the Court's decision halted virtually all research in the State involving children. In September, as a result of these

concerns, Kennedy Krieger and others asked the Court to reconsider the part of its August ruling prohibiting parental consent for the participation of children in nontherapeutic research citing numerous public policy concerns regarding the likely unintended and damaging outcomes of the Court's ruling. In addition, Kennedy Krieger questioned the ambiguous "any risk" and "nontherapeutic" terms used by the Court in its opinion and asked for clarification. It also requested that the Court withdraw its "similar problems" historical comparisons to the Tuskegee Syphilis Study and other horrific protocols noted above.

The Court of Appeals denied Kennedy Krieger's motion for reconsideration and modification of the original opinion, stating that "the *only* conclusion [it] reached as a mater of law was that, on the record currently before [the Court], summary judgment was improperly granted." (emphasis added). Yet, the Court refused to retract its holding that a parent "cannot consent to the participation of a child . . . in nontherapeutic research or studies in which there is any risk of injury or damage to the health of the subject." The Court did note, however, its belief that the definition of "any risk" was clear and meant "any articulable risk beyond the minimal kind of risk that is inherent in any endeavor." The Court defined "nontherapeutic" as a study that "promises no medical benefit to the child whatever, so that any balance between risk and benefit is necessarily negative."

Given the Court of Appeal's confirmation of its holding in *Grimes v. Kennedy Krieger Institute, Inc.*, it is likely that the Maryland General Assembly will consider whether a change in Maryland law is necessary to address any discrepancy with federal regulations. Also, the issue of liability of Kennedy Krieger in the two cases has yet to be determined by the lower courts. These decisions will also be important for the research community in Maryland.

by Lisa Ohrin, J.D.
University of Maryland
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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 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: Diane E. Hoffmann, Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 515 W. Lombard St., Baltimore, MD 21201-1786.

CASE STUDY FROM A MARYLAND MENTAL HEALTH FACILITY

Gregory Hanson is a 16 year old who is in a Maryland detention center being held for trial after attempting to shoot a police officer. He is being tried as an adult. Gregory is sent to Longview Mental Health facility from the detention center for an evaluation of his competency to stand trial. Longview staff evaluate Gregory and conclude that he clearly has bipolar disorder. After talking with Gregory, they become convinced that, compelled by his disease, Gregory attempted to have a police officer kill him by pretending to have a loaded gun with which he threatened the police officer. In order to control Gregory's manic symptoms, the Longview staff administer medication to Gregory, with his consent. Responding particularly well to the medication, Gregory's symptoms begin to recede. Longview staff

complete their evaluation, determining that Gregory is competent to stand trial. The psychiatrist makes a recommendation for Gregory to continue taking the psychotropic medication. Gregory is then discharged back to the detention center to await trial. A week later, Ms. Carney, a Longview nurse who has developed a special connection with Gregory, speaks with him in the detention center and learns that he is not receiving any medication, and that his symptoms are beginning to recur. Apparently, the detention center psychiatrist decided not to follow the treatment recommendations made by Gregory's physician at Longview. Ms. Carney is very upset by this and feels strongly that it is unethical for Gregory not to be treated for his bipolar disease. Unsure of where to turn, she calls for an ethics consult from the ethics committee at Longview.

Comments From a Forensic Psychiatrist

The first clarification needed is the nature of the obligation of the Longview staff. Unlike a traditional provider-patient relationship, the Longview staff are technically not providing treatment—rather, they are merely evaluating Gregory's competency to stand trial. An evaluation for competency asks only whether the defendant has a factual and rational understanding of the charges against him; whether he can meaningfully participate in his trial and give assistance to his attorney in planning a defense. The defendant's mental illness comes into play only if it interferes with competency. The Court, not Gregory, is Longview's client. The danger that Gregory may misinterpret the nature of his relationship with the Longview staff should have been protected by the staff making the terms of their relationship with Gregory clear. For example, as the competency evaluation is not a confidential relationship nor perhaps

even a willing relationship, the evaluator(s) should declare to the defendant at each interview that it is not a confidential interview.

The second clarification needed is whether Gregory is being mistreated at the detention center in not receiving his medication. In all of the detention centers in Maryland, the psychiatric care is provided on a contract with the local health department. In the prisons the care is provided through a private company. In the event that an inmate demonstrates overt symptoms of a mental illness requiring psychiatric intervention, the detention center would have the same mental health professionals assist in utilizing the civil procedure of certifying the inmate into a hospital for treatment. All of the wardens (in Maryland) have had training in the management of the mentally ill defendant and support the mental health clinicians in maintaining recovery. When dealing with inmates or detainees, it has been my experience that staff are more likely to overuse rather than under-use medication to treat exacerbations of a mental illness. Therefore, Ms. Carney's implication that Gregory is having needed psychiatric medication withheld is an unusual one.

One might wonder if it's possible that the detention center psychiatrist or staff have withheld Gregory's psychotropic medications to maximize the likelihood that a jury would find Gregory not guilty if he were exhibiting psychotic symptoms during his trial. This is an unlikely scenario. The defendant who displays symptoms of a mental illness during trial would unlikely be found not guilty, but would rather be sent for another evaluation of competency and criminal responsibility. Criminal responsibility applies to the defendant's state of mind at the time of the offense, not at the time of the trial. As much information as possible is gathered to understand and reconstruct the day of the offense, including the defendant's mental state of mind. Inducing exacerbation of the symptoms of a mental illness to influence jury

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Comments From a Forensic Psychiatrist

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members during a trial is not necessary, nor is it ethically justifiable.

Could it be that Gregory refused the medication? In the State of Maryland, a 16 year old can consent to or refuse psychiatric treatment. If he refuses, there are procedures in place to involuntarily medicate him, but only if he is a danger to himself or others. It is implied that Gregory is not taking his medication because the detention center psychiatrist did not order it, but the facts should be verified.

Another possibility is that the detention center psychiatrist may have opted for a different treatment approach. In the best practice of medicine, the treating psychiatrist from Longview would contact the psychiatrist at the detention center and review the need for medication, establishing continuity of care. However, each of these physicians is an independent practitioner, paid by two different sources and likely to have very different approaches to their patient/defendant/inmate. That two doctors have a difference of opinion on the treatment of an illness does not necessarily indicate that one of them is wrong and/or negligent.

However, if, after communicating with the detention center staff, the Longview psychiatrist believed that Gregory was having needed treatment inappropriately withheld, (s)he would contact the warden, the nurse or other liaison personnel, explain the situation, and let them handle the matter. If it were the case that the detention center psychiatrist was negligent or had malevolent intent in withholding Gregory's medication, that would be made abundantly clear to the Court via the report supplied by Longview staff. It would certainly come out at the competency hearing when the report is read indicating that Gregory has a mental disorder and is competent to stand trial only when medicated because otherwise he will be suicidal and unable to assist in his own defense.

This case highlights some difficulties

that mental health professionals have in drawing lines between treating patients versus evaluating defendants. Yet, more than issues of professional ethics, I think this case raises questions about how we as a society approach criminality and mental illness. What rights do criminals or potential criminals have? What about the rights of those with mental illness? What are our obligations to make sure those rights are protected? What is the influence of age (i.e., being under 18) and mental illness in holding individuals responsible for their actions? In Gregory's case, a public defender will advocate in the court room for his legal rights. Who will advocate for his mental health? In the past, it seemed more likely that someone like Gregory would have been taken to the local hospital and treated, rather than being charged with a crime. However, now there are so few beds in the hospitals that the fastest way into a hospital is through the jail. Therein lies the problem. As a society we have moved toward treating those with mental illness in the criminal system rather than the health care system. Will we soon move even farther by depriving these defendants of mental health care?

by Robin Templeton
Director, Forensic Psychiatry
Crownsville Hospital

Comments From a Maryland Assistant Attorney General

As an attorney with no formal training in ethics beyond the single required law school course, I claim no expertise about ethics consultation. It seems to me, however, that any process of ethical evaluation requires a firm factual grounding and a clear understanding of the context within which the problem arises.

A prison or a detention facility for pre-trial detainees is required by the

Constitution and other law to provide proper medical care for its inmates. Although inmates are not generally entitled to independent medical consultation or treatment, given the facility's legal and policy obligations to provide proper healthcare, concerns about medical treatment ought to be taken seriously, most especially when they are presented by authoritative sources.

In some prisons and detention centers, the obligation to provide inmate healthcare is met by healthcare providers who are government employees. In others, such as institutions in the Maryland Division of Correction, the care is provided by employees of a private corporation that contracts with the State. In either context, Ms. Carney's goal would seem to be to initiate appropriate and effective input into the facility's healthcare framework.

Although the case study implies that there is little doubt that Hanson is receiving inadequate care at the detention center, I have questions about whether there is a good foundation for immediate communication with that facility. For example, I wonder whether Ms. Carney has been able to perform an adequate assessment of Hanson's current care and condition. Did she learn of his current status from a meeting with him or through a telephone conversation? If she did not meet with him, on what basis was she able to assess his credibility? Does the nature of his pathology indicate that he might attempt to manipulate her because he'd rather be at Longview under her care than in a pre-trial detention facility? Was she part of his treatment team at Longview, or were her dealings with him more coincidental? Has her "special connection" with him had any impact on her ability to be objective? Even if her nursing assessment is appropriate, is it alone a sufficient basis to raise the issue with the detention center treatment staff?

To address these issues, I would suggest that the ethics committee first consult with the head of the treatment staff that provided services to Hanson

at Longview. Since part of the goal is to assert a position with regard to Hanson's current care by a detention center physician, there must be a clinically sound foundation for that position. Furthermore, since Ms. Carney's involvement was as a member of the Longview staff, and not as an independent practitioner, I believe that, in the first instance, the supervising clinician at Longview should make a determination as to whether communication with the detention center will be initiated.

An additional issue is presented by Hanson's status as a minor. The case study does not indicate the presence of a parent or guardian, but such a person's potential authority over his medical treatment must be examined, and the appropriate role, if any, of such a person must be considered.

Assuming that the Longview clinician determines there is a basis to raise the issue of Hanson's treatment, a first point of contact might be the detention center physician that coordinated Hanson's transfer to, treatment in, and return from Longview. As an initial communication, an informal follow-up inquiry by the Longview treating physician to gather more information would be appropriate. This would allow the Longview clinician to better assess Hanson's treatment and the rationale for his treatment at the detention center, and to express his or her concerns.

If after informal consultation, the Longview physician still disagrees that the detention center is treating Hanson adequately, the physician might make his or her views known at the next level in the chain of command at the detention center. In exploring any of the following steps that involve communications with other than healthcare providers, Longview must be careful to comply with the rather stringent laws regarding the disclosure of Hanson's mental health care records.

In the case of a jail or detention center, the physician might represent the highest level of review, except for administrators such as the warden or deputy warden. In such a case,

subject to the confidentiality concerns expressed above, Longview might communicate with the warden or the sheriff who is responsible for the operation of the detention center about Hanson's treatment. The reaction may vary, depending upon the administrator's perspective on the autonomy of, and confidence in, the detention center physician. Among the possibilities is that the administrator would seek an independent review of Hanson's care.

In the Maryland Division of Correction, where inmate healthcare is provided by employees of a private contractor, the Division office responsible for overseeing inmate healthcare has on staff a physician who serves as a senior medical consultant. When a complaint about the adequacy of healthcare is received, this consultant, or other appropriate staff, reviews the inmate's chart to determine whether care is adequate. If it is not adequate, steps are taken to have the contractor make adjustments to conform to the appropriate standard.

Hopefully the communication at the top of the detention center chain of command will resolve Longview's concerns. If, however, it does not, and the Longview physician believes that malpractice, and not just a difference of medical opinion, is involved, the options become more complicated and potentially contentious. For example, as the custody and care of pre-trial detainees is particularly within the authority of the committing court, the Longview physician might consult with the hospital's legal counsel to see if an application to the court for review of Hanson's treatment might be advisable. Given the impact of Hanson's mental condition on his pending criminal proceedings, the State's Attorney's office and defense counsel will necessarily be involved in such a process. If Hanson's condition warrants it, the appointment of a guardian of the person might be explored and might offer additional avenues through which the disagreement may be resolved.

In sum, the principle role of the ethics committee appears to be one of

identifying the ways in which the issue of appropriate care for Hanson can be explored and resolved.

by Alan D. Eason, J.D.
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Maryland Department of Public
Safety and Correctional Services

Letters from our Readers

Pain Management

In response to an article in the Spring 2001 issue of the *Mid-Atlantic Ethics Committee Newsletter*, "Ethics Committees and Pain Management," we received the following response:

"One item [Pain Myth #2: The risk of addiction to pain medications increases the longer one continues taking them.] does raise another ethical issue that you may or may not be aware of. The magnitude of ER visits by patients who either refuse all follow-up/chronic pain care/non-narcotic drugs or who have no documented chronic pain syndrome but use the ER as a 'drug-dealer,' is huge and growing. Here's the ethical problem: In an attempt not to under-medicate patients in pain, are we actually contributing/furthering/enabling drug addiction for other patients who don't need narcotics?"

We currently keep a large three ring binder filled with all the registered letters that have gone to patients expressing our concern that they are falling into this latter category."

Dr. Larry Romane, M.D.
Emergency Room Physician

Response from a Bioethicist/ Hospice Nurse

Dr. Romane raises an excellent question about pain management in individuals who are former or active substance abusers. It is possible that some emergency department (ED) staff are more likely than other health

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Letters From Our Readers

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care professionals (HCPs) to encounter substance-addicted individuals who are seeking pain medications. What are the HCP's obligations when (s)he suspects that addiction to pain medications is motivating the patient's request for pain management?

Clearly, some individuals do use pain medication to satisfy an addiction, or sell pain medication in order to support another substance addiction. The recent attention to the misuse of the long-acting opioid Oxycontin has drawn much attention to the latter. If a HCP is certain that an individual complaining of pain is drug-seeking merely to feed an addiction, that HCP has an obligation to address the addiction rather than provide a prescription for pain medications. The problem is that it's difficult to be certain that an individual complaining of pain is *merely* drug-seeking. Let's consider three possibilities: (1) the patient has a substance addiction and is seeking pain medication for its high rather than its analgesic effect, (2) the patient has or had a substance addiction *and* has pain for which he or she seeks relief, and (3) the individual has no substance addiction but has a physical dependence on pain medication to relieve his or her pain. For several reasons, the first possibility looms largest for most HCPs, and influences the care provided to all three types of patients. Patients who fall into #2 or #3 above likely have developed a higher opioid tolerance, which simply means that they need more of the drug to achieve the same analgesic effect. Yet, HCPs are more apt to label them as "drug-seeking" and undertreat their pain. In focus groups with HCPs, patients, and family members, Ann Martino¹ identified three principles that contribute to what she calls the "ethic of underprescribing" for pain: (1) *Just Say No: drug addiction and abuse harm individuals and society*, (2) *Grin and Bear It: pain happens*, and (3) *Avoid Risks: it ensures no harm done*. It's important for HCPs to realize that

this "ethic" predisposes them to err on the side of underprescribing for pain, even though many more individuals are undertreated for pain than are addicted to pain medications.

Ethically, HCPs strive to benefit the patient while avoiding needlessly harming the patient. If a patient has pain *and* a history of substance abuse, it is the HCPs' obligation to attempt to provide effective pain management without exacerbating the patient's addiction. Believe it or not, it is possible to do this. But, it's NOT easy! Typically, it requires consistency, commitment, trust, patience, respect, firm boundaries, and clear communication. Frankly, this cannot be accomplished in a one-time ED visit. The most the HCP in the ED can do is take an accurate history and refer the patient to a clinic or provider who has experience treating pain in former or active substance abusers. Skilled providers would then employ strategies that have the best likelihood of producing benefits for individuals with substance-abuse histories (e.g., developing a written plan of care and giving a copy to the patient, frankly discussing the treatment contract, establishing clear boundaries and consequences, asking for commitment to the plan, limiting prescription-writing to one physician, using a single pharmacy in which the pharmacist is informed, getting the patient's consent to share information with other HCPs, using medication and pain logs, employing periodic drug screens, and having regular face to face assessments). However, finding such clinics or qualified providers is no easy task, particularly with the reimbursement and regulatory barriers such providers confront.

In summary, it's important that the HCP be sure that the patient identified as "drug-seeking" isn't having actual pain relief needs dismissed. When in doubt, erring on the side of believing patients who complain of pain is more ethically sound than discounting a pain complaint, including patients with a substance-abuse history. If the patient reports abuse of drugs or there are good grounds for suspecting addiction

and the HCP can't rule out that the patient's pain is contrived, the ED physician can refer the patient to an outpatient treatment program and prescribe a limited amount of pain medication, one that is less likely to be sold or abused (e.g., drugs like Dilaudid or Oxycontin should be avoided). Narcotics Anonymous and Alcoholics Anonymous have pamphlets called, respectively, "In Times of Illness," and "The AA member— Medications & other Drugs." These address the issue of substance-addicted individuals taking pain medications, and are available online at www.markelliot.com/naillness.html. Even if the provider doubts the patient will follow up with a treatment program, referrals and contact information should be provided.

As for the ED physician's fear of being sanctioned by the state medical board or drug enforcement agency (DEA) for improper opioid prescribing, this is unlikely if the patient's pain complaints and history/physical exam are properly conducted and documented. Those who face a greater challenge than what the ED physicians confront are those HCPs who try to maintain an effective provider-patient relationship with individuals who have pain *and* an active or past substance addiction. Unfortunately, those skilled enough to do this well are rare, and don't get the respect, recognition, and reimbursement that they deserve.

For more information on pain management when addiction is an issue, see D.R. Wesson, W. Ling and D.E. Smith (1993), "Prescription of opioids for treatment of pain in patients with addictive disease," *Journal of Pain & Symptom Management*, 8(5):289-96.

Model guidelines for the use of controlled substances by the federation of state medical boards of the United States are available online at www.medsch.wisc.edu/painpolicy/domestic/model.htm.

¹ A.M. Martino (1998). "In search of a new ethic for treating patients with chronic pain: What can medical boards do?" *Journal of Law, Medicine & Ethics*, 26: 332-49.

Taking a Position

Next, are two responses to the Summer 2001 feature article, "Taking a Position on Taking a Position."

"Let me speak from 42 years of experience in local government policy making. Absolutely the most effective technique we used was to do what you did in the newsletter - we gave with great thought and clarity the two sides of the questions that came before us. Sometimes there was a middle ground, or there may have been several variations on the central theme. All positions were stated with the consequences of each position noted. We were trusted because we were thorough and accurate; and if we made a mistake or an omission, we corrected it and did so without bias.

For most of those years, I was the Director of Public Works in the community. We, of course, always gave the "technical" position for such items as building a road through a park - but we always gave the other side (or sides) including the costs and other impacts, and we were praised for not "just being engineers." Further, when the decision was made, we were wholeheartedly in favor of the outcome - even if it was not what we had hoped for. Frequently, we made presentations defending those decisions - which helped our credibility in future cases.

So, don't take a position, but do present the two (or more) sides as thoroughly as you can, and also present the consequences. I would imagine that you will become a source people will look to for advice."

Bob Goodin
Shady Grove Adventist
Hospital Ethics Committee
(Letter is his own personal opinion)

"I want to add my two cents to the debate on whether or not medical ethics organizations should take official public positions on issues. I believe that organizations such as the ASBH

and the MHECN should not take public positions on issues. Dr. Tarzian sums up reasons for not doing so quite well in her recent article in the *Mid-Atlantic Ethics Committee [Newsletter]* article. Several arguments were advanced in support of taking official public positions:

1) "Not taking a position is taking a position. Complacency in the face of injustice was an essential component of what ultimately allowed Hitler to pursue his 'Final solution' to such an extreme."

In response: Any individual who happens to belong to the ASBH or MHCEN can express their own views, or even officially express the views of other organizations to which they belong and which have official views on current issues. Keeping medical ethical organizations out of this public debate does not prevent anyone from being involved in such debate. It does protect those organizations, allowing them to continue to wrestle with the particular thorny, often delicate problems we do wrestle with, without having to sacrifice the subtleties of the discussion with the blunt attack and defense of public debate.

Furthermore, the expectation that medical ethical organizations should be involved in public debates confuses several meanings of the notion of 'ethics.' Medical ethicists have no special expertise in general notions of right and wrong; fiscal equity; distributive justice. We have training and experience in helping to unravel complex issues, which come before us exactly because right and wrong are not obvious. We are often useful in clarifying the principles involved in these complex issues, and thereby helping contending parties find common ground. Rarely is there an obvious issue before us, which simply requires taking the "moral" position.

Public debates over public issues rarely involve pure good versus pure evil. The Hitler analogy falls short, because the Hitler experience is not tolerated in our current culture. Public debate is overwhelmingly about shades of good, differing perceptions of good, and how and at what cost the good

can be attained. The tendency to Hitlerize public debate tends to weaken the valuable subtleties of medical ethical debate. Medical ethicists are skilled in the latter issues, but have no special expertise in the former.

2) "While bioethicists sit around and theorize about such esoteric topics as the dangers of human cloning or the ethics of post-mortem sperm retrieval, the majority of ethical issues and dilemmas lived by the members of society for whom bioethicists purport to advocate have more to do with inadequate access to quality health care, or the effects of racism, sexism, and other forms of prejudice."

This notion profoundly confuses the role of bioethics. I do not believe that good bioethicists purport to advocate for members of society any more than good butchers, good bakers or good candlestick makers. All persons of good conscience will stand up for the good of their society. Bioethicists as citizens will do the same. But bioethicists as bioethicists will struggle with trying to bring clarity to questions of the appropriate use of biotechnology in difficult situations.

One last reason for bioethics organizations to stay out of the political arena involves the notion of being 'user-friendly.' Within our hospital we feel it is very important that we not be perceived as the 'moral' police. We want health care providers, patients and their families to see us as a useful, capable resource when they are struggling with difficult problems. To politicize our committee, or the MHCEN, would be to create some degree of distrust in whatever groups are at odds with our position. We would inevitably lose credibility.

Perhaps the debate about 'taking a position' would be enhanced by giving up the word 'bioethics.' We could call ourselves 'philosophers of biotechnology' and, like good philosophers everywhere, pursue our love of wisdom and understanding unfettered by political pressures."

James A. Cockey, M.D.
Peninsula Regional Medical Center

Pre-Implantation Genetic Testing Cont. from page 3

hospital policies that call for providing pre-implantation genetic testing for gender selection.

For example, little time is spent teaching ethics committee members such fundamentals as the "is/ought" distinction. This distinction is the traditional philosophic maxim that posits that there is nothing in the reality of what "is" that gets one to the moral proposition of what "ought" to be. And although one can gainfully argue the truth of the fine points of this tenant, for the most part, the "is/ought" distinction is an indispensable staple of philosophic logic and argumentation. Applied to the present discussion, because most ethics committees are not sufficiently cognizant of this basic notion, rather than immediately seeing the intellectual flaw in suggestions that simply because parents wish to, and some professionals provide parents with the means to, pick their baby's gender, they conclude that somehow this fact

of life is, or should be, elevated to a moral obligation on the part of hospitals equipped with the technology.

Additionally, many in a liberal society conceptually confuse the moral obligation of a democracy to create and maintain an environment safe and just enough for individuals to pursue personal goals and to develop public policies that do not impede individuals from pursuing personal goals with the *achievement* of personal goals.

Individual and personal fulfillment is certainly pleasurable. It is not, however, the ends of a morally constructed society. Nor ought individual, personal reproductive choice be the ends of a morally constructed health care system. Achievements of personal goals are too diverse and idiosyncratic to be the ends of a morally constructed society or health care system. Rather, only when a society or community is based on those principles that allow for each individual to pursue his or her personal goals, can one say that one has a moral society or community. To achieve the goal of creating such a society or community, the relevant

body politic, whether in the macro sense of the voting citizenry of a whole society, or in the micro sense of the ethics committee and other hospital committees that set hospital policy, must focus on creating those goods that advance the whole by removing barriers across groups.

Common sense tells one immediately that there are just too many potential problems with gender selection of babies to make it a good idea for a society or community. Just because some family has five boys and would like a girl, there is nothing about having a girl in that particular family that will advance the society's or community's ability to achieve maximum opportunity for its populations. Personal preference ought not be the basis for social obligations. And if we could remember that basic tenant of ethical analysis, we could spend the precious time we have in ethics committee meetings discussing issues that really do elevate the moral climate of our hospitals.

by Evan G. DeRenzo, PhD

CALENDAR OF EVENTS

December

- 13 "Health Policy: Capitol Hill Perspective," Johns Hopkins Bloomberg School of Public Health, Speaker: Congressman Ben Cardin, Hampton House Auditorium, (near Broadway & Monument Streets), Time: 12:00 PM - 1:15 PM. Free.

February

- 7 "Research Ethics," Wilhelm S. Albrink Memorial Lecture in Bioethics, Speaker: Ruth Faden, PhD, MPH, West Virginia University Robert C. Byrd Health Sciences Center. For more information call Linda McMillen at (304) 293-7618.
- 18 "The Risk of Inheriting a Birth Defect: Reflections on Eugenics, Genetic Determinism and Public Health," Johns Hopkins Bloomberg School of Public Health, Speaker: Allen J. Wilcox, MD, PhD. Epidemiology Branch, National Institute of Environmental Health Sciences Hygiene Building, 615 Wolfe Street, Room 3030, 12:15 PM - 1:15 PM. Free.

21 “7 Things to Do with Stories” Shock Trauma Auditorium, University of Maryland Medical Center, Baltimore, MD 5:00PM Speaker: Hilda Nelson, PhD Associate Professor of Philosophy, Michigan State University and Visiting Professor, Center for the Study of Medical Ethics and Humanities, Duke University Medical College. Co-sponsored by the Medical Humanities Hour and the Masters in Applied and Professional Ethics, UMBC. For further information contact Anne O’Neil at 410-455-2214 or oneil@umbc7.edu.

22 “Starting or Strengthening a Palliative Care Team in Your Institution.” Forum, Days Inn Conference Center, Flatwoods, West Virginia. For more information call Linda McMillen at (304) 293-7618.

March

1 “Ethical Problems in Preventive Health Recommendations,” Johns Hopkins Bloomberg School of Public Health, Speaker: Heidi M. Malm, PhD, Associate Professor, Philosophy Dept., Loyola University, Chicago, Hygiene Building, 615 Wolfe Street, Room 3030, 12:15 PM - 1:15 PM. Free.

4-8 “Developing Healthcare Ethics Programs,” a five-day course sponsored by the University of Virginia Center for Bioethics, designed to facilitate or strengthen the implementation of an ethics program within healthcare organizations. Jordan Hall Conference Center, Charlottesville, Virginia. Registration \$1,500. For more information, e-mail Ann Mills at amh2r@virginia.edu or visit hsc.virginia.edu/medicine/inter-dis/bio-ethics/DHEP.htm.

21 “The Evolution of Ethical Standards in National Security Research Involving Human Subjects.” 5:00 PM. Speaker Jonathan Moreno, PhD, Director, Center for Biomedical Ethics, University of Virginia. Co-sponsored by the Medical Humanities Hour and the Masters in Applied and Professional Ethics, UMBC. For further information contact Anne O’Neil at 410-455-2214 or oneil@umbc7.edu.

April

7 “The State Of Bioethics: From Seminal Works To Contemporary Explorations.” Kennedy Institute of Ethics, Georgetown, D.C. Speakers include Tom Beauchamp, James Childress, Tristram Engelhardt, Jr., Edmund Pellegrino, Robert Veatch and LeRoy Walters. Free to members and students, \$25 registration for others, space is limited, register by March 15. For further information e-mail powell@georgetown.edu or call (202) 687-8099. You can also visit www.georgetown.edu/research/kie/.

10 “Current Controversies in Ethics, Law and Nursing,” Seventh Annual Conference of the New York University Steinhardt School of Education, Division of Nursing. For more information contact Gloria Ramsey (212) 998-5356 or e-mail gloria.ramsey@nyu.edu

12 “Just Health Care: Moral Critique, Outrage and Response.” Presented by the Center for Clinical Bioethics and the Office of the President, Georgetown University. Faculty include Dan Callahan, Andrew Jameton, Sister Carol Taylor, and Laurie Zoloth. Georgetown University Conference Center. Non-Georgetown attendee registration: \$300. Visit: clinicalbioethics.georgetown.edu/conferences/.

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