

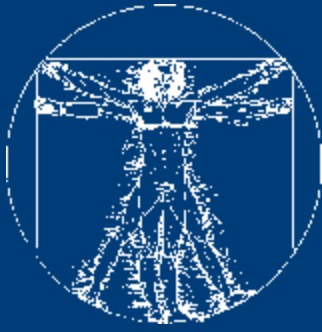
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Mid-Atlantic Ethics Committee
Newsletter, Fall 2009

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MID-ATLANTIC ETHICS COMMITTEE

NEWSLETTER

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 2009

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EMOTIONAL SUPPORT AND ETHICS CONSULTATION – WHO CARES?

Although we don't talk about it much, an important role for ethics committees (ECs) is providing emotional support to patients and family members involved in clinical ethics consultations (CECs), and to health care providers (HCPs) who request the EC's help. Since many CECs involve a patient's impending death or crisis situations where emotions run high, survivors are likely to encode long-term memories of how they were helped—or hurt. HCPs may feel like they have failed patients when a patient's life cannot be saved, and may be unaware of these feelings or how to effectively process them. There is a role here for the EC in providing needed emotional support to those involved in a CEC. Unfortunately, this aspect of CEC is often overlooked. Why?

The main reason I think ethics consultants may not prioritize the long-term emotional well-being of those involved in CEC is that this is not viewed as their main purpose. Rather, the main goal of CEC is to identify ethically justifiable options for delivering patient care to a particular patient when values are in conflict. Ethics consultants do this by fact-finding, hearing all perspectives, mediating conflict (if present), preparing an ethical analysis of the

situation, sharing knowledge, educating those involved, and summarizing the ethically justifiable courses of action. Some may view the ethics consultant's central tasks as being mostly analytical, with affective skills used mostly to support the central analytical process (e.g., to provide emotional support or to resolve conflicts among stakeholders that would otherwise thwart their ability to reason about the case).

In contrast, Edmund Howe (2008) identified the following affective goals of CEC: (1) ensuring that everyone involved in the CEC “mutually care for each others' emotional well-being,” and (2) ensuring that patients and family members involved in a CEC “feel positively toward ethics committee members.” Ways that Howe envisions an EC accomplishing this include: having an EC member meet with the patient or a family member before a formal CEC meeting to make sure they know what to expect, and to encourage them to bring supportive persons with them; having a member of the EC make contact after the CEC to see how those involved are doing; having an EC member arrange a debriefing meeting at a later time so patients/family members and HCPs involved in the CEC can provide feedback and sort through unresolved feelings; and having

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. Each issue includes a feature article, a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing, or related disciplines.

Diane E. Hoffmann, JD, MS
Editor

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REGIONAL NEWS

The Mid-Atlantic Ethics Committee
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Johns Hopkins Berman Institute of Bioethics faculty Ruth Faden, PhD, MPH, and Holly Taylor, PhD, MPH have been informing the national and international public about ethical issues related to H1N1 vaccine testing and access for children, pregnant women, and individuals in developing countries. See <http://www.bioethicsinstitute.org/web/page/917/sectionid/377/pagelevel/4/interior.asp>. The Institute is also soliciting nominees for the Jeremy Sugarman award. The award recognizes research achievement in bioethics. The award carries a cash prize and an invitation to travel to Baltimore to present the winning abstract to the faculty of The Johns Hopkins Division of General Internal Medicine Hopkins. House officers who have conducted research in bioethics and are anticipating a career in academic general internal medicine, are invited to compete. The deadline for nominations is Friday, October 2, 2009. Information is available at: http://www.hopkinsmedicine.org/gim/GIM_Res_Awards/index.html.

The *Maryland Health Care Ethics Committee Network* (MHECN) will soon be distributing an online survey to Maryland hospital risk managers, attorneys, and ICU physicians regarding medically ineffective treatment and related Maryland law. This survey will inform future efforts to determine whether changes to Maryland's law are warranted.

On October 27, MHECN is sponsoring a half-day program at the University of Maryland School of Law, in collaboration with the Center for Health & Homeland Security, on resource rationing in a pandemic. See the Calendar in this issue for more information. MHECN is also planning a Spring conference on the topic of disability and clinical ethics. Contact Anita Tarzian, or MHECN@law.umaryland.edu, for more information.

The West Virginia Network of Ethics Committees (WVNEC) has a full program of educational activities for this Fall, Winter, and Spring posted on its website, <http://www.wvneec.org>. Also, see the Calendar in this issue. Contact Cindy Jamison at cjamison@hsc.wvu.edu for more information.

The Maryland Healthcare Ethics Committee Network (MHECN) is a membership organization, established by the Law and Health Care Program at the University of Maryland School of Law. The purpose of MHECN is to facilitate and enhance ethical reflection in all aspects of decision making in health care settings by supporting and providing informational and educational resources to ethics committees serving health care institutions in the state of Maryland. The Network will achieve this goal by:

- Serving as a resource to ethics committees as they investigate ethical dilemmas within their institution and as they strive to assist their institution to act consistently with its mission statement;
- Fostering communication and information sharing among Network members;
- Providing educational programs for ethics committee members, other healthcare providers, and members of the general public on ethical issues in health care; and
- Conducting research to improve the functioning of ethics committees and ultimately the care of patients in Maryland.

everyone in a formal CEC meeting agree to care for each other's emotional well-being as a core goal of the meeting (Howe, 2008).

One criticism of an approach that calls for mutual caring of all consult participants may be that, if an ethics consultant is committed to upholding certain ethical standards, this approach might unavoidably attract negative, rather than positive, feelings from certain stakeholders. There are times, for example, when an ethics consultant cannot mediate an intractable dispute, or when the ethically justifiable options identified in the process of the ethics consultation are met with anger or resentment by one or more members involved in the consultation. In such cases, the consultant should not sacrifice ethical standards in order to pursue the goal of protecting a given stakeholder's emotional well-being or ensuring his or her positive regard.

However, I remain intrigued with the idea that we should pay more attention to valuing the emotional well-being of those involved in CECs. The benefit for patients/family members is obvious. In addition, there may be benefits for HCPs that could spill over to other areas. In most health care settings, HCPs have too few opportunities to recognize and process their emotions (Halpern, 2001). Because CECs are typically emotionally charged, there is a good chance that, among those involved in a CEC, someone's emotional but-

tons will be pushed. One might argue that focusing merely on analytical problem-solving while ignoring opportunities to expand the emotional awareness and enhance the emotional well-being of those involved in a CEC might constitute a violation of

“... Larry Schneiderman and colleagues (2006) found that one contributor to patients' or family members' dissatisfaction with CEC was that they never heard from the ethics consultation service after the consultation.”

the principle of beneficence.

Barbara Frederickson, a psychologist who studies the field of positive emotions, found that a tipping point for feeling satisfied with one's life and functioning well in it (i.e., “flourishing”) occurs when the ratio of positive to negative emotions one experiences is three to one or better—what Frederickson refers to as the “positivity ratio” (see <http://www.positivityratio.com>). The idea isn't to negate the negative emotions that are part of everyday life (such as sadness, shame, anger, frustration, etc.), but to cultivate positive emotions (such as gratitude, compassion, humor, and joy) to keep the negative emotions in perspective. Doing so produces a myriad of positive secondary benefits, including improved relationships, work performance, and satisfaction with life. Nurturing others' emotional well-being not just during but after a CEC has the potential to produce direct and indirect benefits beyond the level of the individual consultation.

I can imagine the nay-sayer who might wonder how an under-

resourced ethics consultation service would have time to be attentive to the emotional well-being of those involved in ethics consultations. But what kind of time investment are we talking about? When people are emotionally vulnerable, the smallest

actions of others—whether kind or inconsiderate—are often magnified. Therefore, small gestures can go a long way to nurture

emotional well-being. Making a family member feel at ease before a formal case consult meeting might simply involve addressing emotions at the beginning of the meeting, and reminding the family of the purpose of the ethics consultation meeting. Following up with patients/family members or HCPs after a consult could be as simple as a phone call, email, pre-scheduled e-card on the anniversary of a patient's death, or written note with contact information if consult participants wish to follow up. Indeed, Larry Schneiderman and colleagues (2006) found that one contributor to patients' or family members' dissatisfaction with CEC was that they never heard from the ethics consultation service after the consultation. As for HCPs, less is known about how they might value emotional support from an ethics consultant. Common sense and compassion would support efforts to reach out to HCPs after an emotionally difficult case.

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MARYLAND'S DOMESTIC PARTNERS LAW: WHAT IT IS, WHAT IT ISN'T

The Maryland domestic partners law is a partial response to the problem of unjust treatment of intimate partners who are not married, especially but not exclusively same-sex couples. Advocates presented heartwrenching examples of the denial of visitation opportunities in health care facilities, inadequate authority to make health care decisions, and denial of the right to make funeral arrangements for one's partner. Although people in intimate, non-marital relationships could have forestalled these problems through carefully written advance directives and testamentary wills, not everyone thinks to do so, and the legal default was ethically unsound.

With respect to same-sex couples, a straightforward solution would be legislation affording them the opportunity to marry, a right currently granted by court decision or legislation in a half-dozen states. To do so, however, would require repeal of a decades-old law effectively prohibiting same-sex marriage in Maryland, and repeal is politically infeasible. Even the more cautious approach of creating non-marital civil unions, with rights broadly equal to spouses, does not at present have the votes to overcome a filibuster in the State Senate. Consequently, advocates have worked to enact legislation granting partners certain specific rights.

In 2005, they succeeded in gaining General Assembly passage of the "Medical Decision Making Act" (Senate Bill 796), which would have created a State registry recognizing "life partners" and granted them various rights related to medical care. However, then-Governor

Ehrlich vetoed the bill, asserting without explanation that it "could lead to the erosion of the sanctity of traditional marriage."

In 2008, similar legislation, entitled "Health Care Facility Visitation and Medical Decisions – Domestic Partners" (Senate Bill 566) was successful. One key difference from 2005 is that Senate Bill 566 entails no State recognition of domestic partnerships via a registry. The other key difference is that Governor O'Malley supported the legislation.

The legislation, which became effective on July 1, 2008, permits the domestic partner of an individual receiving care in a health care facility:

- To visit one's partner in a health care facility
- To have privacy during a nursing home visit
- If both partners are nursing home residents, to share a room
- To accompany one's partner during an ambulance transport and in the emergency department
- To exercise surrogate decision-making priority under the Health Care Decisions Act equal to that of a spouse
- To have authority concerning organ donation equal to that of a spouse
- To have priority concerning disposition of a body equal to that of a spouse.

These rights are granted to "domestic partners" as defined in the law and not by colloquial usage. "Domestic partners" are adults who are not related to one another and are not married or in another do-

mestic partnership. The relationship between the two is characterized by "mutual interdependence," by which is meant that each partner is "contributing to the maintenance and support of the other," though not necessarily equally. Importantly, the gender of the partners is immaterial. Although this was rightly perceived as a gay rights bill, its benefits are not limited to same-sex couples.

The legislation describes the evidence that suffices to prove the existence of a domestic partnership. One element of proof is an affidavit (a signed statement under penalty of perjury) affirming the existence of the domestic partnership. In addition to this affidavit, people asked to prove that they are in a domestic partnership are to present two other types of documentation, such as documents reflecting joint financial liability or assets; beneficiary designations in a life insurance policy, a retirement account, or a will; a durable power of attorney; coverage under a health insurance plan; and school records or other evidence of joint responsibility for child care.

An important practical question for health care facilities is whether they are required to ask for this evidence. No, advised the Maryland Attorney General's Office in a letter written soon after the law's enactment. When someone claims to be a domestic partner, the facility is free simply to accept this assertion of partner status unless it is challenged, just as facilities do not ask routinely to see a marriage certificate when someone asserts that he or she is the patient's spouse. However, a facility likewise may adopt a

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FINE TUNING CLINICAL ETHICS CONSULTATION

The wife of a gravely ill ICU patient contacts a urologist, requesting that he perform a sperm retrieval procedure on her husband so that she can attempt to conceive a child with her husband's sperm. This troubles the attending physician, who isn't exactly sure what to do about it.

How comfortable would you be referring this physician to the hospital's ethics committee for help? You would probably want some reassurance that those responding

to the physician's request for help would be qualified. Maryland law requires hospitals to have, and nursing homes to have access to, an ethics committee (specifically, a "patient care advisory committee") to address certain disputes or uncertainties involving end-of-life decision-making. These committees provide an alternative to resolving such disputes or uncertainties through the courts. However, Maryland law does not mandate that ethics committee members—including those who perform clinical ethics consultation (CEC)—have specific qualifications.

MHECN serves to provide resources for health care ethics committee members performing such consultations. Toward this end, MHECN and Franklin Square Hospital—in collaboration with the Veterans Health Administration's (VHA's) National Center for Ethics in Health Care—jointly sponsored the day-long program, "Fine Tuning

Clinical Ethics Consultation – A Workshop for Health Care Ethics Committee Members," on Monday, June 8. This workshop focused on select aspects of CEC that influence its quality.

The VHA has been at the forefront of developing standards and resources for CEC at its hospitals. Those same resources are available

"It would be inappropriate, for example, for the ethics consultant(s) . . . to simply call the urologist and tell him he cannot perform the sperm retrieval. Instead, the ethics consultant should clarify the ethics consultation request and proceed through a defined process."

to health care facilities outside of the VHA to improve the quality of health care ethics services provided. VHA's Integrated Ethics program consists of three main areas for improving health care ethics services: ethics consultation, preventive ethics, and ethical leadership. Staff from the National Center for Ethics in Health Care, including Ellen Fox, MD, Ken Berkowitz, MD, and Barbara Chanko, RN, MBA, realized that while many ethics committee members are now knowledgeable about ethical principles and theories, they often lack skills related to the process of ethics consultation. Thus, the VHA developed several educational modules to address specific skills that were most often lacking among those providing ethics consultation services. Three of those modules were presented at the June 8 workshop.

Anita Tarzian, Ph.D., R.N., a research and ethics consultant and MHECN Program Coordinator,

facilitated the first session. Attendees learned about common misconceptions that individuals have about the role of a clinical ethics consultant, and how to correct these misconceptions while informing requestors of what they can do to address the requestor's concerns. Examples of such common misperceptions (e.g., what hospital staff erroneously think

the ethics consultant can do) include making an investigation into physician wrongdoing, or telling the health care practitioner(s) what should be done or what is legally allowed (i.e., giving legal advice). It would be inappropriate, for

example, for the ethics consultant(s) in the case described above to simply call the urologist and tell him he cannot perform the sperm retrieval. Instead, the ethics consultant should clarify the ethics consultation request and proceed through a defined process. The VHA's "CASES" approach, one such process, involves the following CEC steps:

- Clarify the consultation request;
- Assemble the relevant information;
- Synthesize the information;
- Explain the synthesis; and
- Support the consultation process

(Fox, Berkowitz, Chanko, & Powell, 2006). Detailed information about this approach and related resources are available online, at <http://www.ethics.va.gov/integratedethics/>.

Ellen Fox, M.D., Chief Officer for Ethics in Health Care at the National Center for Ethics in Healthcare at the VHA, , facilitated

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the second session. Attendees learned one approach to clarifying the values uncertainties or conflicts giving rise to an ethics consultation request. For example, values that are in conflict in the case above include respect toward the dying patient and compassion toward the grieving wife. Attendees then practiced writing values statements that frame an ethics consultation. An example using the case above would be: "Given that respect for this patient would involve not treating him merely as a means to an end, and that compassion for the wife involves supporting her in her grief over her husband's impending death, the attending physician is uncertain whether allowing the patient's sperm to be retrieved would be ethically justifiable." The ethics consultant(s) would then proceed with a process for addressing this values conflict and providing ethically acceptable recommendations to the involved stakeholders.

Diane Hoffmann, J.D., M.S., Professor of Law and Director of the Law & Health Care Program at the University of Maryland School of Law, facilitated a session in which attendees learned and practiced ways to proactively defuse conflict in a formal CEC meeting. For example, the ethics consultant should first decide if a formal meeting is the best way to proceed with the ethics consultation. In the case above, a formal meeting with the patient's wife should only be scheduled after first talking with the attending ICU

physician and urologist to determine if a meeting with all involved stakeholders in one room would be helpful. If so, goals of the meeting should be defined and relevant information should be accessed in advance. At the beginning of the meeting, the ethics consultant should review ground rules for the meeting, explain his or her role and the consultation process, have participants introduce themselves, and establish the goal(s) of the meeting. Workshop attendees reviewed, practiced, and discussed other components of an effective formal meeting—something the VHA staff have identified as an important area to improve CEC effectiveness.

Edmund Howe, J.D., M.D., University Professor of Psychiatry and Director of the Programs in Ethics at the Uniformed Services University of the Health Sciences, presented the last session of the conference on strategies for avoiding "group think," a menacing threat to ethics committee deliberations. Mutual friendship, power imbalances, and subconscious emotions provide potential catalysts for ethics committee members to fall prey to group think. For example, in the case featured above, members of the ethics committee might be led to agree with one strongly opinionated, influential physician member, who is convinced that the sperm retrieval is "illegal and unethical." In fact, neither the ICU attending nor the ethics consultant(s) have ultimate authority in this case to determine whether sperm retrieval can be done. Any recommendations

provided by an ethics committee or consultation team should take into account various perspectives and be consistent with known norms (see Strong, Gingrich & Kutteh, 2000 and Strong, 2006). Furthermore, ethics committee members involved in ethics consultations should develop the emotional insight to know when they may be vulnerable to group think decisions, and the moral courage to speak up.

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MR. M AND THE DISABILITY GULAG

William J. Peace, Ph.D., submitted this editorial in response to Rebecca Elon's article in the Spring 2009 Newsletter, "The Case of Mr. M – The Study of Dichotomies."

Many people with a disability live in nursing homes, acute care hospitals, group homes, and other "total institutions" (Goffman 1961) These people have little control over their lives and live in an institution because no other options exist.

Institutional care is a measure of last resort, one that is based on financial and not medical necessity. In 2003, Harriet

McBryde Johnson, a well-known disability rights activist, described the system that forces people with a disability into an institution as the "disability gulag." The obvious allusion to the former Soviet Union system of prison camps is as accurate as it is deadly. Fear, isolation, separation from family, loss of personal autonomy, and substandard living conditions existed in gulags and institutions that dot the American landscape. Mr. M lived in this metaphorical gulag. While Mr. M did not vanish nor was he physically abused, he had no control over his life and destiny. Mr. M's life post-disability was a modern version of an old story that dates back to the late 1860's when several states had ugly laws making it a felony for a person with an obvious disability to appear in public. The goal of these laws was to

preserve quality of life in the community, and this public policy led to the creation of institutions designed to protect society from the insane, feeble minded, and physically defective. American society failed the first people with disabilities that lived in institutions circa 1900, and Mr. M is a grim reminder that not much has changed.

I am very much like Mr. M and have no doubt our health care system fails to meet the needs of people with a disability. More than half my

For more information on disability rights, visit the Disability Rights Education & Defense Fund at <http://www.dredf.org/>. For more information on independent living centers in Maryland, visit Making Choices for Independent Living, Inc. at <http://www.mcil-md.org/index.htm>.

body is paralyzed and I fear I will end up in a similar situation. My fear is quite real and grounded in a gritty reality that life with a physical disability is difficult socially, and expensive. This fact is becoming increasingly common and problematic for paralyzed people and those professionals involved in their health care. What separates me from Mr. M and many other people with a disability is that I have an advanced education and economic independence via strong familial support. Between work and my family I can afford to be independent. I am lucky, very lucky, that I do not need to rely on government assistance, or as in Mr. M's case, Maryland Medicaid. If I did, I have no doubt that I would be like Mr. M: noncompliant, ranting, angry, rude, difficult and paranoid. All these words were used to

describe Mr. M. and reinforce an ableist bias. Ableism is used here to describe prejudicial attitudes that are imposed by social institutions on top of an existing physical or cognitive deficit. Ableism is a political paradigm that describes "a set of often contradictory stereotypes about people with disabilities that acts as a barrier to keep them from achieving their full potential as equal citizens in society" (Pelka 1997). Mr. M's post-injury life was a classic case of ableism run amuck from which there is much to learn.

Mr. M was powerless, given a defacto diagnosis of angry young man, and the author makes it clear he grossly mismanaged

his life. What did his care providers expect from Mr. M? He lived in a hospital for eight years and was "very difficult for the staff." Did anyone ponder exactly why he was embittered and malevolent? I doubt any person that lived in an institution for eight years, whose life was controlled by others, could be expected to say thank you for society's largesse or treats from the local deli. I cannot help but conclude Mr. M's death was tragic and unnecessary. As such it is an indictment on the lack of value placed on the lives of people with a disability. Whatever dreams Mr. M possessed were ground down and destroyed by an institution and society that deems people like Mr. M as too costly. This is a social—not a medical—failure. Mr. M's life is accordingly a measuring stick for

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society in which the technology exists to extend the life of people like Mr. M, but the required long term structure to ensure quality of life is grossly inadequate. Thus, no one asked the hard questions disability rights activists pose—Why does an electric wheelchair cost as much as a used car? Why are 66% of people with a disability unemployed? Why are mass transportation systems difficult or impossible to access? Why are children with disabilities sent to "special schools"? Why do hemiplegics and quadriplegics often end up in nursing homes? Why did Maryland Medicaid pay \$1,500 a day to care for Mr. M yet is adamantly opposed to community based care?

In my estimation, what separated Mr. M from others was that his physical disability was perceived to be singularly unusual, without precedent. This false assumption was compounded by the fact that a medical model of disability was accepted without question; that is, everyone assumed Mr. M's primary problem was a physical deficit. This assumption ignores the social model of disability, a construct based on the belief that disability is a social malady. This is not merely a "hip" theory, but a way of looking at life that has had a seismic impact not just on disability studies but also on the lives of people who are "disabled and proud." The medical establishment has been painfully slow to acknowledge, much less react to, the social model of disability. This is particularly unfortunate because there is a network of scholars and activists in the disability community that could have had a positive impact

on Mr. M. For example, most major cities in the United States have at least one Independent Living Center. These centers are usually non-residential, private, non-profit community based organizations designed to provide services and advocacy by and for people with a dizzying array of disabilities. These organizations provide a voice for and advocate on behalf of people like Mr. M. Even if a formal solution could not be found, an independent living center or virtually any other advocacy group for people with a disability could have helped Mr. M tap into the informal network of people that survive and thrive in their respective communities. Mr. M might have been inspired had he met other people who faced similar problems, and become more involved in securing a better future.

I do not mean to imply that an independent living center or social activism alone could have provided all the answers for Mr. M, but they could not have made the situation any worse. Indeed, I think Mr. M's death was inevitable once he was discharged from the hospital. This is an indictment on all those involved in Mr. M's care. It is particularly troubling to me that the author deeply cared about Mr. M, did her best to help him, and is haunted by his death. Many physicians do not display this sort of dedication. I do not lay blame with the author for Mr. M's death but rather on the failure of the medical establishment to forge a working relationship with disability rights activists and scholars. This lack of cooperation highlights that not only has the independent move-

ment stalled, but disability rights has not as yet resonated with the general public and those who work in the health care system. Mr. M's death was all too real and demonstrates that doctors and disability activists must learn how to work together. To date, few doctors have expressed any interest in disability rights, and disability activists are unwilling or unable to engage in open minded debate. Disability studies scholars meanwhile are more concerned with their place in academia than in the daily struggles of the people they study. The end result is people like Mr. M. who need help at multiple levels do not receive it from those directly involved and those who should be involved. Confrontation, professional and personal angst, and discord might be the inevitable consequence of such a working relationship, but may save lives. Surely, such an effort is needed and worthwhile.

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CASE PRESENTATION

One of the regular features of this 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 FROM A MARYLAND HOSPITAL*

Joe is a 17 year old who has been treated for leukemia. Joe also has schizophrenia, which is generally controlled with psychotropic medications. He has been an active decision-maker in his medical care, and his parents support his right to make his own decisions. However, at various junctures where important medical decisions need to be made, Joe has "gone missing" for up to several hours. He has always returned after these absences, explaining that he just had to get some space to "clear his mind." The oncologist consults the ethics committee with a question about future options for Joe. If the current regimen of chemotherapy does not control the disease, standard of care would include a bone marrow transplant (BMT). However, the nature of this therapy requires strict adherence

to immune-protective measures to avoid contracting infections, which can be life-threatening. This is due to the toxic effects of the pre-BMT irradiation procedures on the body's immune system. The oncology staff has wondered whether they would be able to confine Joe to the hospital at critical points in his treatment, were he to undergo BMT. That is, given his history of impulsively fleeing the hospital to "clear his mind," would confinement or restraint be ethically justifiable if Joe needed a BMT to give him the best chance of achieving a leukemia remission?

**Some details of this case were changed to mask the patient's identity.*

COMMENTS FROM A PHYSICIAN ETHICS CONSULTANT

Joe is a seventeen-year-old boy who is being treated as an adult, although he is legally still the ward of his parents. Because Joe's parents agree with his medical choices, and because Joe generally behaves in a mature fashion and is very close to the age of majority, one is tempted to treat Joe as an adult, but, in fact, he is not. If Joe's healthcare providers, and Joe's parents, are considering the possibility of confining Joe to a sequestered environment in order to protect Joe from a life-threatening infection during the 20-40 day period that his immune system is recovering from the bone marrow transplant, the question of who is actually making the medical decisions for Joe becomes very important.

It is certainly possible that the courts might ultimately get involved in Joe's care, which should be avoided if possible, it being preferable to reach an acceptable solution for all parties outside of the court system. If, towards the end of the consultative process, Joe's parents and doctors conclude that it is necessary for Joe to be confined during the period of engraftment, in order to protect him from hurting himself, such confinement would probably be legal, given that Joe's parents are acting in his best interest. However, if Joe were to contest this decision and appeal to the courts, he is justified to do so under the mature minor doctrine, based on both common law and on case law from other states. Joe would simply need to convince the court that he is capable of making an autonomous decision about his own health care. If Joe were to actually become eighteen years of age during the period of his bone marrow replacement, he could be confined for medical treatment against his wishes only if he was found by a judge to be incapacitated by his schizophrenia, and subsequently placed under guardianship.

In any event, confinement of a seventeen year old for a period of 20–40 days would be very awkward, not only for Joe but also for his parents and the facility where he is being treated. Hopefully, a more palatable solution would be discovered during the consultative process; for instance, the BMT team might be able to come up with special accommodations for Joe's period of confinement that would be more acceptable to Joe and yet decrease the chance of his fleeing the facility.

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Case Presentation

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It is really not the function of an ethics consultant to advise healthcare providers on the legality of medical care, but it is obviously useful for a consultant to have some familiarity with institutional policies, state and federal laws and major judicial decisions. One of the most valuable services that an ethics consultant can provide is to re-frame the ethical issues of a case. Joe's case is certainly loaded with ethical issues, and it might be advantageous to Joe and to Joe's family and his healthcare providers to explore some of these issues and come up with a more useful set of questions regarding Joe's care and his future. This is one way that an institutional ethics committee can enhance healthcare within an institution; that is, by refocusing ethical questions.

The other way that an ethics consultant or committee can facilitate solutions to complex healthcare problems is by enhancing communication between parties. Often what seems to be a challenging problem resolves once all decision-makers and healthcare providers share and understand the principal issues and key medical information.

From an ethical perspective, the biggest medical issue here is the schizophrenia, not the leukemia. The schizophrenia intermittently robs Joe of his autonomy to make appropriate decisions about the management of his otherwise almost certainly fatal leukemia. And so, the first medical question from the ethicist may be: is the schizophrenia being maximally managed? This question needs to be thoroughly discussed with the attending psychiatrist. Have all therapeutic options been considered? Is Joe in his best possible condition to deal with this very dangerous

medical situation? How likely is it for Joe to leave his sequestered area during the post BMT period?

Another part of the equation concerns the management of the leukemia, and the oncologist also needs to be interviewed. What are all the options for therapy, with their attendant risks and likelihood of success? Have all options short of BMT been explored? What will happen to Joe if ablative chemotherapy and bone marrow transplantation are not pursued? How life threatening would be an infection following chemotherapy? Would Joe be able to return to a sequestered environment if he leaves it for a period of time?

A third part of the ethical equation involves Joe and his parents. Both need to be interviewed in order to appreciate Joe's understanding of his leukemia therapy and his commitment to its successful outcome, as well as his parent's understanding and support of the regimen. Are there interpersonal issues within the family that need to be addressed?

Lastly, and equally important, is assessing the understanding and commitment of the hospital team who will be caring for Joe. In a case such as Joe's it would not be surprising if he remained in the hospital for 20 to 40 days while his bone marrow recovered. Most centers that provide BMT services have large and highly experienced teams of providers that have taken care of hundreds, if not thousands of patients. They have a collective wealth of experience in dealing with patients like Joe, and their input needs to be solicited and utilized. They, in conjunction with Joe's main specialist physicians, should ultimately render the final judgment

on the medical appropriateness of this treatment plan.

After gathering all of these facts, both medical and social, the consultants would meet with the principal parties, including Joe, as a group. The consultants would help them generate a list of relevant ethical questions regarding Joe's care. In fact, the group may be able to identify more than one question of importance. But, assuming that there are no other significant ethical issues to address, they may perhaps simply rephrase the original question. Instead of "Would confinement or restraint be ethically justifiable?" a more useful question might be "Given Joe's unreliability regarding his staying in seclusion throughout the period of greatly increased susceptibility to infection, would it be ethical to expose him to this dangerous regimen?"

Thinking more about this new question may point to other *therapeutically useful questions*, such as "Is it ethical to expose Joe to a highly risky procedure in an effort to save his life?" and "What can we do to facilitate Joe's cooperation?" and "If confinement is judged to be justifiable, what types of confinement would be most acceptable to Joe, his parents and the healthcare team?"

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I would like to thank Sigrid Haines, of Lerch, Early & Brewer; Chartered, for a helpful discussion of the legal implications of this case; Allen Chen, MD, for a brief discussion of the BMT process at Johns Hopkins University; and also the Ethics Committee of Shady Grove Adventist Hospital, for a general discussion of issues.

RESPONSE FROM A NURSE ATTORNEY

The use of restraints for any patient in the acute care setting involves determining if principles of medical, psychiatric, legal, ethical and patient safety have been considered and fully met in the decision making process. In this case, Joe is a seventeen year-old patient with a history of schizophrenia, who is currently being treated for leukemia. Joe's schizophrenia is generally controlled with psychotropic medications but he does engage in unique "coping" measures when stressed. One of those "coping" measures is that he "goes missing" for several hours "to clear his head." In anticipation of future treatment options, the oncology team presents the question of whether it would be ethically justifiable to confine or use restraints for Joe post bone marrow transplant (BMT).

The use of any type of physical restraints is limited by both CMS and Joint Commission standards. In Maryland, we follow the standards put forth by the CMS in the use of restraints. CMS defines physical restraints as:

Any manual method, physical or mechanical device, material, or equipment that immobilizes or reduces the ability of a patient to move his or her arms, legs, body, or head freely; or a drug or medication when it is used as a restriction to manage the patient's behavior or restrict the patient's freedom of movement and is not a standard treatment or dosage for the patient's condition (CMS, 2007).

The standard for use of restraints requires that the restraint is used to avoid or prevent harm to the patient and the use of the restraint is the least restrictive means to prevent harm. All other less restrictive measures must be tried first.

In caring for Joe, the first priority is to ensure that the medical procedure is both safe and effective. Knowing that the BMT requires strict adherence to immune protective measures to avoid life threatening infections, the use of medical restraints would be ethically and legally justified. In keeping with CMS standards, all least restrictive measures must be tried unsuccessfully before the use of restraints or confinement could be implemented. Joe's history of schizophrenia would necessitate that the use of psychotropic medications be used as well in order to avoid the physical restraints.

The team caring for Joe must incorporate into his multidisciplinary plan of care treatment measures for his schizophrenia as well as treatment of his leukemia. The plan would require the use of measures that would offer him the most chance of success in terms of compliance and control of his symptom/behaviors.

Providing him with a larger room or suite of rooms to freely walk around, thus avoiding a feeling of confinement, would benefit him. Ensuring compatibility of psychotropic medications with those of his leukemia would possibly prevent a psychotic episode. The treatment team, Joe, and Joe's parents should understand that the use of physical confinement or physical or psychotropic restraints would only be

implemented as a measure of last resort to protect Joe. This should only be done if the burden to Joe of temporarily limiting his freedom of movement is outweighed by the benefit of avoiding a life-threatening infection.

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RESPONSE FROM A PSYCHIATRIC ETHICS COMMITTEE

Joe, as a 17 year old male being treated for leukemia and schizophrenia, presents several unique ethical considerations and questions, most of them based on the issue of whether it is ethically justifiable to confine or restrain this young man to maximize his opportunity for a remission of his leukemia. Here are some of the ideas and queries our committee proffered.

One, as a minor, is there a legal issue as to whether or not this teenager has the right to make medical decisions for himself. Does a judge have to rule on his legal ability to refuse, delay or otherwise compromise his treatment? Even though Joe has not refused treatment for the leukemia, is he legally competent to understand the dangers of disappearing during the preparation for the bone marrow transplant (BMT)? Does he understand the potential

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lethality of his leukemia? Does he understand the consequences of not cooperating with every effort to ensure the success of a BMT, i.e. that he could acquire a life-threatening infection if he left the hospital while immunosuppressed?

Two, if Joe's schizophrenia is "generally controlled with psychotropic medications," does this imply that he is mostly compliant with the medications and psychiatric appointments, i.e. is he optimally being treated for his psychiatric illness? Are there any residual symptoms of schizophrenia getting in the way of Joe's cooperation with leukemia treatment protocols? Has anyone spoken with Joe to understand what he believes he is doing when he is "clearing his mind" and disappears from the hospital? Is he depressed and/or frightened about the treatments, thus resulting in his running away? Is he hearing voices that insist he leave the hospital? Is he paranoid, believing that he is being treated for something other than his leukemia?

Three, how does his stage of emotional and intellectual development play into his ability to make sound medical decisions for himself? Children and adolescents have good perception but are not good at being prospective about their future.

Four, what are the legal and ethical issues involved in forcibly restraining Joe for this treatment? Can and should sterile rooms be locked? Would restraint, passive or active, be considered cruel and unusual punishment?

Five, how soon does the BMT have to be considered if the chemotherapy is not successful? Would the patient's life be in imminent danger?

Six, would there be any effects of the BMT protocol on this patient's mental status, either physiologically or psychologically, or perhaps both? Forcing him to undergo and strictly follow the treatment protocol for the BMT might be traumatizing to him. He might thus become psychiatrically worse, making it more difficult to treat both his illnesses.

Considering these questions, our committee would make the following recommendations:

1. Obtain a complete psychiatric assessment to determine Joe's current mental status, considering his mood, the extent of his current psychotic symptoms if any, and his ability to make sound and insightful decisions about himself and his treatment. Is he competent psychiatrically?
2. Ask for a social work assessment to better understand the history of his psychiatric illness and to assess how his parents have determined historically that their son is able to make sound medical decisions about his care. Explore their motivations for letting him make his own treatment decisions related to the leukemia.
3. Obtain a psychopharmacology consultation to ascertain the possible effects of immunosuppressant drugs on the mental status of this patient.

4. Search out legal opinion as to whether this minor patient can make legal decisions such as consenting to a BMT.

5. All staff that interact with the patient, psychiatrically and medically, should meet together to discuss the ramifications of doing a BMT. All staff should be encouraged to explore together how to best serve and treat this patient. Staff on the medical side and on the psychiatric side must be able to communicate clearly and with empathy and positive regard for this young man to understand the possible consequences of treating this complex case. Working together before treatment is begun may mitigate any future disagreements and provide a template for discussion, instead of potentially dividing staff if complications arise.

6. Consider a patient navigator to help Joe and his family maneuver through the complexities of treatment, medically and psychiatrically. Or, perhaps a health care advocate outside the institution could assist the patient and/or family in understanding treatment protocols and facilitating treatment decisions.

Sheppard Pratt Ethics Committee
Mark Komrad, MD, Chair
Sheppard Pratt Health System
Towson, Maryland

***Emotional Support and Ethics
Consultation – Who Cares***

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I would like to thank Edmund (Randy) Howe, MD, JD, who wrote the lead article for the Spring, 2008 Newsletter, "How Ethics Committees May Go Wrong." A portion of that article was cut due to space limitations. It served as inspiration for this article.

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***Maryland Domestic Partners Law
Cont. from page 4***

policy requiring asserted domestic partners to provide an affidavit plus two other pieces of evidence.

Those wishing to consult the full text of the legislation will find it at this link: http://mlis.state.md.us/2008rs/chapters_noln/Ch_590_sb0566T.pdf

The Attorney General's advice letter is available at: <http://www.oag.state.md.us/Healthpol/sollins2.pdf>

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EthicShare: NEW ETHICS RESOURCE TOOL

EthicShare (www.ethicshare.org) is a new way to search for and access bioethics research materials and a space for scholars to collaborate. EthicShare content is drawn from PubMed, WorldCat, major news sources, and eventually, commission reports, dissertations, images and text from digital collections, blogs, and more. EthicShare has been designed to address the needs of interdisciplinary ethics scholars, specifically giving users the ability to organize their research materials, share them with colleagues, and discuss current topics or resources. Over 200 scholars from the fields of bioethics and other applied ethics disciplines informed the site's design. The planning and development of EthicShare was funded by the Andrew W. Mellon Foundation, with additional support from the University of Minnesota and the National Science Foundation.

CALENDAR OF EVENTS

OCTOBER

- 6** (8-4PM) Ethical Problems in Health Care: The Role of Consultation in Analyses and Resolution, Presenter Patricia O'Donnell, PhD, LICSW, Center for Ethics, Inova Health System, Inova Fair Oaks Hospital, Medical Plaza Bldg, 3700 Joseph Siewick Drive, Auditorium, Fairfax, Virginia. For more information, call Patricia O'Donnell at 703-289-7592, e-mail patricia.o'donnell@inova.org, or register at 703-750-8843.
- 8-10** Health Care Access and Allocation of Resources. 5th Annual Health Ethics Conference. Sponsored by the Center for Health Ethics and University of Missouri. The Reynolds Alumni Center and Hilton Garden Inn, Columbia, MO. For more information, call (573) 882-2738, e-mail healthethics@missouri.edu, or visit <http://som.missouri.edu/CME/Health%20Ethics/Agenda%202009.pdf>.
- 14** (12-1PM audio-conference). Ethics Consultation from A-Z. Sponsored by the West Virginia Network of Ethics Committees. For more information on registration and pricing, contact Cindy Jamison at cjamison@hsc.wvu.edu, call 1-877-209-8086, or visit www.wvethics.org.
- 15-18** Translating Bioethics and Humanities, Annual Conference of the American Society for Bioethics & Humanities, Hyatt Regency Capitol Hill, Washington, D.C. For more information, visit <http://www.asbh.org>.
- 19** (6:30-7:15 pm). Good Medicines – Bad Behaviors: The Scope of Nonmedical Use of Licit Drugs. J. David Haddox, DDS, MD. Robert C. Byrd Health Sciences Center Learning Center, Morgantown, WV. RSVP requested by October 5. Contact Cindy Jamison at 877-209-8086.
- 19** (8:00-9:15 pm). Good Practices - Good Outcomes: Optimizing Opioid Therapy and Minimizing Harms. Perry G. Fine, MD. Robert C. Byrd Health Sciences Center Learning Center, Morgantown, WV. RSVP requested by October 5. Contact Cindy Jamison at 877-209-8086.

- 23** “Meaningful Survival: How Much of a Challenge Is Electronic Health Record Adoption for Your Medical Practice?” Sponsored by the Maryland Healthcare Information and Management Systems Society (MHIMSS). Sheppard Pratt Conference Center, Towson, MD. For more information or to register, visit <http://www.mdhimss.org/>.
- 23-25** Bridging the Gaps in Pain Care, 20th Annual Meeting of the Alliance of State Pain Initiatives. Hyatt Regency San Francisco, San Francisco, CA. For more information, visit <http://www.aspi.wisc.edu/20meeting/index.htm>.
- 27** The Ethics of Pandemic-Driven Health Care Rationing. Co-sponsored by MHECN and the Center for Health and Homeland Security at the University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD. For more information, call (410) 706-4457, e-mail MHECN@law.umaryland.edu, or visit <http://www.law.umaryland.edu/mhecn>.

NOVEMBER

- 7-11** American Public Health Association Annual Meeting & Exposition. Philadelphia, PA. For more information, visit <http://www.apha.org/meetings/>.
- 10** (8-4PM) Professionalism: Actualizing Values in Clinical Practice and Organizational Base, Presenter Patricia O’Donnell, PhD, LICSW, Center for Ethics, Inova Health System, Inova Fair Oaks Hospital, Medical Plaza Bldg, 3700 Joseph Siewick Drive, Auditorium, Fairfax, Virginia. For more information, call Patricia O’Donnell at 703-289-7592, e-mail patricia.o’donnell@inova.org, or register at 703-750-8843.
- 11** (12-1PM audio-conference). Clinical and Legal Context of Ethics Consultation. Sponsored by the West Virginia Network of Ethics Committees. For more information on registration and pricing, contact Cindy Jamison at cjamison@hsc.wvu.edu, call 1-877-209-8086, or visit www.wvethics.org.
- 14-16** Navigating the Future Using the Belmont Compass. Public Responsibility in Medicine and Research (PRIM&R’s) Annual Meeting. Gaylord Opryland Resort & Convention Center, Nashville, TN. For more information, visit <http://www.primr.org>.

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