

Health Care Law

Mid-Atlantic Ethics Committee Newsletter

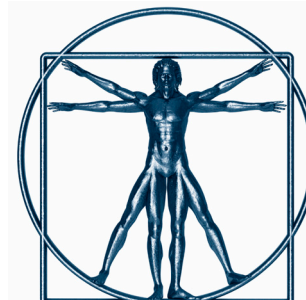
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Mid-Atlantic Ethics Committee
Newsletter, Winter 2011

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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

Winter 2011

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MEDICAL FUTILITY & MARYLAND LAW

On November 30, 2010, over 200 individuals attended the Maryland Health Care Ethics Committee Network's (MHECN's) symposium on medical futility and Maryland law at the University of Maryland, Baltimore campus. Medical futility typically refers to a type of conflict over end-of-life medical treatment, usually the type of treatment provided in a hospital's intensive care unit. In these disputes, the patient almost never has capacity (sometimes referred to as competence) to understand and make treatment decisions. So, health care decisions are made by the patient's substitute decision makers: whether patient-appointed, court-appointed, or default. The paradigmatic medical futility dispute is one in which the surrogate requests aggressive treatment interventions for an imminently dying or catastrophically chronically ill patient. However, that patient's providers consider such treatment to be medically ineffective (i.e., unable to achieve the desired goal) and/or ethically inappropriate. For example, patients over age 85 undergoing in-hospital cardiopulmonary resuscitation (CPR) have only a 6% chance of surviving to hospital discharge. Those with pre-existing co-morbidities are even less likely to survive. And many of the very few that do survive have significantly poorer neurological and functional states than they did before cardiac arrest. In short, physicians are reluctant to pound on a patient's chest, break ribs, and otherwise cause suffering and burdens, when there is no corresponding benefit to be gained.

When death is unavoidable and continued life-sustaining interventions can only make death more uncomfortable, providers frequently determine that palliative care (which focuses on the relief of pain, symptoms and stress of serious illness) is most appropriate.

Fortunately, the vast majority of medical futility disputes are resolved through good communication. When the treatment team meets with the patient's family (often on several occasions) and carefully explains the prognosis, they almost always reach consensus. Toward this end, palliative care teams have made progress at some hospitals. Still, in a small but significant subset of cases, conflict remains intractable. The conference focused primarily upon these intractable cases and whether Maryland's Health Care Decisions Act (HCDA) is effective in providing ethical resolution. The HCDA provides that life-sustaining medical treatment (such as dialysis, a ventilator, artificial nutrition and hydration) may be withheld or withdrawn from incapacitated patients only with the consent of an authorized decision maker, except in two circumstances: (1) where treatment is "medically ineffective" and/or (2) where treatment is "ethically inappropriate." But the statute defines these terms in such a narrow way that these exceptions do not apply to most futility disputes. Furthermore, even when these exceptions do apply, the statute still requires providers to continue complying with treatment decisions unless or until

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.

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Medical Futility
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the patient is transferred to another provider or facility. Since such transfer sites are almost never found, the statute effectively requires providers to comply with surrogate requests for aggressive curative treatment that they consider non-beneficial, burdensome, and even cruel.

A survey conducted by MHECN in 2010 by hospital attorneys, risk managers, and ICU physicians revealed that physicians comply with surrogate requests for medically ineffective treatment for dying patients due, in part, to fear of being sued. Furthermore, there are varying interpretations of the HCDA that create inconsistencies in end-of-life decision-making from one patient and health care provider to the next. In short, the “medically ineffective” and “ethically inappropriate” provisions in the HCDA—either due to the way the law is written or how it is interpreted and applied—do not provide an adequate mechanism for resolving intractable

medical futility disputes.

Speakers at the November 30 symposium described alternatives to Maryland’s HCDA. Charlie Sabatino, J.D., Director of the American Bar Association’s Commission on Law and Aging, reviewed state laws related to medical futility. One example is Texas’s law, which allows physicians to withhold or withdraw treatment considered “ethically inappropriate” after a period of ten days, providing that certain due process standards are met.

Lawrence Schneiderman, M.D., Professor Emeritus in the Department of Family and Preventive Medicine and Adjunct Professor in the Department of Medicine at the University of California, San Diego, described the approach taken by a consortium of California hospitals. They sought a community standard of medical futility among local hospitals. University of California San Diego (UCSD) Medical Center adopted the resulting majority

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 works to 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.

REPLACE THE SURROGATE?

A separate Maryland Health Care Decisions Act (HCDA) provision may be of some use in intractable futility disputes between a surrogate and health care providers. When a surrogate makes a treatment decision that clearly contradicts what the patient would have wanted, the provider need not comply with that decision. The HCDA provides: “Any person authorized to make health care decisions for another under this section shall base those decisions on the wishes of the patient and, if the wishes of the patient are unknown or unclear, on the patient’s best interest.” In other words, surrogates must make decisions that reflect the patient’s values, preferences, or best interests. Otherwise, they act outside the scope of their authority. Surrogates who are not faithful agents can and should be replaced. While effective and functional in some cases, surrogate replacement is hardly a complete solution to medical futility disputes. Most patients have not completed any advance care planning. Of the 34% of Marylanders who have completed advance directives, those directives are usually unavailable when needed. And even when available, those directives usually fail to speak to the patient’s current clinical circumstances. In short, there is often no evidence of patient preferences. Consequently, it is impossible to demonstrate any contradiction between those preferences and surrogate decisions. While we know, statistically, that few of us would want to live in an extremely compromised condition, particularly if cognitively unaware, providers often do not know what any particular patient is willing to live with. In such cases, there are rarely grounds to replace a surrogate requesting treatment that providers determine is inappropriate.

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community standard, which defines medical futility in their institutional policy as: “Any treatment without a realistic chance of providing an effect that the patient would ever have the capacity to appreciate as a benefit, such as merely preserving the physiologic functions of a permanently unconscious patient, or has no realistic chance of achieving the medical goal of returning the patient to a level of health that permits survival outside the acute care setting of UCSD Medical Center.” UCSD also offers a process for compassionate dispute resolution and effective comfort care. This policy defines the professional standard of practice at UCSD Medical Center and serves to inform the public and as a guideline for the courts. A hospital could also adopt a minority standard in which it defines futility

differently and/or chooses not to limit life-sustaining treatment. Accordingly, it should declare this as its professional standard of practice, formalize it as policy to inform the public as well as a guideline for the courts. Importantly, such a hospital should also accept transferred patients desiring treatments considered medically futile at other hospitals.

In the afternoon sessions at the November 30th symposium, attendees shared their ideas and suggestions for how to improve conflict resolution related to medical futility disputes. Most participants seemed to agree that revisions to the Maryland HCDA are in order. Providers need to be able to “stand up” for their patients. The tough work is designing a dispute resolution mechanism that can act with the real-time speed these cases de-

mand, yet include sufficient safeguards to ensure due process protections like neutral and unbiased adjudication. “Next steps” based on round table discussions from the November 30 symposium are currently being explored by University of Maryland School of Law professors Diane Hoffmann, J.D., M.S. and Jack Schwartz, J.D., and Maryland Assistant Attorney General Paul Ballard, J.D.

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THE PHILOSOPHER'S CORNER: DETERMINING DEATH

In the early twentieth century, defining death as the cessation or absence of life was straightforward. A person was dead when his heart stopped beating and air no longer flowed through his lungs. A clinical test of death involved either listening for a heartbeat or placing a mirror in front of a patient's mouth to see if fog appeared. Although these clinical techniques were imperfect, and occasionally resulted in premature burial, there was general agreement that death was determined by the permanent and irreversible cessation of cardiopulmonary function.

Beginning in the 1960s, however, advances in life-sustaining technologies made it possible not only to resuscitate people whose respiration and heartbeat had ceased, but also to artificially maintain their cardiopulmonary function in the absence of brain function. In recognition of that possibility, the Ad Hoc Committee of the Harvard Medical School recommended in 1968 that patients on life support, who had sustained irreversible and complete brain damage, be declared dead (Ad Hoc Comm. of Harvard Medical School to Examine the Definition of Brain Death, 1968). There were two practical implications of this recommendation. First, it allowed for the withdrawal of expensive life support from patients the Committee believed would no longer benefit; and second, it facilitated organ transplantation by increasing the supply of organs from the newly dead (Shaw & Miller, 2010).

In the aftermath of the Harvard Committee's report, the "whole brain" definition of death gained important legal grounding. The President's Commission for the Study of Ethical Problems in Medicine

and Biomedical and Behavioral Research accepted the whole brain criteria in 1981, arguing (in the face of some controversy) that because the brain is the command center for the whole organism, when it dies, so too does the organism (The President's Commission, 1981). That same year, the National Conference of Commissioners on Uniform State Laws incorporated the whole brain definition of death into the Uniform Determination of Death Act (UDDA), which defined death as either "irreversible cessation of circulatory and respiratory functions" or "irreversible cessation of all functions of the entire brain, including the brain stem" (Uniform Determination of Death Act, 2008). Today, all fifty states legally recognize both cardio-pulmonary and whole-brain definitions of death.*

Despite what appears to be nationwide agreement on the legal standards for determining death, some scholars are now expressing concern that, in practice, cardiopulmonary and whole-brain criteria are simply legal fictions to increase the number of available organs for transplantation (Shaw & Miller, 2010). In the context of cardiopulmonary criteria for death, critics argue that the working definition has changed over time from one based on the impossibility of resuscitation, to one based on the decision not to resuscitate.

In the 1990s, several hospitals began practicing controlled organ donation after circulatory determination of death (DCDD). These protocols, which continue today, involve removing life-sustaining treatment based on a patient or his proxy's wishes, and then waiting a set amount of time for the heart to stop beating before procuring organs. Critics argue that in these circumstances, death is

based on an affirmative decision not to resuscitate the individual, rather than the impossibility of cardiac resuscitation or the irreversibility of cardiopulmonary function. According to some scholars, DCDD protocols fudge the cardiopulmonary definition of death by declaring the imminently dying patient's organs available for transplant before the patient is actually dead (Evans, 2007).

Many scholars also have criticized whole brain death criteria on the ground that it, too, is misconceived and open to manipulation. These critics challenge the claim that total brain death signals the loss of an organism's integrative functioning. Relying on scientific advances, they proffer evidence that important biological functions, including gestation and some brain functions, can continue in patients considered dead under whole brain criteria (Halevy, 2001; Shewmon, 2001; Shewmon, 2009). In response to this evidence, the President's Council on Bioethics issued a white paper in 2008 that acknowledged the shortcomings of whole brain death criteria and the need to reassess it (The President's Council, 2008). In the meantime, critics argue, "the declaration of death for most patients diagnosed as dead on the basis of neurological criteria is inconsistent with the UDDA, which requires irreversible cessation of all function of the entire brain (Shaw & Miller, 2010, p. 552)."

If the critics are correct that our modern definitions of death are legal fictions to accommodate organ transplantation, then the time has come for all of us to consider whether these are legal fictions we can live with (like the notion that corporations are persons), or whether our story needs revisions.

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* Two states, New Jersey and New York, permit patients to object to neurological declarations of death based on the patient's religious views. See N.J. STAT. ANN. § 26:6A (2010).

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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. We may also change facts to protect confidentiality. Cases and comments should be sent to MHECN@law.umaryland.edu, or MHECN, Law & Health Care Program, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201.

CASE STUDY FROM A COMMUNITY HOSPITAL

A 17 year old female is admitted to the medical ward of a community hospital for malnutrition and weight loss due to anorexia nervosa. A nurse on the floor contacts the ethics committee to inquire about the ethical standard of care for such patients. The nurse was told by the patient's physician and nursing supervisor to interact minimally with the patient to avoid being "manipulated" by her, and to use restraints as necessary to ensure that the patient receives the ordered tube feedings via nasogastric tube. The nurse who requested the ethics consultation believes that it is the nurse's duty to attempt to establish a therapeutic bond with her patient whenever possible, and that actively force feeding the patient—including with the use of hand restraints—will thwart trust-building and may do more harm than good.

COMMENTS FROM A NURSE CASE MANAGER

My experience as a registered nurse leaves me with many questions of process after reading of the anorexic, manipulative patient whose nurse was ordered to restrain and force feed her. The first thought that comes to mind when reading the scenario is the lack of empathy that is being directed and instituted towards this

particular patient. It is imperative that empathy and compassion be at the forefront when deciding matters of importance and impact for others. The manner in which we approach decision making is crucial in forming a trusting caregiver patient relationship as well as developing the patients' confidence in medical science. The interpersonal relationships that we build in return create a therapeutic milieu to enhance and nurture the healing process. In cases where medical professionals are making decisions for those whose judgments may be impaired, empathy for and understanding of the condition being treated must be applied. Throughout the healthcare spectrum all decisions should be weighed carefully with this premise close to mind, in order to professionally and ethically provide the optimal care that is warranted and deserved by those entrusted to our services.

A seventeen year-old female diagnosed with anorexia nervosa being treated in a community hospital would most likely be an inappropriate setting to institute the extreme measures the doctor and nurse manager are calling for. A community hospital, in most circumstances, would not provide the expertise needed to adequately address the patient's medical, emotional, as well as psychological needs. The needs of this young woman would be better served at a specialty hospital or facility with physicians and nurses

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who are trained and experienced with the array of complicated medical as well as psychological aspects of this devastating disease. A full history of the patient, previous treatment with regard to successes and failures along with the course of progression the disease has taken is needed to best treat the underlying causes of anorexia nervosa. There are many similar aspects to a population suffering from anorexia, but each individual's disease has an identity and trigger of its own. Isolation of a patient does not help us gain insight on what the root causes may be.

The patient at this time is not legally able to make her own medical decisions because of her age but her autonomy should be valued and explored. The input of her family should also have impact and guidance on the course of her treatment. A comprehensive plan would be in the best interest of this patient, devised by all parties involved in her care. More facts on the medical condition of the patient's health status would be necessary to make a confident decision. The determination of her condition as stable or critical would be a vital piece of information. The duration of her illness would also determine how fragile her organ systems may be. There are numerous complications associated with anorexia which would make frequent observation essential in order to support the best interest of the patient. The patient's rights as a human being must be at the forefront in any aspect of care.

My concerns lie with the physician and nurse manager who appear to be overstepping their professional boundaries and scope of practice. There seems to be an air of stereotyping and "one-size-fits-all" approach that is dictating the doctor's

order set. Have the current standards of care been investigated? Have they been discussed with the patient and her family? A referral to a trained colleague specializing in or having experience in the treatment of anorexia nervosa would be the initial step a prudent practitioner would utilize in this particular patient's plan and execution of care.

I believe the player who has shown the highest ethical standards and critical thinking is the nurse who advocated for the rights of her patient. Her first appropriate action was to question the therapeutic effectiveness of the orders she received for isolating and restraining a manipulative patient. An act of conscious professionalism followed and resulted in a decision to consult the ethics committee. The culture of nursing is patient-centered, focusing on the individual needs of each patient. The nurse fulfilled her oath by questioning the orders she has received and seeking further expertise on the matter at hand.

Our duty is to find the motivation behind the young woman's behavior, not to label, isolate, violate and restrain her. These extreme measures are to be weighed carefully with prudent judgment, taking into account what is in the best interest of the young woman. The potential benefits versus the burdens of our actions must be fully examined before an individual's rights are compromised. An ethical analysis utilizing the principles of patient autonomy, medical beneficence and justice or fairness is imperative before complying with the physician's and nurse manager's orders.

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COMMENTS FROM A PEDIATRIC INTENSIVIST & PEDIATRIC CRITICAL CARE NURSE

Good medical ethics first and foremost requires good medicine, and good medicine requires adequate medical knowledge as well as good communication. Knowledge of the psychopathology of anorexia nervosa and the pathophysiology of starvation are essential to the proper treatment of this young lady. Nurses are taught to encourage patients to express their feelings and to validate them. However, the therapeutic relationship as perceived by the nurse is not necessarily the one which is appropriate in this situation. The nurse caring for the patient is suffering "moral distress" because the prescribed minimal interaction is in conflict with her perception of her duty to establish a therapeutic relationship. Anorexia nervosa is best treated in a specialized unit, usually of a psychiatric facility, with staff who have experience and expertise in treating eating disorders. However, most units of this nature will not accept patients with acute life-threatening conditions which may occur as a result of anorexia, such as electrolyte abnormalities or cardiovascular compromise. Therefore, before definitive treatment of the eating disorder can begin, including establishment of therapeutic relationships, the patient must be stabilized in an acute care medical facility. It is very likely that most medical floors in community hospitals do not have extensive experience with teenagers with eating disorders.

It is a characteristic of anorexia nervosa that patients frequently refuse to engage with treatment, in spite of danger to health and life. This is so characteristic of the disorder

that it is described in the DSM-IV, immediately following the list of criteria given above, as follows: “The individual is often brought to professional attention by family members after marked weight loss (or failure to make expected weight gains) has occurred. Individuals with Anorexia Nervosa frequently lack insight into, or have considerable denial of, the problem and may be unreliable historians. It is therefore often necessary to obtain information from parents or other outside sources to evaluate the degree of weight loss and other features of the illness” (American Psychiatric Association, 2000). Treatment is sometimes given compulsorily, although there is much variation in its use (The Royal College of Psychiatrists, 1992).

Competence to make treatment decisions is an important issue to consider when the patient is at risk and compulsory treatment is being contemplated, but there is very little research to help in the understanding of this area in anorexia nervosa. The treatment of anorexia nervosa often involves implementing a re-feeding program that may require the use of strict supervision, enforcement of prescribed dietary plans, prevention of exercising or purging, and naso-gastric or gastrostomy tube feeding. All these measures restrict freedom and can be experienced as intrusive and coercive by the patients, their families, and the clinical staff. Those involved can, for these reasons, feel concern about imposing treatment irrespective of whether they believe it to be effective (Beumont & Vandereycken, 1998).

Patients with anorexia nervosa often refuse to cooperate with treatment, in spite of danger to health and life. They often lack insight into, or have considerable denial of, the problem. They may be extremely manipulative, and may try to circumvent the

measures instituted to establish nutrition. All of this can cause moral distress in those whose task it is to implement these measures.

There is also evidence that insight may be further compromised by the malnutrition itself, and that until the patient is in a better nutritional state, there may be even less understanding and insight than there would be otherwise. In order for this nurse not to feel moral distress, she needs to understand the nature of the disease and the treatment. If the degree of malnutrition is immediately life threatening (electrolyte or cardiovascular abnormalities), then the priority of treatment is establishing effective correction, by any means possible. The nurses caring for the patient need to understand the nature of the illness and their role in caring for this young lady before psychiatric care is instituted. In order for that to happen, the nursing staff should discuss the priorities and essential elements of this patient’s care with the attending physician, psychiatrist, and others to implement (and understand) a safe and appropriate plan for this patient. This will also enable staff to explore the difficulties and distress perceived by the nursing staff, and to reassure the nursing staff that they are not providing “cruel and unusual” care.

This, of course, is not to say that the nurse caring for the patient should be abrupt or appear uncaring in any way. The necessary procedures to restore physical health to the patient so that she can begin her journey to mental health should, of course, be carried out in a sympathetic manner, and any distressing procedures should be explained and described to the patient as they are being implemented. However, the risk of the patient subverting the procedures by entangling the nurse in long

negotiations is a very real one, as patients with anorexia can be very good at manipulating their caregivers.

The issue of capacity for decision-making is a complex one in this case. Although the patient is 17 years old, and not of legal age for medical decision making (assuming she is not an emancipated minor), she is certainly old enough that her assent should be sought for most treatment decisions. However, in the face of psychiatric disease which limits insight and is associated with denial, she most likely would not have capacity to make decisions for consent or assent surrounding the treatment of the disease (regardless of age). Psychiatric input for establishment of capacity would be crucial. Again, as the nature of the disease involves denial or lack of insight, there would be no ethical obligation to obtain her assent to treatment, and indeed, good ethics as good medicine would demand nutrition with or without her assent. Just as one would not let a young child dictate their care, and a good parent would implement those things necessary to ensure the health of their child, the establishment of effective medical therapy in this case is the first priority. Similarly, we would not allow a suicidal teenager to proceed in their quest to end their life, no matter how distressing the intervention may appear to the child.

It seems to us that to optimally resolve this case, a meeting should take place including the attending physician, the psychiatric consultant, nursing leadership and the nurse who requested the ethics consultation, as well as any other nurses caring for the patient who have questions or concerns regarding her care. The plan of care, both acutely in the community hospital, as well as ultimately, in a psychiatric facility, should be

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explained in detail to the nursing staff, and they should have adequate time and opportunity to express their concerns. The physician staff and nursing leadership should likewise be afforded the opportunity to express their concerns regarding the risk of the patient subverting her care, and a mutually agreed-upon plan of care should be formulated.

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COMMENTS FROM SHEPPARD-PRATT ETHICS COMMITTEE

The patient with severe anorexia nervosa (AN) often poses a complex and daunting challenge, even in settings with significant experience in treating such individuals. The illness is often conceptualized in

a biopsychosocial frame with a multifactorial etiology. The core symptom of AN is a significant self-imposed starvation coupled with a profound, morbid fear of fatness in the context of an individual who does not or cannot acknowledge this as a problem. Complicating matters are a range of psychiatric and medical comorbidities which propel the death rate to 5% per decade from the point of diagnosis, the highest of any mental illness. Since the earliest references to the illness in the mid 1600's, and the more modern characterizations by Gull and Lasegue in the 19th century, eating disorders have been the subject of extensive research in psychiatry, clinical psychology, somatic medicine, and more recently, ethics. The question at the heart of the ethical consideration is to what extent a person should be allowed to make an autonomous decision to starve, and what constitutes an ethically-sound approach to the seriously compromised patient with AN. So began the discussion of our ethics committee stimulated by the case presentation above. We grappled with the case and its nuances, leading us to reaffirm some basic principles, and then ask some broader questions.

Pertinent Basic Principles in the Treatment of AN

1. Treatment of the severely ill patient with AN (absent extreme physical compromise and/or need for cardiac monitoring) best occurs in specialty eating disorder settings with a clinical staff with significant experience in eating disorders. Often, highly resistant patients will autonomously eat and refeed in such settings without the need for involuntary (physically forced) feeding.
2. Involuntary feeding of patients with AN should only be used

as an absolute last resort in patients with physical and cognitive deterioration and compromise, and only after significant attempts have been made to repeatedly encourage autonomous feeding. Involuntary feeding itself, via nasogastric tube or hyperalimentation through central or venous access, carries significant potential for morbidity and mortality. These risks must be carefully balanced with the risks of chronic emaciation and nutritional deprivation for the individual patient.

3. Repeated attempts should be made to engage the physically compromised, resistant patient through development of a therapeutic alliance. This often requires great patience, empathy, and a willingness to tolerate repeated rejections by the patient of the efforts of caregivers to provide help. While power struggles should be avoided, only "minimal interaction" with the patient is unlikely to facilitate alliance and is not advised. In forced treatment situations, the patient should receive ongoing explanation of the rationale for the prescribed treatment.
4. Education of all providers is essential. In the case presented, the nurse has made a sound judgment to engage the ethics committee in discussion of the case. Efforts should be pursued to educate the nurse about the need for and the reasons for the proposed treatment, as well as the risks to the patient of not providing the treatment. In a culture that overemphasizes the importance of thinness, some caregivers tend to minimize the extent of the patient's illness and

thus struggle with exerting control through paternalistic measures. Splits and disagreements within the treatment team will generally lead to a poor outcome. Input from a consultation-liaison psychiatrist might be indicated in such a situation.

Autonomy versus Paternalism

In discussion of this case, our ethics group grappled with the complex interface between the autonomous right to choose one's course in life, and the paternalistic treatment of individuals with cognitive impairment, distorted thinking, and physical deterioration. What constitutes autonomy? Is a patient's decision to starve a truly autonomous decision? Is the patient acting under the influence of a brain disorder which distorts thinking in the area of body shape, weight, and appearance? To what extent do patients have a right to pursue the symptoms of AN if that is what they "want"? What behaviors are dangerous enough to warrant paternalism and involuntary treatment? Is the pursuit of compulsive exercise, or other compensatory behaviors such as vomiting, enough and to what degree must such behaviors exist?

In our final analysis, we agreed that there are not bright-line, definitive answers to such questions. Clearly, the nuances of each clinical presentation of treatment refusal in AN will require thoughtful and careful analysis of these issues going forward.

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*The Center for Eating Disorders
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Members of
Sheppard-Pratt Ethics Committee*

COMMENTS FROM AN ATTORNEY WHO REPRESENTS CHILDREN WITH DISABILITIES

The two key legal questions presented in this case study are:

1. Is the 17 year old patient capable of providing informed consent and thus, informed refusal to the tube feedings and to the hand restraints?
2. Does the use of restraints in this situation comport with the requirements of the Centers for Medicare & Medicaid Services (CMS) and the Joint Commission?

In answer to the first question, the general rule is that individuals under the age of 18 do not have the capacity to consent to medical treatment. Their parents or legal guardians provide informed consent or informed refusal on their behalf. Thus, unless it is an emergency or other specific situation covered by Maryland's minors' consent to treatment statutes, the patient's parents must provide or withhold consent to the forced feedings (Health General Article 20-101 et seq). In order to meet informed consent legal requirements, the parents must be told the child's diagnoses, the proposed treatment, the alternatives to those treatments including the option of no treatment and the material risks of the proposed treatments and the alternatives. Even if the minor patient does not have the capacity to consent, it is good practice to also provide her with all of the information provided to her parents and to answer all of her questions about her treatment. Another important consideration for the clinicians to review is the extent to which the patient's psychiatric impairment and/or medication regimen impairs her cognition and thus, her decision making capacity.

From an ethical perspective, the clinicians should work to preserve the patient's autonomy to the greatest extent possible even if the patient does not have the legal capacity to consent. The patient is much more likely to be an active and willing participant in her treatment if she knows what is happening to her and why from a medical and psychiatric perspective. The direction from the physician and nursing supervisor to "interact minimally" with the patient, makes no legal or ethical sense. From a legal perspective, it could mean that vital information related to patient care will be missed and that the patient may be harmed as a result of this lack of information. From an ethical perspective, it greatly diminishes the patient's autonomy by diminishing her participation and voice in her care.

With respect to the second question, both CMS and the Joint Commission have requirements for the use of restraints in hospitals. Standard PC.03.05.09 in the Comprehensive Accreditation Manual for Hospitals includes the definition of restraint and seclusion and also what is not a restraint. The Joint Commission follows the CMS definition of restraint, which is, in relevant part "[a]ny 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" 42 CFR 482.13(e)(1)(i). The Case Study's description clearly includes the authorization of the use of "hand restraints." It is unclear from the case study whether the physician's ordering of restraints under these circumstances meets the requirements established by either CMS or the Commission which are specific as to who can authorize restraint, the circumstances under which restraints can be authorized, the

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Case Presentation

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length of time during which restraints may be used, and how often the patient must be reevaluated for the use of restraints. All staff members who authorize or use restraints must have specialized training in the use

of restraints. The Joint Commission's Acute Medical and Surgical (Nonpsychiatric) Care restraint standards are found in Standards PC.03.05.01 through PC.03.05.19 (effective July 1, 2009).

*Ellen A. Callegary, Esq.
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Baltimore, MD*

CALENDAR OF EVENTS

APRIL

- 11** (12-1:30 p.m.) Speaker: Jerry Menikoff, MD, JD, Director of the Office for Human Research Protections, (topic TBA). Sponsored by the Berman Institute of Bioethics Seminar Series. Armstrong Building, West Lecture Hall, Hopkins medical campus (near E. Monument St. & N. Bond St.). For more information, visit <http://www.bioethicsinstitute.org>, or contact Michelle Martin-Daniels at mmartind@jhsph.edu.
- 21** Practical Clinical Ethics: The ABC's of Palliative Care. Sponsored by Harbor Hospital. Harbor Hospital, 3001 S. Hanover St. For more information, contact Marissa Popkin at 410-350-3552.
- 25** (12-1:30 p.m.) Speaker: Jim Lavery, MSc, PhD, research scientist in the Centre for Research on Inner City Health and Centre for Global Health Research, University of Toronto (topic TBA). Sponsored by the Berman Institute of Bioethics Seminar Series. Armstrong Building, West Lecture Hall. For more information, visit <http://www.bioethicsinstitute.org>, or contact Michelle Martin-Daniels at mmartind@jhsph.edu.
- 26** (12-1:00 p.m.) Informal discussion with Tom Tomlinson, PhD, Co-Director of Bioethics, Humanities & Society and Professor of Philosophy at Michigan State University. Penn Center for Bioethics, 3401 Market Street, Room 321, Philadelphia, PA. RSVP to spaebh@mail.med.upenn.edu. Call 215-898-7136 for more information.
- 26** "Pain is a Four-Letter Word," 5th Annual Bioethics Symposium. Sponsored by the Center for Practical Bioethics. Kansas City, MO. For more information, contact Cindy Leland at cleyland@practicalbioethics.org.
- 29** Clinical Ethics Consultation – The State of the Art. Sponsored by the Bioethics Network of Ohio. Dublin, Ohio (near Columbus). For more information, visit <http://www.beno-ethics.org>.

MAY

- 9** (12-1:30 p.m.) Speaker: Susan Reverby, PhD, Marion Butler McLean Professor in the History of Ideas; Professor of Women's and Gender Studies, Wellesley College (topic TBA). Sponsored by the Berman Institute of Bioethics Seminar Series. Wolfe W3008, Hopkins medical campus. For more information, visit <http://www.bioethicsinstitute.org>, or contact Michelle Martin-Daniels at mmartind@jhsph.edu.

CALENDAR OF EVENTS *(cont'd)*

JUNE

- 2-4** Canadian Bioethics Society 22nd Annual Conference, Saint John, New Brunswick, Canada. For more information, visit <http://www.cbssaintjohn2011.org/>.
- 6-10** Intensive Bioethics Course, Sponsored by the Kennedy Institute of Ethics, Georgetown University, Washington, D.C. For more information, visit <http://www.kennedyinstitute.georgetown.edu>.
- 15-17** “Harvard Clinical Bioethics Course.” Sponsored by the Division of Medical Ethics, Harvard Medical School. Boston, MA. For more information, contact Helena Martins at Helena_martins@hms.harvard.edu.
- 20-24** Teaching Ethics Workshop, sponsored by the Center for Healthcare Ethics at Duquesne University, Pittsburgh, PA. For more information, visit <http://www.duq.edu/chce>, or e-mail tenhaveh@duq.edu.
- 29** Primer for Health Care Ethics Committee Members, sponsored by Harbor Hospital’s Ethics Committee in Partnership with the Maryland Health Care Ethics Committee Network and the Center for Ethics at Washington Hospital Center. Harbor Hospital, 3001 S. Hanover St., Baltimore, MD. For more information, visit <http://www.law.umaryland.edu/mhecn>, or contact Mary Barnes at mbarnes@law.umaryland.edu.

JULY

- 22-23** Seventh Annual Pediatric Bioethics Conference, Sponsored by Seattle Children's Hospital, Bell Harbor International Conference Center, Seattle, WA. For more information, visit <http://www.seattlechildrens.org/research/initiatives/bioethics/events/pediatric-bioethics-conference/>.
- 22-24** Penn Conference on Clinical Neuroscience & Society. Sponsored by the Penn Center for Neuroscience & Society. 3810 Walnut St., Philadelphia, PA. For more information, visit <http://neuroethics.upenn.edu/index.php/events/clinical-conference>, or e-mail conference@neuroethics.upenn.edu.

AUGUST

- 4-7** Annual Rocky Mountain Ethics Congress. Sponsored by the Center for Values and Social Policy, University of Colorado at Boulder, Boulder, CO. For more information, visit <http://www.colorado.edu/philosophy/center/rome>.

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