

Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Mid-Atlantic Ethics Committee
Newsletter, Winter 2017

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MID-ATLANTIC ETHICS COMMITTEE

NEWSLETTER

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ETHICS OF CARING FOR TRANSGENDER PERSONS

Clinicians and ethics consultants may encounter questions regarding the treatment of transgender persons in many medical contexts. Providers may feel less confident when trying to help transgender persons because they do not know enough about their foremost needs and wants.

In this piece I discuss some key considerations for providers to best help these persons. This includes understanding the right words to use, common critical needs, and the importance of advocacy.

Overriding concerns for most transgender persons are two basic desires: the ability to live authentically and to have others respond to them on the basis of who they are as opposed to how they may look.¹ These concerns underlie many of the guidelines I outline below.

I. Using the Right Words

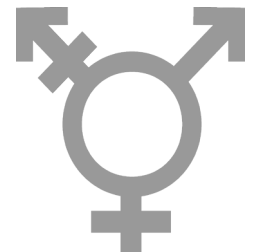
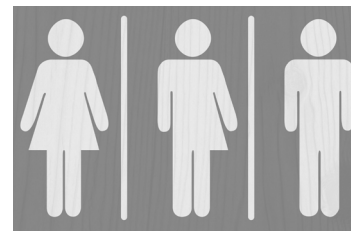
Providers should use the most respectful words to describe transgender persons—the words requested by transgender individuals

themselves. It is particularly important that providers of transgender persons see them as the gender they are, i.e., the gender that they identify with.

Finding the right words here may be difficult: “Trans is a very new term ... [It] is meant to be a new umbrella term to represent all atypical genders. ... Cis is a word used to describe the opposite of trans.”²

First, providers should not refer to transgender persons as “patients.” I have thus far intentionally used the word “person” instead of “patient.” This is because changing or wanting to change one’s gender is not a disorder. Trans people may have disorders. Being trans, however, is not a disorder. There is a distinction between transgender identity and dysphoria. Gender dysphoria is discomfort or distress caused by a discrepancy between an individual’s gender identity and the gender assigned at birth. Some trans people have gender dysphoria but not all. It is a mistake then for providers to refer to these people as “patients” since they may not have a disorder. Further, to refer to them as patients when they may not have a disorder is implicitly stigmatizing.

Some individuals may have symptoms, such as depression, that meet the criteria for a disorder. If this occurs, they should of course be diagnosed and treated. Depression or anxiety, however, may be caused by living in a body that does not reflect their vision of themselves. Thus, their feelings of depression may change after they change



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their bodily characteristics.

I recall one late adolescent male who had, according to both his parents and himself, felt depressed his entire life since early childhood. Once he had surgery to remove his breast tissue, however, he reported feeling happy for the first time, virtually overnight.

Providers should also use the right pronouns. Providers should not choose pronouns for a person, but should simply ask the person, "What pronouns would you like me to use for you?" Transgender persons want their providers to know their gender and how they want to be addressed. Providers should use the pronouns people request, even if the provider is unfamiliar with that pronoun. In addition, it is important for providers to call these individuals by the correct first name, regardless of whether that name is reflected on legal documents. Some providers believe that these persons should have to take the initiative to tell the provider if they would like their providers to call them a name that corresponds with their gender. This view, however, is not ethically optimal because it discriminates against transgender persons less willing to take this initiative. Thus, it may be better for providers not knowing how to refer to these individuals to take the initiative and ask them.

II. Respecting Transgender Persons' Individual Needs

Attempting to use the right words is just one of many ways that providers should attend to transgender persons' individual needs. Another consideration is the much publicized concern regarding bathroom use. I recall meeting years ago with a LGBT group of professionals. One of its transgender members suggested that, when feasible, there should be three bathrooms instead of two, one for men, one for women and one for people of all genders. Some places

are now creating these all-genders restrooms. This is optimal as it demonstrates the most respect for trans identities, especially trans people who are non-binary (i.e., they do not identify as either men or women). This third bathroom may, though, be suboptimal if some transgender persons are fearful of revealing their transgender identity by entering the bathroom.

Some may assert that this concern is not problematic because transgender persons should be as proud of who they are as anyone else. While true, this assertion fails to take into account important subjective differences, as well as the increased likelihood of harassment and violence against transgender people. For bathrooms, as for all considerations, providers should take into account the full range of individual experiences. Some transgender persons may not feel sufficiently confident in their status to let others know about it or may be unwilling to face the increased risk of harm. Providers should thus adjust to what these persons *individually* need rather than over-generalize based on all transgender persons.

Transgender persons' sexual orientation—which indicates the partners to whom they feel sexually attracted—likewise, lies along a spectrum. Regardless of gender identity, persons may be attracted to others of the same or the opposite gender or both, and this may change over time. The sexual feelings a person experiences may also change if they take hormones. Some trans men may experience increased aggression or agitation due to testosterone and the libido of some trans women taking estrogen may decrease.³ If trans women have bottom surgery, afterward they may have to continue to dilate their vaginas. Providers can benefit transgender persons by sharing this knowledge with the transgender persons in their care. All too often, transgender persons report knowing

more about their medical realities than the providers. Justifiably, transgender persons want their providers to inform *them* rather than the reverse.

III. Advocating for Transgender Persons

Gender identity may differ profoundly from one person to the next and may cause differences in transgender persons' bodily goals. These differences are best understood as lying along a spectrum. Thus, some persons may not want any bodily changes or may want only some of the bodily interventions available. Some may want to stop after only having taken hormones or after top, but not bottom, surgery. Some may want all possible bodily changes. Providers should understand and respect this.

Further, some may differ in what they want providers to know. Some transgender individuals may not want to disclose their transgender identity to their providers if their medical needs do not require it. Physicians may be most accustomed to expecting that patients will be open to disclosing most private aspects of themselves. For transgender persons, however, this is not necessarily the case.

In addition to having the freedom to be wholly themselves, transgender persons also may need and want to appear in a way that helps others respond to their identities, not their given physiology. Thus, some may benefit from different kinds of medical interventions that help change their appearance. For example, some trans women change their voice if they feel it is too deep and eliminate facial beard growth.

Transgender persons may need providers to act as their advocates in the pursuit of bodily interventions. This may be especially true where insurers require that prior to covering transgender procedures (e.g., hormone therapy or surgery) the treating physician refer the trans person to a therapist for evaluation and a recommendation and when providers

who are not mental health specialists, such as endocrinologists, want psychological consultation prior to prescribing medications. While this in itself may be ethically questionable in that it is highly paternalistic, it may also raise ethical conflicts for the therapist and the trans person. This is the case when, for example, an endocrinologist asks for a psychiatric or psychological consult and a mental health provider has already been seeing the trans person for therapy to support gender confirmation surgery or other related interventions. If the trans person knows that the provider they are seeing for therapy may have to make a recommendation regarding an intervention in the future, the trans person may be faced with having to choose between sharing their genuine feelings during therapy and taking the risk that this will not maximize the likelihood that the therapist will recommend what the trans person wants *and* sharing what they believe will maximize the likelihood that the therapist will approve the intervention. The therapist may be in the position of either supporting his/her client by advocating what his or her client most wants or being an objective evaluator of what the therapist believes is best for the client. If the therapist takes this latter approach, he or she is acting on his or her own view as opposed to respecting the autonomy of the trans person. This may harm the patient/therapist relationship. Accordingly, transgender persons and their therapists should discuss potential conflicts.

These evaluations may be unwarranted. They may also discriminate against trans persons in that other persons seeking treatments in comparable contexts are not required to undergo such evaluations. Therapists should then ask this question: By offering an opinion, are they morally complicit in this implicit discrimination, and if not, why not? If an evaluation is necessary for the trans person to receive the intervention he or she wants, the therapist then

could refer the evaluation to others and/or advocate for the trans person by telling the insurance company that such evaluations are discriminatory. Alternatively, transgender persons and their therapists may agree on objective criteria to decide whether to recommend surgery. They may agree in advance, for instance, on a length of time that the transgender person should live openly in the gender they seek as a trial to help determine whether this person still wants, and thus should have, the desired intervention.

In other instances, providers may also need to specifically advocate for transgender persons. For example, trans men may want contouring surgery to achieve visual traits consistent with being male, which can help avoid unwanted attention.⁴ Likewise, trans women may want breast augmentation in addition to estrogen.⁵ Providers should support these interventions. Providers, more than others, should know how exceptionally important these additional interventions may be to transgender persons.

Adults rarely change their minds after making bodily changes to affirm their identities but children may be different. The most difficult decision for providers may be when and whether to advocate for early adolescents or even children who want hormones or surgery to bring about the body changes they want. Children may want medications to prevent or delay puberty that causes certain changes. Children and adolescents who want to change their bodies may more commonly change their minds. For example, recognized experts Drescher and Pula report that, "as the World Professional Association for Transgender Health . . . notes in its latest Standards of Care, gender dysphoria in childhood does not inevitably continue into adulthood."⁶ Only 6 to 23 percent of boys and 12 to 27 percent of girls treated in gender

clinics showed a persistence of their gender dysphoria into adulthood. Gender dysphoria is different from gender identity, however, so it is unclear what clinical significance, if any, this statistic should have.

The best approach may be to give these younger persons more time to be able to better determine who they are and what they think is best for them. This may be especially true because there is still limited research on this question.⁷ Puberty-suppression regimes can provide this extra time to children and adolescents. Providers should be more cautious when treating these individuals when the interventions they want are more irreversible.

A frequently used guideline for determining when to initiate gender-affirming treatments is the length of time transgender persons have lived openly as their gender identity. The strictness with which this criterion should be applied, however, may vary depending on several circumstances such as the age of the person wanting the intervention and the degree to which this intervention can or can't be reversed. Here, however, providers should also be aware that in many contexts, it may be difficult or impossible for transgender persons to spend time living as the gender they are. Thus, this criterion may best remain open to allowing exceptions.

Finally, transgender persons may want to have and raise children. They may want medical help to do this. Here again providers may find that they can serve an important role as advocates. Unfortunately, trans persons may encounter exceptional difficulties when seeking to have children because of lingering false beliefs that LGBT persons may be less effective as parents. Providers should know that this is not the case and they should be willing to advocate accordingly for transgender persons who seek to be parents.⁸ Fortunately, this and similar false

and discriminatory beliefs are now changing. For example, one court has recently held that a non- biological, non-adoptive partner should have legal standing for both visiting and custody privileges. The court said that discriminatory views regarding same sex partners are currently "unsustainable."⁹

Providers seeking an excellent and regularly updated source of optimal standards of care may find guidance from the World Professional Association for Transgender Health website (WPATH).¹⁰ The most recent guidance, Number 7, was issued in 2011 and is used worldwide.

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ORGAN DONATION & TRANSPLANTATION: ETHICS, RELIGION, & INTERPROFESSIONAL COLLABORATION

On November 1, 2016, MHECN, in collaboration with the University of Maryland, Baltimore (UMB) Schools of Law, Medicine, Nursing, Pharmacy, and Social Work, the UMB Graduate School, and the Institute for Jewish Continuity, co-sponsored the Third Annual Interprofessional Forum on Ethics and Religion in Health Care: *Challenges in Organ Donation and Transplantation*.

Silke Niederhaus, MD, clinical assistant professor of surgery at the University of Maryland School of Medicine, provided a unique perspective on being both a transplant surgeon and an organ recipient (she received a kidney transplant in 1988). She recounted a school assignment after her kidney transplant to “Describe what your life would be like as a 12-13 year old if you had been born one century ago.” She turned in the following minimalist (and self-proclaimed “cheeky”) essay: “I would have been dead.” Indeed, lives saved by transplant medicine burgeoned after advances in post-transplant immunosuppressants reduced organ rejection rates and improved transplant outcomes. Still, demand for organs outstrips supply, raising ethical questions about methods for increasing supply and fairly allocating available organs.

A precursor to transplant ethics occurred when Scribner and colleagues invented the “Scribner shunt” in 1960, which allowed people otherwise dying from kidney failure to receive outpatient kidney dialysis. Given the limited supply of dialysis machines, a lay committee was assembled in Seattle in 1961 to decide who should get access to the twice-weekly dialysis. The seven committee members (dubbed the “God Committee” in a landmark *Life Magazine* article) grappled with the

value-laden task of selecting recipients. They notoriously considered social worth criteria and favored individuals like themselves. The Seattle committee stands in contrast to today’s transplant review committees and ethics committees, which are held accountable to more objective and transparent criteria when faced with decisions about allocating scarce resources.

Dilemmas associated with allocating kidney dialysis were averted after more dialysis centers emerged and a patient advocacy campaign led Congress to pass the End Stage Renal Disease (ESRD) Act in 1972, which provides reimbursement for kidney dialysis through a Medicare supplement. While individuals with kidney failure have an option in dialysis, 18 people waiting for a life-saving organ transplant die every day. In the 1980s, news of organs being bought and sold raised concerns about exploitation. Congress responded by passing the National Organ Transplant Act (NOTA) in 1984, which made it illegal to compensate organ donors. NOTA was amended in 1988 to establish Organ Procurement Organizations (OPOs) through a contract with the United Network for Organ Sharing (UNOS), which currently oversees 58 OPOs in the U.S. and territories in 11 regions. NOTA’s Final Rule, implemented in 2000, called for reducing the criteria for organ wait list candidates, prioritizing medical urgency, and identifying standardized objective medical criteria to assess medical urgency of those on an organ



transplant wait list.

Another milestone in transplant medicine was the passing of the Uniform Anatomical Gift Act (UAGA) in 1968, which regulates the donation of organs, tissues, and other human body parts in the U.S. Notably, to facilitate adherence to the “Dead Donor

Rule” (that a person must be dead before life-preserving organs can be procured), the UAGA established death of a person as occurring when there is irreversible cessation of *either*: (1) circulatory and respiratory functions, or (2) all functions of the entire brain, including the brain stem. This established two protocols for procuring cadaver organs: (1) after neurologic death (“brain death”) or (2) after cardiac death.

Living Legacy Foundation (LLF), Maryland’s OPO, in collaboration with staff from the University of Maryland Medical Center (UMMC), presented two simulations at the November 1 conference depicting best practices for approaching family members about organ donation after neurologic death. The first simulation involved the mother of a teenager who had been shot (played by Laurel Gaffney, MS, LLF’s Manager of Hospital Services), the physician in charge of the boy’s care (played by Nirav Shah, MD, Program Director for the Pulmonary and Critical Care Fellowship program at UMMC), a nurse transplant coordinator (Tyree Nutter, RN, MA, UMMC’s Organ and Tissue Donor Program’s in-house coordinator), an OPO family services coordinator (Heba Youssef, LLF’s Family Services Coordinator), and a

hospital chaplain (Rabbi Ruth Smith, UMMC's Lead Chaplain for organ transplant). The goal for this encounter was to explain to the mom that her son had died, based on tests confirming irreversible loss of brain function (e.g., unreceptivity/unresponsivity in absence of hypothermia or central nervous system depressants, no movement or reflexes, no breathing after ventilator removal for 10 minutes, a flat EEG, and lack of blood flow to the brain). Communicating this news with compassion, addressing the mom's strong emotions, and minimizing medical jargon, were key.

The second simulation involved the same individuals with Youssef taking the lead in explaining the option of organ donation to the mom. Separating these discussions is one way in which clinicians protect against role conflicts resulting from dual obligations to care for a dying patient and to support the organ donation process for the benefit of organ transplant recipients. One challenge that OPO staff deal with is explaining the process of organ procurement to grieving family members. The bodies of patients confirmed to be dead by neurologic criteria are "treated" with mechanical ventilation, drugs, and (if allowed by family) even cardiac resuscitation attempts (if the heart stops beating before the surgical team is ready to procure the organs) to preserve organs for donation. In donation after cardiac death, loved ones have a matter of minutes to "say goodbye" after the patient is pronounced dead before the surgical team initiates organ procurement surgery. OPO staff do all they can to minimize loved one's grief and distress by explaining procedures and their purpose in advance and respecting patients' and families' spiritual and religious beliefs and practices.

Another challenge faced by OPO staff is complying with a revision to the UAGA implemented in 2006, which directs OPOs to *notify* family

of a designated donor rather than obtain surrogate consent for organ procurement after brain death is confirmed (called "first person authorization"). Some OPOs have gone to court to compel organ procurement for a designated donor if a family objects to organ donation. In states like Ohio, where OPOs have taken such a strong stance, there has been some backlash against organ and tissue donor registration; critics argue that current organ donor registration practices (e.g., at motor vehicle administrations) do not provide valid informed consent (Iltis, 2015). Thus, OPOs and other organizations that promote organ and tissue donation are looking for ways to educate the public and encourage designated donors to talk with their loved ones about their preferences.

Anita Tarzian, PhD, RN, MHECN's Program Coordinator and member of LLF's ethics committee and Clinical Advisory Board, touched on some of the many ethical conflicts arising in transplant medicine (*see Focus on Organ Procurement Strategies on page 7*). She told the story of Marylander Daniel Canal, who in 1992, at age 13, ended his five-year wait on a transplant list after raising national media attention about his long wait in Pennsylvania for a liver and intestines transplant. The combination of media attention and shorter organ wait list times in Florida led to Daniel finally getting the transplant surgery he needed. Daniel subsequently had three surgeries to transplant a liver, intestines, pancreas, and stomach from three donors. His body rejected the intestines from the first donor. The emergent nature of the second surgery resulted in a less-than-ideal match and subsequent liver transplant failure. The final set of organs from a deceased child in Puerto Rico have worked to this day. Daniel's case embodies many of the ethical issues transplant medicine presents, including:

- Is it fair to give multiple organs to one person?

- Is it fair to re-transplant someone with organs that could go to those on the wait list awaiting an initial transplant?
- Is preserving geographic priority of cadaver organs the fairest way to allocate them?
- What is the proper role of media appeals for those on an organ transplant list?
- What constitutes informed consent (and assent) for organ transplant?
- What obligations do we owe to donor families?
- What obligations do we owe to patients after transplant?

Rabbi Shmuel Silber addressed the role of religious beliefs in decision-making related to organ donation and transplantation. Most religions place high value on saving lives and thus are generally supportive of organ donors and recipients. Regarding living organ donation, risks include physical harm to oneself, lost wages, time away from family, or disappointment if a recipient's transplant outcomes are not what was hoped. These risks must be weighed against the benefits of altruistic feelings of accomplishment, personal growth, increased self-esteem, and for some, fulfilling religious duty. However, religious persons may also succumb to feelings of guilt serving as primary motivator. Truly informed consent requires understanding the risks and benefits, and making a free choice that is consistent with one's life plans, beliefs, and values. Such decisions require thoughtful reflection/prayer and, when appropriate, consultation with a trusted member of the clergy.

One area of misunderstanding is Orthodox Jewish interpretations of when a patient is considered dead such that organs may be procured. Many observant Jews define death as the moment when cardiopulmonary function irreversibly stops, so if

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FOCUS ON ORGAN PROCUREMENT STRATEGIES



Should family be allowed to direct the donation of a loved one's organs?

In general, directing organs from a dead donor to a social group is not allowed. However, a surrogate can direct a loved one's organs to a named person, hospital, or health organization. The opposition to these requests is mostly justice-based. If the organs would otherwise be wasted, utilitarians would lean toward allowing this, but would also consider the bad press that could result, which could damage the transplant enterprise. Thus, OPO staff encourage non-directed donation before pursuing requests for directed donation.

Is it OK to advertise for an organ?

Individuals have mounted media campaigns to solicit either a living organ donation or a directed cadaveric donation. While this favors those with financial means and social connections for such campaigns, it may also increase public awareness, which could lead to increased organ donor registration. OPO staff and transplant programs must remain vigilant to avoid commercializing the process of organ donation and transplantation (Veatch & Ross, 2015).

What's wrong with buying and selling organs?

The National Organ Transplant Act (NOTA) prohibits selling organs in the U.S. In other countries, evidence of widespread exploitation and human organ trafficking has highlighted the dark side of allowing an open market for organ trade. Exploitation of the poor and marginalized individuals in China, Israel, India, Pakistan, and Bangladesh have made headlines. So far, Iran is the only country that has legalized and regulates marketed living donor organs. Payment is between \$4,000 to \$8,000. In 2010, 70% of kidneys transplanted in Iran were living unrelated, 5% related, and 25% deceased. Proponents claim this induces less familial pressure, especially on women (Veatch & Ross, 2015). Conditions in the U.S. make it highly unlikely we will ever adopt a market approach to resolve the issue of shortage of organs for transplantation.

Why not switch to an opt-out model for organ procurement after death?

An "opt-out" model for organ procurement after death involves allowing organ procurement to proceed unless one has registered beforehand to opt out. Countries closer to a communitarian or socialist culture are more apt to use this method. Veatch and Ross (2015) criticize the terminology of "presumed consent" for this model, arguing that it's inaccurate to conclude that individuals who failed to opt out have given valid informed consent. An unintended consequence could be that larger numbers than anticipated would opt out, resulting in the number of organs being procured dipping below the current rate of about 75%. Deontologists (ethicists focusing on duties regardless of outcomes) might argue that those who would want to opt out might be different from others in ways that discriminate and thwart their ability to opt out, such as applying for a driver's license or having access to the opt-out information and process steps. Deontologists might also propose that even if an opt-out procedure resulted in a net gain of organs for transplantation, it would not be worth it to procure organs from some objectors who failed to opt out. Since most cadaveric organs in the U.S. are procured by family consent at the time of death, rather than by people registering as designated donors, it's unlikely that we will take the risks described above by switching to an opt-out system.

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a patient is declared dead based on neurologic criteria but is on a ventilator and his or her heart is still beating, an Orthodox Jew may consider the person to still be alive. Clinicians who don't appreciate the distinction between a medical or legal definition of death and a religious interpretation may think such individuals don't understand what brain death means. Observant Jews may fully understand that their loved one's brain function is permanently lost and accept the "brain dead" diagnosis, but they simply may not equate the irreversible loss of brain function (a *medical* judgment) with the death of the person (a *value* judgment). How clinicians and policy makers should accommodate this religious belief deserves thoughtful reflection.

Sterling Brown from the Jordan Taylor Brown (JTB) Foundation (<http://www.jtbrownfoundation.org>) opened the morning panel session describing how the Foundation honors the legacy of its namesake, Sterling's younger brother, who became an organ donor after his untimely death from senseless gun violence. Mr. Brown described his family's experience learning that Jordan had registered as an organ and tissue donor as they were absorbing the news of his death. Jordan's organs saved seven others' lives and restored two individuals' eye sight. The JTB Foundation is working to spread a message of peace over violence, and to encourage individuals to register as organ and tissue donors. When asked how to approach someone resistant to registering as an organ donor for fear that clinicians won't work as hard to save his or her life, Mr. Brown suggests that such individuals can always decline to register and still tell their families that they wish to be an organ and tissue donor if they are ever in a position to donate.

Laurie Thompson, RN, UMMC's Paired Kidney Exchange (PKE) Coordinator, described how the PKE helps match donors with recipients. If a live donor wants to give a kidney to a friend or relative but is incompatible with the recipient, the program lists that individual as a potential donor to another recipient. In exchange, the donor's friend or relative is guaranteed a kidney from a matching donor on the list. It's critical to ensure that all parties are adequately informed and that living donors are making a free choice.

The morning conference panel culminated with Lindsey Pote, PharmD, Program Director of the PGY2 Solid Organ Transplantation Residency at The Johns Hopkins Hospital, giving an overview of the role of the transplant pharmacist in educating transplant patients about their lifelong need for immunosuppression and how post-transplant medication management must be tailored to each individual. Adherence barriers such as excessive medication costs, incompatibility with other medications, and managing side effects are routinely addressed.

The conference afternoon session included a simulated ethics committee discussion about a case involving a patient declined by a transplant program to be listed for a liver transplant due to lack of six months of alcohol sobriety. The ethics of transplant medicine involves balancing efficiency (e.g., maximizing benefit and minimizing harm) and equity (justly allocating scarce resources). From an equity perspective, some feel alcoholics in general don't have as high a claim to a liver transplant because their actions caused their liver failure. Yet, equity also demands treating like cases alike. Many would judge barring alcoholics from liver transplants but not others whose self-injurious behaviors contributed to their organ failure as unfair, particularly

since alcoholism is a chronic disease, with alcohol recidivism a symptom of that disease. From an efficiency perspective, research has shown that alcoholics with cirrhosis do well after transplant, and that requiring six months or more of sobriety prior to transplant has not been shown to produce better post-transplant outcomes (particularly if patients have strong social support and lack other predictors of poor outcomes) (Chodhary et al., 2016). While NOTA and UNOS provide guidance to transplant programs regarding organ wait listing criteria, actual listing criteria and the wait list vetting process varies among transplant programs. Usually, decisions are made by the program's transplant review committee, but occasionally, a hospital ethics committee is asked to weigh in. What makes these decisions so difficult is the reality that listing a sicker patient for an organ transplant will deprive another patient farther down the list of that organ. Veatch and Ross (2015, p. 354) acknowledge this dilemma, but conclude: "We know of no sound theoretical basis for arguing for any particular formula that would establish exactly what the proper ratio should be for considering present need and over-a-lifetime need." The work of transplant review committees, clinicians, and ethics committees in weighing these decisions is no small task.

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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 Francis King Carey School of Law, 500 W. Baltimore St., Baltimore, MD 21201.

CASE STUDY FROM A TERTIARY CARE HOSPITAL

“Brenda” is a 79 year old former Opera soprano who has been separated from her husband, “Vince,” for the past 10 years. They never divorced and remain friends. Brenda moved in with her partner, “Janice,” after separating from Vince 10 years ago. Brenda has no children. Brenda has moderate to severe Alzheimer’s disease, and has been managed thus far with support from an extensive network of friends and family, and home health assistants who visit the home 3-5 times a week. Until about three months ago, Brenda was attending an adult dementia daycare program and enjoying outings such as concerts and visits to the Botanic Gardens. Despite her memory and cognitive deficits, she seemed to enjoy daily activities. Over the past three months, her physical condition deteriorated, with a hospital admission two months ago for pneumonia.

Brenda is now admitted to the hospital again for pneumonia, thought to be caused by aspiration. A swallow study confirms she is at risk for aspiration. The medical team recommends that she avoid oral intake and that a g-tube be placed and tube feedings initiated to avoid repeat aspirations. Hospital staff determine that Brenda lacks capacity to make medical decisions. Janice tells the team that Brenda would not want the g-tube placed, as she loves to eat (particularly sweets and red wine). Janice requests that Brenda be allowed to eat and drink what she wants. She says the home caregiving team will try to minimize the risk of aspiration as best they can but that making Brenda forego oral food/nutrition is not worth the impact on her quality of life. In other words, she thinks Brenda would prefer to take the risk of aspirating by eating foods she likes, even if this hastens her death. She asks that Brenda be allowed to resume oral feedings pending discharge home, and says she will follow up with home hospice. The physician in charge is reluctant to certify that Brenda is in a terminal condition to qualify for hospice. He asks for an ethics consultation to explore whether allowing Brenda to resume oral feedings while in the hospital or at home—foregoing the g-tube—might be considered a form of elder neglect. Brenda has no advance directive.

COMMENTS FROM A SPEECH-LANGUAGE PATHOLOGIST

Ambiguity of ethical decision-making can be reduced by considering multiple perspectives and attending to facts. Toward this end, I will address the following questions:

- What is the physiology of the swallowing disorder?
- What are the proposed intervention certainties and uncertainties?
- Who is the legal health care decision maker?
- Who else should be contacted to contribute relevant information?
- What constitutes elder neglect?

- Is a hospice referral appropriate at this stage?
- Is it ethically justifiable to ask a patient or surrogate to sign a waiver to acknowledge risks of behaviors not medically recommended?

Physiology & Disease Progression

Brenda has advanced Alzheimer’s dementia (AD). Some aspects of the disease can be tempered but AD is incurable. Inherent in the disease are features leading to a gradual loss of appetite, influenced by changes in taste, loss of cognitive abilities to process what food is, and changes such as narrowing of the visual field. Adaptations may delay the inevitable

weight loss (such as creating color contrast between the plate, the table and the food to promote self-feeding as an adaption to visual changes). The swallow mechanism will be affected (dysphagia), initially with food staying in the mouth because the person does not realize what it is. This results in food falling from the front of the mouth, staying unswallowed in parts of the mouth, such as the cheeks, and at times falling back into the throat before the person is ready to swallow. This may lead to coughing as the food enters the airway (aspiration). If the cough reflex is depressed and there is no reaction, this is called “silent aspiration.”

Why do clinicians exhibit alarm



when the concept of aspiration is raised? Historically, clinicians noted that people with dysphagia got chest infections and thus blamed the poor swallow. However, research has shown us that it is not *whether* one aspirates but *what* one aspirates that is the problem. People who fall into cold rivers and nearly drown have lungs full of water but do not necessarily go on to develop chest infections. How then might a little food and drink cause a problem, and how is it that people who are not taking oral food or drink still get chest infections? To be brief, the mouth is a dirty place with many microbes, some of which are not meant to be there. But the healthy person has defenses and a lower risk of chest infections. The primary defense is to keep the microbes under control, which requires manual brushing of the teeth and gums (or dentures, or just gums!), to have a working swallow mechanism, to eat and drink in a position that lessens the chance of material sneaking into the lungs, and to have a good infection-fighting mechanism. Impairments in any of these cause problems. The factor most strongly associated with developing a chest infection is dependence on others for feeding (Langmore et al., 1998). Other factors include poor oral care (which no one wants to do), number of decayed teeth, tube feeding, comorbid

conditions, multiple medications, and smoking—but *not* dysphagia.

To continue living, a person with AD will at some point need supplementation, which typically is tube feedings. A feeding tube is a medical intervention and so it (and feedings through it) can be withheld or withdrawn just like any other treatment. In reality, the emotional connections and symbolism of eating and of providing food and drink to those we love as an act of caring results in greater psychological discomfort when considering withdrawing this treatment, even among physicians (Christakis & Asch, 1993). Thus, the treatment may be continued in the absence of benefit, keeping people alive long after a natural death might have occurred, at times causing increased burden, or hastening death in some cases.

Evidence shows that feeding tube use in dementia does not ameliorate the problems historically presumed, such as poor nutritional status, skin breakdown, and slowed wound healing (Teno et al., 2012). There are downsides to tube feedings: increased risk of reflux from the tube feed, leading to aspiration of stomach contents, leading to pneumonitis (Marik, 2001). Infection at the feeding tube's entry site is more likely to occur (Blomberg, Lagergren, Martin, Mattsson, & Lagergren,

2012). Discomfort and associated behaviors such as pulling at the tube and resulting combative actions may result in the use of chemical or physical restraints. Thus, the potential use of a feeding tube requires careful consideration of the disease path, the costs, benefits, and possible harms. Appropriate professionals should be consulted, such as a speech-language pathologist who can provide advice such as how to maintain oral health and minimize the risk of lung infections (e.g., positioning Brenda upright when she is eating and drinking, not feeding her when she is drowsy, letting her choose finger foods, and making nutritious AND palatable items easily available to her to graze on).

Who is the Legal Decision Maker?

From the information we have, it sounds like Brenda and Janice did at least have “The Conversation” (see <http://theconversationproject.org/>), but Brenda’s wishes were never formally documented, such as in an advance directive appointing Janice as Brenda’s health care agent (HCA). Maryland’s Health Care Decision’s Act (HCDA) recognizes the “patient’s spouse or domestic partner” as the authorized decision-maker for patients lacking decision-making capacity who have no appointed HCA or guardian and are considered to be in a terminal or end-stage condition. “Terminal” is defined as an “incurable condition caused by injury, disease, or illness which, to a reasonable degree of medical certainty, makes death imminent and from which, despite the application of life-sustaining procedures, there can be no recovery” (HG §§5-601(u)). “Imminent” is not defined. “End-stage condition” is defined as “an advanced, progressive, irreversible condition caused by injury, disease, or illness that has caused severe and permanent deterioration indicated by incompetency and complete physical dependency, and for which,

to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective” (HG §§5-601(j)). It’s unclear whether Brenda meets criteria for either.

Since Brenda separated from Vince a decade ago but never divorced, it’s unclear whether Vince’s legal status as Brenda’s husband trumps Janice’s status as domestic partner, unless Vince is unwilling to serve as surrogate, or Brenda retains the cognitive capacity to appoint Janice as her HCA. That Brenda and Vince have remained friends may bode well for cooperative decision-making between Vince and Janice. Whether Vince has a legal claim in decision-making is a secondary concern to whether Brenda, if she could tell us, would value or dismiss his input. Even when people are divorced they sometimes remain close and value each other’s advice. As with other scenarios where the patient cannot speak for herself, we try to gather information from all sources to build a picture of what the person might have wanted. If uncertainty remains regarding Brenda’s wishes, her extended network of friends and family, and her primary care provider may also provide insight.

Appropriate Hospice Referral or Elder Neglect?

Any person of sound mind can refuse medical interventions. This becomes more difficult when someone else is making a decision to refuse an intervention (e.g., tube feedings) and consent to a plan of care that prioritizes quality of life over life prolongation (e.g., hospice and pleasure feedings). If Brenda is considered to have a terminal or end-stage condition, then it is acceptable to withhold artificial nutrition/hydration. If she is not considered to be in either condition, then decision-making may require more discussion, particularly absent an advance directive. The physician

raises the serious issue of elder neglect. The ethics consultant should acknowledge that the physician is thinking broadly about consequences, perhaps framing the lack of nutrition and possible increased pneumonia risk with oral feedings as the primary considerations. The physician may feel that allowing Brenda to forego tube feedings and to eat or drink by mouth represents a professional breach of ethics. Why? Until very recently the received wisdom was that physicians must maintain life. But equally we might consider whether an unwanted medical intervention with the possible negative consequences outlined above would be a form of physical (and psychological) abuse. The medical team should focus on what is the standard of care for this *particular* patient in her *particular* condition.

Whether a patient is considered to be hospice eligible is a matter of professional judgment. The designation as “terminal” for hospice differs from the definition in the HCDA—generally, a patient should have a life expectancy of six months or less. Physicians who do not routinely certify patients for hospice may be unfamiliar with the criteria used to designate a patient as terminally ill. There is often a fear from physicians that: a) if they certify a patient for hospice care and the patient lives beyond six months, the clinician will be penalized, and/or b) the patient or family might perceive it as the medical team giving up on them. In most cases, a discussion with the hospice medical director or palliative care colleagues will clear up any ambiguity, and the earlier the better (American Academy of Hospice and Palliative Medicine, 2017).

Pleasure Feeding & Waivers

Allowing Brenda to eat or drink by mouth for pleasure despite her swallowing impairments understandably makes some

clinicians fearful of doing more harm than good. This issue often comes up in the long-term care environment, where patients or surrogates are sometimes asked to sign “waivers” (see *Alternative Treatment Consents on page 12*) releasing the facility from liability if they choose to engage in a behavior contrary to clinical recommendations. Is this ethically justified?

According to the Centers for Medicare and Medicaid Services (2016), patients’ rights (and those of their health care decision-makers where decisional capacity is an issue) must be respected in their care plan—they can consent to and refuse treatment, without fear of retribution, coercion or cessation of general care. It’s stated:

“This provision addresses assisted nutrition and hydration, and, like all treatments, residents have the right to accept or refuse. Accepting a resident’s refusal, or deferring to their documented preferences, does not absolve a facility of its responsibilities to provide adequate nutrition or permit the facility not to meet a resident’s nutritional needs. It does recognize that a competent resident has the right to make choices about assisted nutrition and hydration and that there are circumstances where failure to maintain acceptable parameters of nutritional status are not a reflection of failure(s) of care” (Centers for Medicare & Medicaid Services, 2016, p. 68849).

This means that if a patient chooses an approach different to that advised by the facility, even if the patient cannot maintain her nutritional status or has increased risk of lung infections from oral intake, then such outcomes will not be considered a fault of the facility (presuming the decision is informed and efforts are made to minimize risks).

Cont. on page 12

~~WAIVERS~~ ALTERNATIVE TREATMENT CONSENTS

Medicare and Medicaid regulations affirm an individual's right to refuse medical recommendations, even if this exposes the individual to harm. The Centers for Medicare and Medicaid Services (CMS) provides guidance to health care facilities (such as nursing homes) regarding how to address such refusals. Facility administrators and staff may fear being blamed and sanctioned if patients or residents under their care choose to disregard medical advice and experience harm. One solution implemented by some facilities is to have the resident or surrogate sign a waiver document in which they absolve the facility from liability. This is not recommended. Instead, CMS encourages facilities to ensure that the following duties have been met when faced with refusal of medical recommendations (CMS, 2016):

- Assess the resident's decision-making capacity and involve the health care agent or legal representative if capacity is determined to be lacking;
- Determine and document what the resident is refusing;
- Assess the reasons for the refusal;
- Advise the resident about the consequences of refusal;
- Offer pertinent alternative treatments; and
- Continue to provide all other appropriate services.

Lawyers Kelly MacDonald and Michael Seale provide examples of "Alternative Treatment Consents," which allow a facility to document their efforts to honor a patient's or resident's choice while meeting CMS' regulations. Their list of "Do's and Don'ts When Developing Alternative Treatment Consents," and examples, is available at https://www.healthlawyers.org/Events/Programs/Materials/Documents/LTC15/ee_mcdonald_seale.pdf.

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Case Presentation

Cont. from page 11

Crucial in this situation is that the *dialogue of discussion* has been carefully documented. That is, a clear record should be kept of all discussions documenting the information given to Vince and Janice and their responses, including verbatim quotes to demonstrate their understanding. This is what the courts will require if a case is ever brought forth. Any signed "waiver" document without the aforementioned documentation of discussions is at best useless in the eyes of a court, and at worst, may be considered a form of coercion—which is also clearly addressed in the Federal Register document (Centers for Medicare & Medicaid Services, 2016).

What Should be Done?

Discussions about end-of-life preferences, including decisions about feeding tubes, should happen more routinely for all people, but particularly for persons with AD (and much earlier in the disease process). These discussions need to be documented in the form of HCA appointments, living wills, and summaries in the medical record. Absent that, the best the team can do in this case is to identify the stage of Brenda's disease (i.e., whether she is considered "terminal" and hospice-eligible), clarify her wishes, reflect these in appropriate discharge orders on the Maryland Medical Orders for Life-Sustaining Treatment (MOLST) form, and if appropriate, work with hospice to arrange for home support.

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Disease Control defines neglect as: “failure by a caregiver or other responsible person to protect an elder from harm, or the failure to meet needs for essential medical care, nutrition, hydration, hygiene, clothing, basic activities of daily living or shelter, which results in a serious risk of compromised health and safety” (<https://www.cdc.gov/violenceprevention/elderabuse/definitions.html>).

When examining whether or not placing a feeding tube may be a form of elder neglect, one must examine first whether its placement would be clinically and ethically justified. Feeding tubes are used to provide or supplement nutrition when a patient is incapable of taking (sufficient) food orally, like Brenda. Although they may be used to minimize aspiration of stomach contents, this may still occur with tube feedings. They may be contraindicated in the face of terminal illness, when a patient is physiologically unable to tolerate the placement of the tube, when the patient would be unable to assimilate the nutrition provided by it, or when the patient is unable to tolerate the tube itself and intentionally or unintentionally pulls it out.

Before addressing the question of neglect, Brenda's decision maker and her physician have to decide whether the placement of a feeding tube is ethically justified. Brenda did not complete an advance directive, so there is no clear evidence of her wishes about tube feedings. There is also no evidence that placing her on tube feedings will prolong her life or improve her quality of life. Brenda is still able to take food by mouth, although it may not be sufficient to sustain her. There is evidence she is aspirating and she has now been hospitalized twice for aspiration. Even if steps are taken to minimize the chance of aspiration, it is likely that she will continue to aspirate. Janice notes that Brenda would not want a feeding tube because

she continues to enjoy eating and drinking. Janice believes Brenda's quality of life will be significantly diminished if she is unable to eat or drink. Even if it was decided that a feeding tube would provide needed nutrition/hydration, it seems unnecessary to restrict Brenda from taking food and drink she enjoys. There is a risk of aspiration present in both circumstances. Further, withholding things that enhance her quality of life, given her presumed inability to understand the risk they pose for her, could be seen as harmful to Brenda, as she may not understand why she is not allowed or offered food and drink. Though continuing to eat and drink may constitute a safety risk for Brenda, her legal decision maker can discern that this risk is acceptable given the benefit it provides. The physician and team are responsible for educating the decision maker and caregivers on the risks and ways of minimizing the risks to Brenda, with or without the feeding tube.

With regard to the question of neglect, this requires not providing for a basic need. What one needs is dependent on circumstance. Brenda suffers from a chronic, progressive, long term illness that will bring about her death, possibly within the next six to twelve months. What care is appropriate for her is discerned by her physician and legal decision maker in light of her “big picture.” As the burden of the feeding tube may outweigh its benefits, one can argue that for Brenda, the tube may not be appropriate. Though neglect does not require intention, it is clear here that if the feeding tube is not placed, the intention is not to hasten or cause Brenda's death, but rather, to avoid the physiologic and possible emotional burdens that providing tube feedings may cause.

Brenda's physician is “reluctant” to certify that Brenda is in a terminal condition to qualify for hospice. This

COMMENTS FROM A HOSPITAL ETHICS CONSULTANT

When one receives an Ethics Consultation, the question originally asked may or may not fully capture the matter at hand. Brenda's physician has asked whether forgoing the g-tube might be considered a form of elder neglect. The Centers for

is not uncommon. Physicians often hesitate to make this determination for a multitude of reasons. Ethics consultants can ask the “surprise” question: “Would you be surprised if your patient were to die in the next 6 months?” This, coupled with the explicit criteria provided by CMS for Hospice admission for patients with dementia, can be useful to physicians in making this assessment. It is not the case, however, that a patient must meet the criteria for Hospice eligibility to decline life sustaining treatment. If it were, then there would be no place for informed consent and surrogate decision makers, as CMS would take on the role of surrogate and prolong all life sustaining treatment until Hospice eligibility. Even if Brenda does not have a prognosis that currently meets Hospice eligibility criteria, the extent to which life sustaining treatment is going to be pursued is important to explore. Regardless of whether or not a feeding tube is placed, conversation must be had about under what conditions Brenda will return to the hospital. If she aspirates and gets aspiration pneumonia or suffers other complications, what treatments are appropriate for Brenda? It may be decided that treatment with antibiotics would be acceptable if they provide more good than harm, but that the harms of intubation for (pending) respiratory failure would outweigh any good, justifying withholding intubation and mechanical ventilation. Whether treatment refusals by a surrogate are considered appropriate or inappropriate requires consideration of Brenda’s prognosis, known preferences, and the medical standard of care.

Under Maryland law, if Brenda is considered “terminal” as defined in the Health Care Decisions Act, her spouse or domestic partner would be her legal decision-maker. The legislature did not anticipate that someone would have both at the same time so legally it might be an issue as to who can speak for Brenda. Regardless of who fills this role legally, her surrogate should make decisions using substituted judgment, deciding as Brenda would, taking into consideration her current illness, her values, her quality of life, and the benefits and burdens a particular treatment would provide. It may be prudent to engage both Vince and Janice in Brenda’s decision making. Even if Vince is the legally authorized decision maker, it is likely that Brenda would trust Janice to speak on her behalf, given their relationship. Even if we do not know that Brenda would have chosen Janice as her health care agent, if Vince believes that she would have valued speaking with Janice about this decision, she (and anyone else she would have engaged) should be included in Vince’s discernment. Vince may choose not to act as Brenda’s surrogate decision maker, given Brenda and Janice’s relationship, even though he remains legally married to Brenda. If Vince remains as decision maker, and he and Janice disagree on Brenda’s plan of care, the Ethics Consultant could assist in an exploration of Brenda’s values, what now enhances her quality of life, and whether a feeding tube (or other life-prolonging interventions) would benefit her. The consultant could also assist in identifying any gaps in understanding

the benefits and burdens of a feeding tube, the locus of any disagreement between Vince and Janice, and assist in ensuring that Brenda remains the focus of the decision at hand. If the disagreement remains, Janice could petition the court for guardianship of Brenda, but this is a lengthy process and a decision would likely have to be made on a more expedient timeline. While Brenda is certainly a vulnerable person deserving of care and protection, it seems from the case that she is surrounded by persons who have her best interests in mind. In fact, she is likely receiving more direct caregiver interaction than she would in a nursing home, and much of the care is being provided by her friends, those who knew her before her cognitive and physical decline. This bodes well for patient-centered decision-making that yields compassionate, positive outcomes.

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CALENDAR OF EVENTS

MARCH

- 2-4** Conflict Resolution and Clinical-Setting Mediation for Healthcare, sponsored by the Center for Conflict Resolution in Healthcare LLC, Memphis, TN. Visit: <http://www.healthcare-mediation.net/trainings.html>.
- 22 (1-2PM)** The Choice to Become a Research Subject: A First Person Perspective, Webinar Discussion led by Rebecca Dresser, JD, Washington University in St. Louis, available at [msubioethics.clickwebinar.com/brownbag](http://www.bioethics.msu.edu/brownbag-webinar/2016-2017-series). Visit: <http://www.bioethics.msu.edu/brownbag-webinar/2016-2017-series>.
- 23-24** Fourth National Nursing Ethics Conference, Los Angeles, CA. Visit: <http://ethicsofcaring.org/registration/>.
- 24-25** Clinical Ethics Bootcamp, sponsored by Children's Minnesota, Minneapolis, MN. Contact: Nneka.Sederstrom@ChildrensMN.Org.
- 24-26** Re-enchanting Medicine: Conference on Medicine and Religion, JW Marriott Galleria, Houston, TX. Visit: <http://www.medicineandreligion.com/>.
- 27 (1-2PM)** Webinar with James Mumford, PhD: Reproduction in an Age of Mechanical Reproduction, sponsored by Children's Mercy Bioethics Center. Visit: <https://cmhbioethics.webex.com/>.

APRIL

- 3 (1-2PM)** Webinar with Larry Churchill, PhD, "What would you do if this were your child, Doc?" sponsored by Children's Mercy Bioethics Center. Visit: <https://cmhbioethics.webex.com/>.
- 6** Action for Health Equity, sponsored by the University of Maryland Schools of Medicine and Public Health, Adele H. Stamp Student Union, University of Maryland College Park.
- 7-8** Second Annual Conference on Reproductive Ethics: New Ideas and Innovations, Sponsored by Alden March Bioethics Institute, Albany Medical College, Albany, NY. Visit: <http://www.amc.edu/academic/bioethics/reproductiveethicsconference.cfm>.
- 16 (1-2PM)** Social Determinants of Behavioral Health, Webinar Discussion led by C. Debra Furr-Holden, PhD, Michigan State University, available at [msubioethics.clickwebinar.com/brownbag](http://www.bioethics.msu.edu/brownbag-webinar/2016-2017-series). Visit: <http://www.bioethics.msu.edu/brownbag-webinar/2016-2017-series>.
- 18-21** Intensive Bioethics Course, sponsored by Houston Methodist Hospital and The Center for Medical Ethics and Health Policy at Baylor College of Medicine, Houston Methodist Research Institute, Houston, TX. Visit: <http://events.houstonmethodist.org/bioethics>.

MAY

- 25-28** Workshop in Clinical Ethics Mediation, sponsored by the Program in Clinical Conflict Management at the University of Pennsylvania. Visit: <http://medicaethics.med.upenn.edu/education/master-of-bioethics-mbe/clinical-ethics-mediation>.

RECURRING EVENTS

Ethics for Lunch Seminars, sponsored by the Johns Hopkins Berman Institute of Bioethics and Ethics Committee, Sheik Zayed Tower Chevy Chase Conference Center (1800 Orleans St.) Baltimore, MD. 12N-1:15PM. Visit: <http://www.bioethicsinstitute.org/efl>

March 21

April 18

May 16

Johns Hopkins Berman Institute of Bioethics Seminar Series, either at Sheik Zayed Tower Chevy Chase Conference Center (1800 Orleans St.) or Feinstone Hall, E2030, Bloomberg School of Public Health (615 N. Wolfe St.) Baltimore, MD. 12N-1:15PM. Visit: <http://www.bioethicsinstitute.org/education-training-2/seminar-series>

March 12 - Speaker: Lisa Lehmann, MD, PhD, MSc, Executive Director of the National Center for Ethics in Health Care

March 27 - Speaker: Ruha Benjamin, MA, PhD, Informed Refusal: Towards a Justice-based Bioethics

April 10 - Speaker: Chris Feudtner, MD PhD, MPH, Steven D. Handler Endowed Chair of Medical Ethics; Director, Department of Medical Ethics, The Children's Hospital of Philadelphia

April 24 - Speaker: Dale Jamieson, MA, PhD, Professor of Environmental Studies & Philosophy, NYU School of Law

May 8 - Speaker: Joseph Fins, MD, E. William Davis, Jr. M.D. Professor of Medical Ethics, Weill Cornell Medical College

Ethics Lunch Rounds (lunch & CME provided), Sponsored by the University of Maryland Medical Center Ethics Committee, 22 S. Greene St., Borges Conference Room (N2E30). 12N-1PM. For more information, contact: hsilverm@medicine.umaryland.edu

March 24

April 21

May 12

**The Law & Health Care Program
Maryland Health Care Ethics
Committee Network
University of Maryland
Francis King Carey School of Law
500 W. Baltimore Street
Baltimore, MD 21201**

The Maryland Healthcare Ethics Committee Network (MHECN) is a membership organization, established by the Law and Health Care Program at the University of Maryland Francis King Carey 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 attempts 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 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.

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