Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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MID-ATLANTIC ETHICS COMMITTEE N E W S L E T T E R

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Inside this issue . . .

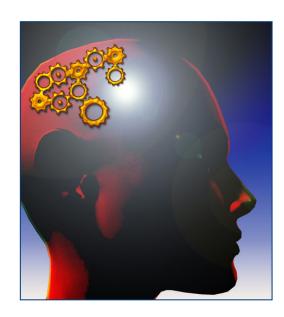
Why Advances in Treating Those with Brain Injuries Require Advances in Respecting Their Rights1
Moral Case Deliberation: Facilitating a Structured Dialogue with Involved Stakeholders4
Policy Statements Provide Guidance for Medical Decision- Making7
Case Presentation8 Comments from a Geriatrician8
Comments from an Ethics Consultant9
Calendar of Events11

The *Mid-Atlantic Ethics Committee Newsletter* is a publication of the Maryland Health Care Ethics Committee Network, an initiative of the University of Maryland Francis King Carey School of Law's Law & Health Care Program. The Newsletter combines educational articles with timely information about bioethics activities. Each issue includes a feature article, a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing, or related disciplines.

Diane E. Hoffmann, JD, MS - Editor

WHY ADVANCES IN TREATING THOSE WITH BRAIN INJURIES REQUIRE ADVANCES IN RESPECTING THEIR RIGHTS

This article was reprinted with permission from the January 26, 2017 issue of The Conversation, <u>http://theconversation.com</u>.



Several years ago a father approached me, concerned about the care his son was receiving. The son had been in a car accident that left him with severe brain injury. He was placed in a nursing home, and his dad stopped by regularly to check in on him. The father feared his son was being ignored or, worse, left in pain or distress.

I could feel the love he had for his son – and his hurt. His boy was so vulnerable.

Over the past two decades, I have worked as an academic physician in the field of neuroethics, focused on advancing the care of patients with severe brain injury and bringing the

fruits of neuroscience to a very marginalized population. I have chronicled my work, and that of my colleagues, in *Rights Come to Mind: Brain Injury, Ethics and the Struggle for Consciousness*, which was published by Cambridge University Press in 2015. To write that book, I interviewed more than 50 families who have been touched by severe brain injury. Their stories of incredible highs and lows take them to the edge of endurance. What they have told me would make you weep.

Yet now, with the last-minute passage of the 21st Century Cures Act in the prior Congress, there is something more we can do for patients with severe brain injury because it provides US\$1.5 billion for brain research. Through the National Institutes of Health's Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, the 21st Century Cures Act can bring to life additional science for this underserved population.

The struggle for rehabilitation

Traumatic brain injuries [TBIs] account for 2.5 million emergency room visits each year. Nearly 90 percent are evaluated and released (for example, many patients

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The information in this newsletter is not intended to provide legal advice or opinion and should not be acted upon without consulting an attorney. with concussion), but almost 300,000 with more serious injury need hospitalization. For those who are most gravely injured, their journey can begin with brilliant, lifesaving neurosurgical care that would have been lost a few decades ago when I was a medical student.

In New York state, for example, death rates for severe TBI dropped from 22 percent to 13 percent from 2001 to 2009. Over that time, doctors began to respond to brain swelling more effectively by shunting off spinal fluid and even removing part of the skull to let the injured brain expand and then recover. These interventions have been a game-changer and saved countless lives.

But after gratitude for a life that has been saved, the truly difficult part begins. Patients and families face a slow-paced and often fickle recovery. Tragically, this phase is often made more challenging by the burden of poorly designed insurance coverage.

Families struggle to get their loved ones needed rehabilitation. If they do get rehabilitation, it is often too short to make a difference. Indeed, if patients are too slow to demonstrate improvement, services can be cut off because of stringent "medical necessity" admission criteria, often from third-party insurers.

This cutoff makes no sense. As I argued with colleagues in the *Journal* of Law Medicine and Ethics, if we don't know how long it takes the injured brain to heal, how do we know the pace is too slow? In the end, the vast majority are placed in a nursing home or institution, which is euphemistically called "custodial care." Fewer than 15 percent of people with moderate to severe TBI get inpatient rehabilitation.

Can rights come to mind?

For years, we thought this was the end of the story. These patients were deprived of skilled and sustained rehabilitation because we thought there was no hope. But in the last decade, neuroscience has made great breakthroughs in our understanding of the brain and its resilience. With proper and state-of-the-art rehabilitation, 21 percent of the most grievously injured can achieve functional independence. That might not seem like a big number, but no one would have predicted this when these people rolled into the emergency room. But with devoted care and sustained rehabilitation, this level of recovery was achieved.

One of the most distressing realizations has been that many patients who are thought to be permanently unconscious or vegetative – and thus ignored and neglected – are in fact conscious and aware. In fact, one study found that two out of every five patients in nursing homes who have a traumatic brain injury and are thought to be vegetative were actually conscious when carefully assessed. It is a staggering error rate, which would be unthinkable if we were talking about making a credible diagnosis of heart disease or cancer.

Recent studies using neuroimaging of the brain have revealed this powerfully in patients who appear vegetative but are in fact minimally conscious. For these patients there is a disconnect between thought and action. Patients demonstrate conscious responses on their scans but don't show external or behavioral evidence of awareness on clinical examination.

It is understandable that the diagnosis can be missed. That's the more innocent explanation. And it can be mitigated with more thorough, and repeated, assessments. More nefariously, many clinicians look at these patients and assume that they aren't there, acculturated by preconceptions and their biases.

Either way, this is consequential and more than just a misdiagnosis. Labeling someone as permanently unconscious becomes a label and a prison. These people are locked away from the rest of us because they are mistakenly thought to be unconscious when they are not.

What does it mean to write these people off? What does it mean to mark a patient as permanently unconscious when he is in fact aware and in the room? Imagine what it must be like to lie in a nursing home bed and be ignored as if you weren't there, estranged from your family and the broader human community. Could anything be more isolating?

New treatments bring new hope

To be sure, we don't want to be overly optimistic about anyone's prospects. For many, pessimism may be justified, but increasingly, progress in neuroscience is making it possible for us to identify patients who are able to make recoveries once thought impossible and to help their brains recover. This is more than a pipe dream as new drugs, devices and neuroimaging are starting to bring some patients back from the abyss.

For example, a flu drug has been shown to accelerate the recovery of consciousness; deep brain stimulation has demonstrated the ability to restore functional communication in a proof of principle clinical trial in which I was involved as a coinvestigator to a patient in the minimally conscious state; and neuroimaging is peering into the disconnect between thought and behavior and helping patients communicate who otherwise couldn't. This is still early research, but the science is incredibly promising. And this makes the challenges posed by insurance barriers all the more troubling.

It suggests we cannot think of this as simply a health care financing question, but something deeper and more fundamental. To me, it's a civil rights issue and one that gets to the core of whom we value and who counts. When these people are misdiagnosed and ignored, they become invisible. I fear they simply don't count.

Just as we have worked to mainstream kids with Down syndrome or autism and worked to better integrate them into society instead of institutionalizing them, we must do the same for those with traumatic brain injuries. We need to reintegrate them back into their communities and develop the tools that will help them recover.

Many people see the 21st Century Cures Act as a boon for medical research, but I also see it as legislation that will help realize the civil rights of people with severe brain injury. With new understanding and better neurotechnologies, we can help patients communicate and reengage with their world.

The long arc of justice demands nothing less for citizens with severe brain injury. At a time of deep national division, the care of people with severe brain injury is something we can all rally around. This collective responsibility speaks to fundamental American values.

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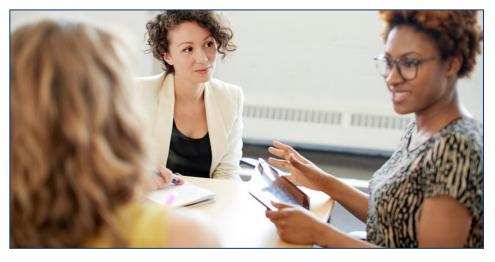
MORAL CASE DELIBERATION: FACILITATING A STRUCTURED DIALOGUE WITH INVOLVED STAKEHOLDERS

Facilitation of moral case deliberation (MCD) is a relatively new form of clinical ethics support (CES) that is rather unknown in the U.S. but is getting increasing attention within Europe (especially the Netherlands, Norway, and Sweden) (Stolper et al., 2015; Molewijk, Slowther & Aulisio, 2016). In MCD, health care professionals (physicians, nurses, social workers, etc.), managers, family, and/or patients discuss a moral question derived from a concrete clinical case with a trained and certified MCD facilitator (Molewijk et al., 2008). Abma and colleagues (2009) identified four main goals of MCD:

- to reflect upon a case and to define and improve the quality of care within that case;
- to reflect on what it means to be a good professional and to enhance a professional's moral competencies;
- to improve multidisciplinary team cooperation and to let teams deal with disagreement in a (more) constructive way; and
- 4. to use insights from MCDs in order to develop, adjust and implement institutional policies and/or guidelines.

MCD can be organized ad hoc (upon request), on a structural basis (e.g. every month one MCD at the ward) or planned within a specific project. For example, say CES staff are asked to help staff at a mental health care institution to reflect upon the use of coercion (e.g., chemical and physical restraints). They may use MCD within this project to help staff reflect upon moral reasons for the use of coercion.

How does MCD differ from ethics consultation? Abma and colleagues (2009, p. 219) write: "... the ASBH



taskforce on the Core Competencies for Health Care Ethics Consultation describes a more procedural and expert approach of the ethics consultant when discussing 'the ethics facilitation approach."" One of the central goals of the ethics consultant is to answer the question, "Who is the appropriate decision maker within this concrete situation?" in a morally and legally right way. When responding to ethics case consultation within this approach, the ethics consultant "focuses more on the answer of the question 'What is [emphasis added] morally right?' In contrast, the MCD facilitator focuses more on the systematic reflection upon the way MCD participants reason about what they think is morally right. The MCD facilitator can also ask about or refer to existing policies, regulations and laws (but specific knowledge about these existing policies, regulations and laws is not a formal requirement for the MCD facilitator). As Stolper and colleagues (2016, p. 3) summarize: "Some key principles of MCD are:

- 1. [using] experience as a starting point for moral reflection;
- 2. tak[ing] into account variations related to interpretations and appreciations of facts by the

participants of MCD plus the conclusions drawn by them;

- linking the values and norms of the participants to concrete facts in the case; and
- 4. [using] dialogue as a process and product in which knowledge and practical wisdom [emerge and are] fleshed out by learning by doing."

All MCD sessions are structured by a specific conversation method. One example is the Socratic Dialogue method (Steinkamp & Gordijn, 2003). Another is the Dilemma method (Stolper et al., 2016). Procedural components of the latter are listed in Table 1. Within MCD, ethical issues are not defined beforehand; the definition of 'the' ethical issue or 'the' key moral question is a result of a structured reflective process focusing on the experiences and viewpoints of the MCD participants. This is because the MCD facilitator is aware of the fact that defining the moral issue is itself a normative process that requires critical inquiry. In MCD, the moral problem under consideration is always a concrete moral issue, experienced by one of the participants. This issue is presented as a case (for example, concerning a treatment decision for

an individual patient). The case is analyzed, not by deductively applying general moral concepts or principles, but by investigating values and norms of the stakeholders in the case. The facilitator, who could be described as a Socratic guide deconstructing conclusions and related presuppositions of MCD participants, aims to stimulate reflection on both personal moral experiences and considerations, and similarities and discrepancies among the views and experiences of other participants in the MCD (Stolper et al, 2016).

MCD emphasizes the variation in thoughts and experiences of health care professionals. In MCD, different viewpoints are examined and scrutinized. The initial aim is not to decide which perspective or answer is morally right, but to ask open and critical questions in order to elaborate assumptions behind the perspective, and find out how it is applicable to the case at hand. When one of the participants brings in an ethical notion, for instance the concept of autonomy, the focus will be on examining what autonomy means for this person in this case, and why it is regarded as important for this person. This may result in a deliberation on various interpretations of autonomy, and their relevance for the argumentation with respect to the dilemma in the case (Stolper et al. 2016). In the end, if the MCD participants aim for a final decision or answer, then the MCD facilitates the MCD participants in the process of weighing pros and cons of various actions in order to let the group make their final decision (or compromise).

Finally, the MCD facilitator usually does not give substantial advice and does not function as an expert of a specific ethics subject. This does not mean that the MCD facilitator does not need any ethics expertise and that he\she is merely focusing on communication or mediation (Metselaar et al., 2015). The

expertise of the facilitator consists of, among other things, fostering a sincere and constructive dialogue among the participants (aiming at a moral inquiry instead of leading a discussion about the question 'Who is right?'), keeping an eye on the moral dimensions of the case, supporting the quality of a joint moral reasoning process, and helping the group in planning actions in order to improve the quality of patient care. In the end, MCD is not a substitute for clinical ethics consultation or ethics committee deliberations: all three CES mechanisms can be used for different purposes.

For those interested in learning more about MCD, an international intensive training for becoming an MCD facilitator is being offered in Amsterdam January 7-10, 2018. For more information, contact the author at <u>b.molewijk@vumc.nl</u>.

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REFERENCES

Abma, T., Molewijk, B., Widdershoven, G.A.M. (2009). Good care in ongoing dialogue. Improving the quality of care through moral deliberation and responsive evaluation. Health Care Analysis, 17(3), 217-235.

Metselaar, S., Molewijk, B., Widdershoven, G. (2015). Beyond recommendation and meditation: Moral case deliberation as moral learning in dialogue. Am J Bioeth, 15(1), 50-1.

Molewijk A.C., Abma, T., Stolper, M, Widdershoven, G. (2008). Teaching ethics in the clinic: The theory and practice of moral case deliberation. J Med Ethics, 34, 120 -124.

Molewijk, B., Slowther, A., Aulisio, M. (2016). Clinical ethics: support. In: Encyclopedia of Global Bioethics (ed. Henk ten Have). Springer Science and Business Media, Dordrecht. Living Reference Work Entry, Encyclopedia of Global Bioethics, 1-8.

Steinkamp, N., Gordijn B. (2003). Ethical case deliberation on the ward. A comparison of four methods. Med Health Care Philos, 6(3), 235-46.

Stolper, M., Molewijk, B., Widdershoven, G. (2015). Learning by doing. Training health care professionals to become facilitators of moral case deliberation. HEC Forum, 27(1), 47-59.

Stolper, M., Widdershoven, G., Molewijk, B. (2016). The dilemma method. A conversation method for moral case deliberation. BMC Medical Ethics, 17, 45.



TABLE 1. THE DILEMMA METHOD FORMORAL CASE DELIBERATION (MCD)

Procedural components of the Dilemma Method for moral case deliberation (MCD) (Stolper et al., 2016) include:

- 1. MCD facilitator introduces self and participants and explains the goals, expectations, and process of MCD, including note-taking and confidentiality of notes;
- 2. Case presenter presents his/her case briefly, using concrete facts;
- 3. Case presenter formulates her/his core dilemma according to the following format: Should I do A or B?
- 4. Participants ask questions for clarification in order to imagine what it means to be in that situation so that later on in the MCD they can answer the dilemma question for themselves.
- Facilitator constructs table identifying 'present perspectives/persons,' 'values,' and 'norms/rules/actions.' Asks each participant to describe his/her core values and norms with respect to the dilemma question. Connects values/norms to original dilemma (A or B).



- 6. Facilitator lists possible alternatives (without discussing feasibility).
- 7. Participants write down on paper the following answers for themselves:
 - (a) I think the right thing to do is . . .
 - (b) Because . . .
 - (c) Therefore I'm not able to do . . .
 - (d) How can I cope with or decrease the moral loss related to the other side of the dilemma?
 - (e) Which virtues and actions are necessary to do the right thing?
- 8. Participants reflect upon possible group consensus or decision:

(a) What are remarkable points of consensus and disagreement? What kind of underlying questions does that raise?

- (b) Given the points mentioned, which answer to the dilemma is possible for the moment?
- (c) If there is any substantial disagreement: how should we deal with that?
- 9. Facilitator schedules follow-up appointments and plans date and place to evaluate those appointments and to identify closure of MCD. Summary of notes provided to participants.
- 10. Participants evaluate (through discussion and by questionnaire) the MCD. What about the process? Have we met our goals? What could be improved the next time?

POLICY STATEMENTS PROVIDE GUIDANCE FOR MEDICAL DECISION-MAKING

The Society of Critical Care Medicine's ethics committee recently issued a policy statement on defining futile and potentially inappropriate interventions (Kon, et al., 2016a). This policy statement clarifies a prior multi-society policy statement (Bosslet, et al., 2015) that recommended only using the term medically futile to refer to interventions that have no physiologic chance of achieving a desired goal, such as antibiotics to treat viral infections.

The more recent policy statement goes into more detail regarding the appropriate goals of intensive care unit (ICU) care (i.e., "treatment that provides a reasonable expectation for survival outside the acute care setting with sufficient cognitive ability to perceive the benefits of treatment" and goals of "palliative care that provides comfort to patients through the dying process"). Further guidance is provided on how case-by-case decisions should be made using a process-based approach.

A companion policy statement drafted by the American College of Critical Care Medicine and the American Thoracic Society provides additional guidance to ICU clinicians regarding shared decision-making (SDM) in ICUs (Kon, et al., 2016b). SDM is defined as "a collaborative process that allows patients, or their surrogates, and clinicians to make healthcare decisions together, taking into account the best scientific evidence available, as well as the patient's values, goals, and preferences." Clinicians are encouraged to use SDM to define a patient's overall goals of care and "when making major treatment decisions that may be affected by personal values,

goals, and preferences." Clinicians' "default" approach to SDM should include: (1) exchanging information, (2) deliberating, and (3) making a treatment decision. The recommendations acknowledge a range of ethically supportable decision-making approaches (e.g., patient-directed, surrogate-directed, or clinician-directed models) that clinicians should select from based on the preferences of the patient or surrogate and contextual details of each situation. The policy statement includes examples of preferencesensitive decisions in the ICU and key communication skills clinicians should master in SDM. For example, a patient/surrogate has the right to defer certain decisions to a clinician; this is distinct from strict paternalism in that in this approach to SDM, the clinician understands the patient's values and uses them to determine the plan of care, and the patient/surrogate is offered as much information as desired (in understandable language) and recognizes that (s)he can change his/her mind and be supported.

The American Thoracic Society also recently published policy and clinical recommendations for medical decision-making for "unbefriended" older adults, updating their 1996 position statement. They call for policy changes to achieve more consistent and fair approaches for this population across states and health care delivery settings. Clinical recommendations include avoiding ad hoc approaches by developing standardized methods to make decisions for these individuals (particularly in urgent situations), considering non-traditional surrogate decision-makers for these individuals, assessing medical decision-making capacity systematically, ensuring

that "patients with long-term incapacity have longitudinal access to a decision-making surrogate who is familiar with the patient's medical condition and specific circumstances," and when applying the best interest standard to these individuals, that ethics committees should "synthesize all available evidence, including cultural and ethnic factors" when they deliberate about treatment decisions (Ferrell et al., 2016).

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REFERENCES

Bosslet, G.T. et al. (2015). An official ATS/AACN/ACCP/ ESICM/SCCM policy statement: Responding to requests for potentially inappropriate treatments in intensive care units. Am J Respir Crit Care Med, 191(11), 1318–1330.

Ferrell, T.S., et al. (2016). AGS position statement: Making medical treatment decisions for unbefriended older adults. J Am Geriatr Soc, epublication November 22.

Kon, A., et al. (2016a). Defining futile and potentially inappropriate interventions: A policy statement from the Society of Critical Care Medicine ethics committee. Critical Care Medicine, 44(9), 1769-1774.

Kon, A, et al. (2016b). Shared decision making in ICUs: An American College of Critical Care Medicine and American Thoracic Society policy statement.

CASE PRESENTATION

The following case study and Dr. Levenson's response are reprinted with permission from the Handbook for Nursing Home Ethics Committees, edited by Diane Hoffmann, Philip Boyle, and Steve Levenson, and published by the American Association of Homes and Service for the Aging in 1995. Anita Tarzian reflects on how Dr. Levenson's analysis holds up over 20 years later.

CASE STUDY FROM A NURSING HOME

An eighty-six-year-old woman, Mrs. Green, was admitted to a nursing home because of progressive dementia due to Alzheimer's disease. She had never made any advance directives and was incapable of doing so. She had significant tardive dyskinesia—uncontrollable movements of the face and mouth—resulting from previous administration of psychotropic medications. She was bedbound, totally dependent in her activities of daily living, and fed via a gastrostomy tube. She was on Dilantin for a seizure disorder. She was alert, but only made some incoherent noises in response to questions. Her family stated that while she had never made an advance directive, she had previously expressed her wish that her life not be prolonged indefinitely by extraordinary measures. After several years in the facility with little change, they felt that her persistent bedbound state and limited cognitive function were not consistent with a desirable quality of life. They requested that her physician treat her as a terminal resident, and discontinue any aggressive medical interventions. Her physician agreed not to implement antibiotics, but did not think that her condition was terminal. A consultant physician agreed that her condition was not terminal but that not using any antibiotics would be appropriate

About six months later, she developed an abscess in her left inner thigh. Her attending physician insisted that antibiotics should be used to treat this, since she was not dying. At the same time, the family found out that the physician had been maintaining her on a long-term prophylactic dose of a urinary anti-infective. The family requested a change in physician. The new physician agreed not to use antibiotics and was prepared to treat her as terminally ill, but the medical director and other physicians in the nursing home met and decided that it was not appropriate to manage her case in this way. The resident's family requests an ethics committee consult.

COMMENTS FROM A GERIATRICIAN

Mrs. Green was in the advanced stages of a progressive, irreversible condition. While she was alert, she was totally dependent and bedbound. There was no way of ascertaining if she was aware of her surroundings.

This case illustrates the difficulties of deciding on the appropriateness of treatment when a person is not terminal but has potentially treatable conditions that could hasten death if not treated. It also illustrates the difficulties of absolute prohibitions of a particular form of treatment contrasted with treatment in a given situation.

The family claimed that she had certain wishes regarding the use of extraordinary measures. Because these had never been documented, they could at best apply a substituted judgment standard in making decisions for her. If this did not seem to apply, then a "best interests" standard would apply.

This case is also complicated by the difficulties in defining terminal, and the problem of laws limiting treatment decisions to the "terminal" situation. [See next commentary for a discussion of the "end-stage" condition.] In Mrs. Green's case, her degenerative condition was advanced, but her death was not necessarily imminent. Many individuals are not necessarily terminal, but nevertheless have little hope for recovery or improvement. Various state laws have been, and should continue to be, revised to allow for more flexible decision making in cases other than terminal conditions. If such a law had been in effect at the time this case was being managed, it would not have been necessary to argue over whether the condition was terminal. Instead, efforts could have been focused on prospects for further general decline or improvement and the likelihood of any intervention

to improve her condition or restore some quality of life in the face of an inevitably progressive condition.

The physician may have been deceptive in his use of prophylactic anti-infectives to prevent urinary tract infections. There had been an agreement not to use antibiotics, in anticipation of an infection that could eventually lead to a terminal state. While an anti-infective is technically not an antibiotic, the basic spirit of the agreement was not being honored. This decision should have been discussed openly with the family.

The occurrence of the abscess raises the issue of the absolute prohibition of various treatments. The typical prohibition against antibiotics is intended to prevent their use to aggressively treat a significant systemic infection (pneumonia, septic shock) that would otherwise probably progress to death. However, a localized abscess is not exactly the same as a major pneumonia or septic shock. In some cases, managing the abscess could be considered a comfort measure. In any event, a week's course of antibiotics probably would have helped resolve the abscess, but it was not likely to significantly prolong this resident's life.

A facility ethics committee should review the case and consider the evidence. If the attending physician does not agree with the wishes of a surrogate decision maker, there should be a mechanism for changing physicians. The ethics committee is an appropriate forum for all sides—facility administration, medical director, other physicians, family, resident—to present their perspectives and reasons. Other physicians should not simply have the prerogative to block an appropriately agreed upon course of action.

In this case, an ethics committee could help all parties review the case and better understand each other's positions. Often, disagreements occur because of different starting premises. The various parties argue over conclusions but may not ever discuss the underlying premises that led them to those conclusions. The ethics committee can play an important role in getting those parties to focus first on these starting premises. If the parties cannot agree on the underlying premises, then the ethics committee should strongly encourage flexible decision making rather than a decision simply imposed by those with the authority to do so. The primary emphasis should be resident-centered, i.e., the potential benefits or drawbacks of the proposed interventions for the resident. Often, the parties can agree on the best clinical course, but some of them may fear the consequences of making a particular decision, based on legal or other considerations. Thus, the parties should be encouraged to think first about the clinical and ethical aspects of the case, deferring considerations that are self-serving (such as questions of legal liability). If they can agree on what is the best ethical

and clinical course of action, they may then be able to address the legal concerns constructively.

If the facility does not agree with limitations on care, the family should have the option to remove the resident to another facility. Although not all circumstances can be anticipated, a facility's policies about limiting or withdrawing treatments should be clarified upon admission, rather than created on an ad hoc basis as cases arise. The ethics committee should play a major role in such policy clarification.

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COMMENTS FROM AN ETHICS CONSULTANT

In the above commentary, Dr. Levenson mentioned the value of state laws that don't restrict decisions to withhold or withdraw life-prolonging interventions to patients in a terminal condition. Maryland's Health Care Decisions Act (HCDA) is one such law. In addition to a terminal condition, it recognizes the "end-stage condition" and persistent vegetative state as conditions allowing a legally authorized decision-maker to withhold or withdraw life-prolonging interventions if consistent with a patient's known wishes or best interests. The HCDA defines "endstage" condition 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" [HCDA, §5-601(j)]. While some disability rights advocates have expressed concern that individuals who are dependent on others for daily care because

of a long-standing disability may erroneously be designated as "endstage" (Carlson, Smith & Wilker, 2012), an "end-stage" condition must be advanced and progressive and have caused severe and permanent deterioration, not physical dependency alone. In fact, the HCDA specifies that a surrogate's decision to withhold or withdraw life–sustaining procedures should not be based on a patient's preexisting, long–term mental or physical disability [HCDA §5–606(c)(3)].

Mrs. Green appears to meet the end-stage definition based on the description of how her Alzheimer's disease has progressed. The first step in an ethics consultation would be to find out whether Mrs. Green's physician agrees that Mrs. Green meets this definition, and if so, whether two-physicians have certified that Mrs. Green is in an end-stage condition. (It would also help to visit Mrs. Green to confirm that how she presents is consistent with others' descriptions.) The HCDA provides direction for who is considered the legally authorized decision-maker. The hierarchy order among family members (assuming there is no appointed guardian; we know there is no health care agent) is:

- 1. Spouse or domestic partner
- 2. Adult child
- 3. Parent
- 4. Adult sibling
- 5. Friend or other relative who knows the patient well.

For a friend or "other relative" to make decisions for Mrs. Green, an affidavit would need to be presented to the attending physician stating that the person is a relative or close friend of the patient who has maintained regular contact with the patient and is "familiar with the patient's activities, health, and personal beliefs" [HCDA §5–606(a)(3)(ii) (2)]. For the purposes of this analysis, let's assume there is consensus among Mrs. Green's family members (including whomever is designated as the authorized decision-maker according to the above hierarchy) that her life should not be prolonged by any means. It may be helpful to review the HCDA's guidance for surrogates – specifically, that "[a]ny person authorized to make health care decisions for another ... shall base those decisions on the wishes of the patient" (i.e., "substituted judgment"), which requires consideration of the patient's:

- current diagnosis and prognosis with and without the treatment at issue;
- expressed preferences regarding the provision of, or the withholding or withdrawal of, the specific treatment at issue or of similar treatments;
- relevant religious and moral beliefs and personal values;
- behavior, attitudes, and past conduct with respect to the treatment at issue and medical treatment generally;
- reactions to the provision of, or the withholding or withdrawal of, a similar treatment for another individual; and
- expressed concerns about the effect on the family or intimate friends of the patient if a treatment were provided, withheld, or withdrawn [HCDA §5–606(c)(2)(i-vi)].

The case study lacks detail regarding whether Mrs. Green's family thought through these considerations. They seem to be basing their request to withhold antibiotics on their appraisal of her poor quality of life, perhaps concluding that she would be better off dead than in her present diminished condition. This is a kind of "best interest" consideration, which the HCDA instructs surrogates to employ "if the wishes of the patient are unknown or unclear." Thus, the ethics consultant(s) should remind the family (and authorized decisionmaker in particular) of the important task of using substituted judgment to inform medical decision-making for Mrs. Green.

The next question that arises is whether, absent an advance directive, it would be likely that Mrs. Green's family would know what her wishes were regarding use of antibiotics in her current situation. A decision to withhold CPR attempts or dialysis carries a different risk-benefit analysis than use of antibiotics. Antibiotics may, for example, improve comfort if they prevent or treat an infection that increases suffering. While health care professionals often share stories of patients who were kept alive by medical technology only to face a prolonged and painful dying process, does use of antibiotics fall in this category? It is worth exploring whether the family's concern is truly her comfort and quality of life or in finding an opportunity for her to "die sooner rather than later." This doesn't mean it's wrong to conclude that Mrs. Green would prefer to die sooner rather than later, or even that dying sooner would be in her best interest. Rather, it's important to consider the burdens and benefits of antibiotic use and ensure that decision-making is consistent with best available evidence and facts. Mrs. Green's wishes (if known), and the goals of care for her.

Absent an advance directive and clear indication of Mrs. Green's wishes, it would be difficult to support goals of care that prioritized hastening her death over maintaining her comfort. For example, if Mrs. Green was moaning and wincing when the leg with the abscess was moved and physicians felt that treating the abscess would improve her comfort but the family insisted on withholding the antibiotic with the goal of hastening her death, it would be appropriate for the physicians to challenge this. Providing palliative care at the end of life is a medical standard and it's right for physicians to advocate for this. However, if that was not the case (e.g., Mrs. Green did not seem to be uncomfortable and/ or the antibiotics seemed to cause other uncomfortable side effects). the ethics consultant(s) should elicit more information about the basis of the physicians' concerns. Do they feel they would be complicit in hastening her death? Do they fear that state surveyors may sanction them for not treating an infection? Do they fear litigation from the family? According to Maryland's HCDA, a physician "who acts in accordance with the recommendation of the [patient care advisory] committee is not subject to liability for any claim based on lack of consent or authorization for the action" [HCDA §5-606(b)]. What's "legal" and "ethical" is grounded in what is considered "good medicine." In this case, applying the legal and ethical standards should reveal the path forward. A decision to withhold antibiotics for Mrs. Green (as well as other potentially life-prolonging interventions) should be based on a thoughtful consideration of what she would want and what would provide the most benefit and least burden to her.

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REFERENCES

Carlson, D., Smith, C. & Wilker, N. (2012). Devaluing People with Disabilities. Washington, DC: National Disability Rights Network. Available at <u>http://www.ndrn.org/</u> <u>images/Documents/Resources/</u> <u>Publications/Reports/Devaluing_</u> <u>People_with_Disabilities.pdf.</u>

Maryland Health Care Decisions Act. Available at <u>http://www.</u> marylandattorneygeneral.gov/ Pages/HealthPolicy/hcda.aspx.

CALENDAR OF EVENTS

AUGUST

10-12- Conflict Resolution and Clinical-Setting Mediation for Healthcare, sponsored by the Center for Conflict Resolution in Healthcare LLC, Memphis, TN. Visit: <u>http://www.healthcare-mediation.net/trainings.html</u>.

17-20- Intensive Workshop in Conflict Resolution, sponsored by The Penn Program in Clinical Conflict Management, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA. For more information, contact: <u>fiester@upenn.edu</u>.

SEPTEMBER

7- Florida Ethics: Debates, Decisions, Solutions: 25th Annual Conference, sponsored by The University of Miami Institute for Bioethics and Health Policy, Miami, FL. Visit: <u>http://www. bioethics.net/events/florida-ethics-debates-decisions-solutions-25th-annual-conference/</u>.

11-13- Ethical Leadership for Tomorrow's Health Care Organizations, sponsored by The Aspen Program for Ethical Healthcare Leadership, Miami, FL. Visit: <u>http://fbn.med.miami.</u> <u>edu/</u>.

14-15- 7th Annual Western Michigan University Medical Humanities Conference, sponsored by the Fetzer Center, Western Michigan University, Kalamazoo, MI. Visit: <u>http://</u> www.wmich.edu/medicalhumanities/events/conference2017.

15- Building an "Inclusive Climate": Addressing "ism" Issues in the Workplace in Trying Times, 2017 Judy Levy Ethics Workshop sponsored by The Kennedy Krieger Institute Social Work Department, The Shepard Pratt Conference Center, Towson, MD. Contact: <u>SwannA@KennedyKrieger.org</u>.

OCTOBER

9-11- A Virtual Conference on Refugee & Migrant Health, Mobility, Human Rights & Responsibilities. Visit: <u>https://</u> resistingborders.com/.

27-29- Crossing Disciplines: Strategies for Humanizing One Another, the 2017 Humanities in Medicine Symposium, Sponsored by the Dolores Jean Lavins Center for Humanities in Medicine at the Mayo Clinic, Rochester, MN. Visit: <u>http://</u> mayoclinic.org.

19-22- Journey to the Center of Bioethics and the Humanities, 195y Annual Meeting of the American Society for Bioethics & Humanities, Kansas City, KS. Visit: <u>http://www.asbh.org</u>.

NOVEMBER

2-3- The Medicalization of Poverty, Co-sponsored through the University of Illinois (Medicine, Law), University of Virginia (Medicine, Public Health, Biomedical Ethics) and the Carle Illinois College of Medicine, University of Illinois, Urbana-Champaign. Visit: <u>https://law.illinois.edu/faculty-research/specialty-programs/epstein-health-law-and-policy/</u>.

7- Transforming Substance Use Disorders - Fourth Annual Interprofessional Forum on Ethics and Religion in Health Care, sponsored by the Institute for Jewish Continuity; the University of Maryland Schools of Medicine, Nursing, Pharmacy, and Social Work; the UMB Graduate School, and the Maryland Healthcare Ethics Committee Network at Maryland Carey Law. UMB's Southern Management Corporation Campus Center, 621 W. Lombard St., Baltimore, MD. Visit: <u>http://www.nursing.umaryland.</u> edu/academics/pe/events/ [Members eligible for MHECN member discount!]

RECURRING EVENTS

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/educationtraining-2/ seminar-series.

September 11- "Should Preference Surveys Measure Health?" Speaker: Dan Hausman, PhD, Herbert A. Simon and Hilldale Professor, Department of Philosophy, University of Wisconsin-Madison (Feinstone Hall)

September 25- Speaker: Shannon Sullivan, PhD, MA, Chair of Philosophy and Professor of Philosophy and Health Psychology at UNC Charlotte (Feinstone Hall)

October 9- Speaker: Joanna Radin, PhD, MS, Assistant Professor, History of Medicine, of Anthropology and of History, Yale School of Medicine (Zayed Tower)

October 23- Speaker: Nicole Civita, JD, Assistant Director, Rian Fried Center for Sustainable Agriculture & Food Systems, Sterling College (Feinstone Hall)

November 13- Speaker: Nancy Berlinger, PhD, MDiv, Research Scholar, The Hastings Center (Feinstone Hall)

November 27- Speaker: Sean Aas, PhD, Senior Research Scholar, the Kennedy Institute of Ethics; Assistant Professor of Philosophy, Georgetown University (Zayed Tower)

December 11- Speaker: Robert Cook Deegan, MD, Research Professor in the Sanford School of Public Policy (Feinstone Hall) 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.

MHECN appreciates the support of its individual and institutional members. MHECN also welcomes support from affiliate members who provide additional financial support.

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