

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

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia Published by the Law & Health Care Program, University of Maryland School of Law and the Maryland Health Care Ethics Committee Network

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Newsletter combines educational articles with
timely information about bioethics activities
in Maryland, D.C., and Virginia. Each issue
includes a feature article, "Network News,"
a Calendar of upcoming events, and a case
presentation and commentary by local experts
in bioethics, law, medicine, nursing and related
disciplines

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ART, EMOTIONS & ETHICS

t MHECN's July 26 conference, Ethics Committees in Action, art therapist Julia Andersen guided attendees through an experiential session to explore how they, as ethics committee members/ethics consultants, might enhance their own self-awareness and emotional health through art therapy techniques. Some attendees had difficulty recognizing the relevance of this activity to the work of ethics committees. This surprised me. Many ethics consultations or cases discussed at ethics committee meetings involve emotionally charged issues such as withholding or withdrawing life support from patients. Are those involved in these case discussions with patients or family members not affected by the barrage of emotions they stir up? If they are affected, how do they process these emotions? One attendee wrote on the conference evaluation form: "I didn't respond to the art. But I realized my feelings are dictated by medicine." Indeed, many health care professionals (HCPs) are trained to strive for emotional objectivity in their encounters with patients or family members. Does this serve HCPs well? Does it serve patients/families well?

In her book, FROM DETACHED CONCERN TO EMPATHY: HUMANIZING MEDICAL PRACTICE, philosopher and psychiatrist Jodi Halpern challenges the practice of teaching "detached concern" to medical students and physicians. Instead, she advocates nurturing empathy so that the clinician can emotionally

connect with the patient/family while not losing sight of his or her role as healer in the process. She argues that connecting emotionally with patients makes physicians more effective healers. Eric Cassell (2002) concurs, stating, "it is impossible to banish emotions from medicine, because both physicians and patients are people, and emotions are as much a part of people as thought." He continues, "[t]he emotions that patients arouse within physicians are also evaluative and tell physicians much about the patients, about themselves, and about their relationship." Unfortunately, the current training and culture of medicine (which pervades other health care disciplines as well) encourages HCPs to deny their patients' and their own emotional responses, and to internalize feelings in unhealthy ways.

Is the same predisposition toward detached concern operative among ethics committee members? We can assume so, since ethics committees operate in health care facilities strongly influenced by the culture of medicine. So one might then ask, is emotional detachment effective in resolving ethical conflicts? From a humanistic perspective, one could appeal to common sense and compassion to support a more emotionally connected response between ethics consultants and patients/families. But for the skeptics, an appeal to science might help. Evidence is mounting that emotions are more at play in the processes of thinking and

as individuals to whom they can formally take concerns or questions. Provide a handout listing the names of all the HEC members with each member's title, department, phone, and pager numbers.

•If you are at a teaching facility, having the HEC members share responsibilities for providing the ethics talks required by the Accreditation Counsel for Graduate Medical Education (ACGME).

•Getting HEC members to serve on as many other committees and review bodies as possible throughout the organization in order to increase HEC visibility and build HEC dendrites.

When all these activities have been put into place and are humming along, when the HEC learns the dance of moving in and out of the traditional medical power hierarchies, and the dance is regularly modeled throughout the organization by those high and low, the HEC will have become a true change agent moving the whole organization towards sustainable excellence; forward movement on which our patients depend.

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Philosopher's Corner – Medical Futility

In the very first sentence of *Principia Ethica*, G.E. Moore observes that "in ethics, as in all other philosophical studies, the difficulties and disagreements of which history is full, are mainly due to a very simple cause: namely to the attempt to answer questions, without first discovering precisely what question it is you desire to answer" (Moore, 1903). Nowhere in contemporary bioethics is this better illustrated than in debates surrounding medical futility.

Since conceptual issues can have enormous practical normative consequences, it is not surprising that the proper role of the term "medical futility" has been the subject of a huge dispute. Definitions have been proposed and exhaustively debated for nearly twenty years. What that debate has shown is that the term is a mere (purportedly neutral scientific) cloak under which various normative judgments have been smuggled. Since health professionals have been unable to reach consensus about the propriety of those underlying normative judgments, many now recommend avoiding use of the term altogether.

That may be too drastic a step. Since the term has been, and continues to be, used in all the relevant medical. philosophical, and legal literature, we ought to bow to convention. As discussed below, we should not use the term "medically futile" to describe a treatment. But, we can still use the term to describe a particular type of dispute. That type of dispute is typically an end-of-life dispute in which a health care provider seeks to stop lifesustaining medical treatment (such as assisted ventilation, artificial nutrition and hydration, renal dialysis, surgical procedures, blood transfusions) that the patient or surrogate wants continued.

In the classic right to die situation illustrated by Quinlan, Cruzan, and Schiavo, the patient or her surrogate wants to limit life-sustaining medical treatment (LSMT) but the health

care providers resist. In contrast, in a futility situation, the roles are reversed: the healthcare provider wants to limit LSMT and the patient or her surrogate resists. It is the health care provider who judges LSMT to be of no benefit. It is the health care provider who wants to stop the train when the patient or surrogate says "keep going" (Lee, 2005).

The provider and surrogate disagree because they have different goals. The patient's goals might include cure, amelioration of disability, palliation of symptoms, reversal of disease process, or prolongation of life. The provider, on the other hand, might, under the circumstances, judge these goals to be either unachievable or inappropriate. Much of the debate over medical futility concerns the validity of the provider's grounds for refusing the surrogate's request for LSMT.

Refusing a surrogate's request on grounds of achievability seems more defensible because the provider starts with the patient's own goals. The provider merely determines either that those goals are not possibly achievable (physiological futility), or that they are not probably achievable (quantitative futility).

Physiologically futile interventions will not produce an effect that measurably affects the patient. Like chemotherapy for an ulcer, they have a zero percent chance of being effective. With physiological futility, the provider does not make any assessment that the effect is not likely enough, not large enough, or not worthwhile. Health care providers can readily ascertain physiological futility based solely upon their clinical knowledge. There is no normative disagreement. The basis for refusing treatment is an empirical one: the treatment simply will not work.

But this objectivity comes at a steep price. Physiological futility has a very limited applicability. It is often difficult to be certain that there is a 100% probability that a given intervention will have zero effect. Most decisions on

withholding and withdrawing treatment are based on probabilities as opposed to certainties. Since technology permits many "effects" such as keeping a heart beating, true physiological futility rarely applies when considering withholding or withdrawing LSMT.

Since physiological futility covers so few cases, some have proposed employing the broader concept of quantitative futility, which refers to treatments that are "virtually" unachievable. Unlike physiologically futile treatments, quantitatively futile treatments might work. But based on clinical studies and scoring systems, they most probably will not work.

Quantitative futility suffers from two serious problems. While it seemingly possesses the precision of mathematics, unlike physiological futility, a quantitative standard is valueladen and cannot be determined by reference to science alone. First, where should we set the threshold percentage for quantitative futility? The most prominent proponent of quantitative futility, Lawrence Schneiderman, argues that "a treatment should be regarded as medically futile if it has not worked in the last 100 cases" (Schneiderman & Jecker, 1995). But some believe that a provider must offer even a chance of "1 in a million." Setting the threshold of probability is a value judgment about which there is considerable variability. Second, even if we were able to settle upon a threshold percentage, how do we ascertain when that threshold standard is obtained with respect to a particular patient? Measures from clinical studies are very imprecise when applied to a particular patient with "individualized symptoms, medical history, character traits and other variables" (Arato v. Avadon, 1993).

While physiological futility and quantitative futility question only the achievability of the patient's goals, qualitative futility questions the worthwhileness of the patient's goals themselves. The focus is on the benefits rather than on the effects of LSMT. There are several versions of qualitative futility.

The most compelling version of

qualitative futility holds that LSMT is medically inappropriate where the prospective benefits of treatment are outweighed by their associated burdens. For example, in the recent Emilio Gonzales case in Texas, providers refused to provide LSMT for Emilio because it would only "serve to prolong his suffering without the possibility of cure." Providers felt that "the burdens associated with his current care plan outweigh[ed] any benefit Emilio [might have been] receiving" (Gonzales v. Seton Family of Hospitals, 2007).

Another version of qualitative futility weighs the prospective benefits against the health care resources used to provide the treatment. When looking just to hard resources like ICU beds, this version of qualitative futility does not differ much from triage. However, a more robust version of resource-focused qualitative futility looks to the rational allocation of soft resources like health care dollars. This is widely condemned on the grounds that rationing should be developed through public policy and not at the bedside.

A third version of qualitative futility provides that regardless of burdens or resources, the expected outcome of the requested treatment is of no value because the patient can derive little or no benefit from continued LSMT. The most notable example involves the patient who is permanently unconscious. No value judgment is required to conclude that such a patient cannot experience or appreciate anything that society or life has to offer. Suggestions to expand this version of qualitative futility have been very heavily criticized because, in application, it is subject to all sorts of biases, especially against the disabled.

While the various definitions of medical inappropriateness have been exhaustively debated over the past twenty years, only physiological futility is supported by a consensus in the medical, legal, and bioethical communities. Yet, physiological futility is inapplicable in the vast majority of futility disputes involving a patient for whom LSMT can produce some effect. Therefore, the relevant question

is whether the expected effect is a benefit to the patient and whether it is worthwhile. But about this there is no consensus.

Many have despaired of reducing the circumstances under which a provider may refuse requested LSMT to a definition or algorithm. Instead, they concede that medical futility (or its cousin, medical inappropriateness) can be identified only like beauty or pornography. It is in the eye of the beholder. We know it when we see it (Pope, 2007). Thus, the focus in recent years has been not on the definition of "medical futility," but rather on the process for resolving futility disputes (AMA Council, 1999). While provider discretion is inescapable, it is not unfettered. The challenge for the next decade is to develop a mechanism that properly balances provider discretion and independent accountability.

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