

Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Mid-Atlantic Ethics Committee
Newsletter, Spring 2014

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MID-ATLANTIC ETHICS COMMITTEE

NEWSLETTER

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

Spring 2014

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"I'M THE CAPTAIN NOW!"

December 1991 was my first month as a teaching attending in the academic hospital with my new junior faculty job. I was responsible for two resident teams. Each resident had two interns and two third year medical students. Each team was on long-call every third night. Each intern managed 10 to 15 patients on any given day. My job was to teach medicine and oversee the care. I rounded with the team seven days a week. My pager was live 24/7, for any calls from the residents. In this pre-"electronic health record" era, I was responsible for writing my own attending notes on the 40 or more patients daily.

I got to the hospital in the early morning hours and typically did not get home until past 10 pm. One night as midnight approached, I found myself writing notes at a nursing station next to a nephrologist, who also was finishing up his ward attending notes for the day. I asked him, "How can you do this for an entire month?" I was totally exhausted after only one week! He had been told this was the busiest month the hospital had ever had, dating back to its founding in 1774. We were in the midst of an Influenza outbreak in the city. Usually it wasn't this busy. He advised me, "If you just get used to the fact that you will spend the entire month in the hospital, it really isn't so bad." He opined further, "It is just a matter of adjusting your expectations. As I see it, if my wife doesn't divorce me and if I don't kill anyone, then my month as a ward attending has been a success!" I wasn't convinced.

Another nephrologist had just recommended initiating dialysis in one of the demented nonagenarians on our service. I told the nephrologist sitting next to me that where I had trained, we would never have brought up the topic of dialysis for this patient. If the patient or family were to ask about dialysis, we would simply tell them it was not advisable, it was not an option. It was extremely rare for a patient or family to challenge our recommendations. I asked my colleague, "How do you decide whether to dialyze frail elders with kidney failure?" He stopped writing his note only for a moment and said, "Well, if they can watch TV, then I would dialyze them. If they can't watch TV, then I wouldn't offer dialysis." We both went back to writing our notes. I shot out the hospital door to try to get some sleep before dawn. I wasn't sure about the TV criterion for dialysis. I'd have to reconsider his comments when rested in the light of day.

Today, 23 years later, I find myself thinking a great deal about the TV criterion for dialysis. In the past two decades, octogenarians and nonagenarians have become the fastest growing cohort of hemodialysis patients. Although it may be hard to know when to start dialysis in frail elders, it is even more challenging to know when the time has arrived to stop it. Since many frail elders ultimately need the services of skilled nursing facilities, increasing numbers of facilities now

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Diane E. Hoffmann, JD, MS
Editor

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University of Maryland
Francis King Carey School of Law
500 West Baltimore Street
Baltimore, MD 21201
410-706-7191

Diane E. Hoffmann, JD, MS, Editor
Anita J. Tarzian, PhD, RN,
Co-Editor

Contributing Editors:

Joseph A. Carrese, MD, MPH
Associate Professor of Medicine
Johns Hopkins University

Brian H. Childs, PhD
Director, Ethics & Organizational
Development, Shore Health Systems

Evan DeRenzo, PhD
Ethics Consultant
Center for Ethics
Washington Hospital Center

Edmund G. Howe, MD, JD
Professor of Psychiatry,
U.S.U.H.S. Department of
Psychiatry

Laurie Lyckholm, MD
Assistant Professor of Internal
Medicine and Professor of
Bioethics and Humanities,
Virginia Commonwealth
School of Medicine

Jack Schwartz, JD
Adjunct Faculty
University of Maryland
Francis King Carey School of
Law

Henry Silverman, MD, MA
Professor of Medicine
University of Maryland

Comments to:
MHECN@law.umaryland.edu

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attorney.**

Advance Directives
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offer on-site dialysis. In response to a growing number of chronically ventilator dependent patients, some nursing facilities also offer pulmonary programs for patients requiring prolonged weaning attempts or chronic mechanical ventilation. A few nursing facilities offer services for patients requiring both chronic mechanical ventilation and hemodialysis.

Of the initial half dozen referrals to a newly established nursing facility ventilator-dialysis program, all were long-term hemodialysis patients who had had a catastrophic event, such as a cardiac arrest or a severe pneumonia, requiring intubation. Post event, they were found to have severe central nervous system (CNS) impairment and were un-weanable from mechanical ventilation. All of them had family requests for "Full Code Status." None of the referring intensive care unit (ICU) discharge summaries discussed prognosis, or the medical effectiveness of cardio-pulmonary resuscitation (CPR), or the ethical appropriateness of ventilating and dialyzing a patient with profound CNS impairment and a terminal prognosis. The medical director of the nursing facility dialysis unit asked of this population, "Why are we continuing to dialyze these unresponsive people on ventilators who are dying?"

It appears that prior to entering the nursing facility, the families are either never told their loved one is dying or have completely dismissed the medical facts, even if the patient is vegetative with multi-system failure. It is not until the nursing facility medical staff provides two physician certifications of medical ineffectiveness for CPR that the families hear, "We will not provide cardiac resuscitation attempts for your family member because it would be medically ineffective." Some of the families push back, saying, "If CPR is medically ineffective, why didn't they tell us that at the

hospital?!" Good question, why indeed?

When families find that the Medicare skilled nursing benefit runs out after 100 days, and they must start spending down for Medicaid at a rate of around \$750 per day for ventilator dialysis care in a nursing home, they ask, "If all of this wasn't going to make mom any better, why did the hospital doctor subject her to all this?" Others bluntly proclaim, "If she spends down for Medicaid, I will lose my inheritance." Those who start this journey with Medicaid in place never have any knowledge of the cost of this care. Taxpayers, who are footing the bill, are unaware of what they are paying for. Some families believe that the prohibition on lifetime benefit caps in the Affordable Care Act applies to this situation, but it does not. There is no prohibition on the cap for skilled nursing services payment under either Medicare or private insurance.

A family member of a recently admitted ventilator dialysis patient (who was unresponsive from both brainstem strokes and anoxic encephalopathy) demanded one day that her mother go back to the hospital. The attending physician explained that there was no rationale to send her mom back to the hospital at that time. The family member began yelling, "That is not your decision to make, doctor. That is my decision and I want her sent out." The attending explained that in fact it was his duty to assess the patient medically and send her to the emergency room only if she needed an urgent evaluation for an unstable problem. He told the daughter that if her mother were to be sent out, it would be against medical advice. The daughter said, "I don't care. I am the one in charge here! Send her out." The patient was taken by private ambulance to the emergency department and returned to the facility with no new orders 12 hours later.

In my role as the chairperson of the hospital ethics committee years ago, the typical cases were about families not accepting terminal prognoses or medical recommendations for de-escalation or withdrawal of non-beneficial therapies. One case in particular stands out in my mind. An octagenarian was living independently in the community. She was diabetic and had undergone coronary bypass surgery years ago. She presented with a diabetic foot ulcer with osteomyelitis, and was admitted for bone biopsy and culture, intravenous antibiotics and a revascularization procedure. On her second post-operative day, she had a catastrophic brain stem stroke and developed respiratory failure, requiring intubation. The patient did poorly, but did not meet brain death criteria. She had no advance directives and had four daughters, who could not agree on the proper course of action. Because she had seemed so healthy and was independent prior to admission, they suspected that the hospital had caused her catastrophe.

They thought the doctors were trying to cover something up and wanted to kill their mother. At the meeting, after the intensivist and three consultants had spoken about the patient's condition, the son-in-law stood up at the table, visibly shaking, and shouted at the participants. "Who is in charge here? Who is at the helm? This ship needs a captain! You ask us, what do we want? We do not know what we want or what is the right thing to do here! Please help us." Then he broke down and cried.

Today, the ship of medicine has been hijacked. Families, insurers, risk managers, plaintiff attorneys, administrators, regulators all declare to the physician, "I'm the captain now! You will do as I say or suffer the consequence!" I fear American medicine is not only without a captain; we apparently have lost our rudder. We are adrift. "Turning, turning in the widening gyre, the falcon cannot hear the falconer...."(Yeats, *The Second Coming*).

There seems to be an endless queue of the profoundly brain damaged,

dying ventilator/dialysis patients in our hospital ICUs, awaiting a nursing facility bed. I am asking the attending physician in each of these cases referred to us with full code status orders, "Do you believe that CPR would be medically effective for this patient?" If the answer is no, then I am asking them to get an ethics committee consultation, if they are unaware of their jurisdictional requirements for writing a DNR order. The discussions and actions necessary to align expectations with reality need to start at the hospital. Otherwise, when medical ineffectiveness is invoked at the long-term care facility, I will be unable to answer the question, "Why did they not tell us this at the hospital?" other than to say, "They should have."

*Rebecca D. Elon, MD, MPH
Chief Medical Officer
FutureCare Health & Management
Corporation*

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.

MCMATH & ETHICS CONSULTATION

In the Winter 2014 issue of the Newsletter, we featured an article about Jahi McMath, the 13-year-old California girl who was pronounced dead by neurological criteria (i.e., “brain dead”) in December, 2013 after complications of a tonsillectomy and adenoidectomy, but whose parents obtained a court order requiring the hospital to continue the ventilator and other medical interventions she was receiving in the hospital’s pediatric intensive care unit (PICU). She was then transferred to an undisclosed facility as her parents hoped for a miracle recovery. The question arose as to whether an ethics committee was involved. The answer is yes. A summary of the ethics committee’s recommendation is appended to an affidavit, which is publicly available at: <http://docs.justia.com/cases/federal/district-courts/california/candce/4:2013cv05993/273213/15/2.html>.

The hoped-for benefits of an ethics consultation in this case may have included: (1) to better inform the judge ruling on the case about ethical and medical standards regarding brain death determination, (2) to facilitate more effective communication between Jahi’s family and hospital staff to avoid intractable conflict leading to continued court intervention, and (3) to help assuage the moral distress of hospital staff involved in this case. Regarding #1, the judge ruling on this case facilitated a negotiation between the hospital and the family that allowed for the transfer of Jahi’s body to an undisclosed facility (without compelling hospital staff to place a gastrostomy tube or perform a tracheostomy). But as for #2 and #3, it appears there was limited involvement of the ethics committee as regards these goals. Accordingly, this case raises questions about the process, role, and value of ethics consultation in similar situations.

Jahi had her surgery on December 9, 2013. She was declared brain dead on December 12. The ethics committee was consulted more than three weeks later, on January 2, 2013. This occurred after a family lawyer became involved (who issued a cease-and-desist letter to the hospital demanding that physicians keep Jahi on the ventilator), as well as a county judge (who compelled the hospital to keep Jahi on the ventilator until a court-appointed pediatric neurologist confirmed her brain death diagnosis, and later, until transfer could be arranged).

Might an ethics consultation have been requested earlier? What should trigger such a consult? Patients die in hospitals every day. We have health care professionals who assist families through this emotional maze. Death alone and the grief that ensues doesn’t in itself constitute an ethical issue or dilemma. But there are several red flags that might single this case out as benefitting from the help of a skilled ethics consultant earlier on. Although public records indicate that Jahi’s surgery was considered high-risk, it was a surprise to those involved that she suffered a hemorrhage and fatal cardiac arrest after the surgery. The family likely had unanswered questions about whether the staff treating Jahi did their best to stop the bleeding and prevent or reverse the ensuing cardiac arrest. As African Americans, Jahi’s family members are more likely to have suffered from health care access and quality disparities and to have questioned whether the health care services they received were “second rate.” Even without these trust roadblocks, conveying to parents that a child undergoing elective (albeit high-risk) surgery has died is a colossal challenge. Add to that the confusion that families often face accepting a

brain death diagnosis (since the patient still “looks alive”), and the added complexity of broaching the topic of organ donation or autopsy to try to determine the cause of death (if either of those topics were discussed), it’s not surprising that Jahi’s family opted to reject the brain death diagnosis and turn to the courts.

The question remains, would it have been appropriate for an ethics consultant to become involved earlier in this case, and if so, how? There is a standard in California, as in other states, of “reasonable accommodation” of family members grieving a patient declared brain dead. The hospital staff initially negotiated a period of time for Jahi’s family that was considerably longer than the usual accommodation for families. This can be depicted as an ethical issue in that it raises questions about justice and fairness (indeed, California law allows the hospital to consider the impact on prospective patients who may be denied a bed). Hospital staff grappled with moral distress as a result, something that is mentioned in the ethics committee’s documentation in the Jahi case. Thus, there may be a role for ethics consultation earlier on to help the staff deal with their moral distress. But as regards Jahi’s family, is there an ethical issue or dilemma warranting interaction of an ethics consultant with them?

The ethics committee at Children’s Hospital and Research Center gave an opinion without involving Jahi’s family. This is consistent with what the Core Competencies for Healthcare Ethics Consultation (ASBH, 2011) refers to as a “non-case consultation,” meaning one that did not involve meeting with the patient or family along with other stakeholders to gather relevant information. Instead, the ethics committee responded to the staff’s request to provide an opinion

about an ethical question that applies across cases like Jahi's—is it ethically appropriate to provide PICU-level technology to a patient declared legally dead? Should hospital surgeons be mandated to place a gastrostomy tube and perform a tracheostomy on a dead body if a transfer option is available? The ethics committee supported the position of the hospital's policy and the hospital staff, concluding that “it is inappropriate to subject a deceased person's body to medically and ethically inappropriate interventions” and that “the hospital and Jahi's health care providers should not be compelled to do so.”

But the perspective of Jahi's family is not represented by the ethics committee. While the facts they provide about the medical, legal, and ethical standard of care for patients declared brain dead would be no different, how the family was involved would likely have been different if the ethics committee were consulted shortly after Jahi's brain death determination. This would be more consistent with ethics “case consultation” as defined by the Core Competencies report.

The hallmark of such an approach is meeting with stakeholders, representing all relevant points of view, leveling power imbalances, and trying to find common interests to work toward rather than arguing over intractable positions. While it appears from court records (available at <http://www.thaddeuspope.com/futilitycases.html>) that the hospital staff did everything they could to support the family and assuage their grief during this difficult time, it's an open question whether an ethics facilitation approach employed earlier would have made any difference in the outcome. Some might argue that involving an ethics consultant is inappropriate in this situation—better a social worker,

chaplain, trusted clinician, grief counselor, or even transplant resource personnel. But if family members are at risk of feeling “wronged,” a trained ethics consultant employing ethics facilitation may allow them to voice concerns and forge a less adversarial path forward. The real question remains, how many ethics consultants are qualified to respond effectively in a case like this?

Another consideration involves the ethic's consultant's role if a family member expresses concern that the patient's death was caused by malpractice or negligence. (There's no evidence to date that the hospital was at fault for Jahi's death.) Should an ethics consultant inform the family of the potential value a timely autopsy might bring in explaining the cause of death? What is the ethic's consultant's obligations in such a scenario—to the patient, the family, the staff, the hospital?

Some states allow for opting out of brain death determinations for religious reasons. This was not the case for Jahi, but raises questions of justice. Some think the issue of resource allocation can be kept out of ‘futility’ decisions like these. I take a different view. I think the role of resource stewardship should be discussed more openly. Jahi was transferred to a private healthcare facility, but her bills are being paid by The Terri Schiavo foundation. For others whose bodies are preserved after death, costs may be passed on to others through health care rate or third party payer premium increases through FICA or other taxes. I believe not discussing this openly thwarts trust-building more so than keeping it in the shadows. Trust-building is essential to keeping such cases out of the courts and finding a resolution that is compassionate, fair, and minimizes regrets and moral distress for those

involved.

*Anita J. Tarzian, PhD, RN
Program Coordinator, Maryland
Healthcare Ethics Committee
Network (MHECN)
Law & Health Care Program, UM
Carey School of Law*

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Brain Death Guidelines/Reports cited by the ethics committee:

- Uniform Declaration of Death Act
- Controversies in the Determination of Death (President's Council on Bioethics, 2009)
- Clinical Report—Guidelines for the Determination of Brain Death in Infants and Children: An update of the 1987 Task Force Recommendations (American Academy of Pediatrics, 2011)
- Ethics Manual (6th Ed.) (American College of Physicians, 2012)
- Guidelines for the Determination of Brain Death (American College of Physicians)

MEDICAL FUTILITY RE-IMAGINED

On April 15, 2014, the Shallenburger Lecture at Johns Hopkins Hospital featured Douglas White, MD, MAS, Endowed Chair for Ethics in Critical Care Medicine, Associate Professor of Critical Care Medicine, and Director of the Program on Ethics and Decision Making in Critical Illness at the University of Pittsburgh Medical Center. White spoke about new conceptions and approaches to medical futility determinations.

The general categories for futility decisions include burdens of one or more medical interventions grossly outweighing the benefits, despite the medical interventions; patients not being able to survive to discharge outside the intensive care unit (ICU); and lack of benefit for patients who are permanently unconscious. Relevant competing ethical considerations in such cases include the patient's interest in living according to his/her values and preferences; clinicians' interests in acting in accordance with their professional integrity; and society's interest in justly allocating medical resources (Truog & White, 2013).

White identified at least three problems with the "mental model" clinicians have of medical futility:

1. Judgments about what is medically futile are not straightforward, as cases hinge on controversial value judgments that rarely involve situations where an intervention is expected to be 100% ineffective (e.g., dialysis can keep patients in persistent vegetative state [PVS] alive).
2. Defining "standard of care" for medical futility determinations is challenging due to the many permutations of how cases present. There are no substantive rules, particularly for 'grey zone' cases.

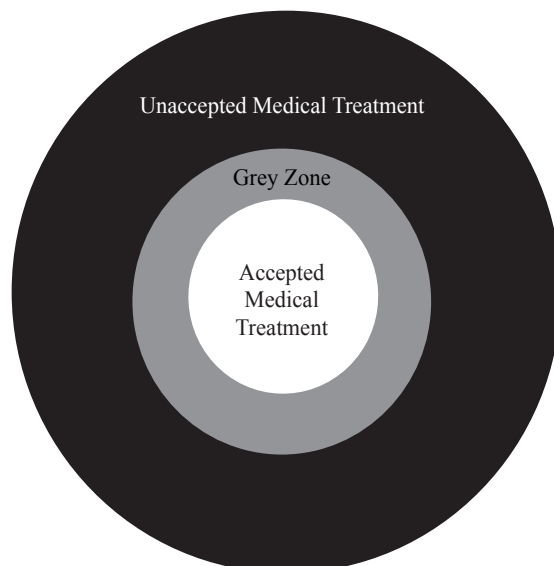
3. Prognostic accuracy is not absolute, and clinicians disagree about how to handle individual cases. For example, in one large survey study, of the 15% of patients whose physician predicted the patient would die before discharge, 15% of those patients lived to discharge (Meadow, et al., 2011). Mebane (1999) found that while only 2.5% of Caucasian physicians preferred aggressive treatment for patients in PVS, 15% of African American physicians favored such treatment.

Alternative Mental Model: Medically Inadvisable Treatment

White proposed a more useful mental model: a circle in the middle representing consensus on accepted medical treatment (e.g., cardio-pulmonary resuscitation [CPR] attempts in a trauma patient expected to recover), an outside circle of unaccepted treatment (e.g., extended ventilator use after death is confirmed via neurologic criteria), and a smaller, middle circle constituting the "grey zone" in between (e.g., CPR attempts in end-stage cancer). White proposes that "futility" is not the best label for the grey zone cases, and proposes instead: medically inadvisable treatment. This refers to treatment that has at least some chance of accomplishing a desired effect, but clinicians believe the following competing ethical considerations justify refusal: (1) it is unlikely to be successful, (2) it is not cost-effective, or (3) it is intended to achieve a goal of controversial value.

The approach to addressing such conflicts is process-oriented. First, clinicians should not conflate any conflict with an intractable conflict,

because the tools to manage them are quite different. Disagreements are common in acute care settings for a variety of reasons. Most can be resolved without unilateral action. The goal, then, is to prevent low-level conflict from escalating to an intractable conflict through proactive communication. Clinicians should be trained in advanced communication skills and if not, should enlist colleagues from palliative care and the ethics consultation service to assist in identifying the causes of persistent disagreement among patients/family members and the treatment team. For example, are disagreements due to lack of information (e.g., misunderstandings about prognosis, conflicting messages from medical specialists involved, lack of awareness about comfort-focused care)? Are emotions of the patient/family affecting the therapeutic relationship with the treatment team (e.g., overwhelming grief, conflict within family, distrust of physicians, inability to act according to patient's values)? Or are there deep moral disagreements about what is in the patient's best interest (e.g., CPR attempts represent trust in God for family and disrespectful treatment of dying patient for staff)? Just as a lung infiltrate requires a specific



medical intervention to remedy, communication breakdowns require specific interventions to adequately address. Only when all has been done to avoid intractable conflict should clinicians proceed to the following process steps.

Proposed Option: Judicious use of procedural dispute resolution strategy

White identified three possible options for addressing intractable conflicts over medically inadvisable treatment, and endorsed the third:

1. Should physicians have all of the authority? No. Variability in physician judgments leads to arbitrariness in decisions, which violates standards of fair decision-making (i.e., “treating like cases alike” and using a fair process to do so). While some patients or family members feel “unburdened” by having a physician “make the hard choice” about withholding or withdrawing treatment at the end of life, this may be overly burdensome for some families who strongly oppose the physician’s decision. Importantly, this removes the incentive for clinicians to do the hard work of finding a negotiated agreement.
2. Should patients/families have all of the authority? No. This may negatively impact the medical profession’s integrity, would likely contribute to an unfair distribution of scarce medical resources, and wrongly conflates negative rights (i.e., the right to refuse medical treatment – a stronger claim) with positive rights (the right to demand medical treatment – a weaker claim). This option may worsen the quality of dispute resolution in cases that are not intractable (i.e., if families have

“all the power,” they may be disincentivized to do the hard emotional/moral work needed to authorize withholding or withdrawing medical treatment when doing so is consistent with the patient’s values) (White & Wicclair, 2012).

3. Should physicians pursue a procedural dispute resolution strategy? Yes. White sees this as the “least-bad option,” to be used only when other strategies fail. Procedural fairness takes on added ethical importance when there are deep disagreements. This includes oversight by a legitimate body (e.g., functioning ethics committee), unconflicted decision-makers, transparency, accountability, and an appeal to reasons that all can accept as relevant. There should be an opportunity for the patient/family to request review and to appeal the decision.

White pointed to Texas’s Advance Directive Act (TADA) as a functioning example of this procedural approach. Of note, the TADA uses the term “medically inappropriate” rather than medically “futile.” TADA steps mirror White’s proposal above, and include the following:

1. The family is given written information about the process to withhold or withdraw medically inappropriate treatment.
2. A designated ethics committee must adjudicate and provide a written report of findings to the family.
3. The family is given 48 hours notice of the ethics consultation and invited to participate in the consultation process.
4. If the dispute is not resolved, the hospital must attempt to transfer the patient to another hospital.
5. The family can ask a court judge to grant an extension, but the

judge cannot evaluate the merits of the case.

6. If no willing provider is found within 10 days, clinicians may unilaterally withhold or withdraw with immunity from prosecution.

White cited the American Medical Association’s Medical Futility in End-of-Life Care policy (1999), which states: “If no transfer is possible, it may be because the request is considered offensive to medical ethics and professional standards ... In such a case, by ethics standards, the intervention need not be provided.” However, White reiterated that the ultimate goal is to avoid using this process whenever possible. In the last issue of this Newsletter (Winter, 2014), we described how Holy Cross Hospital in Maryland has adopted a similar policy.

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'QUALITY ATTESTATION' FOR ETHICS CONSULTATIONS

The process of “quality attestation” of clinical ethics consultants has begun. With funding from The Josiah Macy Jr. Foundation, the American Society for Bioethics and Humanities’ (ASBH) Quality Attestation Presidential Task Force (QAPTF) is implementing a pilot process to evaluate the ability of individuals to perform clinical ethics consultation (CEC), without undergoing a written examination that typically accompanies a professional certification process. Clinical ethics consultants were invited to submit portfolios to the Task Force to help develop the two-step process to gauge their competency. Eighty-two clinical ethics consultants expressed an interest in submitting a portfolio; 40 were randomly selected to submit one, and 32 have done so. Elements of the process are described in more detail in an article published in the *Hastings Center Report* (Kodish, Fins, et al., 2013). The process includes submission of a portfolio and an interview. The required elements of the portfolio include:

- Curriculum vitae or resume
- Copies of diplomas or comparable documents (candidates must have at least a master’s degree in a relevant discipline, but can request a waiver if they have significant CEC experience)
- Summary of candidate’s education and training related to CEC
- Summary of CEC experience, with time frames and settings



- Summary of candidate’s philosophy of CEC, in 500 words or less [i.e., how (s)he recognizes and handles personal beliefs and biases when conducting CEC with others who may or may not share those beliefs, and how (s)he recognizes and addresses institutional bias]
- Three letters of evaluation from individuals with responsibility for clinical oversight who are knowledgeable about the candidate’s CEC activities (e.g., from ethics committee chair, academic ethics faculty member, direct supervisor, clinical service chief, chief medical officer, chief nursing officer, quality improvement director, chief executive officer, or peer; evaluations of the candidate’s consultations collected using a standardized CEC evaluation tool are also accepted)
- Six case discussions of consultations in which the

candidate acted as lead or co-lead consultant and authored or co-authored the chart note/consult documentation, with discussions that demonstrate CEC practice in a variety of clinical settings with a variety of ethical issues; evidence of competency can be demonstrated using sources such as redacted consultation chart notes that include the case narrative, synopsis of relevant ethical issues, ethical analysis, and recommendation(s), and minutes of a case conference or ethics committee meeting

- Six one-page descriptions of additional cases that evidence CEC experience in a wide range of clinical settings and/or with a wide range of ethical issues

As Kodish and colleagues summarized (2013, p. 29): “As other activities in health care have been subjected to methods of measuring quality, it has become ever more apparent that there are no basic qualifying, certifying, or credentialing requirements for clinical ethics consultants.” This is anticipated to be the first step in that process.

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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.

The case (submitted by Evie Marcolini, MD, FACEP, FAAEM) and commentary (by Anita Tarzian, RN, PhD and Eric K. Shepard, MD, FCCM) are reprinted with permission from the Society of Critical Care Medicine. The original work was published in Critical Connections 2013; Vol. 12, No 6, available at www.sccm.org/criticalconnections.

The ethics team was consulted for a middle-aged man with a diagnosis of stage IV adenocarcinoma with multiple abscesses and a large eroding intra-abdominal mass. He is being treated with intravenous medications, including broad-spectrum antibiotics and antifungals for recurring intra-abdominal sepsis/infections. He has developed a small bowel-to-colon fistula that is not amenable to surgical intervention, placing him at risk for dehydration due to high output. There is no role for chemotherapy while he is actively infected, and he is not a candidate for surgical intervention. He is unlikely to have any therapeutic options in the future.

The medical team requested an ethics consult with a question regarding code status and goals of care. The patient has expressed privately to the team that he does not want any further escalation of medical treatment, although he would be interested in alternative treatment options such as naturopathic therapy. He has also expressed to the medical team that cardiopulmonary resuscitation (CPR) in the case of cardiac arrest seems futile to him, and

he wouldn't be interested in it.

The patient has an extremely close relationship with his wife of many years, who has suffered the devastating loss of her mother within the past year. Her mother's death was complicated by miscommunications among the involved healthcare providers, the hospice team and her family. She articulates very strong feelings that hospice and palliative care leads to patients not having a say in their care; she equates these forms of care to euthanasia. Her feelings are buttressed by her extensive research via the Internet. She has a strong spiritual belief system and believes that many people with terminal illness have conquered their disease with prayer and faith.

The medical team has informed the patient and his wife that naturopathic services are not available within the hospital. These treatments would require outpatient visits once the patient is stable enough to transfer out of the hospital.

Even though the patient has privately expressed to the team that he has no interest in further escalation of treatment or resuscitation in the event of cardiac arrest, when his wife is in the room, he acquiesces to her wishes that everything possible be done, including antibiotics, antifungals, vasoactive agents, intubation as needed, and CPR. He is competent and has a clear mind, and does not want to invalidate his wife's feelings or hurt her; thus, he is able to express his own wishes only when his wife is not in the room.

The medical team is faced with the question of whether to respect the patient's wishes as they are stated privately, or as he states in front of his wife.

COMMENTS FROM AN ETHICS CONSULTANT AND AN ANESTHESIOLOGIST

The obvious ethical question confronting clinicians in this case is whether what's best for this patient (let's call him Marty) is to follow his privately expressed wishes to forgo life-prolonging interventions, or to provide any life-prolonging interventions the patient's wife (let's call her Faith*) requests, based on Marty's acquiescence in Faith's presence. A less obvious ethical question is which medical interventions should be offered to Marty. In acute care settings, consensus surrounding "non-beneficial" medical interventions at the end of life has been reached for some interventions, but not for others. For example, a patient who is declared dead based on neurologic criteria is not typically continued on ventilator support. If surgeons can't achieve the goal of a surgical intervention, they don't offer to operate. For a myriad of reasons, we haven't achieved consensus regarding when other medical interventions no longer benefit a patient who is dying and thus shouldn't be offered. Examples include dialysis, ventilator support, extracorporeal membrane oxygenation, ventricular assist devices, enteral and

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parenteral nutrition and hydration, antimicrobials, blood products, and attempted CPR. Our acute care medical technology has complicated the already existentially complex question of when a person is “dying.” No wonder patients, family members and healthcare providers struggle with determining the right thing to do.

In this case, it appears Marty knows he is dying and prefers to forgo interventions such as attempted CPR, but is open to holistic interventions such as naturopathy. Whatever Marty hopes to achieve from naturopathic medicine (better quality of life, prolonged life, or both), it’s his choice to make, as long as he is adequately informed. Clinicians might even consider helping him evaluate available naturopathic services, including practitioners who visit patients at home or in the hospital. This may be an excellent way of building trust, which is essential to addressing the central ethical question this case presents.

The statement that Marty is “unlikely to have any therapeutic options in the future” needs to be re-evaluated. While surgery, chemotherapy and radiation therapy might not be options, Marty could presumably receive intravenous fluid to address dehydration. What about nutritional supplements – for example, total parenteral nutrition? It’s unclear whether this would benefit him at this stage in his disease. Marty and Faith must be informed about what to expect as his disease progresses, and they should be helped in identifying what role the healthcare team can play in supporting them through his current hospitalization and (if possible) discharge from the hospital.

What’s unclear is whether Marty is willing to accept any life-prolonging intervention to help ease Faith’s distress (and whether he believes this

would ultimately minimize her grief), or if he is passively acquiescing to Faith’s wishes because he can’t bear to see her in distress and doesn’t know how else to address her suffering. It’s the rare individual who knows how to navigate the emotional minefield of end-of-life communication without support from those who have walked the path before. A skilled clinician or ethics consultant should be able to help Marty and Faith articulate their understanding of Marty’s condition and identify their hopes, fears and worries (for themselves and for each other). This is the place to begin a discussion about end-of-life care, not whether Marty should be a “full code” or not. The quality of this communication and support will determine whether the healthcare team has “done everything” to minimize Marty’s and Faith’s suffering and Faith’s future regrets.

Clinicians may mistakenly label someone like Faith as “in denial” and focus their energy on convincing her that Marty is dying and that certain interventions should thus be withheld, such as antibiotics or CPR. The problem with this approach is that it is difficult to establish trust when focusing on interventions that won’t be provided. Also, it may seem disingenuous to worry about how Marty is harmed by these interventions – for example, Marty wouldn’t be conscious during a CPR attempt and would thus be unlikely to suffer (recent accounts of “near-death experiences” during CPR attempts notwithstanding). While healthcare providers may suffer moral distress at providing CPR more for Faith’s emotional benefit than for Marty’s well-being, this shouldn’t be misrepresented as a harm to Marty (assuming he first agreed to full code status).

This case highlights the importance of approaching ethics not only from an analytical perspective but also from a

humanistic perspective. Our healthcare system and society fail to prepare us – intellectually, spiritually and emotionally – for death. Healthcare providers are obligated to help remedy this deficit by supporting both patients facing death and those who love them. This isn’t achieved merely by giving factual information and respecting a patient’s expressed wishes. It requires connecting with the patient and family to gain their trust and developing a plan of care that best delivers what the patient and family truly want and what can be reasonably achieved.

It’s clear Marty values minimizing Faith’s sorrow and future regrets. Yet the assumption that the best way to achieve this is to agree to whatever Faith wants without an open and honest discussion needs to be challenged. Marty and Faith must understand that while no available interventions can stop the progression of Marty’s disease, the team will not abandon them. Faith’s disillusionment with hospice is regrettable, given that hospice services are usually a good fit for someone who wishes to take a more holistic approach to care. Perhaps Faith would be amenable to talking with a trusted hospice provider to help her process what happened with her mother and how Marty’s situation (and a different provider) may yield different outcomes. Faith may also benefit from a counseling or spiritual care referral to process her emotions surrounding her mother’s death, which are likely to complicate her grieving process during and after Marty’s death.

There is no mention of an advance directive here. Absent this, Faith would be Marty’s decision-maker in the event that he loses this capacity. Thus, it is important that Marty understands the implications here: if he makes his wishes known in the form of a living will or oral advance directive, this might take away a perceived burden that Faith is deciding

“when he dies”; yet, if he feels that she would be better off, emotionally, opting for whatever life-prolonging interventions are offered, then he may decide to defer to her wishes, which would be his right as long as his choice is free and informed. At that point, the medical team would draw boundaries on what life-prolonging interventions would be available to Marty. It’s not uncommon in end-of-life care to provide some interventions more for the benefit of loved ones than for the patient. However, if skilled end-of-life communication were more accessible, we would see fewer cases where “doing everything” for a dying patient is equated to providing interventions that merely prolong the dying process, probably increase the patient’s discomfort and isolation, and questionably help family members assuage their grief. Regardless of whether Marty dies a “natural” or a “high-tech” death, he and Faith deserve the best of what palliative care has to offer.

*For brevity, mention of other loved ones involved in Marty’s and Faith’s lives was omitted, but these individuals should also be considered.

*Anita Tarzian, RN, PhD
MHECN Program Coordinator
Associate Professor,
UMB School of Nursing*

*Eric K. Shepard, MD, FCCM
Assistant Professor of Anesthesiology
University of Maryland
Medical Center*

COMMENTS FROM A HOSPICE SOCIAL WORKER

To honor Marty’s wishes for no further aggressive treatment (which he verbalized in private) or to honor Marty’s acquiescing to his wife’s wishes that he “not give-up”... that is the question. Cases like these can cause angst and frustration in staff members. During these periods of stress, it is critical that the staff remain

focused on who the client is and what is the plan of care. If confusion exists regarding the plan of care, the staff must work collaboratively to achieve clarity. Most ethical dilemmas are the result of poor communication and lack of understanding; however, there are times when true ethical problems emerge. The staff must consider the four core ethical principles of justice, autonomy, non-maleficence (least harm), and beneficence when evaluating a dilemma. True ethical problems emerge when there is a conflict between these core values. Understanding this conflict can pave the way to resolution.

In the above case study, there are multiple issues at hand, including miscommunication on the part of Marty to the hospice team and to his wife. There is also a conflict between the two core ethical principals of autonomy and non-maleficence. As mentioned previously, Marty has the right to voice his wishes, however, he is expressing two different desires depending on his audience. The problem for the staff in regards to non-maleficence is that Marty has voiced no desire for further aggressive treatment and he has demonstrated an understanding that it will do him more harm. The team is aware that further aggressive treatment will cause more pain and may be futile. The team is caught between respecting Marty’s autonomy to make his own decisions and causing him the least amount of harm. That leads us again to the ultimate questions: How does the hospice team respect Marty’s autonomy when Marty is not clearly articulating his wishes, and how does the team cause him the least amount of harm?

Establishing rapport and promoting open communication between the staff, Marty, and Faith is fundamental with any case but especially in this scenario. Marty and Faith need to see

that they are active participants in establishing the plan of care, and to do this, the team must address the current miscommunication. The team needs to empower Marty to communicate his wishes clearly to the team and his wife. Prior to this dialogue, the team needs to support Marty as he evaluates what he truly desires with his end-of-life care. It is important to help Marty take ownership of the situation. By doing this, it conveys that HIS wishes and values are driving HIS care. In addition, the team must assess both Marty’s and Faith’s understanding of his diagnosis and prognosis in order to ensure that they are making truly informed decisions.

To alleviate speculation and obtain answers, dialogue between the social worker and Marty should be explored. The following is an example of a possible conversation:

Social Worker: “Marty, the team and I wish to honor your wishes and respect your plan of care. In order to do this I need some clarification. Is that okay with you?”

Marty: “Sure, that’s fine.”

Social Worker: “Thank you. Privately with the nurse you verbalized you desired no further escalation of treatment and that you would not want to have CPR if your heart stopped. Is that correct?”

Marty: “Yes.”

Social Worker: “But when the conversation was reviewed with you and your wife, you opted to have every treatment option. Is that correct?”

Marty: “Yes... I don’t know... yes. Whatever Faith wants.”

Social Worker: “We want to respect your wishes and be sensitive to Faith as well. Why do you think she wishes for you to continue with all

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treatment?”

Marty: “We have a strong faith. We believe that Jesus will heal. She just lost her mom. They were so close and she is hurting badly. I want to protect her from more pain.”

Social Worker: “It is clear that you both have a close relationship with lots of love. I can understand your desire to protect her given her recent trauma. I’m sorry that you both are experiencing this, yet again.”

Marty: “Me too...Me too.”

Social Worker: “My question for you is: do you feel having any other tests will be beneficial to you? Will they enhance your quality of life?”

Marty: (sigh) “No ... but she’s not ready.”

Social Worker: “Are you ready?”

Marty: (pause) “Yes...I am ready. I’m just so tired.”

Social Worker: “Have you spoken to Faith about how you feel?”

Marty: “No ... I haven’t. I don’t want to burden her.”

Social Worker: “I can appreciate that, but in order for us to respect your wishes, we need to have a clear understanding of what they are and right now, we don’t. If you wanted, I could support you and Faith in discussing your feelings and concerns. I would also be available to provide any information that is needed and to answer any questions that you or she may have. Would you be receptive to this?”

Marty: “We could try it ... she is still going to want me to do everything.”

Social Worker: “Throughout your relationship I am sure you have had challenges and things you have not agreed upon.”

Marty: (laughing) “Ain’t that the truth!”

Social Worker: “How did you handle it?”

Marty: “Well, it depended on the issue. Sometimes I would just go with whatever Faith wanted but other times, we would discuss it.”

Social Worker: “How did those discussions go?”

Marty: “Really well. Yeah, often, really well.”

Social Worker: “Do you think this situation warrants a discussion between you and your wife? You know her better than any of us and you know how best to support her. We want to be able to support both of you.”

Marty: “It is worth a try. I may still go with everything ... I just love her so much. But I can try.”

Social Worker: “One last question. If your wife says that she wants you to have everything done, regardless of the outcome, you will go along with her wishes. Is that correct?”

Marty: “Yes.”

Social Worker: “Just clarifying, if she says she wants you to have treatment and CPR, you will agree. You want to be a full code, correct?”

Marty: “Yes.”

This dialogue can go in many different directions but the point is that it has been initiated and communication is occurring. The social worker is there to guide and provide support, reinforcement, reflection, education, and clarification when needed. Initiating these conversations are not easy because of the permanency they represent ... death. Everyone knows they are going to die, but it is not going to

happen to them ... or their loved ones. The hospice team’s role is to provide education and guidance to both the patient (our client) and to the family as they navigate their emotions during a time when their reality has been altered. It is also to help them normalize the dying process and the changing relationships it creates. Everyone learns at their own individual pace, manages stress uniquely, and reacts to extenuating circumstances in various ways. In this case, Faith is clearly grieving due to the recent loss of her mother and her negative experiences with that hospice team. This grief and her anger towards the situation are impacting how she perceives her husband’s treatment. It is critical that the staff not only establish open communication with Marty, but with her. Actively listening to her, helping her verbalize her frustrations, and working to ameliorate her anxiety during this experience will demonstrate respect and validation. It appears that Faith is projecting her anger from her recent loss and hospice experience onto the current team. This is her emotional defense at having her world altered yet again in a devastating way. Helping to empower her and her husband can ease that stressor and lack of control that she is experiencing.

Regardless of the outcome, the team’s role is to be respectful of Marty’s wishes and to seek clarification when they are not clear. Providing education regarding the burdens and benefits so that the patient and the family can make educated decisions is a necessity, and honors the patient’s autonomy. Maintaining open dialogue with the family, seeking clarification when needed, and being respectful of their relationships and dynamic help the team to navigate these ethical dilemmas. Throughout

the entire process it is imperative that clear and thorough documentation exists regarding how the team has worked to ameliorate the ethical conflict. Finally, trying to remain objective during these dilemmas,

maintaining healthy professional boundaries, and being supportive of the hospice team, can prevent the plan of care from becoming derailed and reduce the level of anxiety experienced by the team, caregivers,

and most importantly, the client.

*Joni Newby, MSW, LCSW-C
Hospice Social Worker
Seasons Hospice & Palliative Care
of Maryland*

SPOTLIGHT ON COMMUNICATION FROM A PALLIATIVE CARE SOCIAL WORKER

When there are conflicts between a patient's wishes and family members' wishes it is best to get everyone in one room for a family conference. Below are a few examples of ineffective and effective hypothetical family conferences with Marty and Faith.

Family Conference #1:

The following takes places in Marty's room. His wife is at the bedside and the attending physician (Dr. A.) comes in alone with a few resident doctors and the bedside nurse.

Hello, I'm Dr. A. and we wanted to discuss with both of you how your husband is doing. Unfortunately, we have reached the limits of what can be done medically. You are too sick to get any further chemotherapy and you are not currently a candidate for surgery. I'm afraid there is nothing more we can do.

Faith: There has to be something that can be done.

Dr. A.: Well, your husband has expressed to the team that he does not want any further escalation of care.

Faith: (to Marty) Is that really true?

Marty: Well no. We discussed options for naturopathic services.

Dr. A.: We can't do that here in the hospital. I think you should consider hospice care.

Faith: No. That is not what we want.

Dr A: I know how you feel, this is difficult. I wish there was something we could do. Why don't you both think about options and we will come back.

Family Conference #2

The palliative care social worker schedules this meeting ahead of time. This allows someone from the team to get to know Marty's wife. This meeting includes the palliative care physician (Dr. P.), bedside nurse, palliative care social worker and resident.

SW: Thanks for coming in today. It's nice to meet you. We wanted to take this time to discuss how we can continue to work together to help you and your husband. I work on a team here in the hospital and as I mentioned on the phone we are often asked to get involved with seriously ill patients to see how we can be helpful. What is your understanding of your husband's condition?

Faith: Well the doctors told me, there was nothing more that could be done.

Dr. P: Well, first, would you mind telling what the last few months have been like for both you and Marty?

Faith/Marty: Both spend the next twenty minutes explaining how the last few months have been for them.

SW: It sounds like you both have been through a lot the last few months. This must be so difficult for both of you. Marty, what are you worried about?

Marty: My wife.

SW: I thought you might say that. Tell me more about that.

Marty: I'm worried about her, being

Family Conference #3

This meeting takes place in a quiet family meeting room. The palliative team and primary team attend along with Faith.

Dr. P.: I thought you might have some questions you wanted to ask us, outside the room.

Faith: Thank you. I'm worried that at home his death will be painful. I don't want him to suffer.

Dr. P.: We can make sure he is comfortable. The hospice team are experts at taking care of patients at the end of life.

Faith: I feel like hospice is where you start a morphine drip and people die quickly.

SW: That is a common misunderstanding of hospice care. We hear this often.

Faith: I believe that God can perform miracles.

SW/Dr. P.: Yes.

Faith: I don't want to be responsible for killing my husband.

SW: Tell me more about that.

Faith: I would be worried about giving him too much medication. I don't like morphine. When I gave my mom morphine she died right after. (Starts crying.)

SW: I'm sorry for your loss. That must have been difficult for you. (Hands Faith a box of tissues, strokes her back.)

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Communication

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Family Conference #2 cont'd:

alone after I'm gone. I'm not worried about dying. I believe everything is in God's hands.

Dr. P.: That is true. A lot of this is out of the doctors hands and in God's hands. What have the doctors told you about the cancer?

Marty: He said that I'm too sick to get chemotherapy. Any further treatments would be harmful.

SW: Do you feel like the doctors have given up on you?

Marty: Yes.

Dr. P.: I'm sorry to hear that. We never stop caring for our patients, even when a cure is not possible.

Faith: There must be something that can be done.

Dr. P.: There are always things that can be done. What are you hoping for?

Marty: To be able to spend time with my wife.

Dr. P.: You would like to be at home for whatever time God is going to give you?

Marty: Yes

Dr. P.: How do you think we can all work together to accomplish this?

Marty: Well, my grandma died at home.

Dr. P.: I see (long pause)

Marty: Faith, do you remember? She had those people come in ... they helped with her bathing, and medication.

Dr. P.: Hospice?

Marty: Yes.

Dr. P.: What is your understanding of what hospice is?

Faith: Hospice is a place you go to die. We don't want that.

Dr. P.: Well, actually you can have hospice at home.

Faith: I'm not sure that is what we want.

Marty: I'm tired. I don't want to be in the hospital anymore. I don't want to die here.

Dr. P.: Marty, do you mind if we talk with your wife a little more about the details about getting you home?

Marty: Sure.

Family Conference #3 cont'd:

Dr. P.: (after a pause) What you are talking about are all normal feelings and fears regarding end of life. Other medications can be offered instead of morphine, although morphine is very good at managing symptoms. Also, the way we give morphine to treat symptoms, it is not common that it hastens death the way people think. The goal of hospice includes comfort, dignity and peace. It's not about hastening death.

Faith: I don't want to lose him.

SW: I'm sorry. We can see how much you love and care for your husband. He is very fortunate to have you.

Faith: Thanks. I would prefer to have him home. We need to talk more about this.

Dr. P.: Yes and there are a few more things we need to discuss with Marty. We are here to help you and Marty through this difficult time. We should plan on meeting again tomorrow.

Another meeting would need to take place to discuss again with Marty about code status and to finalize the hospice plans.

The above examples illustrate the importance of listening and language. In the first example the doctor's statement's "further escalation of care" and "there is nothing more that can be done" can confuse and anger patients and families. While for Marty there is a lack of "curative medical interventions," this does not mean one would not "escalate care." The statement "there is nothing more that can be done" is never true. The language we choose is powerful and most clinicians are unaware that the language they use can be hurtful (Altilio, 2011).

The ability to listen is a skill that clinicians need to master. Rita Charon refers to clinicians being able to master "listening to narratives of illness" (Charon, 2006). She argues that narrative medicine offers hope in creating a more effective health care system. In Marty's case, taking the time to listen to his narrative allowed the team to realize what Marty and his wife both wanted was for him to be at home and no longer suffering. As clinicians it's important to remember that patients will likely not remember you for the excellent lumbar puncture, biopsy or correct antibiotics you gave them for an infection; they will remember the doctor, nurse, pharmacist, and social worker that took the time to listen.

*Anne M. Kelemen, LCSW-C, ACHP-SW
Palliative Care Social Worker
MedStar Good Samaritan Hospital*

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- Altilio T. (2011). The power and potential of language. In: Altilio T, Otis-Green S, eds. Oxford Textbook of Palliative Social Work. New York, NY: Oxford University Press, 689-695.
- Charon R. (2006). Narrative Medicine: Honoring The Stories of Illness. Oxford University Press: New York, NY.

CALENDAR OF EVENTS

JUNE

9-13

Bioethics Intensive, sponsored by The Johns Hopkins Berman Institute of Bioethics, Baltimore, MD. For more information, visit <http://www.bioethicsinstitute.org/education-training-2/bioethics-intensives>.

12-14

Conflict Resolution and Bioethics Mediation for Healthcare. Sponsored by the Alternative Dispute Resolution Institute, Memphis, TN. For more information, visit: http://www.adrinst.com/mediation_training_healthcare_industry.htm.

16-17

4 Day Intensive Course in Bioethics Consultation Skills, sponsored by Montefiore-Einstein Center for Bioethics, New York, NY. Pre-requisite is the Montefiore-Einstein Certificate Program in Bioethics and Medical Humanities or permission of instructor. For more information, visit <http://www.einstein.yu.edu/masters-in-bioethics>.

16-20

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18-20

Harvard Clinical Bioethics Course, Sponsored by Harvard Medical School, Boston, MA. For more information, visit: <http://cme.med.harvard.edu/courses/bioethics>.

20 (8A-12N)

Ethics and the Affordable Care Act: What it Means to You, Your Patients, and Society. 4th Annual Judy Levy Ethics Workshop, sponsored by Department of Social Work at Kennedy Krieger Institute. Sheppard Pratt Conference Center, Towson, MD. For more information, contact Linda Friend at 443-923-2802.

23 (12:15-1:30P)

Berman Bioethics Seminar, sponsored Berman Bioethics Seminar, sponsored by The Johns Hopkins Berman Institute of Bioethics, 615 N. Wolfe Street, Baltimore, MD, W3008. For speaker information and topic, visit <http://www.bioethicsinstitute.org/>.

JULY

18-19

New Opportunities, New Challenges: Exploring the Ethical Boundaries of Pediatric Research, 10th Annual Treuman Katz Center for Pediatric Bioethics Conference, Seattle, WA. For more information, visit: <http://www.seattlechildrens.org/pediatric-bioethics-conference>.

AUGUST

4-8

27th Annual Summer Seminar in Health Care Ethics, sponsored by The Department of Bioethics & Humanities at the University of Washington School of Medicine. For more information, visit: www.uwcmce.org.

14-17

Intensive Workshops in Clinical Ethics Mediation, sponsored by The Penn Department of Medical Ethics and Health Policy, University of Pennsylvania, Philadelphia, PA. in their role in the healthcare system. For more information, visit: http://medicalethics.med.upenn.edu/uploads/media_items/take-a-course-form.original.pdf.

SEPTEMBER

18-19

Fourth Annual Western Michigan University Medical Humanities Conference, Kalamazoo, Michigan. For more information, visit <http://www.wmich.edu/medicalhumanities/conference2014/>.

OCTOBER

9-11

Conflict Resolution and Bioethics Mediation for Healthcare. Sponsored by the Alternative Dispute Resolution Institute, Memphis, TN. For more information, visit: http://www.adrinst.com/mediation_training_healthcare_industry.htm.

16-19

16th Annual Meeting of the American Society for Bioethics & Humanities. San Diego, CA. For more information, visit <http://www.asbh.org/>.

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