



MID-ATLANTIC ETHICS COMMITTEE

NEWSLETTER

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
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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

HCEC PEARLS AND PITFALLS: SUGGESTED DO'S AND DON'T'S FOR HEALTHCARE ETHICS CONSULTANTS

The following excerpt is from an article by Joseph A. Carrese and the Members of the American Society for Bioethics and Humanities Clinical Ethics Consultation Affairs Standing Committee. HCEC Pearls and Pitfalls: Suggested Do's and Don't's for Healthcare Ethics Consultants.

HCEC PEARLS AND PITFALLS

1. Don't assume that the question you are asked to address is a matter of ethics, or that it is the primary issue or the only issue. Do take the time to clarify for yourself (and your team) the following: What are the relevant concerns, and are they a matter of ethics?

Those requesting an ethics consultation recognize that a problem exists. However, they may not be able to accurately determine whether the problem is truly a matter of ethics or not, and even if they can, they may not be able to correctly articulate the precise nature of the ethical concerns (that is, the values about which there is uncertainty or conflict). Further, requesters may not appreciate that, in addition to the question(s) they have raised, other important ethical concerns may be involved. One important task for HCECs, then, is to determine if the request is appropriate for ethics consultation and, if so, to clarify the ethical concern(s).¹ If the request does not involve an ethics question (that is, what should be done in the face of uncertainty or conflict

about values), it should be referred to other resources in the healthcare system that are better equipped to handle such requests. For example, if the requester is seeking a legal opinion, he or she should be referred to legal counsel. Similar to making a diagnosis in clinical medicine, where precision in diagnosis leads to appropriate intervention, clearly and accurately identifying and describing the ethical concerns in an ethics consultation will more likely lead to a correct and helpful analysis and appropriate recommendations. Another parallel to clinical medicine is that, as the case unfolds over time, new issues may emerge. An initial set of questions, even when addressed and resolved, may lead to awareness of new ethical issues as the case evolves. The consultant should be attentive and open to this possibility and revisit the ethics question(s) in the consultation, as needed.

2. Don't conduct ethics consultations a different way each time. Do have a standardized and systematic approach for gathering, analyzing, and synthesizing information.

“Excellence is an art won by training and habituation: we do not act rightly because we have virtue or excellence, but we rather have these because we have acted rightly; . . . we are what we repeatedly do. Excellence, then, is not an act but a habit.”² Excellence in ethics consul-

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Do's and Don't's
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tation, as in any other pursuit, is not an accident. It is borne of commitment, training, and the habit of approaching our work with high standards and rigor, every single time we do a consultation. One strategy for facilitating high quality ethics consultation is to have a standardized process for conducting consultation that is thorough, systematic, and employed every time. Approaching one's work differently each time increases the likelihood of omissions and mistakes. Many strategies for conducting healthcare ethics consultations have been suggested.³ We do not endorse a particular strategy; rather, we urge HCECs and consultation services to select and use one strategy consistently—that is, to make it a habit, so that quality is enhanced and excellence can be achieved.

Another advantage of a consistent approach is that, over time, those who request assistance from HCECs learn what to expect.

3. Don't come to premature closure about the issues involved and the options available. Do take the time necessary to be thorough in each step of the consultation process.

One basic rule in clinical medicine is resisting the temptation to arrive at a conclusion prematurely.⁴ Instead, the preferred approach is to be careful, deliberate, and thorough before arriving at a conclusion. The same applies to healthcare ethics (HCE) consultation. Thoroughness in all phases of the consultation process may take more time, but this approach is more likely to result in sound recommendations. HCE consultants should adhere to a systematic approach for gathering information (such as one of those referenced in Pearl 2) that begins with careful chart review (for case consultation), proceeds to interviewing stakeholders, and includes careful reflection along the way. Similarly, a thorough approach should be employed when analyzing the gathered

information and when identifying, and, in turn, evaluating, ethically acceptable options. One strategy to contemplate when considering this “Pearl” is to periodically ask oneself and others involved in the consultation the following questions: Have we missed anything? Is there anything we haven't considered or anyone from whom we haven't heard? Have we accounted for all relevant perspectives? Are we aware of our assumptions and have we assessed them? Are there other possible explanations for what is happening? Have any new issues emerged since we started the consultation? Have we challenged ourselves to think creatively to identify additional ethically supportable options?

4. Don't conduct informal “curbside” consultations when making recommendations about a specific patient. Do conduct formal case consultations that are documented in the patient's medical record.

There are times when physicians and nurses ask HCECs for advice over the phone or in the hallway and there can only be a brief exchange of information and ideas. Staff may desire a quick answer and may want to avoid initiating a consultation process that may take some time to complete. Forces conspiring to truncate the ethics consultation process can, at times, be very significant. A concern related to quick, curbside consultations is the possibility of incomplete appreciation by HCECs of all of the relevant facts and considerations. This in turn could lead to inappropriate or unfounded advice. In contrast, a formal, deliberate approach to gathering information and discussing the issues that have been raised enhances the likelihood that the process and outcome will be of the highest quality. In addition, a telephone or hallway conversation is not captured in the medical record, and is therefore not available for other members of the healthcare team to review

and reflect upon. A carefully written formal consultation note placed in the medical record is available to others and serves as evidence that important issues in the case were carefully considered by HCE experts.

However, despite the preference for formal consultation, HCECs should be sensitive to the needs and limitations of those who may desire their services but are not willing or able to engage in a formal case consultation process. Consultants should develop strategies for being responsive, engaged, and helpful, even when a formal case consultation is not being requested.⁵ For example, it is acceptable for HCECs to educate and offer generic advice to colleagues. An HCEC might be asked by a colleague to review and explain the key steps in assessing decision-making capacity, as a point of general information. Similarly, an HCEC, before being invited to undertake a formal case consultation, might advise careful communication between key stakeholders (such as a meeting between staff and family members). The key issue here is role clarification. There is an important distinction between providing general education or coaching about communication principles and giving specific advice about a particular patient that may lead to important decisions about that patient's medical care. HCECs need to be aware of this distinction, be clear about their role, and avoid offering specific advice about a particular patient unless it is in the context of a formal case consultation.

5. Don't allow the HCE consultation discussion to be dominated by particular individuals. Do be facilitative, inclusive, and a good listener.

The work of an HCEC, by definition, involves interaction with multiple parties, including patients, family members, and staff. Clearly, either in one's role as a member or as a leader of a consultation team, it is essential to ensure that all perspectives are given voice and that all stakeholders feel

included and respected. If one person dominates the conversation, there is a risk that important information will not be communicated. Attention to core dialogue skills such as suspension of judgment, identification of the assumptions being made, skilled listening and inquiry, and reflection helps to create an inclusive, facilitative process.⁶ This "ethics facilitation approach"⁷ decreases the likelihood of missing crucial information and enhances the probability of arriving at an optimal understanding of the situation.⁸

6. Don't assume your written consultation note will be understood without verbal communication. Do use the consultation as an opportunity to engage healthcare staff in direct conversation to explain and teach.

One basic premise of optimal HCE consultation is optimal communication. Usually this means direct verbal communication with members of the requesting service to review key recommendations and associated reasoning, in addition to generating a written consultation note.⁹ Direct verbal communication increases the likelihood that consult participants will understand the specific ethical concerns raised during the consultation, in part by creating an opportunity for questions to be asked and addressed. In this way, direct verbal communication reduces the risk of confusion or misunderstanding. In addition, many HCECs consider teaching and education to be part of their core mission—that is, to help those involved learn to work through ethical uncertainties and disagreements on their own.¹⁰ Engaging members of the requesting service in conversations throughout the consultation process is one way to fulfill the HCEC's teaching mission.

7. Don't assume you are doing a good job. Do invite evaluation of your consultations from those requesting and/or participating in them.

A basic principle of quality improvement is to evaluate what you are doing. One way to evaluate ethics consultation is by getting feedback from end users.¹¹ While hard work and good intentions are important, they alone don't ensure that HCECs are doing the best job possible. For example, ethics consultants have blind spots like everyone else: interactions may be perceived by others as suboptimal in ways that HCECs cannot appreciate. Inviting feedback about specific aspects of the consultative process from those who requested and participated in the consultation is a useful way to better understand what is going well and what needs attention and improvement. The Department of Veterans Affairs Integrated Ethics initiative has many useful resources, including an evaluation tool that can be used to assess participants' perceptions of consultation performance.¹² Using this tool or a similar evaluation instrument after every consultation, combined with periodic review and discussion of aggregated feedback results, is an important step toward making necessary adjustments and providing better ethics consultation services. Examples of domains about which HCECs might invite feedback include respecting the opinions of the requestor, giving useful information, explaining effectively, clarifying decisions to be made, clarifying appropriate decision makers, identifying and describing ethically supportable options, and being accessible and timely.

8. Don't assume that everyone who needs an ethics consultation will know that they need one, or even know that a consultation service exists. Do engage in outreach to raise awareness about the existence and role of the HCE consultation service.

Fox and colleagues found that 80 percent of U.S. hospitals and 100 percent of hospitals with 400 or more beds have an ethics consultation

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Do's and Don't's *Cont. from page 3*

service.¹³ However, patients, family members, and members of the hospital community who may be involved in patient care and who may be in a position to request an ethics consultation may not be aware that a consultation is needed, or they may not be aware of the existence of the HCE consultation service as a valuable resource. Lack of awareness that an ethics consultation is needed could be addressed by informational and educational outreach in a variety of forums in both the community and in the healthcare facility. The goal of these efforts should be to increase understanding about clinical ethics concerns and raise awareness about the HCE consultation service as a resource for addressing these concerns. HCECs should be mindful of how they describe and market the ethics consultation service to avoid the common misconception that requesting an “ethics consultation” means that someone has done something “unethical.” In this regard, it may be more useful and less threatening to describe an ethics consultation as a way of protecting a “moral space” for staff to reflect on complex issues.¹⁴

9. Don't assume that everyone who wants an ethics consultation will feel empowered to ask for one. Do take action to reduce barriers to consultation requests.

Individuals who may be in a position to request an ethics consultation may not feel empowered to request one. Lack of empowerment among healthcare providers to request a consultation may occur for a variety of reasons, including a suboptimal work environment, suboptimal relationships with colleagues, or fear of retribution for “rocking the boat” or “whistle-blowing.” Some of these potential reasons may be related to a staff member's location in the organizational hierarchy.¹⁵ An unfortunate consequence of this situation is that

moral distress is often suffered by staff members who believe that requesting an ethics consultation is the right thing to do, yet who feel uncomfortable requesting a consultation, either because the risks are too high or they are actively prevented from doing so.¹⁶ Lack of empowerment among patients or family members to request a consultation may relate to fears of offending members of the healthcare team. Strategies for addressing these barriers include clear institutional policies and procedures asserting open access to HCE consultation;¹⁷ and ongoing outreach and education by HCECs. Education should be directed toward staff, who may desire an ethics consultation but who are not able or willing to request one over and against resistance by others, and those who are likely to be resisting a consultation request in the first place. Attention should be paid to how the service is described and marketed, as mentioned in Pearl 8.

10. Don't confuse legal considerations with HCE consultation. Do recognize the appropriate roles and contributions of legal considerations in HCE consultation.

While legal considerations (including risk management and legal precedent) and ethical concerns related to a particular case may overlap considerably, they are not synonymous. This is not surprising, because their ultimate purposes differ, and the key stakeholders may be different. For example, in risk management, one goal is institutional protection, and the key stakeholder is typically the institution itself. For HCE consultation, the ultimate goal is arriving at healthcare decisions that are ethically optimal and defensible, and the key stakeholder (particularly in a case consultation) is typically a person, such as a patient or a staff member. Similarly, while legal considerations (such as case law or relevant state/federal legislation) may be very germane and inform ethical thinking about a case in important ways, what legal counsel might advise

may differ from what the HCEC might recommend. Accordingly, the HCEC must resist the temptation to simply follow the guidance of legal counsel or risk managers, and instead arrive independently at positions and recommendations based on ethical principles and considerations.

11. Don't be too sure of yourself. Do embrace the complexity of each case with a healthy dose of humility.

Humility in an ethics consultant is a desirable, if not necessary, trait. Important features of humility are self-awareness, careful reflection, and a respectful attitude towards others. There are many reasons to embrace humility: the absence of a clear, right answer; the uncertainty often present in clinical medicine that permeates many cases for which HCE consultations are requested; the fact that reasonable people can and often do disagree about how to regard the same set of facts; the reality that consultants' abilities to know and understand are limited and imperfect. In addition, humility may have the added value of positioning a consultant to be open to and even actively seek alternative perspectives, which may lead to a more complete process, and ultimately to better consultations. Finally, humility may help consultants appreciate the boundaries of their role and serve as a check to overstepping their authority during a consultation.¹⁸ Humility, therefore, is the proper disposition of consultants.

12. Don't do it all on a shoestring. Do advocate for adequate resources and support for yourself and your fellow consultants.

In an era when most of us are accountable to someone for how we spend our time, and for how our time is supported, securing adequate resources for the important work we do is essential. Otherwise, the risk is that the time we are able to spend on this work is shortchanged, and the goal of conducting high quality consultations is threatened. There are many aspects of HCECs' work that could benefit

from financial support. A partial list includes: continuing education related to ethics consultation, and to clinical ethics more broadly, for members of the consultation team; educational sessions provided by the institution's HCEC(s) for staff and for the greater community; compensation for time spent doing HCE consultations. HCECs should establish effective working relationships with institutional administrators to address the issue of adequate support for their work, broadly defined.

The full text of this article is available in the Journal of Clinical Ethics, Fall 2012, volume 23, number 3, pages 234-240. For permission to alter this document in any way, contact Joseph Carrese at jcarrese@jhmi.edu).

NOTES

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FEATURED WEBSITES

In this section, we highlight two websites that may be useful resources for ethics committees.

MARYLAND MOLST

<http://marylandmolst.org/>

The Maryland Medical Orders for Life-Sustaining Therapy (MOLST) website is dedicated to educating patients and health care professionals about the MOLST form. It contains information for consumers and health care professionals about the purpose of the form, how to complete it, and how it should be used to assist in end-of-life care. Readers can also view a list of future train-the-trainer sessions.

The final Maryland MOLST regulations and form became effective on January 1, 2013. Beginning July 1, 2013, certain facilities will be mandated to complete the form for certain patients, including nursing homes, assisted living facilities, home health agencies, hospices, dialysis centers, and hospitals.

ONCOTALK

<http://depts.washington.edu/oncotalk/>

The Oncotalk website is directed toward oncologists and oncology fellows, but is relevant to anyone who wishes to improve their knowledge and skills related to communication at the end of life. Oncotalk faculty include Tony Back, MD, Bob Arnold, MD, Walter Bailey, MD, James Tulsky, MD and Kelly Fryer-Edwards, MA PhD. The faculty have prepared the following downloadable learning modules:

- Introduction to Oncotalk Teach
- Roadmap for a successful teaching encounter
- Setting useful learning goals
- Balancing your commitments to patient & fellow
- Using yourself as a role model
- Feedback that engages fellows
- Closing: Take-home messages that resonate
- Facilitating group learning
- How learners progress

For each topic, there is a background, "how to do it", pearls and pitfalls, and a few key references. The "Tough Talk" section helps clinicians approach difficult conversations with patients, with a host of tools for both learners and teachers, including short video clips demonstrating communication techniques.

The Oncotalk website and materials, funded through a Greenwall Foundation grant, were developed as part of the Oncotalk training program for Oncology Fellows, which was funded by the National Cancer Institute.

Maryland MOLST
Medical Orders for Life-Sustaining Treatment

How do I plan for my health care?

- Home
- About Us
- Consumers
- Professionals
- MOLST Form
- Training
- Resources

Maryland MOLST Train the Trainer Participant

Start by having a conversation with your doctor or nurse practitioner about your current medical conditions and what you can expect in the future. Other professionals, such as physician assistants, social workers, nurses, and chaplains, may also talk with you about these topics. Next, talk with your family and/or anyone else with whom you feel close and decide what medical treatments you want or do not want. Your decisions should be based on your preferences, values, and goals. Remember, you have the right to agree or disagree with medical treatments that are recommended to you.

To help you understand your options and organize your choices, you may use the Health Care Decision-Making Worksheet. You can use this worksheet when talking with a health care professional.

Maryland MOLST (Medical Orders for Life-Sustaining Treatment): This order form makes your treatment wishes known to health care professionals. It includes many sections, but the only sections that are completed are the ones that identify the decisions you've made regarding your treatment preferences. Every time a physician or nurse practitioner completes a MOLST order form, you will receive a copy for your records. If you do not have a Do Not Resuscitate (DNR) order on your MOLST form, medics in Maryland must attempt resuscitation. This form does not expire and it goes where you go - to the hospital, rehab, assisted living, and back home.

Advance Directive: This is a statement of your wishes regarding future medical treatment options. You may also designate who will make decisions for you should you lose the ability to make choices for yourself.

Your health will change over time. You will likely develop new problems. You may decide in the future that you want a treatment that you did not want in the past. As long as you are able to make your own decisions, you can change your advance directive and ask a doctor or nurse practitioner to change your MOLST orders.

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Improving oncologists' communication skills

- ONCOTALK Teach
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Why does Oncotalk have a 9?

CASE PRESENTATION

One of the regular features of this Newsletter is the presentation of a case considered by an ethics committee and an analysis of the ethical issues involved. Readers are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information about patients and others in the case should only be provided with the permission of the patient. Unless otherwise indicated, our policy is not to identify the submitter or institution. We may also change facts to protect confidentiality. Cases and comments should be sent to MHECN@law.umaryland.edu, or MHECN, Law & Health Care Program, University of Maryland Francis King Carey School of Law, 500 W. Baltimore St., Baltimore, MD 21201.

CASE STUDY FROM A MARYLAND HOSPITAL & NURSING HOME

Mrs. K was 101 years old. She enjoyed robust health throughout her life, but experienced progressive cognitive and functional impairment over the last 12 years. She lived with her son's family. Shortly after her 101st birthday, Mrs. K developed lung congestion and lethargy and was taken to an academic teaching hospital. She had no advance directives or any documented conversation with a health care provider about her end-of-life wishes. The physicians asked her son what should be done in the event of a cardiac arrest. Her son took some offense at the question and said, "I want you to do everything for my mother." As the physicians explained what cardiac resuscitation meant in more detail, he became indignant. "So if a young person has a cardiac arrest, you try to save her. But with an old person, you wouldn't even try? You would just let her die?! You need to do everything for my mom. She deserves the best."

After two days in the hospital for treatment of aspiration pneumonia, Mrs. K became more congested and developed respiratory failure. Because of her "full code" status, she was intubated and placed on mechanical ventilation. She developed multiple complications. She was agitated and received sedation. When the sedation was discontinued, however, she did not regain consciousness. She did not respond well to weaning trials, so

a tracheostomy was performed. She could not eat, so clinicians inserted a feeding gastrostomy tube. She developed a sacral decubitus ulcer, and had a Foley catheter in place. On the 27th day of hospitalization, she was transferred to a nursing facility near her son's home, on the mechanical ventilator.

The attending physician at the nursing facility found that Mrs. K could open her eyes in response to verbal or tactile stimulation, but she did not track and did not respond to visual threat. She did not make spontaneous purposeful movements. She withdrew from painful stimuli and grimaced when suctioned. She did initiate breaths, but had visible signs of distress with trials of weaning from the ventilator. Her large stage 4 sacral wound was clean and her gastrostomy tube was functioning well. Her vital signs were stable. She was transferred from the hospital as a full code status patient. Upon nursing home admission, when reviewing the options in the Medical Orders for Life-sustaining Treatment (MOLST) form with the team, her son insisted that "everything be done" to keep his mother alive. The nursing facility attending physician and medical director notified him that cardio-pulmonary resuscitation (CPR) would not be attempted in the event of a cardiac arrest at the facility, because it would be medically ineffective. The son was taken aback by this, asking, "If CPR were medically ineffective, why didn't they tell me that at the hospital?" An ethics consult was

requested to discuss the topic of medical ineffectiveness and to consider what constituted ethically appropriate treatment options for this 101 year-old woman.

COMMENTS FROM A PHYSICIAN & NURSING FACILITY MEDICAL DIRECTOR

As more members of our society live past 100 years of age, the goals of medicine in an aging society are called into question. There are more centenarians alive today than in any other time of human history. The United States leads the world with the greatest number of centenarians, with Japan close behind. The 1950 U.S. census identified 4,440 centenarians in the United States. The number rose to 10,369 in the 1960 census, 32,194 by 1980 and 53,364 by 2010 (Knach & Velkoff, 1999; Werner, 2010). Of those who reach their 100th birthday, about one in 10 will reach their 105th birthday, and one in 1,000 will reach their 110th birthday. Approximately one in 10,000 persons in the U.S. today are expected to live to be 100, while only one in five million are expected to live to be 110. The longest documented human life span was a woman who lived 122 years and died in 1997. Eighty percent of centenarians are women. The burden of disability is very high in the centenarian population, with about 80% experiencing cognitive impairment, and less than 20% reporting no significant functional impairment. Half

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Case Presentation

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of all centenarians in the U.S. live in nursing facilities (Perls, 2004).

In the absence of advance directives, the most important information in guiding medical decision making for the 101 year-old woman in the case study should have been her health trajectory prior to her hospitalization. Regardless of age, a person with a decade long history of a progressive dementing illness that has resulted in functional dependency, incontinence, dysphagia, and weight loss has entered a period of terminal decline. The episode of aspiration pneumonia with respiratory failure is an expected event in the terminal trajectory of dementia. The physiologic reserves in a centenarian are diminished and are not able to withstand or rebound from such an event. When the son asked for “everything” to be done for his mother, the physician should have explained to him that all appropriate and effective interventions would be performed. Procedures that would simply prolong the dying process should not be performed, since they would not provide benefit to the patient. They would not restore health. A patient with this person’s history should not have been intubated and supported on mechanical ventilation, because respiratory failure was an expected part of her terminal illness. The support of mechanical ventilation would not be expected to change her outcome, other than to prolong an inevitable dying process and contribute to unnecessary suffering on the part of the patient. It is also not a justifiable use of health care resources. A decade ago the question was whether every person with dementia had to die with a gastrostomy tube in place. A consensus emerged over the past decade that demented patients do not benefit from gastrostomy tubes at the end of their lives. Therefore their use in demented patients with a terminal trajectory gen-

erally is not recommended (Finucane, Christmas & Travis, 1999). Today the discussion is whether every end-stage dementia patient dying of pneumonia must receive mechanical ventilation when the family requests that “everything be done.”

The primary care physician had a duty to this patient and her family to discuss the typical progression and outcome of her illness long before she presented to the hospital with her acute illness. There were no advance directives, however, and no history of any such discussions having taken place prior to the acute event. In one study, health care proxies of demented patients who were presented prognostic data and understood the clinical complications expected in advanced dementia were less likely to undergo burdensome interventions during the final three months of life. And yet only 18% of the health proxies in the study stated they had received any prognostic information from a physician (Mitchell, et al., 2009). Physicians may not feel capable or confident in presenting prognostic estimates to patients. Prognostic tools are now available online at www.eprognosis.com to help physicians estimate prognosis for elderly patients in various settings and with various clinical conditions.

Physicians in all settings shy away from considering and implementing the concept of medical ineffectiveness. Perhaps some physicians feel that talking about death is a form of elder abuse. Breaking through our deep cultural denial of death, telling our patients “memento mori” (“remember you must die”) may seem to some as unkind. However, it is a greater disservice to older adult patients not to ask about their end-of-life preferences when they are still able to state their opinions. Older adults generally have more realistic expectations about

dying than do their adult children. Physicians may fear being a target for a lawsuit if they do not do the family’s bidding in the absence of advance directives. Avoidance of dealing with hard issues in the name of fear, however, is nothing more than cowardice. In Atul Gawande’s brave new world of “Cheesecake Factory Medicine” (2012), if physicians are simply taking the family member’s “order,” without assessing the effectiveness or appropriateness of the intervention, they are reduced to the role of simply being a “wait staff.” In some settings it is the risk managers who may override the physicians and ethics committee and tell physicians, “Do whatever the family says and wants,” since the hospital does not want to face the threat of a potential law suit from a disgruntled family member. Within a fee-for-service environment, although there may be a moral imperative to discuss prognosis and medical ineffectiveness, there is a profound financial incentive not to do so, for both the physician and the hospital. While medically ineffective treatment and care may be offered as the path of least resistance with a family, the arrival of global budgeting will create a new battleground, as the provision of ineffective medical interventions may not be considered an acceptable expense. It will be interesting to watch the dynamics of global budgeting on clinical decision-making at the bedside. If physicians are rewarded for “cost effective” practice, there may be a not-so-subtle conflict when invoking the withholding of interventions due to medical ineffectiveness. Global budgeting may further the distrust that already exists between some family members and the treating physicians.

Should otherwise healthy, non-demented 101 year-old persons with pneumonia and respiratory failure have a trial of intubation and mechanical ventilation? If it could benefit

them, the answer should be yes. But the change to global budgeting might deny such a person that opportunity in the name of medical ineffectiveness based upon advanced age alone. The physicians in the case presented should have looked to the pre-hospitalization trajectory of illness to guide their prognostication and determination of an ethically appropriate plan of care for this patient.

Medical effectiveness or ineffectiveness of various interventions can depend not only on the specific intervention, but also on the site in which it is being provided. The term “CPR” has many different levels of meaning. For example, if the standard of care in the nursing facility for CPR is to provide basic life support [with or without an automated external defibrillator (AED)] and call 911, CPR attempts would be expected to have a much lower rate of effectiveness than CPR efforts for a patient in an emergency department or intensive care unit in a hospital. In a nursing facility, most cardiac arrests are unwitnessed. When CPR is instituted, it is often performed on patients who have been dead for an undetermined amount of time. CPR is most effective when it is performed immediately in a witnessed arrest, in a monitored patient with full advanced cardiac life support capacity readily available. Patients within intensive care units may request administration of medication for cardiac arrhythmia but no electro-cardioversion. They may request attempts at cardioversion without intubation. The new Medical Orders for Life Sustaining Treatment (MOLST) form process does not take these distinctions into account. Although the MOLST is intended to be valid across sites of care, “code status” and health care preferences should be re-evaluated at every transition of care, to validate the preferences outlined at the preceding site of care,

and to translate those preferences into appropriate and site-specific effective interventions.

The goals of medicine in an aging society should be to promote health and to prevent premature mortality (Callahan, 1987). The question of how to determine what mortality is premature is often problematic. The Centers for Disease Control has historically categorized premature mortality as that occurring prior to age 65. The deaths of some people dying even after the age of 100, however, could be categorized as premature. The goals of medicine for centenarians should be to promote health, to preserve function, to cure acute illness when possible, and to relieve suffering. An essential goal of medicine in an aging society is to be able to recognize a terminal trajectory. Once a person has entered the terminal trajectory, the goal of medicine should be to relieve suffering and to refrain from providing burdensome interventions that will only serve to prolong the dying process.

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COMMENTS FROM A NURSE ETHICS CONSULTANT

The ethical issues at the center of this case stem from the following systemic failures in our health care system:

1. to provide high-quality palliative end-of-life (EOL) care throughout the disease trajectory.
2. to adequately educate individuals and communicate with them about end-of-life (EOL) care, and to document an individual's EOL preferences so these are readily accessible when needed.
3. to define an appropriate medical standard of care at the end of life and treat like cases alike across health care delivery settings.
4. to acknowledge that being a good steward of limited health care resources must involve decisions made by healthcare providers at the bedside.

When a patient has received excellent palliative care and has participated in good EOL care planning, it's less likely that withholding or withdrawing interventions against the patient's or surrogate's wishes based on medically ineffective or non-beneficial treatment criteria comes up. The latter may create distrust or animosity between the staff and the patient/surrogate that can complicate the dying and bereavement

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Case Presentation

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process, so efforts should be made to avoid adversarial standoffs. Health care providers can usually avoid this by planning ahead to identify when the main goal of care will shift from cure to comfort, and by supporting loved ones along the way. When that happens, patients/surrogates usually recognize when it's time to shift from "doing everything" to keep the patient alive to "doing everything" to maximize the quality of the patient's remaining time. Minimizing emotional burden and addressing the psychospiritual hurdles that are often a part of the dying process for patients and loved ones is an appropriate goal of medicine because how individuals experience the death of someone they love can have a long-lasting impact on their future well-being.

The ethics consultant(s) should explore whether anyone has information about Mrs. K's wishes, regardless of the absence of documentation of EOL preferences. It would be the rare 101 year old who, if she had the cognitive ability, did not ponder her own mortality. I recall a conversation with one centenarian who pointed out that death became less of a threat the older she got because "there's less life to miss out on." Yet, centenarians like Mrs. K may also be cherished family matriarchs whom others hold onto dearly as stalwart branches of a deeply-rooted family tree. They are survivors who have beat the odds, and as such, should not be "given up on." Yet, family members may also fall prey to the pitfall of their own emotions clouding their judgment of what the patient would want, or what would be in the patient's best interests. They may demand that "everything be done" to keep the patient alive for the wrong reasons. Focusing the discussion on what the patient would want can help family members avoid feeling like they are being asked to "choose

death" for their loved one.

Unfortunately, acute care medicine complicates the task of family members sorting through these complex emotions by failing to draw bright lines between what can be done and what should be done medically. Let's assume we don't, and can't, know what Mrs. K wants. Although Mrs. K's son believes his mother would want to continue all life-prolonging treatments, including CPR attempts, without any evidence of her wishes, the question, then, is whether doing so is in Mrs. K's best interests.

An individual patient's best interests are determined by calculating the likelihood of achieving an appropriate goal from a particular treatment plan and whether the burden of treatment is tolerable. "Appropriate goals" are those that fall within the medical standard of care. Low-burden interventions that are likely to achieve a desired goal (e.g., antibiotics to treat a painful urinary tract infection) may easily pass the test of acceptability. High-burden interventions that are unlikely to achieve a desired goal (e.g., treatment in an intensive care unit [ICU] to return an actively dying patient to pre-ICU functional status) may readily be deemed unacceptable. But burden is subjective. For example, some consider CPR attempts in persons with advanced co-morbidities to be a high-burden intervention due to the assault-like nature of chest-compressions and the possibility of breaking ribs, while others consider this to be a low-burden intervention because the patient in cardiopulmonary arrest is unconscious and thus can't "suffer." Burden notwithstanding, many question whether prolonging life, in itself, is an appropriate goal of medicine, particularly when a patient has reached her final days or weeks of life.

Life-prolonging medical interven-

tions are most often limited at the end of life by acute care triage practices, such as allocating ICU beds and equipment. But there is considerable variation from one health care facility to the next in what types of medical technology is offered to patients considered "terminal." The challenge is in knowing when a patient is dying and can no longer benefit from high-tech medical interventions. Clinicians sometimes argue that if a patient like Mrs. K can be "kept alive with machines," she's not "dying." At the age of 101, with over a decade of progressive decline preceding her 100th birthday, and an inability to breathe or eat on her own, there should not be such ambiguity among clinicians as to whether Mrs. K is dying. This ambiguity confuses family members. Was Mrs. K's son simply asked if he wanted to "keep his mother alive"? Or was he told that his mother was dying, and asked how staff could best support his mom and family through that process?

We can and should work to avoid ethical conflicts by better educating individuals about EOL care and making individuals' EOL preferences available through accessible and up-to-date advance directives and properly-executed MOLST forms. But this alone won't solve the problem of high-burden, low-benefit interventions at the end of life diverting health care resources from others who are more likely to benefit. While a "rational rationing" plan needs to happen at the societal level, providers at the bedside are also obligated to use limited resources wisely, and ethics consultants should be prepared to assist with these considerations (Stretch, Hurst & Danis, 2010). As Sheehan (2003) stated, "Providing expensive medical therapy with a curative or life-sustaining intent when a person is incurable and dying is arguably unjust in squandering resources that are needed elsewhere."

CRITERIA SUGGESTED BY THE SOCIETY FOR CRITICAL CARE MEDICINE FOR POLICIES TO LIMIT INADVISABLE TREATMENT

- Disclosure in the public record
- Reflection of moral values acceptable to the community
- Avoidance of an exclusive basis on prognostic scoring systems
- Provision of appeal mechanisms
- Recognition by the courts.
- Recognition by payers that they should formally address criteria for determining when treatments are inadvisable and should share accountability for those decisions.

Consensus statement of the Society of Critical Care Medicine's Ethics Committee regarding futile and other possibly inadvisable treatments (1997). Crit Care Med, 25, 887-891.

How can this be done ethically? In 1991, the American Thoracic Society (ATS) opined that, “[b]ased on the ethical principles of beneficence and nonmaleficence, the purpose of a life-sustaining treatment should be to restore or maintain a patient’s well being.” In 1997, the ethics committee of the Society of Critical Care Medicine (SCCM, 1997) concluded that “[t]reatments should be defined as futile only when they will not accomplish their intended goal. Treatments that are extremely unlikely to be beneficial, are extremely costly, or are of uncertain benefit may be considered inappropriate and hence inadvisable, but should not be labeled futile.” SCCM’s ethics committee advised using a rationale in such cases that is “explicit, equitable, and democratic; that does not disadvantage the disabled, poor, or uninsured; and that recognizes the diversity of individual values and goals.” (See box above.)

In Maryland, medical interventions may be withdrawn or withheld if they are considered “medically ineffective” or “ethically inappropriate.” Maryland law defines medical ineffectiveness as: “... to a reasonable degree of medical certainty, a medical procedure will not prevent or reduce the deterioration of the health of an individual or prevent the impending death of an individual.”

Clinicians would have to determine whether the ventilator or feeding tube (or dialysis, in the case of kidney shut-down) met this definition for Mrs. K. CPR attempts would meet the definition, based on Mrs. K's constellation of co-morbidities, together with her advanced age.*

Addressing goals of care with excellent palliative care and communication handles most of the cases. We are far from achieving this level of excellence and thus need to improve on this front. But for those who believe that “prolonging life, regardless of its quality or treatment burden, is a worthwhile goal,” we lack a valid rationale for denying high-burden treatments if we insist that distributive justice does not come into play. Our zeal to avoid this potential conflict of interest further confounds the issue because we do not openly discuss the role of resource stewardship with patients and family members. As the Affordable Care Act provides more Americans with health care coverage, we will be better positioned to address this openly and fairly (Danis, 2012; Donley & Danis, 2012; Stretch & Danis, 2012).

So, here we are with Mrs. K and her son in the nursing home, trying to figure out the most compassionate and ethically appropriate way to provide her care, given all the systemic

failures presented. Unless evidence can be revealed that she would not want to continue on life support, the “middle ground” of “no escalation of treatment” appears to be a valid compromise, given the complicity of the medical system in getting her to this point of dependency on machines during her dying process. This would allow for continued ventilator and feeding tube use until deemed medically ineffective, but no additional high-burden treatments such as CPR attempts, dialysis, or ICU transfer. In cases like these, the nursing home staff should provide the same comfort measures as they would for any dying patient (see box on p. 12).

In short, staff should focus on what will be done for Mrs. K and her family, rather than what won’t be done. However, clinicians should make clear recommendations to the son (including a recommendation to withdraw life support and focus mainly on comfort care), rather than offering a “platter of choices” to the son. The fact that Mrs. K had many prior encounters with health care providers, but none of them documented a conversation about end-of-life preferences, speaks to a bigger issue that needs prompt attention. The ethics consultant(s) should follow up in some way on this,

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CARE OWED TO DYING PATIENTS

- Make sure the patient's symptoms are adequately treated/prevented.
- Offer the family information about what they are likely to see as their loved one dies.
- Address any religious traditions that are important to the patient/family.
- Encourage the family to invite loved ones to say goodbye to the patient.
- Discuss options for where the patient may spend her final days (e.g., in nursing home with or without hospice support, or transfer to hospice if possible).

Arnold, B. (February, 2011). What to do after the patient is made comfort measures only (CMO) Pallimed case conferences, 11(2). Available at <http://cases.pallimed.org/2011/03/what-to-do-after-patient-is-made.html>.

in an effort toward addressing the systemic failures contributing to cases like these.

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*If two of Mrs. K's physicians certified that CPR, or any other medical intervention, would be medically ineffective or ethically inappropriate, they could withhold or withdraw it after informing the daughter of the option for transfer. If the daughter requested a transfer, the Health Care Decisions Act requires that life-sustaining interventions be maintained while awaiting transfer. However, this need not include CPR attempts, based on an interpretation that attempted resuscitation would be ineffective in prolonging Mrs. K's life.

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CALENDAR OF EVENTS

FEBRUARY

21-22

Empirical Bioethics: Emerging Trends for the 21st Century. Sponsored by the Center for Clinical and Translational Science and Training. Kingsgate Marriott Conference Hotel, Cincinnati, OH. For more information, contact Bettie Durant at bettie.durant@cchmc.org, 513.803.2610.

27 (8:30-10AM)

What is Wrong with Markets to Obtain Organs for Transplantation? Public Lecture by Art Caplan, sponsored by the Center for Bioethics, New York University, New York, NY. Translational Building, 227 East 30th St. (between 2nd and 3rd Ave). 6th Floor, Conference room 619. For more information, visit <http://bioethics.as.nyu.edu/page/events>.

MARCH

7

Henrietta Lacks Symposium: The Dignity of Difference. Sponsored by the University of Maryland, University of Maryland SMC Center and University of Maryland School of Nursing, 621 W. Lombard St., Baltimore, MD. For more information, visit www.umm.edu/hela.

8

Helping Grieving Children and Families. Presenter: Sarah Montgomery, LCSW-C, Coordinator of Children and Family Programs. Sponsored by Chesapeake Life Center. Baltimore – Living Legacy Foundation, 1730 Twin Springs Road, Suite 200, Baltimore, MD. For more information, visit chesapeakelifecenter.org.

14 (7 PM)

Tenth Annual John Collins Harvey Lecture. Speaker: Daniel Sulmasy, MD, PhD, Kilbride Clinton Professor of Medicine and Ethics and Associate Director of the MacClean Center for Clinical Medical Ethics at the University of Chicago. Sponsored by Georgetown University's Center for Bioethics. Salon H of the Leavey Conference Center on the Georgetown Campus, Washington, DC. For more information, contact Marti Patchell at patchelm@georgetown.edu.

14-16

First Annual Professional Skills Program in Dispute Resolution, sponsored by the Center for Dispute Resolution at the University of Maryland School of Law (C-DRUM), in partnership with the Straus Institute for Dispute Resolution at Pepperdine University. University of Maryland King Carey School of Law, Baltimore, MD. For more information, visit <http://www.law.umaryland.edu/faculty/conferences/>.

14-16

9th International Congress on Clinical Ethics Consultation. Munich, Germany. For more information, visit www.iccec2013.de.

15

Facts of Illness/Acts of Profession: Edmund Pellegrino and the Ethics of Health Care. Sponsored by Georgetown University Medical Center's Center for Clinical Bioethics, Salon G of the Leavey Conference Center on the Georgetown Campus, Washington, DC. For more information, contact Marti Patchell at patchelm@georgetown.edu.

15

Helping Grieving Children and Families. Presenter: Sarah Montgomery, LCSW-C, Coordinator of Children and Family Programs. Sponsored by Chesapeake Life Center. Baltimore – Grassroots Crisis Intervention, 6700 Freetown Road, Columbia, MD. For more information, visit chesapeakelifecenter.org.

20

Creating Dignified Dialogue: The Role of Health Care Professionals in Ethical Decisions at the End of Life. Presenters: Shahid Aziz, MD, Medical Director for Adults and Pediatrics at Hospice of the Chesapeake, & Karen Frank, RN MS, CHTP, Director of Chesapeake Life Center. Sponsored by Chesapeake Life Center, 445 Defense Highway, Annapolis, MD. For more information, visit chesapeakelifecenter.org.

21-22

Cultivating Ethical Awareness: Moments of Truth. Second Ethics of Caring National Nursing Ethics Conference. Universal Hilton Hotel, Los Angeles, California. For more information, visit <http://ethicsofcaring.org>.

21-22

The Politics of Caring: Ethical Issues of Distributive Justice in an Era of Scarce Resources. Sponsored by Emory University's Center for Ethics and the Health Care Ethics Consortium of Georgia (HCECG). Atlanta, Georgia. For more information, visit www.hcecg.org.

CALENDAR OF EVENTS (cont'd)

MARCH (cont'd)

22

Digital Ethics: The Impact of Electronic Communications and Social Media on Direct Practice with Clients. 3rd Annual Judy Levy Ethics Workshop, sponsored by Social Work at Kennedy Krieger Institute, Conference Center at Sheppard Pratt, 6501 N. Charles St., Towson, MD. For more information, contact Linda Friend at 443-923-2802, friend@kenedykrieger.org.

APRIL

5 (12N-1PM Webinar)

Should Parents Be Allowed to Test Their Children for Adult-Onset Conditions? Debate between geneticist and bioethicist Kelly Ormond and philosopher Rosamond Rhodes. Sponsored by Children's Mercy Bioethics Center. For more information and to register, visit <http://www.childrensmercy.org/cmbc/>.

18

Palliative Care: Healing the Mind, Body and Spirit of Patients and Families Experiencing Serious Illness. Sponsored by Stella Maris, in the Stella Maris Auditorium, 2300 Dulaney Valley Road, Timonium, MD. For more information, call 410-252-4500, ext. 7208.

18 (4PM)

Palliative Care Seminar Series, Sponsored by the Department of Medical Ethics & Health Policy, University of Pennsylvania, 3401 Market Street, Suite 320, Philadelphia, PA, Joan Karnell Cancer Center (Room TBD). Topic: Pain & Supportive Care Program Team.

25-26

Clinical Ethics Case Consultation Workshop, sponsored by MedStar Washington Hospital Center. For more information, contact O. Mary Tawose at Olubukunola.M.Tawose@medstar.net.

MAY

2-3

Intensive Workshop in Healthcare Ethics; Special Topic: "Relating to Cancer." Sponsored by the Division of Medical Humanities, College of Medicine, University of Arkansas. For more information, visit <http://www.uams.edu/humanities/>.

9-10

Bedside, Boardroom, and Boulevard: Health Care Ethics at the Intersections. Sponsored by the Colorado Healthcare Ethics Forum, Stonebrook Manor Event Center and Gardens in Thornton, Colorado. For more information, visit <http://coloradoethicsforum.org/>.

13-14

Intensive Course in Bioethics Consultation Skills, sponsored by the bioethics consultation service at the Montefiore Medical Center and Albert Einstein College of Medicine, New York, NY. For more information, visit <http://www.einstein.yu.edu/masters-in-bioethics>.

14 (9A-12:15PM)

Becoming Fully Alive Through Working with the Dying. Sponsored by Stella Maris, in the Stella Maris Auditorium, 2300 Dulaney Valley Road, Timonium, MD. For more information, call 410-252-4500, ext. 7208.

16 (4PM)

Palliative Care Seminar Series, Sponsored by the Department of Medical Ethics & Health Policy, University of Pennsylvania, 3401 Market Street, Suite 320, Philadelphia, PA, CHOP Abramson Building Room 123-AB featuring the CHOP Pediatric Advanced Care Team (PACT).

16-17

Palliative Care and Ethics Conference. Sponsored by the Center for Healthcare Ethics at Duquesne University, Pittsburgh, PA. For more information, visit <http://www.duq.edu/academics/schools/liberal-arts/centers/center-for-healthcare-ethics>.

22-23

Medical Humanities in Clinical Practice, Medical Humanities Consortium's Eleventh Annual Meeting. Drew University, Caspersen School of Graduate Studies, Madison, NJ. For more information, contact Phyllis DeJesse at pdejesse@drew.edu.

28-30

What Does It Mean to Care? Religious Traditions and Health Professions Today. Sponsored by the Program on Medicine and Religion at the University of Chicago, Westin Hotel, Chicago, IL. For more information, visit <https://pmr.uchicago.edu/events/2013-conference>.

JUNE**3-4**

Intensive Course in Bioethics Consultation Skills, sponsored by the bioethics consultation service at the Montefiore Medical Center and Albert Einstein College of Medicine, New York, NY. For more information, visit <http://www.einstein.yu.edu/masters-in-bioethics>.

3-7

Bioethics: More Relevant Than Ever. Intensive Bioethics Course sponsored by the Kennedy Institute of Ethics, Georgetown, MD. For more information, visit <http://kennedyinstitute.georgetown.edu/programs/ibc.cfm>.

12-14

Harvard Clinical Bioethics Course, Sponsored by the Harvard Medical School Division of Medical Ethics and Department of Continuing Education. For more information, visit <http://medethics.med.harvard.edu/education/bioethics/>.

19-21

Working Together to Shape the Future: 3rd Cambridge Consortium for Bioethics Education, Sponsored by Cambridge University Press. Reid Hall, Paris France. For more information, visit cambridgebioethics.com.

20 (4PM)

Palliative Care Seminar Series, Sponsored by the Department of Medical Ethics & Health Policy, University of Pennsylvania, 3401 Market Street, Suite 320, Philadelphia, PA, PCAM A- CC (conference center) featuring Joshua B. Kayser, MD, MPH, Assistant Professor of Clinical Medicine, Division of Pulmonary, Allergy and Critical Care.

The Johns Hopkins Berman Institute of Bioethics hosts bioethics seminars on the second and fourth Monday of each month from 12:15 PM to 1:30 PM. Lunch is provided. To receive emails of seminar speakers or for more information, contact Tracie Ugamoto at tugamoto@jhu.edu, 410-614-5550.

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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