



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

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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

GETTING THE MOLST OUT OF MARYLAND MOLST

The Maryland MOLST form will be fully implemented on July 1, 2013. To help prepare health care professionals and Marylanders to comply with the spirit (and not just the letter) of the law, Tricia Nay, Medical Director of Maryland's Office of Health Care Quality, and Paul Ballard, Assistant Attorney General, Counsel for Health Decisions Policy for the Attorney General of Maryland and Counsel to the Office of Health Care Quality, have been busy educating and training individuals about how to use the form. They conducted one of many MOLST training workshops at the University of Maryland Francis King Carey School of Law on April 2, 2013. Video recordings of the sessions from that workshop are available online at <http://www.law.umaryland.edu/mhec>. The bottom line motivating these efforts is the desire to ensure that the type of end-of-life (EOL) care provided to Marylanders is consistent with their known wishes or best interests.

In the last issue of this Newsletter, we featured a case involving a 101 year old woman ("Mrs. K") with a 12 year prior physical and mental decline who had no documented wishes regarding her EOL treatment preferences. Mrs. K was transferred to a nursing home with a tracheostomy, on mechanical ventilation, receiving tube feedings, with a "full code" status in place, based on her son's insistence

that "everything be done" to keep her alive. Come July 1, patients like Mrs. K will need to have a MOLST form completed before being discharged from the hospital to the nursing home. Would this have changed the outcome for Mrs. K? That likely depends on the quality of the conversation between the clinician completing the form and the patient (or the patient's surrogate). Also, it is preferable, when possible, to discuss MOLST options directly with patients before they lose decision-making capacity.

Dr. Nay talked about the importance of getting insight into a patient's understanding of his or her condition by asking general questions, such as, "How do you think your health is?" or "What did the doctor at the hospital tell you about your condition?" If a patient referred for hospice replies, "Oh, the doctor said I'm doing better and ordered home health so I can walk again," the clinician would know to spend time clarifying medical facts and plausible goals of care. It's also important to determine how much information the patient wants from the clinician. Some patients may not be in a place to hear everything the clinician thinks they need to know, the timing may not be right, or the patient may prefer less information in general. It's a tall order to ensure that informed

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upon without consulting an attorney.**

MOLST

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consent drives MOLST orders. Dr. Nay carries around actual equipment to show to patients or surrogates to inform decisions about EOL treatment—for example, a feeding tube, a foley catheter, a nasal cannula, a non-rebreather mask, PIC lines, intravenous lines, etc. She has found that this is very effective in explaining things that might otherwise take a long time to describe verbally.

Dr. Nay also emphasized the distinction between letting the clinician's bias inappropriately influence EOL treatment orders and the clinician's expertise appropriately informing treatment recommendations. She gave the example of a patient known to her facing a decision about renal dialysis, summarizing: "I think it's fine to say, 'You're not a candidate for transplant, and while dialysis is an option for some people, here are the reasons why I don't think it's good for you. We've never been able to get vascular access into you, you've had recurrent episodes of sepsis and we can't clear the bacteria from your bloodstream, you have panic attacks every time you go into the hospital setting ... So for you, I don't think the dialysis is even an option.' I don't think that's a bias. I think that's being honest about what the benefits and risks and burdens are."

On the contrary, if patients or surrogates are not adequately informed about EOL treatment options and their implications, the informed consent process driving the MOLST orders will be flawed. Consider this exchange from the 2010 PBS Program "Facing Death" (available at <http://www.pbs.org/wgbh/pages/frontline/facing-death/>, Chapter 4) featuring a patient named Norm who has been hospitalized for the past two months for life-threatening complications of an organ transplant. His girlfriend, Jima, has just told doctors that Norm wants to sign a Do-Not-Resuscitate

(DNR) order. Here is an excerpted conversation between Norm and his physicians [he has just refused to have his intravenous (IV) catheter changed]:

Physician 1: An IV needs to be changed every three days. Tell me what is happening. Are you having pain in your belly?

Norm: Yeah. I'm scared.

Physician 1: Scared of what? What are you scared of?

Norm: [Unintelligible ... about the catheter]

Physician 1: Norm, we don't have to do it. There's nothing wrong with the catheter.

Physician 2: Let me ask you something. Jima said that you've been thinking a little bit about if you needed a vent, what you would do or what you would want us to do. And have you thought about that more and do you want to tell me something about that?

Norm: [Quiet ... staring ahead]

Physician 2: Hmmm?

Norm: [Quiet]

Physician 1: If something should happen and you would have trouble breathing, do you want to be put on a respirator to help you breathe?

Norm: [pause, then shakes head]

Physician 1: You do. Is that a yes? OK. Alright.

Physician 2: That's what you always did express to me but I wanted to make sure that hasn't changed. Listen, I want to say something that you should think about today. You don't have to say anything about it now, I just want to say it to you, OK? If you're tired and you don't want us to do this anymore, that's OK with me. But you've got to let me know.

I don't want to put you through procedures that you don't want to go through. But I don't want to not do the things that are right in terms of trying to get you better. OK?

Norm: [stares ahead]

(PBS Program "Facing Death," 2010, Chapter 4; available at <http://www.pbs.org/wgbh/pages/frontline/facing-death/>)

There are positive features of this exchange, notably the physicians' open-ended questions (e.g., "What are you scared of?" and "...do you want to tell me something about that?"). But it's unclear what Norm really understands about his prognosis and the options available to him.

For example, how likely is it that he can "get better"? What options are available if Norm has trouble breathing, other than intubation and mechanical ventilation? Why did Norm tell Jima he wanted a DNR order and now is changing his mind?

It is a daunting task to communicate treatment options to patients and family members, to offer recommendations based on medical expertise without undue personal bias, and to accurately document a patient's EOL treatment preferences. While use of a MOLST form alone wouldn't necessarily result in a different outcome for Mrs. K, the spirit behind MOLST legislation is to ensure better continuity of care across

settings as regards EOL treatment. It will no longer be acceptable that EOL care differs from one health care facility to the next because clinicians fail to educate patients and surrogates about EOL treatment options and document EOL treatment preferences. While there will be a steep learning curve before we can be confident that clinicians' EOL communication skills are comparable across health care settings, if we support the spirit of MOLST legislation, we can at least be confident that we are moving in the right direction.

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MARYLAND LEGISLATIVE UPDATES

By Paul Ballard, JD, Assistant Attorney General, Attorney General of Maryland

Physician Assistants' Scope of Practice

House Bill 723 expands the scope of authority of a physician assistant ("PA"). Effective October 1, 2013, PAs have been given certain new authorities under the Health Care Decisions Act, including the ability to:

- Witness an advance directive for a patient if acting in good faith;
- Document and sign an oral advance directive in the presence of one witness who also signs the documentation;
- Sign a MOLST form;
- Give an oral emergency medical services "do not resuscitate order" when physically present on the scene with the patient and the emergency medical services personnel in the outpatient setting;

- Participate in updating or implementing a MOLST form by a health care facility upon request of a patient;
- Have their orders in a MOLST form complied with by a health care facility regardless of whether the PA has admitting privileges or is otherwise credentialed by the health care facility;
- Decline to provide a medical treatment to a patient that is medically ineffective or that the PA determines to be ethically inappropriate.

Advance Directive Registry

Senate Bill 790 requires the Department of Health and Mental Hygiene to set a fee in regulation to fund the advance directive registry and the Department is required to take all steps necessary to make the advance directive registry operational by October 1, 2014.

Palliative Care Programs in Hospitals

House Bill 581 requires the Maryland Health Care Commission to select at least five palliative care pilot programs in hospitals with 50 or more beds in a manner that ensures geographic balance in the State. In accordance with the Commission's core data measures and standards, the pilot programs are required to:

- Collaborate with palliative care or community providers to deliver care;
- Gather data on costs and savings to hospitals and providers, access to care, and patient choice; and
- Report to the Maryland Health Care Commission on best practices that can be used in the development of statewide palliative care standards.

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Legislative Update

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The pilot programs must establish policies and procedures that:

- Provide access to information and counseling regarding palliative care services;
- Identify the authorized decision maker, if any;
- Require providers to discuss benefits and risks of treatment options in a manner that can be easily understood;
- Encourage the patient or authorized decision maker to include relatives and friends in the counseling regarding palliative care; and
- Facilitate access to appropriate palliative and associated pain management consultations and services.

When pilot programs provide counseling about palliative care, the counseling must include information regarding the right of the patient to continue with disease-targeted treatment with or without palliative care and the right of the patient to receive comprehensive pain and symptom management.

By December 1, 2015, the Maryland Health Care Commission, in consultation with the Office of Health Care Quality and the Maryland Hospital Association, must issue a

report to the legislature regarding the findings of the pilot programs, including best practices and data outcomes experienced during the pilot period. The report must include recommendations to be used to develop minimum standards for palliative care programs with the goal of expanding access to palliative care programs in a manner that ensures geographic balance and promotes racial and ethnic diversity. The report will be used by the Department of Health and Mental Hygiene to develop regulations related to standards for palliative care programs.

Medical Marijuana

House Bill 1101 establishes the Natalie M. LaPrade Medical Marijuana Commission which will approve academic medical centers to operate medical marijuana compassionate use programs consistent with criteria set forth in the bill and to license medical marijuana growers to provide marijuana to these programs. A medical marijuana compassionate use program must provide daily data to the Commission regarding patients and caregivers and the Commission shall make that data available in real time to law enforcement. Patients, growers, and employees of the program and

persons associated with the operation of the program may not be subject to criminal, civil, or licensing penalties for their approved activities. The Governor may suspend implementation of this law if the Governor makes the determination that there is a reasonable likelihood that the federal government will prosecute State employees for their involvement with the implementation of this law.

House Bill 180 creates an affirmative defense from criminal prosecution for a caregiver designated in writing by an individual with a debilitating medical condition to provide physical or medical assistance to the patient, including assisting with the medical use of marijuana. This means that the caregiver (who is an immediate family member, spouse, or domestic partner of the patient) may be found not guilty of marijuana possession if the caregiver proves that they were an eligible caregiver under the bill's criteria and the marijuana was intended for medical use by the individual with a debilitating medical condition.

FUTILITY WEBINAR DINNER DISCUSSION

Western Maryland Medical Center (WMMC) hosted a dinner discussion on April 24 in Hagerstown, Maryland to view and discuss the Mercy Children’s Center for Bioethics webinar, “Does the Concept of Medical Futility Help Clinicians?” The webinar was originally broadcast on February 5, 2013, and featured Robert Truog, MD, Professor of Medical Ethics, Anesthesiology, and Pediatrics and Director of Clinical Ethics at Harvard Medical School; Robert Fine, MD, Clinical Director in the Office of Clinical Ethics and Palliative Care at Baylor Health Care System; and Thaddeus Pope, JD, PhD, Director of Health Law Institute and Professor of Law at Hamline University.

Dr. Fine described how the Texas Advance Directive Act allows for withholding or withdrawing medically inappropriate treatments if a prescribed process is followed, and believes there is value in the law, although still room for improvement—for example, in better defining the composition of the ethics committee that reviews cases.

Dr. Truog pointed out flaws in the Texas law and concluded that withholding or withdrawing treatment based on medical “futility” is a relatively rare event if other measures are implemented to avoid such standoffs, and that these “hard cases” make bad law. He suggested we seek a fairer mechanism to resolve intractable conflicts (for example, a community ethics committee comprised of a diverse membership and driven by fair process guidelines).

Dr. Pope outlined four mechanisms to resolve conflicts: (1) prevention (e.g., using MOLST or POLST forms



Attendees of the Futility Webinar Dinner Discussion at Western Maryland Medical Center in Hagerstown, MD, including therapy dog Brandi

for end-of-life treatment orders, ensuring better access to quality palliative and end-of-life care); (2) consensus (i.e., getting stakeholders to agree – this works about 95% of the time); (3) appointing a new surrogate (i.e., through court intervention); or (4) unilateral withholding/withdrawing of life-sustaining treatment (i.e., through futility legislation like that in Texas). Regarding the fourth option, concerns exist about fairness of the third party review—particularly, the composition of ethics committees that review futility cases brought before them.

WMMC webinar dinner attendees discussed challenges implicit in providing non-beneficial interventions to dying patients, including being good stewards of limited and costly medical resources, treating dying patients with dignity, “doing everything” to support distraught and grieving family members of dying patients,

and supporting staff (particularly nurses) who perceive that they are doing more harm than good for dying patients. Most agreed that health care providers across settings need to do a better job communicating with patients and families about appropriate end-of-life care, documenting patients’ preferences for end-of-life interventions, providing access to palliative care, and presenting a unified front among clinicians when identifying recommended standard of care options for a patient.

To view the Mercy Children’s Center for Bioethics webinar, visit <http://www.childrensmc.org/cmbc/> and click on “bioethics topics.” E-mail Anita Tarzian (atarzian@law.umaryland.edu) for a copy of the slides.

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.

Today's case study is excerpted from the book, "Complex Ethics Consultations: Cases that Haunt Us" (2008, New York: Cambridge University Press) edited by Denise Dudzinski and Paul Ford. The following includes excerpts from the chapter, "Why do we have to discharge this patient?", by Sarah E. Shannon. Reprint permission from Cambridge University Press. Do not reprint without permission from the publisher.

CASE NARRATIVE

Mr. Leary was described as an independent 76 year-old curmudgeon prior to a stroke eight weeks ago. The stroke left him with complete left-sided paralysis. He suffered a second stroke two weeks after the first, resulting in both receptive and expressive aphasia - he could neither understand speech nor could he formulate words. He also appeared depressed after the second event. Three weeks ago, he suffered a third stroke. While this stroke worsened his physical condition, it seemed to improve his mood. At times, he appeared almost jovial. He became cooperative with care, even attempting to assist with shaving each morning. Mr. Leary needed a feeding tube for nutrition and hydration since the first stroke due to an impaired swallow reflex. He tolerated a nasogastric feeding tube and had never attempted to remove the tube. His physician had written in the medical record that Mr. Leary's prognosis for survival was probably less than a year due to expected further cerebral events but that he might live as long as three to five years.

The clinicians who knew Mrs. Leary described her as overwhelmed with her husband's situation. In the eight weeks of hospitalization since Mr. Leary's first stroke, she had occasionally

agreed to a "no-code" order when his condition was grim but would ask that he be restored to a full code when he improved. These changes appeared to follow discussions between the attending physician and Mrs. Leary but were never documented. In the last two weeks, Mr. Leary's condition had finally stabilized to the point where he could be discharged to a nursing home. The social worker had located two possible placements, but Mrs. Leary refused both. The first had been a 75-minute drive from her home, making visits difficult, and she had described the second as "too awful." Late Thursday, someone from the hospital business office approached Mrs. Leary to inform her that on Monday Mr. Leary would be decertified by Medicare because he no longer required acute care and two nursing home placements had been offered. Since Mrs. Leary had refused transfer she would be responsible for hospital charges from that date forward. In line with hospital policy, no notation of this conversation was made in the medical record, but the nurses on the floor overheard the conversation.

On Friday afternoon, Mrs. Leary called the attending physician and asked that the feeding tube be withdrawn, which they had discussed on other occasions but which Mrs. Leary had previously refused. She

said that she had decided to take Mr. Leary home and care for him herself. The physician phoned the unit and left verbal orders to remove the feeding tube, discontinue nutrition and hydration, and discharge Mr. Leary to home as soon as feasible. The nursing staff was very upset by the order to stop tube feeding and called the physician back to discuss it. He stated, "This is congruent with the patient's stated values prior to his strokes. The patient asked me not to 'overdo' it." The feeding tube was pulled Friday afternoon.

The nurses remained distraught over the weekend and consulted the hospital chaplain, also a member of the ethics committee. They complained that while this physician spent a good deal of time with his patients and their families, he did not document conversations in the medical record and was curt with nursing staff when they tried to discuss patient or family issues. They felt silenced by him. A social worker was not available over the weekend to help with discharge planning, but basic arrangements were made for the patient to be sent home Monday. On Sunday morning, the patient took a drink from a glass of water placed at his bedside for mouth care and aspirated water into his lungs. By Monday pneumonia was evident. Mrs. Leary was nearly hysterical. She

“The ethics consultation process failed to stop the train.”

had not participated actively in her husband’s care and the nurses realized she was physically unable to turn and position Mr. Leary because of her diminutive size. Nonetheless, Mr. Leary was discharged home Monday afternoon with a significant fever. He died late Monday evening.

As details of the case were discussed in committee, many of the players saw their roles in a new light. The person from the business office was horrified when she realized the impact of her conversation on the patient’s wife. She explained that Medicare regulations limited the number of times patients and families could reject transfers to nursing homes, but her words trailed off into silent tears. The patient’s attending physician, an experienced clinician, had listened first with confidence. But when he learned about Mrs. Leary’s conversation with the business office on Thursday he visibly blanched. He had not questioned Mrs. Leary’s request to stop tube feeding because he felt she had been overly aggressive in her treatment preferences and assumed she had finally “seen reason.” He spoke of the patient, clearly identifying with him on a personal level, and restated that he had promised the patient he would “not overdo it.”

The oncologist gently questioned the attending physician about treatment of symptoms related to withdrawal of nutrition and hydration. The attending physician replied that the patient did not have pain so nothing was ordered. A discussion ensued about the duty to treat hunger, thirst, and anxiety related to withdrawal of life-sustaining treatments. The oncologist suggested that the patient’s obvious symptoms of thirst should have been treated with good mouth care (as was done) and with medication.

Next, the oncologist asked why the patient was being discharged at all. He pointed out that once the decision was made to withdraw tube feeding the patient’s condition changed and he would have been recertified for Medicare reimbursement. Silence pervaded the room while everyone absorbed this crucial fact, somehow missed. Disbelief and horror were palpable in the room. The social worker talked about her struggle to find placement during a period of high demand for nursing home beds. She was frustrated by recent budget cuts that limited social work coverage on the weekend, even for urgent discharge planning. She supported Mrs. Leary’s refusal of the first nursing home because Mrs. Leary would not have been able to visit daily. The social worker was reluctant but obligated to offer the second placement, saying “I wouldn’t put my dog in that place!”

Throughout the discussion, the nurses did not speak. They sat together, arms crossed, and directed hostile glances to the attending physician every time he spoke. Questions posed to the nurses were answered with terse replies. Their anger was palpable. When they realized that the attending physician had not known that losing Medicare reimbursement may have influenced the wife’s decision, the nurses looked disbelieving, then distrustful. They repeated that Mr. Leary would assist them when they shaved him each morning, that he had never tried to remove his feeding tube, and that he laughed and had seemed happy the last two weeks. They had never heard him speak, so they had never heard him say he did not want tube feeding. They commented that the attending physician’s notes were brief to the point of being cryptic. They said that

what had happened to Mr. Leary was “wrong, simply wrong.” They could not adequately provide discharge support over the weekend without social work assistance. Mr. Leary was dying when he was sent home; Mrs. Leary was in crisis. Though they did not say it, they appeared to blame the attending physician principally for these failures. But they also felt profound guilt. They had removed the tube. They had left the cup of water by the bedside. They helped put him on the stretcher, sick with fever, to go home with his wife to die. They had failed Mr. Leary.

The hospital administrator who attended the meeting sat silently through the discussion until the end. Then he spoke. “This isn’t what we do. We don’t abandon people. If we needed to eat a few days or even a week of care in order to adequately do discharge planning or to find a nursing home placement, then we would do that. But we don’t abandon people.” A policy decision was made on the spot. In the future, if a patient were being decertified for Medicare reimbursement, the physician would be notified prior to the patient or family being informed by the business office.

HAUNTING ASPECTS

This case stands out for me as an example of ethics failure. First, this was a genuinely difficult case that needed careful ethical analysis. But the full consultation occurred too late to benefit the parties intimately involved in the case: most important, the patient.* This highlights the second and perhaps most serious failure. The ethics consultation process failed to stop the train. The ethics consult was initiated on Friday. Yet, it

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Case Presentation

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failed to identify this as a situation that needed to be slowed down for careful reflection. The ethics consultant did not recommend that the level of care continue until careful reflection could occur. The consultant should have recommended that the feeding tube be left in place or replaced, whatever was necessary until the case could be discussed at the Tuesday morning meeting. The third failure is that the ethics committee, upon realizing at the Tuesday meeting that a tragedy had occurred, failed to take action to help the many who were wounded by this case: the nurses who had correctly sensed that the situation presented authentic ethical issues yet continued to “follow orders” because they could not see other options; the social

not matured to a point where we could envision our role as providing solace for traumatized colleagues. Perhaps we were humbled by the complexities of this case, particularly the regulatory issues. Perhaps we responded like clinicians confronting medical errors by not fully admitting the error, not discussing it openly, and then not disclosing it to the affected parties (Hilfiker, 1984).

PROFESSIONAL REFLECTIONS

There are four unique aspects to this case that continue to influence my practice in ethics consultation. The first was illustrated by the nurses’ plaintive observations that although Mr. Leary could not understand verbal communication, he would cooperate

how she weighed his prior verbal preferences against his current behavioral cues. Would his “former” self have judged his current quality of life unacceptable? Did his “current” self agree with that judgment? Perhaps she had no more insight into Mr. Leary’s wishes than the nurses who shaved him each day and laughed with him about putting his slippers on the wrong feet. One study of quality of life for nursing home residents found that physicians, family members, nurses, and certified nursing assistants (CNAs) rated the importance of quality of life similarly but rated their ability to influence residents’ quality of life differently (Kane, Rockwood & Hyer, 2005). CNAs rated their ability to influence the quality of life of

“When people can no longer speak, do their actions give voice to their wishes? Or, do their former voices shout while their current tears or smiles merely whisper?”

worker who felt personally responsible for not finding an adequate nursing home placement and frustrated to have not been at work during Mrs. Leary’s acute discharge planning needs; the woman from the business office who was emotionally devastated and felt a distinct moral culpability for Mr. Leary’s death; the attending physician who thought he had a sound clinical plan only to discover that several key facts were incorrect and that he had failed his longtime patient; and, of course, Mrs. Leary, who was now home alone, having spent the final ten hours of her husband’s life frantically trying to care for his feverish and dying body alone and unaided. We, as a committee, did nothing about any of the wounded beyond our case discussion. Perhaps this was because we were overwhelmed or shamed by our own failure, or because we had

with shaving each morning, turning his head from side to side, flattening his upper lip, and trying to hold the razor. He had not attempted to pull his feeding tube. And recently, he had seemed content, even laughing at times with the nurses as they cared for him. I came to understand that while the attending physician referenced prior verbal statements as indication of Mr. Leary’s wishes, the nurses were reflecting on his current behavioral cues. Since it is not unusual for patients in Mr. Leary’s condition to be withdrawn and rejecting, pushing away a helping hand and pulling out tubes, Mr. Leary’s behavioral cues suggested to them that he accepted his situation and found meaning and contentment in life.

We do not know how Mrs. Leary saw her husband’s situation or

nursing home residents highest, while physicians rated theirs lowest. One explanation may be that the kind of patient care provided may carry with it a set of beliefs about the value that care has on the patient’s quality of life. In this case, providing the intimate care of shaving, bathing, and dressing may have sensitized the nurses to the patient’s nonverbal cues.

How can we as ethics consultants adjudicate between verbal or written preferences made by a “prior” self and the behavioral cues of the “current” self? When people can no longer speak, do their actions give voice to their wishes? Or, do their former voices shout while their current tears or smiles merely whisper? How should ethics consultants consider advance directives in light of these behavioral whispers (Dresser & Astrow, 1998)? I am unsure whether stopping nutrition

and hydration was the best decision for Mr. Leary. The lack of discussion about his prior verbal statements balanced against his current behavioral cues denied him the opportunity to have these multiple voices heard.

The second lesson from this case was the power of interprofessional representation in ethics consultation. This was a complex case involving Medicare reimbursement, symptom management, neurological assessment, surrogate decision making, autonomy, and withholding life-sustaining nutrition and hydration. Interprofessional meetings bring expertise that allows multiple insights, questions, and possible solutions to emerge. This case also illustrates how ethics runs through an organization - from the business office through the service delivery groups to the administration. Representatives from each facet of the organization saw their role in this tragedy - from the business office person who delivered the news about decertification to the head of administration who would have gladly absorbed the cost of Mr. Leary's care for a limited time to avoid abandoning him. In ethics consultations, I have become more attuned to the need to gather information from multiple professionals and to have wide representation in case discussions.

The third lesson was the potential role of the ethics consultant in guiding clinicians toward moral certainty and courage. In retrospect, I believe that the ethics committee/consultant failed the nurses in this regard. The nurses requested the consultation. They recognized that something was not right. They also made mistakes. They did not tell the attending physician that the business office had visited Mrs. Leary because they assumed he knew. They did not try to talk farther with the physician. They were angry with him and considered this to be the

“final straw.” They came to the ethics committee with their minds made up, perhaps hoping to see the attending physician publicly humiliated. Instead, they saw their own culpability. They stopped communicating with the physician, and in so doing, failed their patient. And where was the ethics consultant in this? Given what was known on Friday afternoon, we should have called the attending to share our recommendation to delay discontinuation of the tube feeding until after the interdisciplinary case discussion. If necessary, we should have supported the nurses in respectfully refusing to stop tube feeding until the discussion could occur. The ethics consultant could have spearheaded the process of contacting administration to clarify discharge and reimbursement issues. The alternative was unacceptable. Ethics consultants should see their role as guiding clinicians through situations where a clear stance and recommendation is warranted as a precursor to a final treatment decision. By demonstrating clear reasoning and a commitment to investigate the many dimensions of a complex case, the ethics consultant can support the clinicians in gaining clarity and taking a moral position.

OUTCOME

Within ten hours of being discharged home, with a fever, and in the sole care of his terrified and unprepared wife, Mr. Leary died. The ethics case discussion was too late and guilt for his death likely haunts the care providers, his wife, and ethics committee members to this day. I have used this case frequently and successfully in my teaching. While it is an excellent teaching tool, I use the case also to process my own guilt and to prevent other “Mr. and Mrs. Leary’s” from being abandoned.

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*At this medium-sized urban hospital, the chair of the ethics committee usually responded to requests for ethics consultations by either personally doing consults, referring others to another member of the committee who was either on-call or knowledgeable about a specific issue, or by convening the entire ethics committee to discuss challenging cases. I was a community member, recruited by the chair due to my academic appointment and credentials in ethics. I received a phone call over the weekend that there would be an urgent ethics committee meeting on Tuesday morning at 7 a.m. An ethics consultation request had been received on Friday. The ethics committee chair had reviewed the case and decided it merited full committee review. [This happened the following Tuesday morning.]

REFERENCES

- Dresser, R., Astrow, A.B. (1998). An alert and incompetent self: The irrelevance of advance directives. *Hastings Cent Rep*, 28(1), 28-30.
- Hilfiker, D. (1984). Facing our mistakes. *N Engl Med*, 310(2), 118-22.
- Kane, R.L., Rockwood, T., Hyer, K. et al. (2005). Rating the importance of nursing home residents' quality of life. *J Am Geriatr Soc*, 53(12), 2076-82.

CALENDAR OF EVENTS

JUNE

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 (7:45A-12P)

Practical Clinical Ethics: Three Pieces of the Ethics Puzzle, sponsored by Medstar Harbor Hospital, Baum Auditorium, Harbor Hospital, Baltimore, MD. For more information, call 410-350-3139 or email nancy.eddy@medstar.net.

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/>.

14

Bioethics Intensive Course: Social Media and Health: Meeting the Ethical Challenges, sponsored by Johns Hopkins Berman Institute of Bioethics, Baltimore, MD. For more information, visit: www.bioethicsinstitute.org/intensives, e-mail bioethics@jhu.edu, or call 410-614-5550.

17-21

(9A-12P)

Bioethics Intensive Course: Foundations of Bioethics, sponsored by Johns Hopkins Berman Institute of Bioethics, Baltimore, MD. (See June 14 for contact information.)

(9A-5P)

Bioethics Intensive Course: Teaching Bioethics (combines above Foundations of Bioethics plus afternoon workshop), sponsored by Johns Hopkins Berman Institute of Bioethics, Baltimore, MD. (See June 14 for contact information.)

(5-8P)

Bioethics Intensive Course: Reinvigorating Clinical Ethics: From Theory to Practice, sponsored by Johns Hopkins Berman Institute of Bioethics, Baltimore, MD. (See June 14 for contact information.)

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

Pediatric Palliative Care Conference, Sponsored by the University of Maryland Children's Hospital's Palliative Care Committee. University of Maryland Baltimore Campus Center, Baltimore, MD. For more information, contact (410) 328-6257 or professionaldevelopment@umm.edu.

20 (4-5P)

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

24-28

(9A-12P)

Bioethics Intensive Course: Ethics, Policy and Emerging Biotechnologies, sponsored by Johns Hopkins Berman Institute of Bioethics, Baltimore, MD. (See June 14 for contact information.)

24-28

(1-4P) Bioethics Intensive Course: Ethics of Human Subject Research: U.S. and International Perspectives, sponsored by Johns Hopkins Berman Institute of Bioethics, Baltimore, MD. (See June 14 for contact information.)

(5-8P) Bioethics Intensive Course: Ethics of Human Subject Research: Public Health Ethics, sponsored by Johns Hopkins Berman Institute of Bioethics, Baltimore, MD. (See June 14 for contact information.)

JULY

19-20

Cases That Keep Us Awake at Night: Challenges in Pediatric Bioethics, sponsored by Seattle Children's Hospital, Bell Harbor International Conference Center, Seattle, WA. For more information, visit <http://www.seattlechildrens.org/research/initiatives/bioethics/events/pediatric-bioethics-conference/>.

AUGUST

5-9

Summer Seminar in Health Care Ethics, sponsored by University of Washington, Seattle, WA. For more information, visit <http://depts.washington.edu/cme/live/course/MJ1402>.

9

International Bioethics Conference "Caring for Our Kupuna (elders): Balancing Human Dignity and Economics," sponsored by St. Francis Healthcare System of Hawaii. Sheraton Waikiki Hotel, Honolulu, Hawaii. For more information, visit <http://www.stfrancishawaii.org/mission-services/ethics/international-bioethics-conference>

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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Maryland Health Care Ethics
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