MID-ATLANTIC ETHICS COMMITTEE

NEWSLETTER

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
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Fall 2013

Inside this issue . . .

ADVANCE DIRECTIVES, AUTONOMY, & DISABILITY

Brooke Hopkins was emblematic of the type of person who completes an advance directive. A college English professor, he was highly educated, financially secure, and married to Peggy Battin, a bioethicist whose lifework focused on aid-in-dying advocacy. Most individuals who complete an advance directive do so to put limits on interventions that may be used to prolong their life if they are in a terminal or end-stage condition or permanently unconscious and unable to make decisions for themselves. Yet, misperceptions abound regarding when an advance directive is in effect, particularly when individuals are stabilized but reliant on life-supportive technology. For the last five years of his life, Brooke used various life-prolonging interventions—a ventilator, external oxygen, cardiac and diaphragmatic pacemakers, and feedings through a gastrostomy tube—after a bike crash in 2008 broke his neck and paralyzed him from the shoulders down.

Brooke's story, recently featured in a New York Times Magazine article by Robin Henig (July 17, 2013), raises important questions about how advance directives are understood and interpreted. Health care professionals working in long term care and acute care settings tell stories of dying patients whose end-of-life wishes or best interests are ignored by family members or clinicians who insist on using life-prolonging interventions that extend the dying process and cause more harm than good. They advocate for more people completing advance directives and holding clinicians accountable for honoring those directives. Disability rights advocates tell stories of how disability stigma and prejudice threaten the lives of people who are not terminally ill but are considered by others to be "better off dead." They are not as confident that advance directives are in their best interests. Brooke's story spans both sides of the issue.

For the last five years of his life, Brooke (who died on his own terms ten days after the Henig article was published online) ambulated in a wheelchair and relied on others to groom and bathe and transfer him. He couldn't swallow but appreciated the look, smell, and taste of food and the pleasure of shared company during a meal. He enjoyed teaching adult-education literature classes and having long conversations with family and friends. While he had bouts of pneumonia and other health crises after becoming paralyzed, he survived these episodes with expert medical intervention and the love and support of Peggy and his circle of friends, family, and caregivers. Yet, consider the language in the Henig article, describing the immediate aftermath of Brooke's bike crash:

> *If Peggy had been there and known the extent of Brooke's injury, she might have urged the rescuers not to revive him. Brooke updated a living will the previous year, specifying that*

Cont. on page 2

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.

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Advance Directives

Cont. from page 1

> *should he suffer a grievous illness or injury leading to a terminal condition or vegetative state, he wanted no procedures done that "would serve only to unnaturally prolong the moment of my death and to unnaturally postpone or prolong the dying process." ... By the time Peggy arrived and saw her husband ensnared in the life-sustaining machinery he hoped to avoid, decisions about intervention already had been made.* (Henig, July 17, 2013)

Immediately after his injury, Brooke was not in any of the conditions stipulated in his living will. Is Henig's portrayal a reporter's fluke, or a reflection of a more widely held misunderstanding of when a person's living will actually goes into effect? Anthropologist and disability rights advocate Bill Peace attributes this to a widespread disability bias that threatens the lives of people with disability. Bill wrote on his blog:

> *The descriptions of Hopkins body are deeply offensive. The not so subtle sub text is that life with a disability, especially for a vent dependent quad, is filled with pain and suffering. Such a life is terrible for Hopkins and by extension his wife. This point is made with the subtlety of a brick thrown through a plate glass window. Prior to his injury Henig makes it clear that Hopkins was a virile man who traveled the world. He was a larger than life figure and to be rendered a quadriplegic is a fate worse than death and his only saving grace is his powerful intellect.* (Peace, July 17, 2013)

Both Bill and Peggy—although from very different positions—highlight how respecting individual autonomy in the "real world" is not as simplistic as many like to think. About a year before Brooke's death, he decided he was ready to die and wanted to come off his life support machines. He dictated a "Final Letter" to his family clearly stating his wishes. Shortly after that, he developed a pleural effusion (fluid in the lungs) that made his breathing difficult, even with the ventilator support. He became delirious. Peggy opted to ignore Brooke's letter so that he could be treated in the hospital. She reasoned that allowing him to die then, in that way, didn't feel right, that Brooke "… had always spoken of a 'generous death' for which he was alert, calm, present and surrounded by people he loved." In the end, about a full year later, his death was just that.

Bill figures that many people in situations like Brooke's (particularly those who don't have Brooke's level of education, financial stability, or social support) don't fare as well as Brooke, who had Peggy in his corner, trying her best to let him die on his own terms. Bill writes:

> *"... [T]he fact is nationwide resources for people with a disability are grossly inadequate. Talk about patient centered care and autonomy do not mean much when you are a young man facing life in a nursing home. Suicidal thoughts ... are a logical reaction to an impossible situation."*

Bill, a paraplegic (he prefers the term "cripple" as more honest), has had many experiences on the receiving end of disability bias. He wrote about one such experience in The Hastings Center Report last year. After developing his first serious wound since he was paralyzed over 30 years ago, a hospitalist he had never met explained to him, at two in the morning, after he had endured several hours of vomiting, that his situation was grave. His wound might never heal. The antibiotics could cause permanent organ damage. He would be financially ruined by the care he would need over the next six months.

He was “looking at a life of complete and utter dependence” (Peace, 2012). Then he offered Bill the option of foregoing treatment and choosing comfort care instead. I’m happy to report that Bill is physically healed and enjoying his new bike, which replaced his kayak. But his memory of that conversation with the hospitalist still haunts him.

What lessons do Brook and Bill teach us about honoring patients’ end-of-life wishes? Advance directives communicate our wishes about end-of-life treatment when we are dying or permanently unconscious and we can’t tell others what we want. Neither Brooke nor Bill were in these conditions. While people who retain decision-making capacity don’t have to be dying to refuse life-saving treatments like ventilators or antibiotics, how we respond to their requests to die should be different from how we respond when a patient lacks decision-making capacity and the conditions of his living will are in effect. That is, a dying patient with a living will clearly prohibiting a feeding tube or a ventilator should not receive a feeding tube or ventilator, period. But for patients who are not dying but facing disability and reliance on medical technology to live, their requests to stop life support should not be met with a mere confirmation of their decision-making capacity, but with a concerted effort to persuade them to consider alternatives. Persuasion is different from manipulation or coercion. Unfortunately, clinicians are often unaware of the alternatives available to maximize independence and quality of life for disabled persons, and their own biases that the burdens to the patient, to caregivers, and to society aren’t worth the benefits may influence the conversations they have with patients, as Bill’s essay illustrated. How we spend money on health and well-being in the U.S. also reinforces disability bias. Third party payers cover joint replacements, implanted cardiac defibrillators, and extended ICU-stays but not non-invasive ventilators and wheel chairs for patients paralyzed by injury or disease (Bach, 2013). Until we do better to address health disparities among disabled persons and pervasive disability bias, our progress in providing better end-of-life care across the board will be thwarted. A good place to start is by educating ourselves about disability advocacy. (See BOX for suggestions.)

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LEARN MORE ABOUT DISABILITY PERSPECTIVES

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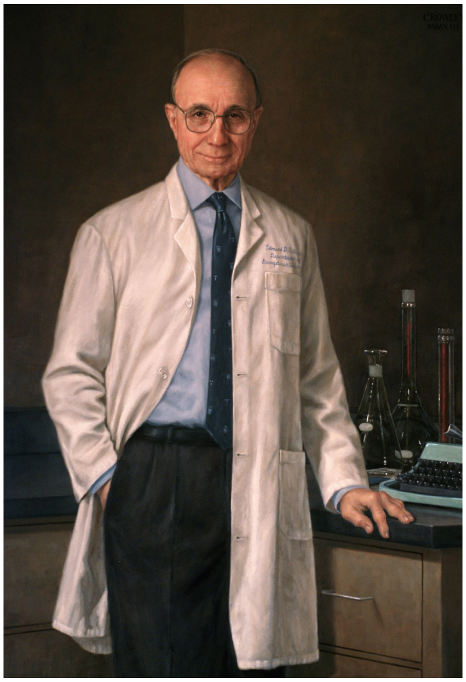
BIOETHICS LOSES A FOUNDING FATHER

Medicine is the most scientific of the humanities and the most humane of the sciences.
-Edmund Pellegrino

On June 13, 2013 bioethics lost a member of its founding generation, Edmund D. Pellegrino. Pellegrino started life in Brooklyn as the studious son of a tailor. Graduating summa cum laude with honors in chemistry from a Brooklyn college, Pellegrino, like others in his generation, was initially barred from medical school by the vowels at the end of his name: telltale signs of his Italian heritage and Roman Catholic religion. Advised to shorten his name to remove the offending vowels, Pellegrino refused. His refusal to yield to prejudice, his embrace of his heritage, and his principled stance were characteristic of the man.

Eventually Pellegrino was admitted to New York University medical school, where he also did his internship and residency at Bellevue Hospital. After two years of service in the military medical corps and a short stint at a tuberculosis hospital in upstate New York, Pellegrino joined the faculty of NYU. In the mid-1960s he moved south to chair the Department of Medicine at the University of Kentucky. While there he began to write notable articles on medical education ("Beehives, Mousetraps and Candlesticks—A Dilemma for Medical Educators, 1963), medical ethics, and the philosophy of medicine ("Medicine, Philosophy and Man's Infirmity," 1966). In the mid-1960s Pellegrino moved back to New York as chair of the department of medicine and dean of the medical school at Stony Brook. In the 1970s he returned to the south to serve as vice president at the University of Tennessee, Memphis, where he helped to create a groundbreaking program in the medical humanities. By the end of the decade Pellegrino was championing the medical humanities to the World Council of Churches, on the pages of medical journals from JAMA to Pharos, and at the Medical College of Yale University, where he became president and chairman of the board. After that he became president of the Catholic University of America (1978-1982), stepping down to assume the directorship of the Kennedy Institute of Ethics at Georgetown University (1983-89), where he remained as James Carroll Professor of Medicine and Medical Ethics for the rest of his career. From 2005-09 Pellegrino chaired President George W. Bush's Council for Bioethics.


Edmund Pellegrino
(artist: James Crowley)

Pellegrino's career spans six decades (1950s to 2010s) during which he wrote about 600 papers; authored, edited, or co-edited twenty books; founded *The Journal of Medicine and Philosophy*; gave thousands of lectures and yet still found time to mentor innumerable students. He was awarded forty eight honorary degrees and innumerable prizes including the American Association of Medical College's Abraham Flexner Award for Distinguished Service to Medical Education, the American Medical Association's Benjamin Rush Award for Citizenship and Community, and the Hasting Center's Henry Knowles Beecher Award for Lifetime Contribution to Ethics and the Life Sciences.

For Pellegrino, any medical ethics or bioethics not grounded in a philosophical understanding of medicine was fundamentally groundless. In his writings and those that he co-authored with his friend and fellow medical educator, David Thomasma (1940-2002), Pellegrino sought for "the philosophical basis of medical practice" (the title of their 1981 book). Several themes thread their way through Pellegrino's writings: a keen appreciation for the fragility of life, the discernment that the healing arts are a humanistic response to patients' vulnerability, and the insight that any comprehensive medical ethics must address virtues as well as duties. For Pellegrino, the core of medical humanism is encapsulated by the following line in the Hippocratic oath, "I will follow that system or regimen which, according to my ability and judgment I consider for the benefit of my patient and abstain from whatever is deleterious and mischievous." He read this line as generating an internal morality for clinical medicine (the title of an essay in his 2008 book) with a profound commitment to human dignity and human life. Moving from theory to practice he championed the "humanities in medical education for a post-evangelical era" (to paraphrase a chapter title in his 2008 book), and urged fellow medical educators to challenge any medical curriculum that failed to convey to the next generation of physicians a reflective analysis of the humanistic foundations of medicine.

Pellegrino was a conservative and a Fellow of the Center for Bioethics and Human Dignity. Yet his was a humanistic conservatism that relished dialogue with open-minded liberals, like his colleague at the Kennedy Institute of Ethics, Robert Veatch. I last met Pellegrino four years ago on the occasion of a lecture he gave at a small Catholic college in Albany. President Obama's Affordable Care Act was being vigorously debated at the time and a student in the audience asked Pellegrino for his opinion of "Obamacare." Pellegrino's reply startled many in the audience. "As a philosopher," he observed, "I am not qualified to discuss funding mechanisms, but as a physician and a humanist I can only applaud the intent of the act, which is to insure that everyone needing healthcare receives it."

Edmund Pellegrino personified the ideal of a medical humanism grounded in scholarship and reflected in medical education and clinical practice. He played a pivotal role in founding bioethics and reforming medical education; everyone in our field benefitted from his foresight and leadership.

Robert Baker, PhD
Union Graduate College-Icahn Mt. Sinai Bioethics Program

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BIOETHICS, WISDOM, AND THE END-OF-LIFE CONVERSATION

Dr. B is a nephrologist whose patient had renal failure and multiple other advanced diseases. The patient did not accept that dialysis would not change his outcome, so he went "doctor shopping" until he found a nephrologist who would continue to order dialysis.

Dr. R is an intensivist who is often asked to treat very sick patients whose primary care physician never told the patient that he or she is beyond medical rescue.

Dr. S was asked by a dying patient's family to conceal the prognosis from the patient. Dr. S knows that if she lies to the patient, he will not trust his physician's advice or plan of treatment again.

The hospital's Ethics Committee was asked to gather a panel to help a patient's adult children, who could not agree on "what comes next" for their dying father.

These are actual bioethical scenarios that have become all too familiar in today's hospital environment. I have heard anecdotes like these numerous times as a member of Washington Adventist Hospital's Ethics Committee, and as a trainer in end-of-life communication.

Peter Vaslow and I founded The Wisdom of Ruth Project to enhance the skills of medical team members when dealing with patients and their families in end-of-life scenarios. Hospital physicians, physician assistants, nurses, social workers and clergy are often uncomfortable when giving bad news to patients, or dealing with a patient's response to the bad news. However, discomfort is just the tip of the iceberg.

The first in our series of five Grand Rounds, "Why Have the End-of-Life Conversation?" elicited considerable frustration from physicians who frequently deal with patients at the end of life. As healers, they have difficulty telling patients that they have nothing left to offer medically. Some admitted they felt their job was over when their patient was beyond cure. Still others were unfamiliar with cultural differences, which sometimes prevented them from dealing directly with the patient, but instead, dealing with a family elder. Other physicians felt that they must always offer curative treatment, no matter how remote the chance of benefit.

Our workshops in end-of-life discussions demonstrate that medical team members enjoy participating in an interactive forum, where they have the opportunity to learn the skills of effective end-of-life conversations not only from us, but even more importantly, from each other.

All the stakeholders in these situations stand to gain from appropriate and effective end-of-life conversations.

The medical team learns that they can continue to provide care, even when the illness is beyond medical rescue. Medical team members have greater effectiveness and job satisfaction when they understand they don't have to "abandon" the patient; they can focus on care that actually provides benefit, rather than harm.

The patient benefits by understanding his medical situation and prognosis, allowing him to approach the end of life on his own terms. Patients often adopt a reflective attitude when they understand they are facing death, and may strive to mend fences, request the company of family and friends, be free from pain, discuss final arrangements with a spouse, or spend time with clergy, all of which improve their quality of life in the final

Cont. on page 6

Bioethics

Cont. from page 5

days or weeks. The family can relate to the patient without guilt, knowing that the patient is comfortable and his wishes are being fulfilled.

The hospital benefits in many ways. Quality of care is improved by focusing on the patient's needs, while resources are conserved by avoiding interventions that cannot improve outcomes. Patient and family satisfaction metrics improve with open, honest and empathic communication from providers. Family conflict is reduced, often avoiding confrontation and the need for intervention by the Ethics Committee. A realistic prognosis leads to a realistic and effective post-discharge plan of care, avoiding potentially preventable readmissions.

Our training workshops have raised awareness of the need for these end-of-life conversations and enabled clinicians to go about them in a more effective and satisfying way. We are gratified that our discussions of cultural issues have educated physicians in more appropriate ways of dealing with culturally diverse patients and families.

The Wisdom of Ruth Project has as its central mission to change the way patients and clinicians deal with each other in end-of-life situations. We have found that facilitating open and forthright communication between our training team and clinicians has raised awareness of the issues involved, allowing examination and improvement of techniques employed to make these interactions more effective, compassionate, and medically appropriate. This ensures a better outcome for the physician, patient, family, and hospital.

Sandy Elson
Co-Founder,
The Wisdom of Ruth Project
www.TheWisdomOfRuth.com

INSTITUTE OF MEDICINE SEEKS PUBLIC COMMENT ON END-OF-LIFE ISSUES

A committee of the Institute of Medicine, Approaching Death: Addressing Key End of Life Issues, has requested public comment from individuals who care for people who are approaching death. The committee is especially interested in hearing about the following topics. All comments must be received by November 1, 2013.

Visit http://www.iom.edu/activities/aging/transformingendoflife.aspx to contribute (see Public Comment).

The following questions are asked in the feedback survey:

1. If you are an individual living with a serious progressive illness or condition, or a loved one of an individual, please describe your experiences receiving care. Your stories may include how you have talked with health care providers, your family, and friends; how you have discussed and reviewed your spiritual or religious needs, your finances, or any other issues. Your stories may also include what you liked and did not like about communication with your providers and others who gave you support, treatment approaches, or any other aspects of care.
2. If you are a family member or friend of an individual who passed away, what care or supports did you need and/or receive while your family member or friend was in the advanced stages of their condition. What care or supports did you need and/or receive after they passed? What care or support did you NOT receive and wish you had received during the illness, at the time of death, or afterwards?
3. If you are a health care professional, please tell us about your experiences in providing care to individuals with serious progressive illness or condition and their families. What are the problems, opportunities, challenges, and successes you encounter? Does the term "end of life" impact the willingness of the individuals you work with to engage in the provision of care or the willingness to receive it? Please indicate what type of professional you are (discipline/specialty).
4. What do you see as the biggest barriers to care (for individuals with serious progressive illness or condition) that is appropriate and easy to access?
5. What three changes in the U.S. health care system could improve care of individuals with serious progressive illness?
6. If you have additional thoughts about improving research, care, and education for or about individuals with a serious illness or medical condition who are likely approaching death, or if you would like to share information related to the committee's work, please use the space provided below to do so. You may also email documents or articles to support your testimony to eol@nas.edu.

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 NURSING HOME

Mr. J. is a 78 year old man re-admitted to a nursing home after being hospitalized for seizures (status epilepticus). He retains a tracheostomy with oxygen to trach collar but no longer needs a ventilator to breathe. Prior to the hospitalization, he resided at a nursing home for a little over a year. He is dependent on others for activities of daily living due to a prior stroke. He has a history of diabetes and high blood pressure. Mr. J. was active in his Baptist church prior to his decline in health. Staff describe him as a pleasant man with a stubborn streak. His wife and daughter are actively involved in his care. Two other children who don't live nearby are not actively involved.

The nursing home social worker called for an ethics consult because the Maryland MOLST form that was completed at the nursing home prior to his hospital transfer indicated that he did not want g-tube feedings. Yet, a feeding tube was placed during his recent hospitalization and he arrived at the nursing home with orders to continue tube feedings. All the other choices on the last MOLST form completed at the nursing home indicated that all life-prolonging measures should be implemented (e.g., CPR, ventilator, blood products, antibiotics, but not tube feedings). The staff are convinced that Mr. J. does not want to be fed through a tube, that his health has been deteriorating steadily and that he is "tired" and ready to die. They believe that Mr. J's wife and daughter have pressured him to agree to interventions he doesn't want (like the g-tube). He has no documented advance directive.

Currently, Mr. J is alert but it's unclear whether he has decision-making capacity, as he only nods yes or no to questions, and doesn't always seem to respond in a way that demonstrates decision-making ability. The nursing home staff, however, firmly believe that Mr. J. had the ability to make decisions about his care when his MOLST form was previously completed. They are concerned that he is currently receiving tube feedings in contradiction to his previous MOLST, and don't know how to proceed.

COMMENTS FROM AN ETHICS CONSULTANT

Nursing home staff believe that Mr. J expressed a clear wish not to receive tube feedings. However, Mr. J also expressed a wish to receive other life-prolonging measures, like ventilator support and cardio-pulmonary resuscitation (CPR) attempts. This raises a question about his actual end-of-life (EOL) treatment preferences. While an individual may decide that he would not want to live under certain conditions (for example, if reliant on a ventilator for breathing or tube feedings for nutrition), these preferences for future treatment are more appropriately expressed in an advance directive rather than in a MOLST form. Furthermore, research has shown that people change their minds and opt for adaptive life-prolonging technology if they are faced with a choice of life or death, and that such individuals who are able to communicate rate their quality of life positively, despite their prior predictions that they would rather not live in such a state.

On the other hand, we spend more medical resources in the U.S. during the last six months of a patient's life without achieving improved outcomes, in the process bringing loved ones through a roller coaster of emotions that may complicate the grieving process, and often disregarding the patient's wishes along the way. Given our death-denying culture, it is not uncommon for loved ones to urge a patient who is dying to "keep fighting" when the patient would rather let go. The MOLST form evolved out of a motivation to provide better EOL care. But we are still on a learning curve.

The ethical principle of respect for persons is relevant in this case. It obligates us to do two things: (1) protect the autonomy of individuals with decision-making capacity by respecting their wishes; and (2) protect vulnerable persons who cannot make decisions on their own from harm. For Mr. J, harm related to tube feedings could come from either: (a) more suffering during the dying process if the tube feedings are continued too long, or (b) a premature death if the tube feedings are stopped too early. This raises the question of whether the ethically appropriate course of

Cont. on page 8

action for Mr. J is to stop his tube feedings based on #1 (assuming he does not want the tube feedings) or #2a (assuming he is now terminally ill and the tube feedings are prolonging his dying process and causing him to suffer), or to maintain the tube feedings for the time being based on #2b (assuming if he stopped tube feedings now, he would die, and it is "not his time").

The first step here would be to determine whether Mr. J currently has decision-making ability and can communicate his preferences. If not, two physicians should certify that he lacks such capacity. If appropriate, a certification of end-stage condition could also be made, giving Mrs. J authority under Maryland's Health Care Decisions Act to make decisions about his EOL treatments. Yet, Mrs. J is still obligated to base her decisions on her husband's known wishes. On what basis did Mr. J decline tube feedings but request other life-prolonging measures? Did he choose to forego tube feedings even if that meant he would die as a result? Did he simply want to keep taking oral feedings as long as possible? Is Mr. J at the point of transitioning from being chronically ill to terminally ill, for which a "comfort care" approach under hospice care would best fit his needs and wishes?

Given the information at hand, it is reasonable to conclude that uncertainty remains whether or not Mr. J would want the tube feedings stopped now. When making a decision to forego life-sustaining interventions that would result in a patient's death based on the patient's wishes, it is appropriate to require a standard of clear evidence. Because Mr. J's stated desire to forego tube feedings was not implemented in the form of a legally valid advance directive, and given the contradictory nature of his MOLST order, clear evidence of his wishes here is lacking. Therefore, it is ethically acceptable to continue the tube feedings. However, Mr. J's physician and family need to discuss his goals of care moving forward and how best to achieve them. His condition should be re-evaluated on a regular basis to see if short-term goals are being met, and if not, how to proceed. For example, one short-term goal could be to see if Mr. J could resume oral feedings, at least eating for pleasure.

Given Mr. J's prior conversations with staff about not wanting tube feedings, the family should remain open to the idea that he is transitioning toward the dying process when the goals of care shift from cure/restoring function to maximizing comfort and psycho-spiritual support for the patient and family. But nursing home staff should also remain open to the possibility that Mr. J may not be considered terminally ill, and that as long as Mr. J remains alive, he may prefer using life-prolonging medical technology if he (or his surrogate) thinks the benefits outweigh the burdens.

While individuals for whom staff complete a MOLST form may choose not to complete an advance directive, the latter should be encouraged to avoid situations like this one. At a minimum, Mr. J could have appointed a health care agent, and this would at least have provided some indication that he trusted his wife's decisions about his EOL treatment orders. Because Mr. J's wishes were not documented in the form of an advance directive, the clinician completing the MOLST form, after discussion with Mrs. J (assuming Mr. J lacks decision-making capacity; this should be confirmed), will need to consider what interventions are most appropriate to achieve the hoped-for goals of care. Mr. J's physician should give clear recommendations based on Mr. J's prognosis and best assessments of what medical interventions can achieve the goals of care. If Mr. J would not want tube feedings continued, then they should be stopped. If it is unclear or unknown what he would now want, then a decision should be made based on his best interests. In addition to whether to continue tube feedings, decisions should be made about the other life-prolonging medical interventions listed on the MOLST form, as well as whether/when to involve palliative care/hospice.

Unfortunately, the MOLST form focuses on what will not be done, instead of what will be done, so it is important to explain to patients and families how they will be supported at every stage of the illness trajectory. For example, it is common for patients with life-limiting illnesses to feel isolated from loved ones and poorly supported to express their EOL preferences. Steps should be taken to minimize this risk. Mrs. J and her daughter should be encouraged to communicate with Mr. J that it is okay with them if he is ready to stop working so hard to get better. Even if he is not verbally communicative, he may still hear and understand. It might help for Mr. J to hear directly from his wife and daughter that they give permission for him to make these choices, as sometimes family members are not ready to "let go" and push patients to "get better" when that is not what the patient really wants. These are difficult decisions, particularly when there is uncertainty about the patient's prognosis and wishes. It is appropriate to give the family time to think about these options and to respect their choices as long as they are informed and do not contradict clear evidence of Mr. J's wishes.

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INTERVIEW WITH ROBERT E. ROBY, MD, CMD

Q: How would you handle a case like this?

RR: On one hand, this is a very simple algorithmic exercise. The MOLST form was created when Mr. J was in one condition. Now his condition has changed, so you have to start over. You start at the top of the algorithm: has a determination of incapacity been made for Mr. J by two doctors? If yes, has Mr. J been determined to be in a terminal or end-stage condition, or in a persistent vegetative state [PVS]. If so, then as the authorized decision-maker, Mrs. J can decide to continue or to stop her husband's tube feedings, taking into account what she knows of his wishes. If Mr. J is not considered to be terminal, end-stage, or in a PVS, then Mrs. J is more limited in which of Mr. J's treatments she can request be withheld or withdrawn. As for the MOLST form that was filled out in the nursing home before Mr. J's hospital transfer, it doesn't make sense to provide all life support interventions while withholding tube feedings, so this needs to be clarified.

Q: So assuming Mr. J lacks decision-making capacity, you would let Mrs. J make decisions and you would complete a new MOLST form?

RR: Yes. Unfortunately, I've seen a trend among some nursing home staff to view a MOLST form as a binding legal document—kind of a de facto advance directive—instead of a medical order that changes when the patient's condition changes. From an ethics point of view, I don't want patients to get treatment they don't want. But on the other hand, patients (or their surrogates) have a right to change their minds. In almost every case where I've encountered staff resistance around a MOLST order, it's when the patient or the patient's appropriate decision-maker decides to change the MOLST form to request more life-prolonging interventions, not to limit them. For example, a patient with end-stage cancer or ALS might decide they would like to void a prior MOLST order to pursue a trial of antibiotics and ventilator support to treat a pneumonia. Yet, I have seen staff try to block this in various ways because they believe that less aggressive end-of-life (EOL) interventions are more appropriate for patients who are terminally ill, and they feel obligated to follow through with MOLST orders that limit EOL interventions.

I've seen some ridiculous situations, such as staff telling patients who are clearly their own decision maker that they can't change the MOLST form that they themselves created. In some cases, the very request to change the form was taken as evidence that the patient must have lost capacity, with staff then pressuring physicians to certify incapacity on that basis alone. Another variation is for staff to tell the physician who signed the original MOLST form (the very act that completed it and made it an order) that (s)he cannot change the form because it is now an "order" and as such cannot be altered, even by a physician.

The long term care staff really bond with their patients. They feel protective of them and want to advocate for them. But what does it mean to advocate for a patient when it comes to MOLST forms? To some nurses, MOLST is an order that shouldn't ever be changed except to remove more healthcare interventions. Maybe this comes from seeing advance directives ignored. But a MOLST is not an advance directive.

Q: Considering Mr. J, how do you think the hospital and nursing home differ in their approach?

RR: In Mr. J's case, it seems that the MOLST form was filled out incorrectly at the nursing home. For example, it wouldn't make sense to withhold tube feedings if he couldn't eat, but to offer CPR. So I can see how Mr. J or his wife reconsidered the tube feedings in the hospital. But in my experience, we have more time in the nursing home to fill out the form right. The time factor in hospitals is a real problem. Families are usually coping with a major health crisis, so it's hard to have a meaningful discussion about EOL treatment limitations. Most hospital physicians don't know how to have these conversations, and they don't know how to interpret and correctly fill out MOLST forms.

What I've seen more commonly is that the hospital physician completes a MOLST form incorrectly, and this puts the nursing home in a difficult position. It's almost better for the nursing home if there is no MOLST form accompanying a patient discharged to the nursing home from the hospital because there is about a five to seven day grace period allowed to address this. Yet, if a MOLST form is sent that is incorrectly completed, nursing home staff perceive that we need to correct this immediately. Nursing home social workers, in particular, are afraid of failing an audit if the MOLST form is not filled out 100% correctly.

Say we get an admission from a hospital on the weekend, when there's no social worker, and the MOLST

Cont. on page 10

Case Presentation

Cont. from page 9

form that came from the hospital indicates on the first page that the form was completed based on a discussion with the patient's health care agent. Then the nursing home staff discover there is no appointed health care agent. Once the social worker discovers this, she wants the form redone immediately. Yet, nine times out of ten, the correction made to the form doesn't change the patient's care.

Mr. J's case centers on tube feedings. This is the MOLST order I've seen most commonly ignored in the hospital setting, whether before July 1 when nursing homes were using MOLST voluntarily, or after July 1. Hospitals are focusing on achieving shorter patient lengths of stay and fewer readmissions. I think hospital physicians believe putting a feeding tube in a patient who is having trouble eating or swallowing helps achieve these goals, even though the literature doesn't really support this. From the nursing home perspective, they usually won't take a patient back if the patient isn't eating or swallowing well and doesn't have a feeding tube, unless the patient is enrolled in hospice, for fear of being sanctioned by state surveyors. But in Mr. J's case, what concerned the staff was his prior stated wishes that he didn't want tube feedings. It could be that staff really believe he doesn't want the tube feedings and they feel compelled to advocate for him. But it could also be another example of this trend I've seen to think that once a MOLST form is issued with any limitation on treatment, it can't be undone. A MOLST form is not a replacement for an advance directive. Ideally, you should have both. I think facilities are filling out MOLST forms but not advance directives because the MOLST is legally mandated, while the advance directive is not. That's a problem.

Q: Do you think an ethics consult might help in cases like these?

RR: I think if staff continue to have concerns, an ethics consult could help clarify the process and the legal and ethical standards. In cases I've seen like these, there can be a lot of anger built up on both sides. It can help to let those involved vent their emotions. You have to rebuild trust. In the end, we need to really listen to the family here. If they are telling us something we think doesn't make sense, let them explain why they think it makes sense. Our tendency is not to listen, especially if the conversation isn't going the way we want. What's most important is that the medical orders support good end-of-life care that's consistent with the patient's known wishes. We still have a ways to go to get this right.

2014 GOAL FOR MARYLAND ADVANCE DIRECTIVE REGISTRY

In 2011, the Office of the National Coordinator for Health Information Technology awarded the Maryland Health Care Commission $1.6 million to pilot the electronic exchange of clinical documents between long-term care facilities and hospitals through the statewide health information exchange (HIE, see http://crisphealth.org/). Funding for this pilot also calls for Maryland to plan for and test the availability of electronic advance directives and MOLST forms. Senate Bill 790 requires the Department of Health and Mental Hygiene to set a fee in regulation to fund an advance directive registry in Maryland, which would be operational by October 1, 2014. Details have not been finalized. Oregon, New York, and Virginia have advance directive registry initiatives in place. For more information about efforts in Maryland, visit http://mhcc.dhmh.maryland.gov/hit/hie/Pages/hie_main.aspx.

Tanio, C.P. & Steffen, B. (June, 2012). Strategy for Implementing Electronic Advance Directives and MOLST forms. Maryland Healthcare Commission Information Brief. Available at http://mhcc.dhmh.maryland.gov/hit/hie/Documents/AD_MOLST_Final.pdf.

CALENDAR OF EVENTS

OCTOBER

5 (10A-12N)

Henrietta Lacks Memorial Lecture. Sponsored by the Johns Hopkins Institute for Clinical and Translational Research. Speaker: Gary Gibbons, MD. Turner Auditorium, Johns Hopkins Medical Campus. Free to public but registration required. For more information and to register, visit http://ictr.johnshopkins.edu/service/lecture/.

15 (6:30 pm)

The Ethical Responsibility of Physicians in Response to Violence or the Threat of Violence. The Second Annual Medical Ethics Lecture and Forum sponsored by Dr. & Mrs. Thomas Allen and MedChi. 2211 Cathedral St., Baltimore, MD.

24-27

Tradition, Innovation and Moral Courage, Annual meeting of the American Society for Bioethics and Humanities, Hilton Atlanta, Atlanta, GA. For more information, visit: http://www.asbh.org/.

NOVEMBER

1-4

Clinical Ethics Immersion, Center for Ethics, MedStar Washington Hospital Center, Washington, D.C. For more information, contact Christian Carrozzo, Christian.Carrozzo@medstar.net, 202-877-0246.

DECEMBER

9

MOLST: A SIX MONTH CHECK-UP, Sponsored by the Maryland Healthcare Ethics Committee Network, University of Maryland School of Law, 655 W. Lombard St., Baltimore, MD. For more information, visit http://www.law.umaryland.edu/mhecn (click on Conferences).

12 (12:30 PM)

Difficult Conversations When Life is Short, Bioethics Grand Rounds, Shady Grove Adventist Hospital, Sycamore/Birch Room, Rockville, MD. For more information, contact Paul Van Nice, (301) 509-2225, paul@vannice.com.

JANUARY

17-20

Clinical Mediation Intensive, sponsored by the University of Pennsylvania Department of Medical Ethics and Health Policy. For more information, visit http://medicalethics.med.upenn.edu/events.

MARCH

7

Social Work Ethics Conference – Practicing Social Work in a Digital World: Ethical and Risk-Management Challenges. Sponsored by the National Association of Social Workers, North Carolina Chapter, McKimmon Center, Raleigh, NC. For more information, visit: http://www.naswnc.org/.

7-9

Responding to the Limits and Possibilities of the Body – 3rd Annual Conference on Medicine and Religion, sponsored by the Program on Medicine and Religion, University of Chicago and the Institute for Spirituality and Health, Texas Medical Center. Hyatt Chicago Magnificent Mile, Chicago, IL. For more information, visit: www.MedicineandReligion.com.

19

Ethics of Caring, Annual National Nursing Ethics Conference, Los Angeles, CA. For more information, visit http://ethicsofcaring.org/.

The Johns Hopkins Berman Institute 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 Ugamato at *tugamato@jhu.edu,* 410-614-5550.

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