

Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Newsletter, Fall 2016

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MID-ATLANTIC ETHICS COMMITTEE

NEWSLETTER

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
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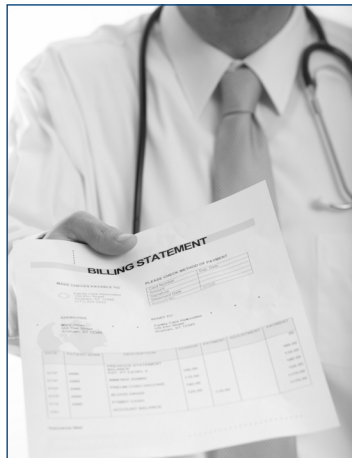
Fall 2016

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GLOBAL BUDGET REVENUE AND POPULATION HEALTH: MARYLAND'S RESPONSE TO THE NEW MODEL AGREEMENT WITH CMS

Hospitals across the country have been under increasing pressure to cut costs, but Maryland's new Global Budget agreement with CMS has put a spotlight on the state's hospitals which may feel as though they are the subject of significant scrutiny as they make efforts to comply with the agreement. Peter Parvis is a lawyer who represents hospitals, and other health care organizations on corporate and health care regulatory matters. Here he explains Maryland's new hospital reimbursement agreement with CMS and implications for healthcare services provided both in hospitals and in the community.



Background

Maryland is the only state where hospitals are not reimbursed for Medicare covered patients using the inpatient (diagnostic-related group) and outpatient prospective payment systems. The State of Maryland has operated its acute care hospitals under a unique statewide rate regulated system ("the waiver") since 1977, under which Medicare paid acute care hospitals at rates set by a state agency—the Health Services Cost Review Commission (HSCRC)—instead of making payments under traditional Medicare methodology. At around that time, waivers to Maryland and a few other states were granted by CMS to allow them to experiment with setting hospital rates. In order to secure the waiver, rates at each hospital in Maryland had to be approximately the same for all payors: Medicare, Medicaid, commercial insurers, private payors and the uninsured (hence the term "All Payor"). Each hospital's payment rates were based on historical cost data, the health status of the patient population served, and the level of uncompensated care provided to that population. In order to maintain the waiver, the state was required to keep the growth in Medicare

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Diane E. Hoffmann, JD, MS - Editor

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Global Budget Revenue and Population Health: Maryland's Response to the New Model Agreement with CMS *Cont. from page 1*

payments per inpatient case below the growth of inpatient Medicare costs nationally.¹

For over 30 years, using this all payor model, Maryland was able to successfully control the growth in per admission hospital costs relative to the nation. While the system worked well for three decades, incentives established by the waiver, as well as hospital efforts toward better population health (consistent with the Affordable Care Act), pushed hospitals to provide more outpatient care. This change in the site of care increased the intensity and costs of inpatient services. As a result, Maryland was unable to keep its cost growth rate below the national average.

The New Waiver

Facing the reality that it could not continue to meet the statutory requirement to maintain its waiver, the State negotiated for a replacement for the waiver.² The five-year Model Agreement became effective January 1, 2014 and ends on December 31, 2018.

The Model Agreement is essentially a cap on the increase in per capita hospital expenditures. Under the old model, the focus was on controlling increases in Medicare inpatient payments per case. However, the new model “focuses on controlling increases in total hospital revenue per capita.”³ Under the new methodology, the Commission prospectively establishes a fixed annual revenue cap for each hospital.

The Challenge for Maryland: Controlling Utilization

The cap requires Maryland hospitals to control hospital spending on a per capita basis for both Medicare and all other patients. Since Medicare pays a much greater portion of the cost

of uncompensated care in Maryland than in the rest of the country, hospital charges in Maryland to Medicare patients are generally higher than Medicare payments in the rest of the country. While Maryland hospitals charge *all* patients, regardless of the payor, the same rates, elsewhere, hospitals get paid a fixed amount (with variances for labor costs and various other add-ons) for each Medicare admission, emergency department visit, or outpatient service depending on its coding. That payment is frequently lower than payments by other insurance despite the fact that Medicare beneficiaries use hospital care at disproportionately higher levels. Maryland hospitals charge for the services used at approved rates per unit of service. As a result, the *only* way Maryland could achieve the necessary results for the new Model would be to control hospital utilization. The issue was, how?

The State's response was a new total revenue approach. Trying to save money by paying less for each service on a per service basis—the model Medicare uses everywhere else and for physician services—ends up with providers providing more services to make up for reduced revenue per case/visit/test. Maryland tackled revenue reduction by capping the total revenue each hospital could collect in any given year through one of two similar mechanisms—Total Patient Revenue (basically for rural or smaller hospitals); or Global Budget Revenue (GBR, for every other hospital). A hospital's total revenue in any year is set in advance. It is adjusted for increases in population in its defined service area. If its market share increases in its service area (the goal of every marketing effort by every hospital everywhere else), it does not get to keep the increased revenue.

Under the GBR, hospitals are encouraged to jump start population health efforts to provide more care

outside the walls of the hospital setting, as long as that care is likely to reduce hospital utilization and cost—whether in the E.D., outpatient, or inpatient admissions.⁴ The challenge is stark—how to get physicians, who refer patients, and the patients themselves to accept as a premise that “Less is More.” Worse, the federal government has a panoply of statutes that are designed to prevent the payment of financial incentives to physicians to reduce services to Medicare patients (generally called gain sharing), and the State to date has not received a waiver from these statutes.⁵ Moreover, a hospital gets no credit for the simple expedient of shifting services outside the hospital setting. Any such attempt has to be reported and results in a reduction of the GBR total revenue so that *total* costs do not increase when expensive hospital services are moved to less expensive non-hospital settings.

Under Maryland law, hospitals must charge every patient for all services used at rates approved by the Commission (within corridors for over and undercharges). It would seem that providing less service to keep costs down would reduce utilization, but it is not that simple.⁶ The GBR is also tied to other initiatives such as to reduce readmissions to the hospital within 30 days, to reduce hospital acquired conditions and to reduce potentially avoidable utilization. Therefore, hospitals are punished financially if they reduce the level of services but there is a readmission within 30 days or a hospital acquired condition.

The challenge is to reduce utilization in a system where every other player in the health care industry is incented to provide more volume to generate more revenue. The task is enormous, especially given that the Commission only regulates hospitals and not physicians. Hospitals have engaged in a wide variety of efforts to improve care at the community level, using caseworkers to follow the patient post discharge, creating programs

focused on high utilization diseases (diabetes, COPD, and hypertension are favorites), establishing outreach programs (frequently involving non-medical or volunteer personnel) as well as medical home projects, integrated case management intended to avoid duplication as a result of lack of information, and efforts to get the patient invested in their own healthcare. However, since federal and State laws meant to prohibit undue influence by hospitals over referring physicians remain in effect, it is difficult to financially incentivize physicians and other providers to do less. Of course, the State argues that the goal is not to do less, but only to eliminate services that may not be necessary for the well-being of the patient. Regardless of the view, “less is more” is not universally accepted.

As a result, the total spending per Medicare beneficiary presents problems, which was foreseeable in that the State only regulates hospital revenue, and hospital revenue is not the majority of health care spending.⁷ Since other provider costs are paid in the same manner in Maryland as in the rest of the country, utilization is the issue in controlling these costs, but unlike GBR for hospitals, there is no financial approach to incentivize all of the providers to work to reduce utilization.⁸ The jury is still out on the new Model and on GBR, but the results have been promising in the first two and a half years of the new Model Agreement, at least as far as controlling the increase in hospital spending per capita, reducing the Hospital Acquired Conditions Rate, and producing Medicare savings (over \$300 million in the first two years). While challenges remain, the State is supposed to apply for a Phase II five-year Model in 2017, which at a minimum is supposed to cover more services, with the goal of covering all healthcare services.

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ENDNOTES

¹ Under section 1814(b)(3) of the Social Security Act; the statutory requirement focused on the rate of increase in Medicare payments to Maryland vs. the rest of the country.

² The HSCRC negotiated for this waiver replacement with the Centers for Medicare and Medicaid Innovation, an entity under the Centers for Medicare and Medicaid Services that was created by the Affordable Care Act.

³ It requires the State to keep its increase in cumulative annual all-payer per capita total hospital revenue growth for Maryland residents receiving care at regulated Maryland hospitals to less than or equal to Maryland’s ten-year growth in gross state revenue.

⁴ The Commission explains: GBR and TPR agreements prospectively establish a fixed annual revenue cap for each hospital to encourage them to focus on care improvement and population-based health management. From Report to the Governor FY 2015. The HSCRC is in the process of putting all hospitals on the GBR.

⁵ These waivers are available for accountable care organizations under the Medicare Shared Savings Programs.

⁶ The HSCRC’s premise is that all hospitals have to do is reduce unnecessary utilization, which includes readmissions, potentially preventable conditions and hospital acquired conditions.

⁷ At \$972 billion in 2014, it is the biggest single expenditure, compared to \$802 billion for physicians, dentists and other professional care; \$400 billion for drugs and supplies, and \$389 billion for home health and nursing home care nationally in 2014. Medicare accounts for 20% of total healthcare spending. Source: National Health Expenditure 2014 Highlights.

⁸ The HSCRC has been working with hospitals and other constituencies to develop approaches that will permit hospitals to incentivize physicians to participate in utilization reduction approaches, and to present its proposal for the 2019-2023 time frame, but those have not yet been formalized.

INTRODUCING ... DAVID MOLLER, DIRECTOR OF HEALTH CARE ETHICS, ANNE ARUNDEL MEDICAL CENTER

David Wendell Moller arrived at Anne Arundel Medical Center on June 1 to develop a program in health care ethics. He comes to Maryland after a long bioethics career in the Midwest. We share his brief bio here by way of introduction, and hope you join us in welcoming him back to the East Coast and to our health care ethics community.

David earned his PhD in Sociomedical Sciences from Columbia University. He spent twenty years at Indiana University where he was a faculty member in the Schools of Liberal Arts and Medicine. He was one of the core medical ethics faculty members at IU, and directed the community outreach and educational programs for the palliative care team at Wishard Health Services (now Eskenazi Health). While at Indiana University he received the system-wide President's Award for Distinguished Teaching and the Outstanding Resident Faculty Award, as well as numerous Trustees Awards for Teaching Excellence. He most recently served as Senior Director of the Office of Human Values at Truman Medical Center in Kansas City where he pioneered an innovative curriculum in diversity and cultural competence for internal medicine residents, which included home visits

to hospice patients living in the inner city. He has lectured extensively in international and national settings and has published five books on end-of-life care, which have been reviewed as "breaking new ground," and "destined to become a landmark in the death and dying literature." His most recent

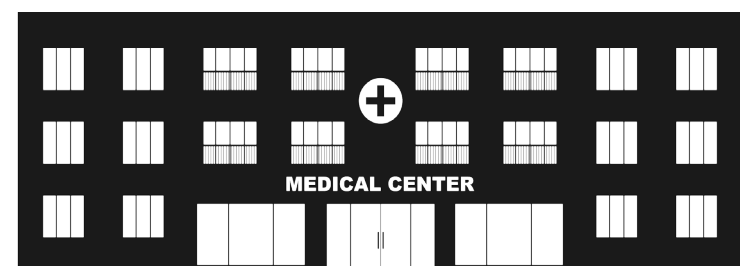


work is exploring what it is like to live and die in urban poverty and the challenges providers face when caring for vulnerable populations that live and die at the margins of society.

David's plans for program development at AAMC are focusing on "bringing clinical ethics upstream," whereby ethics awareness and

capability can be more broadly disseminated in patient care. This includes implementing an ethics screening for all patients admitted into the hospital so as to identify issues earlier. A contingent of "ethics ambassadors" are being identified and trained and will be present on each unit throughout the hospital to assist in identifying and resolving issues related to clinical conflict earlier and more systematically. In addition, he is working at establishing Unit Based Ethics Rounds (UBER), whereby the ethics team conducts hour-long, weekly rounds for each of the relevant units—on the unit itself. The program is being developed with explicit concern for addressing issues related to moral distress, compassion fatigue, and demoralization of clinical caregivers in addition to its focus on clinical conflict resolution.

Born in New York City and having spent so many years in the Midwest, David is delighted to be returning to the East Coast, and in the interest of full disclosure, he must declare that he is a diehard NY Yankees fan, which has been a difficult thing lately, as in recent years the Yankees have performed in most "un-Yankee-like" fashion.



MY PATIENT

By Suzanne Minor, MD, FAAP*

Reflective MedEd Blog

This essay was posted on August 9, 2016, on the Reflective MedEd blog, which is supported by the Ralph P. Leischner, Jr., MD, Department of Medical Education at Loyola University Chicago Stritch School of Medicine. It is published here with permission. To read other entries or to submit your own blog post, visit <https://reflectivemeded.org/>.

The student used the phrase “my patient” six times during the brief patient interaction: “I don’t like my patients to not exercise.” “I like it when my patients eat healthy.” “I like it when my patients take their medications” and so on. Many students use this phrase occasionally, but this was striking. I wondered what his motivation was. Was he nervous? Or did he think the patients were his? After the interaction, I debriefed with him, asking him what went well and what he could improve. He did not bring up his use of “my patient” so I did. He was unaware of his saying “my patient” and could not reflect on why he was doing so. I asked him what he thought this phrase might mean to the patient.

“The patient,” he queried, “what does that have to do with it?” I was frustrated, somewhat aghast that this third-year student, steeped in patient-centered interviewing throughout his first two years of school, missed that the patient had something to do with their own care and that the phrase “my patient” might claim ownership of another person or their attributes, such as soul, physical being, or responsibilities...

I asked him, “Who is responsible for the patient’s care?”

“I am,” he responded quickly. Specifically relating the discussion to patient autonomy from his clinical skills training, he voiced some understanding that the hypothetical patient shared some responsibility for her care, but could not imagine this actual patient playing a chief role in their well-being as he felt that was his role as the physician-in-training.

I left the discussion unsatisfied and shared the interaction with a fellow health educator that evening. She said that as a social worker it was important to avoid this phrase because it meant that person is the only person responsible for the patient’s care, negating the patient’s ownership for her care as well as the interprofessional team members working to improve the patient’s well-being, such as the social worker, nurse, dietitian, and physical therapist.

I then discussed “my patient” with residency faculty. One physician detailed orienting residents that the patients were their patients rather than her patients, impressing on residents that they were responsible for the patient’s care, not her. “My patient” represented accountability and ownership of the role of physician.

Not long after the “my patient” interaction in clinic, I said goodbye to my patients. Yes, “my patients!” I had been seeing some of them for 10 years; it was difficult to say goodbye. I completely accepted responsibility for my part of their care and strived to not claim responsibility for their roles. These patients were a part of my life. It felt incomplete and disrespectful to call them “the patients” rather than “my patients.” I think this was a way of honoring our relationship. It felt uplifting to put to words this connection to another human being, however humble it may be. I felt like I’ve come full circle, from ownership to relationships.

I think this phrase, “my patient,” has struck me so because of this value of connecting to others. Just as I encouraged the student to open his mind to other meanings, I can open my mind to the intricacies of our language. I love that I can continue to evolve as a physician, educator, and person. As much as possible, my goal now is to empower the patient by helping them to take ownership for their care and well-being and to empower the learner to be the patient advocate as well as empowerer. I want to empower patients to take responsibility for their well-being, their care, their bodies, their selves.



**Dr. Minor is the Director of Clinical Faculty Development and an Associate Professor at the Florida International University Herbert Wertheim College of Medicine.*

HOPKINS PERFORMS FIRST HIV+ TO HIV+ ORGAN TRANSPLANT

Last Spring, Hopkins performed a first in organ transplant medicine: an HIV-positive dead donor provided a liver and kidney to two HIV-positive recipients. Transplanting organs from HIV-positive donors was banned in the U.S. in 1984. Over the years, concerns escalated about the lack of ethical justification for letting HIV-positive patients awaiting an organ transplant die when they could safely receive an organ from an HIV-positive donor. The 2013 HIV Organ Policy Equity (HOPE) Act, signed in 2013, ended the ban on using HIV-positive donor organs. However, it took another three years before the United Network for Organ Sharing (UNOS) approved the first hospital to conduct such transplants. That honor went to



Hopkins, perhaps in part due to the advocacy of Hopkins surgeon Dorry Segev in getting the HOPE Act drafted and passed (Cohn, 2016). Given breakthroughs in anti-viral medications to suppress the HIV virus, most HIV-positive donors have sufficiently low viral loads to make donation safe for an HIV-positive recipient. Transplantation of an organ from an HIV-positive donor into an HIV-positive individual will be done under a research protocol requiring, among other things, that the donor and recipient be on similar anti-viral drug regimens. Research protocols are currently being developed to allow living HIV-positive individuals to donate organs to other HIV-positive individuals. Providing these transplants under research protocols will allow comparison of outcomes between HIV-positive

individuals transplanted with organs with and without prior exposure to the HIV virus. One concern is that the organ recipient could contract a more aggressive strain of the HIV virus, but the criteria for matching donor and recipient incorporates safeguards to minimize this risk. Although the number of HIV-positive donors will remain relatively small in the near future, it will grow over time, and will effectively shorten organ wait times for everyone.

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HORIZON FOUNDATION ANNOUNCES HOWARD COUNTY SPEAK(EASY) PROGRAM

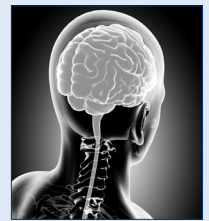
This article was adapted from a press release available at: <http://www.thehorizonfoundation.org/horizon-foundation-announces-speakeasy-howard-campaign/>.

The Horizon Foundation has announced the launch of Speak(easy) Howard, a new campaign that aims to encourage Howard County residents to take two critical first steps in planning for end-of-life care: have a conversation about health care wishes with loved ones and identify a health care proxy who can communicate these wishes. The campaign kicked off June 23, 2016 with the launch of a community collaborative made up of nearly a dozen organizations. Collaborative participants—including faith groups, health care providers, community centers and others—will commit one year to learning and implementing best practices in end-of-life care planning. The collaborative will receive guidance and support from experts with The Conversation Project and the Institute for Healthcare Improvement. In 2017, the Horizon Foundation will launch a countywide outreach and promotion campaign for Speak(easy) Howard to expand the collaborative's efforts to all individuals in Howard County. An important goal is to increase the number of people who have designated their health care proxy, a trusted person who will make health care decisions if they are unable to communicate those decisions themselves. Another important goal of this effort is to ensure doctors can connect with chosen health care proxies and learn each person's care decisions so these wishes can be respected. Horizon is partnering with the Howard County government and Maryland's official health information exchange, Chesapeake Regional Information System for our Patients (CRISP), to establish an electronic registry that will allow individuals to designate their health care proxy online, and have that information easily accessible by hospital and medical providers statewide. For more information, visit <http://speakeasyhoward.org/>.

JAHl MCMATH UPDATE

In December, 2013, then-thirteen year old Jahi McMath was pronounced dead after physical exams and confirmatory criteria indicated irreversible cessation of brain function. Her family sought legal intervention to maintain Jahi on ventilator support, along with artificial nutrition/hydration. Her body was ultimately moved across country from California, and currently resides in a facility in New Jersey, which allows an exemption from declaration of death based on neurologic criteria for those who have a religious belief that if a person's heart is still beating, the person is still alive. Jahi's parents claim to have new evidence that Jahi has brain function precluding a brain death determination.

Complaints filed by the McMath family in a medical malpractice action against Oakland Children's hospital include opinions from a pediatrician with expertise in brain death who reviewed Jahi's medical records, magnetic resonance imaging (MRI) and magnetic resonance angiography (MRA) scans done in September, 2014 (about 10 months after Jahi's anoxic brain injury), and 22 videotapes of Jahi's movements. The pediatric neurologist concluded that Jahi does not meet brain death criteria. Specifically, the MRI reportedly showed vast areas of the brain that are structurally preserved (including areas in the cerebral cortex, basal ganglia and cerebellum), and the MRA showed intracranial blood flow. Moreover, Jahi reportedly underwent menarche and developed breasts since her brain injury. If this were true, it would demonstrate hormonal interaction between the hypothalamus, pituitary gland, and ovaries that demonstrates some level of brain function. Lastly, Jahi is reportedly able to respond intentionally at times to verbal commands (Pope, n.d.). Those doubting the assertion that Jahi does not now meet brain death criteria point out that the scans and videotapes have not been released for others to view, and that she may well have reached menarche before her injury (i.e., continued menstruation after a brain death determination does not signify brain function at odds with a brain death diagnosis). Given that confirmatory testing initially done (and repeated before Jahi's transfer out of California) indicated that Jahi had irreversible and complete loss of brain function and thus met legal criteria for death, if new data reveal otherwise, this may have widespread implications for how death is defined in the U.S. and elsewhere.



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NIH'S CENTERS OF EXCELLENCE IN PAIN EDUCATION (COEPE) MODULES

The National Institutes of Health Pain Consortium has funded 11 health professional schools as designated Centers of Excellence in Pain Education (CoEPEs). The CoEPEs will develop, evaluate, and distribute pain management curriculum resources for schools training health care professionals (including medical, dental, nursing, and pharmacy schools). The awardees are University of Alabama at Birmingham, University of California, San Francisco, Harvard University,

University of Connecticut, University of Iowa, Johns Hopkins University, University of Pennsylvania, University of Pittsburgh, University of Rochester, Southern Illinois University Edwardsville, and the University of Washington.

The first CoEPE module, released July 20, 2016 from the University of Pittsburgh, features a case study of "Edna," an older adult with chronic low back pain. (To access this and other CoEPE modules, visit https://painconsortium.nih.gov/NIH_Pain_Programs/CoEPES.html.)

Sponsors of NIH's Pain Consortium include the National Institute on Drug Abuse, the National Center for Complementary and Integrative Health, the National Institute of Dental and Craniofacial Research, the National Institute of Nursing Research, the National Institute of Neurological Disorders and Stroke, the Office of Behavioral and Social Sciences Research, and the Office of Research on Women's Health.

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 TERTIARY CARE HOSPITAL

Mrs. R. is a 96 year old female who was admitted from home to a community hospital with pneumonia. She was living at home before that with increasing assistance from paid caregivers. There, she was treated in the community hospital's ICU for three days before being transferred to a larger hospital, where she remains intubated in the ICU, on a ventilator, non-communicative. She has a feeding tube in place and is transitioning to intermittent dialysis from continuous dialysis to manage her high blood volume. Her blood pressure is being supported by medication. General surgery is consulted to assess for tracheostomy placement. Mrs. R has a living son (K, who lives in state) and a daughter (H, who lives in a distant state) involved in her care. H. wants to maintain life support and is in favor of the trach. She believes her mother is a fighter and would want to live. K. disagrees. He states that while his mother never discussed end-of-life preferences with them, and didn't complete an advance directive, she did not like to see people in wheelchairs, and was uncomfortable when her husband spent time in the nursing home (he died 4 years prior). K. describes his mother as "lively," she enjoyed casinos, going out, and keeping her appearance. He feels confident that "she would never want to live like this hooked up to all these machines." But to avoid conflict, he defers to H's wishes. The team thinks it's nearly certain that Mrs. R. will not leave the ICU. The surgical team requests an ethics consultation to inform whether they should proceed with the trach.

COMMENTS FROM ETHICS COMMITTEE MEMBERS

This case demonstrates what happens with families in hospitals every day. Medical decision making can be extremely difficult when there are differences in opinion among family members and little or no previous discussions have taken place to communicate wishes. Uncertainty frequently happens and this case is the perfect example of why care planning is so important and how hospital ethics committee members facilitate conversations and collaborate with families to assist them in medical decision making. Since Mrs. R, a widow, does not have an advance directive, Maryland surrogacy law dictates that her children have equal say in all decision making (<https://www.oag.state.md.us/Healthpol/HCD.A.htm>).

In this case, there are at least four competing perspectives regarding

treatment, the clinical team, Mrs. R and her two children. What does each perspective believe is the best for Mrs. R.? For the clinical team, a treatment plan which promotes beneficence while avoiding maleficence. For Mrs. R., in the absence of an advance directive, it is difficult to assess her true perspective. This leads to the competing and complex perspective of her two children. Her son articulates his belief that she would want a lively quality of life not dependent on machines while her daughter expects her mother to fight to live at all costs. These competing narratives warrant open discussion and examination.

In a patient and family centered model of care, it is critically important that a family meeting be conducted which would provide an opportunity for the expression and discussion of these competing perspectives. Since the goal for this meeting is to help the children facilitate a plan of care for their mother, it is important for the clinical

team to review Mrs. R.'s illness with the family and to address the risks, benefits and probable outcome(s) for Mrs. R. and to answer any of the children's questions.

This supportive conversation would include the patient's advanced age and medical history, her current condition, current and proposed interventions including details about the tracheostomy, ventilator, and feeding tube. It is also paramount that members of the clinical team are able to address specific questions regarding care, treatment and potential prognosis in a manner that family members can understand.

After the medical information is presented, the discussion would move to other aspects of the patient's values, beliefs and spiritual background. This helps frame the difficult question of quality of life for someone who can no longer speak for herself. With this framework, her children would then be encouraged to express their

thoughts and feelings and to identify areas of agreement and disagreement with respect to their mother's quality of life. The family meeting would include the opportunity for Mrs. R.'s children to discuss amongst themselves, and with any other family they would like to include, the options for this patient. It is not unusual after a family meeting for a follow up conversation to address any questions that may have come out of the first meeting. The result of this meeting would hopefully lead to an agreement between both children on how to proceed with the patient's medical care.

Unfortunately, not all families come to an agreement even with extensive discussions. While not completely the scope of this current response, if disagreement persisted, several new questions would arise. One issue would be if one of the children agreed to abdicate their right for equal say in decision making, the other child could become the patient's sole surrogate decision maker. Clear documentation of an affidavit of surrogacy should then be done and care would proceed based on that child's decisions. Another outcome of a disagreement could be the failure of either child to forgo their decision making right. This would likely require more in-depth conversations and family meetings. If disagreement persisted, petitioning for guardianship could be done to allow the courts to weigh in on who should be guardian. This process can be onerous and lead to further acrimony among family members. Finally, if clinical teams fundamentally disagree with decisions that have been made in a patient's plan of care, documentation and discussions of futility may happen. The concept of medically ineffective treatment, i.e. futility, is incorporated in Maryland law (Sabatino, 2010), and informed by ethical guidelines (Bosslet et al, 2015; Kon et al., 2016). Families must still be included in these discussions and have to be notified of the decision to

withhold or withdraw treatment based on futility.

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COMMENTS FROM A PHYSICIAN ETHICS COMMITTEE CHAIR

The immediate question being asked regarding tracheostomy is really fairly straightforward, but there are much larger issues lurking in the background. In my opinion, looking at the question through the eyes of a recovering adult intensivist, the question of tracheostomy can be answered from a straightforward medical risk-benefit viewpoint, based on the ethical principles of beneficence and non-maleficence. The endotracheal tube which is already in

place is an acceptable way to maintain mechanical ventilation. While “early trach” is sometimes recommended for a variety of reasons, it is not mandatory. Since the patient is not expected to survive the ICU stay, it is difficult to justify trach as being beneficial at all, and there certainly are risks to the procedure. Thus, it seems medically prudent to maintain a wait and see attitude, as tracheostomy may never be required if the patient dies of her underlying disease process within the next few weeks. Time is also gained for potential resolution of the underlying end-of-life issues.

The larger issue is how did R wind up on invasive life support measures in the first place, and why is there dispute about her wishes regarding end of life care? Rather than limit our opinion to placement of the tracheostomy, I believe it is imperative to question the current course of treatment R is enduring. We know that R and her children never had “The Conversation.” Apparently she never had it with her physician either, although we are not specifically told that her primary doctor was appropriately contacted—something that seems to get overlooked more and more in our fragmented medical delivery system. Clearly the uncertainty about R's wishes represents a failure on many levels, not just medical. If she filled out a financial will, why didn't her lawyer introduce a medical directive too? We freely talk about how to spend down assets or distribute someone's possessions after they die, so why not how they want to spend their last days? Religious communities can also do a better job at facilitating end of life conversations with families.

Since there is no advance directive or medical agent named, R's children, since her spouse is dead, are now her surrogates and each has equal power under the law. Unfortunately, it is common that there is disagreement

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Case Presentation

Cont. from page 9

between children as in this case. Her son, K, provides insight into his mother's personality, believes his mother would not want to die this way, and does not want to proceed with tracheostomy. His sister H, however, claims that her mother is a fighter and wants to proceed with tracheostomy. In order to keep peace in the family, K is deferring to H, as is his right. One can only speculate about the psychologic dynamics leading to their difference in opinion.

As tracheostomy is medically unnecessary at this time, why were the children asked to provide informed consent for this procedure? We can only speculate that H has also informed the medical team that R is to be a full code, and the medical team is now asking, probably by reflex instead of reasoning, for tracheostomy (the ritual of PEG tube placement having already been performed). To be clear, even if R is a full code at the moment, there is no ethical obligation to offer non-beneficial treatment and in my opinion consent for a trach should not have been requested.

We have now reached the point where we must discuss autonomy. There seems to be a common perception in our society that autonomy means that a patient, or surrogate, has the right to determine what treatments will be given, and many physicians think they are required to offer all possible treatments, not just those that would be beneficial to the patient. This is one of the root causes of many of the dilemmas clinicians face especially when treating patients at end of life. Rather than the right to determine what treatments will be given, autonomy is the right of the patient to say "don't do that to me." It is the right to say what you don't want done to your body, and is the ethical

basis for the entire informed consent process.

Some may fear that such an interpretation of patient autonomy places us on the slippery slope to paternalism. However, I believe this interpretation is entirely consistent with the current acceptance of "shared decision-making" as the model for determination of goals of care. In too many cases, however, the physician's share of the decision is almost totally subordinate to the patient or surrogate. The above interpretation of autonomy should help even this balance.

Now that tracheostomy has been deferred, it is time to resume negotiations with the family regarding goals of care. We have not been told if Palliative Care has been involved; if not, they should be consulted to present their recommendations and how they would care for R. Perhaps there are other family members or friends who would be willing to participate and share their perceptions of what R would want given her current condition. During the family meeting, which hopefully H will be able to attend in person so she can see her mother, I would review the ethical principles involved, including the physician's obligation to advocate, first and foremost, for their patient, and to alleviate suffering, not cause it. We need to make it clear to H that withholding non-beneficial treatments that simply prolong the dying process does not mean that we are withholding care. I would inform H that R's physicians do not expect R to survive the ICU stay even with the invasive treatments being provided. Therefore, these treatments are inherently non-beneficial and medically ineffective, as they will not prevent the death of the patient from her underlying disease but only prolong R's death and suffering, violating the principle of non-maleficence. I would speak of autonomy as the right of the surrogate to put limitations on treatments

they think R would not want in her current condition, but not the right to require non-beneficial and harmful treatments be given. The medical team should present the treatment options that they believe can benefit and provide proper care for R, as well as their recommendations. In this way, surrogates can choose between medically and ethically acceptable treatments.

In the course of such negotiations, questions of withdrawal and withholding occur. While withdrawal and withholding are considered ethically and legally the same, emotionally they are quite different. If withdrawal is more than the family or surrogate can bear, compromises, such as no escalation of life-sustaining treatments including no CPR, may be warranted. While not an ideal resolution, as patient suffering can still be prolonged, it certainly provides some limits on medically ineffective treatments which would otherwise be given.

If negotiations fail, the last recourse is to use the process stipulated in the Health Care Decisions Act to declare specific treatments to be medically ineffective. It is beyond the scope of this commentary to review this process, other than to say it is an option with which our physicians and ethics committees should be familiar.

*Lee Edward Schwab, MD, FCCP
Chair, Ethics Committee
Holy Cross Hospital*

RECOMMENDED READING

Scneiderman, LJ, Jecker, NS. *Wrong Medicine: Doctors, Patients, and Futile Treatment*, second edition. Baltimore: The Johns Hopkins University Press; 2011.

CALENDAR OF EVENTS

OCTOBER

19 (4-6P)

Advancing Public Policy to Recognize and Support Family Caregivers. Sponsored by the Geriatrics and Gerontology Education and Research Program and UM partners. Contact: rcornman@umaryland.edu.

20 (5:30-7P)

2016 Presidential Election Panel: The Affordable Care Act: Too Big to Fail? Sponsored by the Law & Health Care Program, Maryland Carey Law, Ceremonial Moot Court Room, 500 West Baltimore St., Baltimore, MD. For more information, contact vrowthorn@law.umaryland.edu.

20

Recovering Inside? Ethical Challenges in Correctional Mental health Care. Sponsored by the Department of Medical Ethics & Health Policy, University of Pennsylvania, Philadelphia, PA. Visit: <http://medicalethics.med.upenn.edu/events/2016/10/20/recovering-inside-ethical-challenges-in-correctional-mental-health-care>

24 (12-1:15P)

Johns Hopkins Berman Institute of Bioethics Seminar Series. Speaker: Susan Goold, MD, Professor of Internal Medicine (School of Medicine) & Health Management and Policy (School of Public Health), University of Michigan. Feinstone Hall, E2030, Johns Hopkins Bloomberg School of Public Health, 615 N. Wolfe St., Baltimore, MD. Visit: <http://www.bioethicsinstitute.org/education-training-2/seminar-series>.

NOVEMBER

1

Challenges in Organ Donation & Transplantation, Third Interprofessional Forum on Ethics and Religion in Health Care. Sponsored by the Institute for Jewish Continuity and UM Schools of Dentistry, Medicine, Law (MHECN), Nursing, Pharmacy, and Social Work. Visit: <http://www.law.umaryland.edu/mhecn>.

4-7

Clinical Ethics Immersion, Sponsored by the Center for Ethics at MedStar Washington Hospital Center, Washington, DC. Visit: <http://www.medstarwashington.org/our-hospital/center-for-ethics/clinical-ethics-immersion/#q={ }>.

11-12

The 28th Annual Dorothy J. MacLean Fellows Conference on Clinical Medical Ethics, University of Chicago Law School, Chicago, IL. Visit: <http://MacLeanConference2016.eventbrite.com>.

14-16

Bioethical Challenges in Neurogenomics from an Interreligious and Multicultural Perspective. Sponsored by MD Anderson Cancer Center, Houston, Texas. For more information, contact cmgallagher@mdanderson.org.

28

Johns Hopkins Berman Institute of Bioethics Seminar Series. Speaker: Bob Arnold, MD, Professor of Medicine, Chief, Section of Palliative Care and Medical Ethics, Director, Institute for Doctor-Patient Communication, University of Pittsburgh. Chevy Chase Conference Center, Sheik Zayed Tower, Johns Hopkins Hospital, Baltimore, MD. Visit: <http://www.bioethicsinstitute.org/education-training-2/seminar-series>.

28

Johns Hopkins Berman Institute of Bioethics Seminar Series. Speaker: Kimani Paul-Emile, PhD, JD, Associate Professor of Law, Fordham University School of Law. Chevy Chase Conference Center, Sheik Zayed Tower, Johns Hopkins Hospital, Baltimore, MD. Visit: <http://www.bioethicsinstitute.org/education-training-2/seminar-series>.

DECEMBER

12

Johns Hopkins Berman Institute of Bioethics Seminar Series. Speaker: John Wilbanks, Chief Commons Officer, Sage Bionetworks. Chevy Chase Conference Center, Sheik Zayed Tower, Johns Hopkins Hospital, Baltimore, MD. Visit: <http://www.bioethicsinstitute.org/education-training-2/seminar-series>.

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University of Maryland
Francis King Carey School of Law
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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.

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