

Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 2015*

Mid-Atlantic Ethics Committee
Newsletter, Fall 2015

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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 2015

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CPR – WHAT HAS HISTORY TAUGHT US?

Dr. James Jude, a Hopkins-trained thoracic surgeon, died in Florida last July. Jude was one of a number of physicians in the Baltimore area who helped develop modern cardiopulmonary resuscitation (CPR) techniques in the late 1950s. Back then, sudden cardiac arrest was often triggered by medical procedures performed on hospitalized patients, such as anesthesia during surgery. Until that time, the standard method of resuscitating a patient involved direct cardiac massage—something that typically required a thoracic surgeon to cut open the patient’s chest (Jude, 2003). CPR offered the opportunity to save many lives. Before that goal could be fully realized, widespread education and training was needed. The evolution from CPR’s innovation to its widespread application offers some lessons for the challenges encountered in its current use.



CPR is unique in that it is administered as a default procedure unless a medical order is written that it be withheld. This raises the question of how the decision is—and should be—made to withhold CPR attempts. Dr. Baxter’s essay and the case study in this issue raise this very question: If a patient’s death is imminent and the goals of care thus shift toward preserving dignity and comfort, should CPR even be offered?

For a growing number of individuals, death is preceded by extended stays in intensive care unit (ICU) settings that obfuscate the line drawn where death is deemed “imminent.” This is relevant because the imminence of death marks a clear transition from a clinician’s duty to preserve life (often at the expense of comfort) to a duty to prioritize comfort and dignity during the dying process. Of course, we should prioritize a patient’s comfort and dignity throughout the disease trajectory. However, as unavoidable death draws nearer, maintaining comfort and dignity becomes a central focus. The burden of a particular life-saving intervention should thus be weighed against its benefits. When death is truly imminent, CPR provides no benefit to the patient. Benefit to the bereaved who may view failed CPR as the ultimate evidence that everything was tried to save their loved one’s life raises the question of whether it’s appropriate to provide CPR merely for the psychological benefit to survivors—what some have depicted as a modern “death ritual” (Lantos, 1992; Truog, 2010).

The *Mid-Atlantic Ethics Committee Newsletter* is a publication of the Maryland Health Care Ethics Committee Network, an initiative of the University of Maryland Francis King Carey School of Law’s Law & Health Care Program. The Newsletter combines educational articles with timely information about bioethics activities. Each issue includes a feature article, a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing, or related disciplines.

Diane E. Hoffmann, JD, MS
Editor

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CPR

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Jude and his colleagues foreshadowed this situation. He and his collaborator and coauthor James Elam made it clear that CPR should only be used with patients who experience sudden cardiac arrest who could be successfully defibrillated/revived. In their 1965 book, *Fundamentals of Cardiopulmonary Resuscitation*, Elam and Jude emphasize that CPR is inappropriate to use with dying patients. Consider this exchange between Elam and an attendee of the ad hoc conference on cardiopulmonary resuscitation, convened by the National Research Council of the National Academy of Sciences in 1966.

Q: When do you start or decide not to start CPR?

A. (Elam): "This has been critically reviewed by the committee ... You start CPR whenever there is a sudden cardiac arrest. You do not start it on a patient with an incurable or intractable chronic disease. You do not start it when you are sure that the patient has been clinically dead for so long that resuscitation with a viable brain is out of the question. If you are not sure about starting, the patient deserves the benefit of the doubt. If in doubt, start CPR and then determine the pre-arrest time and status of the patient as quickly as possible so that you can decide whether to continue CPR or to stop it." (NRC-NAS, 1966, p. 195)

There are three critical points here: (1) Whether to attempt CPR is a medical decision; (2) CPR is inappropriate when death is expected and unavoidable; and (3) If valid ambiguity exists among clinicians at the bedside, CPR can be started but should be stopped as soon as it is deemed inappropriate. The first point was less controversial in the 1960s, when physicians routinely made decisions without much input from patients and families about which



end-of-life treatments to provide or withhold. In today's legalistic and patient-rights-driven era, clinicians prefer getting permission to withhold CPR attempts. However, this implies that patients or their surrogate decision-makers have the final say. This often doesn't "feel" right when involving patients who won't survive discharge from the ICU—not to the bereaved who feel implicated in the decision to "allow" their loved one to die, nor to clinicians who prefer a more peaceful send-off for a dying patient than "ritualized CPR."

Once again, revisiting CPR's origins may provide some guidance. Several organizations, such as the American Red Cross and the American Heart Association, spent concerted, widespread, long-term efforts at training first responders to do CPR. Initially, training was limited to health care providers, then expanded to emergency medical technicians, and later, directed toward lay persons. Early education and training, such as the ad hoc CPR conference mentioned above (NRC-NAS, 1966), went into fine detail about all aspects of CPR provision, such as how to outfit ambulances to allow enough physical space to properly perform CPR, and how to address attitudinal barriers.

Consider this exchange between Dr. Larry Birch and an attendee:

Q: Will considerable psychological training be needed? I find that most nurses who have been trained say they would not use CPR because it is a doctor's job.

A (Birch): "I think nurses who have been reluctant to use CPR are not doing so because of a psychological block. This hesitancy relates to the question of what is nursing practice and what is medical practice." (NRC-NAS, 1966, p. 190)

With adequate training, nurses overcame their resistance to providing CPR and soon accounted for the largest group of health care professionals to perform the technique. Today, clinicians' moral distress related to CPR relates more to whether or when they can refuse to perform it. Moral concerns about attempting CPR on dying patients is sometimes centered on the unnecessary suffering this causes the patient. This is not a compelling logical argument, as it's unlikely that a patient undergoing chest compressions and cardiac

defibrillation is conscious enough to feel pain and discomfort (future suffering if they are successfully revived notwithstanding). More likely, clinicians at the bedside feel that CPR attempts are not the appropriate way to demonstrate care and respect for a dying or dead person's body.

Granted, what constitutes appropriate respect for a dead body depends on context and culture. Methods of attempting to revive the recently deceased have existed for centuries, and include whipping the body with stinging nettles, blowing smoke into an animal bladder and then into the rectum, hanging the body upside down, or over a barrel that is moved back and forth, or over a trotting horse, and burying a body up to the chest and splashing water on the face (National Research Council, 1966). Such indignities were justified if meaningful life was saved. Thus, the burden of the indignity needs to be weighed against its benefit. This weighing process has become more complex in today's healthcare climate. Concerns of patients, bereaved loved ones, and clinicians at the bedside

all deserve attention, as well as how to fairly allocate finite healthcare resources. Education and training for when *not* to attempt CPR, and what will be done instead, is multi-layered, complex, and a grand undertaking. It's time to delve into the fine details, as we learned from the CPR pioneers. Clearly this is still a work in progress.

*Anita Tarzian, PhD, RN
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ADVANCE DIRECTIVES AND THE MARYLAND MOLST FORM: HOW CAN WE DO BETTER?

The following are two relatively recent initiatives aimed at improving end-of-life care:

1. Completing an advance directive that specifies a person's end-of-life preferences in order to guide future decisions (usually, when a person can't make decisions for himself and is considered terminal or irreversibly unconscious); and
2. Having a clinician complete a Maryland Medical Orders for Life-Sustaining Treatment

(MOLST) form, which specifies the patient's present resuscitation status and which life-sustaining treatments he wants or doesn't want.

Unfortunately, both documents are only as good as the conversations informing how they are completed. Hospice physician Shahid Aziz proposes one approach to a better-quality discussion about end-of-life preferences. Instead of completing a traditional living will that asks individuals to select how much technology they would want clinicians to use to keep them

alive if in a terminal condition, persistent vegetative state, or end-stage condition, Dr. Aziz instructs individuals to answer the following three questions and discuss their answers with their healthcare provider and the person who will make medical decisions for them when they lack capacity to make their own decisions:

1. What is the minimum level of mental functioning that is acceptable to you with the help of life-prolonging treatments?

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Advance Directives

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2. What is the minimum level of physical functioning that is acceptable to you with the help of life-prolonging treatments?
3. What life-prolonging treatments are acceptable to use (indefinitely, or for a trial period) or not acceptable to get you to your minimum acceptable level of functioning?

Dr. Aziz recently led a workshop entitled, “Courageous Conversations on Death and Dying,” where he encouraged attendees to dialogue about how they would answer these questions. Workshop attendee “Bob” volunteered for some role play, and initially ran into a few roadblocks with how such conversations can go. When pondering his minimum level of mental functioning, after a long pause, he replied, “I’d want to be happy.” Of course, happiness is subjective, and it’s likely that clinicians around Bob’s bedside would have different impressions of whether they could

restore him to a baseline state of happiness. With some additional probing, it became clear that Bob valued being able to meaningfully communicate with others. Dr. Aziz suggests that instead of telling clinicians what treatments you want or don’t want (unless there are absolute restrictions such as religious prohibitions on blood product use), you should let them use whatever tools available in their medical toolkit and scope of practice to get you to your minimum acceptable level of functioning. They would then write MOLST orders based on a better understanding of your goals of care.

Of course, the challenge in such an exercise is that it’s difficult to imagine all possible scenarios and to accurately predict how your future self will judge what makes life meaningful. Perhaps it would be more useful to communicate where you fall on a continuum of “wanting everything” the ICU has to offer (let’s call that person a “vitalist”) versus “wanting nothing” done to prolong life (let’s call that person a

“non-interventionist”). Relying on a traditional living will to inform which treatments to use, withhold, or withdraw at the end of life may be more useful for those who fall on the extremes of the continuum; less so for the vast majority in the middle—i.e., those willing to try life-prolonging interventions and stop them if they don’t achieve their intended goal (let’s call them “pragmatists”).

Could using Dr. Aziz’s three questions and knowledge of where a person falls on the continuum be a useful replacement or complement to traditional living will forms? Perhaps. Again, the usefulness of this approach rests on the quality of the conversation that elucidates a person’s end-of-life preferences, the ability to effectively communicate those expressed preferences (i.e., in written wishes through a living will, or to an informed appointed health care agent), and the success in translating those wishes into appropriate orders on a MOLST form. Table 1 lists suggested duties the clinician has

Table 1. Continuum of End-of-Life Preferences and Ensuing Clinician Duties

	VITALIST “Do everything possible to keep me alive”	PRAGMATIST “Try your best to achieve [goal] in [time or burden estimate], and if it doesn’t work, stop”	NON-INTERVENTIONIST “Never put me on machines! Ever!”
CLINICIAN DUTIES	Clarify understanding of exceptions (e.g., brain death, medically ineffective interventions)	Discuss “three questions” – focus on minimum acceptable levels of physical and mental functioning	Clarify whether any exceptions are allowed (e.g., anaphylaxis, choking); persuade to consider less extreme position (e.g., allow short trials)
<i>Get consensus on standard of care and invest time to get treatment team and supportive staff on same page, acknowledge “reasonable degree” part of medical certainty, have treatment team communicate with one voice, don’t offer false choices, make clear medical recommendations and communicate them directly and compassionately, ensure buy-in via fair practices (i.e., treat like cases alike at systems level), educate patients and surrogates about the moral justification for withdrawing life support to allow natural death, provide exceptional end-of-life care regardless of patient’s code status.</i>			

Table 2. Duties of patients, surrogates, and clinicians in end-of-life planning and care

PATIENT	SURROGATE	CLINICIAN
<ul style="list-style-type: none"> Choose someone you trust to speak for you when you can't Appoint that person as your health care agent (HCA) Discuss your preferences with your appointed HCA Document your preferences (either in a standard living will or written letter) Have your documented end-of-life preferences available when needed Discuss your preferences with your health care provider (give him/her a copy of what you wrote down) 	<ul style="list-style-type: none"> Keep a copy of the patient's written end-of-life wishes and HCA appointment Discuss the patient's preferences with him/her Recognize your obligations to know the patient's preferences and advocate for him/her (not for what you would want for yourself) If the patient would agree, consider the value of limited trials of life-prolonging interventions and their withdrawal when clinicians decide they won't achieve their intended goal 	<ul style="list-style-type: none"> Recognize that facilitating a "least-bad" death for a patient and minimizing future regrets/ psychological angst among the bereaved is a valued public health goal and laudable goal of medicine Find ways to enhance your end-of-life communication skills (e.g., http://depts.washington.edu/oncotalk/) Identify standard of care practices, achieve consensus from your colleagues, and give clear recommendations rather than offering false choices

when conversing with individuals falling on different places along the end-of-life intervention preferences continuum. Most individuals need to be educated about what realistic options are available, and may need to be persuaded to consider alternative perspectives. For example, given the complexity in determining when death is imminent and the value that comes with limited trials of therapy, a great advance in end-of-life care may come with more widespread acceptance of limited trials of life support technology that is then stopped if it doesn't achieve its intended goal. This is easier said than done. The "technology-creep" of acute-care life-

prolonging interventions often makes it more difficult for clinicians and loved ones to accept that the physical and emotional investment in such therapies has not paid off. Patients and their loved ones need to be prepared in advance for what "stopping" aggressive life support will look and feel like, and how the patient and family will be supported. Palliative care should be embraced and held up as a new version of "doing everything" (rather than the oft-repeated phrase heard in ICUs of "withdrawing care" to indicate the switch to comfort care). Having these courageous conversations about end-of-life preferences and documenting them can

take the burden off of individuals (e.g., surrogates, clinicians) for making the final decision to let a patient die. The focus can then shift away from guilt or moral distress toward the tasks of dying and bereavement. Each person (the patient, the surrogate, the clinician elucidating end-of-life preferences) must do his or her own part (see Table 2). To learn more about Dr. Aziz's three question approach to end-of-life conversations, visit his blog, "You Deserve a Good Death," at <http://death.blogspot.com/?m=1>.

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QUINLAN'S and CRUZAN'S LEGACIES: IMPLICATIONS FOR ADVANCE DIRECTIVES AND MARYLAND MOLST

Forty years ago, Karen Ann Quinlan suffered brain damage that caused irreversible unconsciousness. She was kept alive with ventilator support and medically-provided nutrition and hydration through a gastrostomy tube ("g-tube feedings"). Her parents won an appeal to the New Jersey Supreme Court that allowed Karen's ventilator support to be withdrawn, something that was previously considered by many to violate a physician's professional code of ethics and possibly to constitute homicide. Karen breathed on her own and lived nine years longer on the g-tube feedings. She died thirty years ago, from respiratory failure.

Five years later—this year marks the 25th anniversary—Nancy Cruzan died after a long legal battle to allow her parents to stop her g-tube feedings. She entered into a persistent vegetative state (PVS) seven years earlier, in 1983, after she suffered severe brain damage in an automobile collision. The U.S. Supreme Court confirmed that the state of

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Missouri could impose a “clear and convincing” standard to determine that an incapacitated person’s g-tube feedings could be stopped. Subsequent to the Supreme Court case, a lower court in Missouri decided this standard had been met, resulting in Nancy’s g-tube feedings being withdrawn. She died shortly after, in 1990. This influenced the creation of health care directives (“advance directives”) and the passage of the Patient Self-Determination Act, a federal law that requires health care institutions to inform adult patients being admitted to their facility (with some exceptions) about advance directives, and to honor a patient’s advance directive.

While a living will is the gold standard for providing “clear and convincing evidence” that life-prolonging measures such as g-tube feedings, dialysis, or ventilator support should be withheld if one is dying or irreversibly unconscious, most adults don’t complete one. For those who do, their living will is sometimes ignored, either because a surrogate demands treatment despite it being precluded in the living will, or the living will isn’t accessible when it’s needed, or physicians do not consider the patient to be in a “qualifying” condition triggering the living will (e.g., a terminal condition or death being “imminent”).

Some think the Maryland Medical Orders for Life-Sustaining Treatment (MOLST) form is a preferable method of communicating a patient’s end-of-life treatment preferences. MOLST orders are transferable medical orders that reflect what should be done now if a patient experiences a potentially fatal circulatory or respiratory crisis, while an advance directive reflects what should be done in the future—usually, when an individual has reached a point where she/he is less willing to undergo medical procedures that produce discomfort because the resulting life prolongation would not be worth the burden and discomforts associated with those procedures.

A recent study MHECN undertook this year with funding support from the Maryland Department of Health and Mental Hygiene explored the use of the MOLST form and advance directives in Maryland healthcare facilities. Excluding non-psychiatric, non-obstetric, non-trauma admissions, 47.5% of adults had a MOLST form on hospital admission, and 84% who were discharged from the hospital to a “qualifying” facility (i.e., home health, hospice, long-term care, a sub-acute facility, or a dialysis center) had a completed MOLST form on record. However, only 30.5% of hospital patients included in the study had an advance directive.

Of note, 68% of patients who died during hospitalization had no documentation in their medical record that they were in a terminal condition. A qualitative review of the causes of hospital admission for these patients revealed that many of these deaths would have been expected. This suggests that the most common condition triggering a living will to be in effect—a terminal condition—is often not recognized by clinicians. The difficulty identifying when a patient is considered “terminal” or “imminently dying” and the low living will completion rate threatens the likelihood that the MOLST program will achieve its ultimate goal of complementing advance directive use and improving end-of-life care in Maryland. However, as Quinlan’s and Cruzan’s legacies demonstrate, attitudes and end-of-life practices evolve—hopefully for the better.

The Maryland Healthcare Ethics Committee Network (MHECN) is a membership organization, established by the Law and Health Care Program at the University of Maryland Francis King Carey School of Law. The purpose of MHECN is to facilitate and enhance ethical reflection in all aspects of decision making in health care settings by supporting and providing informational and educational resources to ethics committees serving health care institutions in the state of Maryland. The Network attempts to achieve this goal by:

- Serving as a resource to ethics committees as they investigate ethical dilemmas within their institution and as they strive to assist their institution act consistently with its mission statement;
- Fostering communication and information sharing among Network members;
- Providing educational programs for ethics committee members, other healthcare providers, and members of the general public on ethical issues in health care; and
- Conducting research to improve the functioning of ethics committees and ultimately the care of patients in Maryland.

MHECN appreciates the support of its individual and institutional members. MHECN also welcomes support from affiliate members who provide additional financial support.

A PHYSICIAN'S PLEA

Dr. David Baxter is an internal medicine physician who teaches at Memorial University Medical Center and Mercer Medical School in Savannah, Georgia. He writes here about harms that occur when family members insist that a dying loved one's death be prolonged in the intensive care unit (ICU) at all costs, and how compassionate health care providers should respond.

His earthly journey was finally over. A man imminently and obviously dying, now finally released from his captors. He did not clearly express his will earlier in life, and his family did not seek his will but their own. A lone, long distance family member threatened, cajoled and harassed the other family members as well as the clinicians. The clearly appropriate, medical treatment was comfort care, but because of one strident voice, comfort was substituted for the ICU, ventilators and vasopressors.

The initial stage of his illness was thought only to be a chronic obstructive pulmonary disease (COPD) exacerbation. Subsequent respiratory failure led to the revelation of a previously unknown advanced lung malignancy. Surgery would be an immediate sentence of death. Chemotherapy was demanded and reluctantly given with no result except for severe, almost deadly side effects. All but one family member could see the situation with emotional clarity.

Ethics meetings and family meetings followed, but the lone, shrieking voice of compulsion could not be abated. Ethical “futility” was proclaimed. The threat of litigation drove the ICU stay to continue. The lawyers thought they had made the decision, but death—the final arbiter—would eventually prevail. As professionals we must remain in our clinical roles, but in these times of turmoil and conflict, we are torn by our humanity. As humans we are aware of our rights but less so our responsibilities. In our current health care world, we clinicians are aware of our responsibility yet sense a limitation of our rights. Patient autonomy has become the prime meridian. This has led to clinicians being told what to do (most often by

families) when clinical benefit is not easily documented and often obviously absent.

Anger and frustration abound while watching this sight of sadness. Not being allowed to provide the appropriate comfort care, but to flog a fellow human being is morally repulsive. I don't care how much you argue that with good pain control the patient would not suffer, I don't believe you. Intubated and sedated in the ICU, even with the best care, is not comfortable. When is “do everything” going to be accepted to mean “everything reasonable”? When are we going to allow physicians to practice their art and not be held hostage to a belligerent, berating bully?

Medical therapies are utilized based on reasonable and likely results. Risks and benefits are weighed daily—almost unconsciously—as we artfully apply science to individual patients. As medical care is offered, it is either accepted or refused. Every day patients refuse medical care we deem important. This refusal of care is bothersome, but in a patient of age and capacity, the patient's will is allowed to prevail. When the clinicians know the clear will of the patient a demand to “do everything” is usually refined with reasonable goals of care. Everything possible should be defined as clinically rational and reasonable. To amputate a toe for a hang nail would be clinically wrong and morally repulsive. To intubate, sedate and essentially flog a patient dying of terminal disease near death is also, in my view, clinically inappropriate and morally repulsive.

When medical care that is not clearly indicated is demanded by family, the physicians should not be held hostage, particularly by the fear

of litigation. Treatments that are not medically appropriate are not care but cruelty. These demands lead to moral conflict in the treating team.

Examples of patient demands abound. The relatively common demand for antibiotics for viral illnesses driven by physician pacifism and fear of litigation has led to the death of many from worsening antibiotic resistance patterns. As participant pawns in this drama, the medical caregivers feel helpless. Helplessness leads to hopelessness. Anger and frustration are quickly birthed.

“We” as health care professionals never cure the real problem. Death, the inevitable enemy, is always lurking. Our earthly technologies and potions only temporize the pangs of death. The mysteries of science only prod the inherent miracles active in the body. The surgeon cuts and sews, but the body heals. The internist pokes, prods and prescribes potions, but the body has to absorb and process so the true miracle, life itself, may continue.

Currently the law, which in reality is designed to prevent harm, not compel good, allows fellow human beings to be forced to go beyond the reasonable, often in the guise of hoping for a miracle. Often we are told that a “miracle” of the Lord is what is expected. In these situations God has already spoken. We just won't accept what He has said.

The true miracle is life itself.

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CASE PRESENTATION

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

This case study and the first commentary are reprinted with permission from The Journal of Hospital Ethics, 2014, Volume 3, Number 3.

CONSULTATION REQUEST FROM A NICU

Baby CE is an 11-day-old female who was born at 23 weeks and 5 days of gestation and is now in multi-organ failure. She is the surviving neonate of a twin pregnancy. She was designated Baby A in utero.

Baby CE's mother went into labor at 23 weeks and 5 days. She had a spontaneous rupture of membranes, at which time her cerclage was removed and purulent drainage was noted coming from the cervical opening. The twins were then delivered via cesarean section. Baby B was stillborn. Baby A, named Baby CE, was successfully resuscitated and stabilized, weighing a mere 550 g (1 lb 3 oz).

Baby CE's prognosis was grim at birth. She had a critical, though expected, course for the first 5 days of life. She required significant ventilator support and developed pulmonary interstitial emphysema. She was hypotensive, which required pressors for support, and ultimately received medical treatment for a patent ductus arteriosus (a congenital disorder wherein a neonate's ductus arteriosus fails to close after birth). She was hyperglycemic and required an insulin drip. She was found, by head ultrasound, to have bilateral grade 2 intraventricular hemorrhages. As is typical, she received blood

transfusions and broad-spectrum antibiotics.

Day 6, however, was a turning point in the wrong direction. Baby CE had a pulmonary hemorrhage but managed to survive. She was coded with chest compressions and epinephrine. She required multiple blood products in order to be stabilized. She also required increased pressor support, and was found to have several new, extensive bilateral cerebellar hemorrhages. In addition, she was found to have a significant liver hematoma, which may have been secondary to the known physical trauma a code can induce.

During the night of her eighth day of life, Baby CE once again became severely hypoxic and bradycardic from a presumed pulmonary hemorrhage. Over the next several days, Baby CE's overall status worsened. The team was becoming increasingly uncomfortable continuing to provide life-extending therapy they felt was not indicated and would never help Baby CE.

Now, on day 11 of life, the baby's course is not going well. The NICU team, including a neonatologist, nurse, social worker, and chaplain, meets with the parents to discuss their concerns about Baby CE. The team explains that Baby CE has no meaningful expectation of survival and has signs indicating respiratory, cardiac, liver, and kidney failure at this time. Additionally, if she were to survive, she is expected to have profound neurologic impairment.

Baby CE's parents are quiet through much of the meeting, but express

their faith that the NICU team will do everything they can to save their baby. The team explains that at this point they can continue to support Baby CE with the current management if that is the family's desire. They feel, however, that should she decline further, cardiac compressions and epinephrine no longer would be indicated. The team explains that cardiac compressions are generally not useful in the NICU, especially when the cardiac failure is a result of overall multi-organ failure. They point out that cardiac compressions can cause substantial trauma to infants. Baby CE's parents remain quiet, tearful, and undecided as to whether they believe compressions ought to be performed or not.

The NICU team is distraught at the end of the meeting; the team is uneasy with the parents' unwillingness to accept that resuscitative efforts are likely not in the baby's best interests. The NICU group knows that in some jurisdictions, including their own, a patient's or surrogate's permission is not needed for a physician to write an AND/LT (Allow Natural Death/Limited Therapy) order. The team involves other NICU physicians and senior nurses in a discussion about the care and ethical dilemmas surrounding Baby CE. Some members of the team feel that if cardiac compressions will not be helpful to the infant, then they should not be offered or provided. Other members feel that the parents' lack of agreement with the NICU physicians means that the NICU

team should do everything possible, regardless of the potential harm and lack of expected benefit to the infant, to keep this infant alive, at least for now. Other members still are hopeful that with some additional time the parents will be able to accept the physicians' recommendation not to resuscitate. Some members point out that because many parents feel this decision is too burdensome — that to agree not to resuscitate would mean that they were giving up on their child, something they could never live with — the team should not even be asking the parents anything at this point; they should simply tell them that resuscitation would not be attempted in the face of a cardiac arrest. Having already lost one of their twins, this family may simply be unable to say that it is okay to stop resuscitative efforts. An ethics consult is requested to help determine the best course of action.

RECOMMENDATIONS FROM A NEONATOLOGIST & CLINICAL ETHICS STAFF

Neonatologist Dr. Courtney De Jesso and Staff from the Center for Ethics at MedStar Washington Hospital Center (WHC) provide here (reprinted with permission) what an ethics consultation chart note with recommendations would look like for this case.

CHART NOTE AND RECOMMENDATIONS

Ethics consultation requested by neonatology intensive care unit (NICU) regarding an 11-day-old female infant born prematurely at 23 weeks and 5 days gestation and currently suffering multi-organ system failure. Ethics holds a discussion with the infant's primary physician and the rest of the NICU team in an effort to learn the specifics of the medical circumstances and to gather a comprehensive picture of the team's

concerns in relation to the parents' inability to make a decision. Primary concerns of the team surround an ethical justification to act on what they feel is in the best interest of the infant in light of the parents' indecision. The NICU team wants to explore the ethics of the possible paternalism of making the decision about future resuscitation themselves. Further, the team is interested in the ramifications if the parents decide they want full coding efforts taken and the team remains opposed. Another concern is about whether asking them to essentially "give up" on their infant places an overwhelming emotional burden, which they are currently psychologically unfit to bear — how would the team know that and if they could determine that was the case, what should they do?

Subsequent to the team meeting, a separate conversation was had with the parents. The parents were still visibly distraught, though tranquil, having come no closer to making a decision themselves. They did, however, recognize the gravity of their infant's prognosis and were able to reasonably understand the futility and further trauma that would likely come as a result of additional resuscitative measures. They confessed to an inability to come to terms emotionally with making the finite decision to actually request measures not be taken. The father's last statement was, "We just can't tell them to stop, but they should do whatever they think is best." Ethics communicates the results of the meeting to the NICU team.

Ethics recommends that the physician, with at least 1 or 2 other members of the NICU team, meet with the parents to explain that if the baby codes (unless there is improvement in the baby from where she is right now), resuscitation will not be initiated—that is, if the baby's heart stops, that will be the way everyone knows it is time to stop.

REASONING

This case illustrates an often occurring and dilemmatic feature in a clinical ethics consultation involving parents of a dying infant—that is, when what is in the best interest of a patient is reasonably understood by all, but rendered emotionally unacceptable by family or loved ones. Often, some additional time is all that is needed for family members to negotiate the psychological resistance to coming to terms with what they are able to rationally accept. However, just as often, family members simply cannot bear the weight of making such a decision no matter how long they are given, or the time to lengthily reflect is simply not available given the clinical circumstance.

Sometimes, it may be best that the medical team refocuses around the cessation of the demand for a decision, rather than continuing to insist. Sometimes the insistence itself is ethically objectionable. Often, just taking the proper steps to gain the parents' understanding and acceptance that, without a definitive position from them, the medical team will do what they believe is in the patient's best interest. Often, the relief associated with not having to make a decision of this significance, and thus carry the moral distress and emotional weight related to the choice, is often all that may be unconsciously sought by parents and/or other family members suffering through the tremendous anxiety that comes with such a responsibility.

Identifying this complex state of mind in family members is no easy task. Clinicians ought to be mindful, however, of communicative signs that indicate a person's acceptance or resignation to the clinical circumstance. The removal of the absolute requirement for parents and/

Cont. on page 10

Case Presentation

Cont. from page 9

or other family members to make a decision may be needed in order to reduce said anxiety and allow these individuals the ability to release the guilt associated with making this difficult decision.

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COMMENTS FROM A NEONATOLOGIST

Sharing treatment options with families in the neonatal ICU is not a straightforward task.

How do I know which treatment decisions to share? Should I offer choices of antibiotics for urinary tract infection? Choices of formula? Choices of pain management for central line placement? And should I offer every family those choices? The 15 year old mother? The non-English speaking parent with a 4th grade education? How should I help them make the decision? How can I be certain that my colleagues would offer these same choices—and should we disclose to parents that we all have different practices in this regard? Should I formally obtain and document the parents' consent for these treatments—and how detailed does that consent have to be? If the family agreed that I should choose the specific antibiotic, is it valid to document that “the family agreed with my choice of amoxicillin?”

These considerations are contrived, but their essential elements underlie discussions regarding cardiopulmonary resuscitation with families of sick infants in the NICU. Consistency, fairness, transparency, and autonomy are core components of collaborating with families to make decisions about CPR. Compassion

and equanimity are just as important: these decisions require hard work, and we (both families and clinicians) are all doing the best we can.

A decision for, or against, neonatal CPR is usually one element of a much larger and complicated narrative. Whereas code status for adult patients is often discussed upon routine hospital admission or during outpatient discussion of advanced directives, the need to plan for neonatal CPR is not routine or hypothetical. Families of these infants are always in the midst of chaotic and emotional experiences, and rarely prioritize factual information—such as chance of successful CPR—the way that clinicians do.

As Blinderman et al. (2012) described, if clinicians present CPR to families as the default option (“we will plan to resuscitate unless you tell us not to”) it may be perceived as a recommendation. Averting this scenario requires upstream and intentional decisions by clinicians about whether or not CPR is a valid intervention (Mercurio, et al., 2014). All too often, clinicians perceive their duty to be to offer all families the option of CPR regardless of the medical scenario. In the case of Baby CE, once it became clear that the infant was dying, the clinicians could have decided to not offer CPR to the family at all. Instead, the clinicians told the family that CPR was “not indicated” and “generally not useful.” Following Blinderman’s approach, the clinicians could have more clearly indicated that CPR does not work for patients like Baby CE and therefore would not be used. By not offering it, the family is relieved of the burden to decide. If the family had actively objected to withholding CPR, ethics consultation would be the next step.

In this case, it appears that the NICU clinicians considered taking the CPR

decision back from the parents after offering it, and invited the broader NICU team to discuss this approach. Predictably, there was not 100% agreement among the clinicians about what should be done. This is nearly always the case, and can heighten staff distress because it highlights conflict within the team. But consensus decisions do not require 100% agreement, they require majority agreement. Protocols for conscientious objection ought to be discussed with those clinicians who feel they cannot participate in the plan of care.

The language of ethical, professional, and legal guidelines that help clinicians approach end-of-life decision-making with families always includes some measure of ambiguity (“medically indicated,” “inevitable demise,” “potentially helpful”). An understandable motivation to reduce our decisional burden can lead us to oversimplify our approach and simply “offer everything” for every patient. It is important to recognize when our decision-making paradigm merely offsets the burden to families.

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REFERENCES

- Blinderman, C.D., Krakauer, E.L. & Solomon, M.Z. (2012). Time to revise the approach to determining cardiopulmonary resuscitation status. *JAMA*, 307(9), 917-8.
- Mercurio, M.R., Murray, P.D. & Gross, I. (2014). Unilateral pediatric “do not attempt resuscitation” orders: the pros, the cons, and a proposed approach. *Pediatrics*, 133(Suppl 1), S37-43.

CALENDAR OF EVENTS

DECEMBER

14 (12N-1:15pm)

JHSPH Centennial Celebration Seminar, sponsored by The Johns Hopkins Berman Institute of Bioethics, Baltimore, MD. For more information, visit <http://www.bioethicsinstitute.org/education-training-2/seminar-series>.

JANUARY 2016

11 (12N-1:15pm)

Berman Bioethics Seminar Series: Jeremy Greene, MD, PhD, MA, sponsored by The Johns Hopkins Berman Institute of Bioethics, Baltimore, MD. For more information, visit <http://www.bioethicsinstitute.org/education-training-2/seminar-series>.

25 (12N-1:15pm)

Berman Bioethics Seminar Series: Mark Rothstein, JD, sponsored by The Johns Hopkins Berman Institute of Bioethics, Baltimore, MD. For more information, visit <http://www.bioethicsinstitute.org/education-training-2/seminar-series>.

FEBRUARY

4 (12N-1:30pm)

Berman Bioethics Brin Lecture: Steven Joffe, MD, MPH, sponsored by The Johns Hopkins Berman Institute of Bioethics. For more information, visit <http://www.bioethicsinstitute.org/education-training-2/seminar-series>.

8 (12N-1:15pm)

Berman Bioethics Seminar Series: Adnan Hyder, MD, PhD, MPH, sponsored by The Johns Hopkins Berman Institute of Bioethics. For more information, visit <http://www.bioethicsinstitute.org/education-training-2/seminar-series>.

22 (12N-1:15pm)

Berman Bioethics Seminar Series: Julian Savulescu, PhD, sponsored by The Johns Hopkins Berman Institute of Bioethics. For more information, visit <http://www.bioethicsinstitute.org/education-training-2/seminar-series>.

MARCH

4-6

Approaching the Sacred: Science, Health and Practices of Care, JW Marriott Galleria, Houston, TX. For more information, visit www.MedicineandReligion.com.

14 (12N-1:30pm)

Berman Bioethics Seminar Series: Anita Tarzian, PhD, RN, sponsored by The Johns Hopkins Berman Institute of Bioethics. For more information, visit <http://www.bioethicsinstitute.org/education-training-2/seminar-series>.

17-18

Professional Skills Program in Dispute Resolution, sponsored by The Center for Dispute Resolution at the University of Maryland Francis King Carey School of Law and the Straus Institute for Dispute Resolution at Pepperdine University School of Law. MD Carey Law, Baltimore, MD. For more information, visit <http://www.law.umaryland.edu/adrskills>.

17-18

Are We Hearing Our Patients' Voices? Healthcare Ethics Consortium Annual Conference. Atlanta Evergreen Marriott Conference Center, Stone Mountain, GA. For more information, visit http://www.hcecg.org/HEC_Conference_2016.

17-18

Bioethics: Preparing for the Unknown, sponsored by Western Michigan University's Center for the Study of Ethics in Society, Kalamazoo, MI. For more information about the Center, and updates about the conference, please visit www.wmich.edu/ethics.

28 (12N-1:15pm)

Berman Bioethics Seminar Series: John Wilbanks, sponsored by The Johns Hopkins Berman Institute of Bioethics. For more information, visit <http://www.bioethicsinstitute.org/education-training-2/seminar-series>.

APRIL

11 (12N-1:15pm)

Berman Bioethics Seminar Series: Jerry Menikoff, MD, JD, sponsored by The Johns Hopkins Berman Institute of Bioethics. For more information, visit <http://www.bioethicsinstitute.org/education-training-2/seminar-series>.

15-17

Interfaces and Discourses: A Multidisciplinary Conference on Islamic Theology, Law, and Biomedicine, sponsored by The Initiative on Islam and Medicine at the University of Chicago, Ida Noyes Hall – Cloister Club, Chicago, IL. For more information, visit <https://pmruchicago.submittable.com/submit>.

25 (12N-1:15pm)

Berman Bioethics Seminar Series: Ellen Clayton, MD, JD, MS, sponsored by The Johns Hopkins Berman Institute of Bioethics. For more information, visit <http://www.bioethicsinstitute.org/education-training-2/seminar-series>.

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