

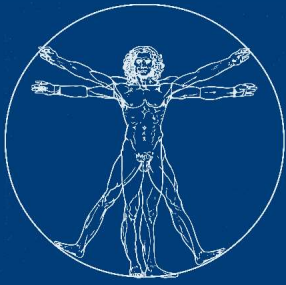
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 2018*

Mid-Atlantic Ethics Committee
Newsletter, Fall 2018

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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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ETHICS COMMITTEES VS. COURTS – A ROLE FOR REGIONAL ETHICS COMMITTEES IN ADDRESSING DISTRIBUTIVE JUSTICE?



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

Clinicians, hospital ethics committee members, and ethics consultants generally embrace the aphorism: “we must not ration at the bedside.” Justifications for withholding or withdrawing interventions that prolong the life of a patient who is not expected to survive hospital discharge are generally grounded in an autonomy-preserving or a benefit-burden analysis rather than a resource allocation argument. One reason for this is to avoid concerns about conflict of interest, that is, that financial gain to the institution or its staff influenced the medical decisions or recommendations made

for a particular patient. However, keeping stewardship and resource allocation out of the discussion about decision-making sometimes violates logical reasoning, which can create confusion. For example, the motivation to justify withdrawal or withholding of life support as fulfilling a duty of nonmaleficence (i.e., not harming a dying patient by continuing “aggressive” life support or attempting cardio-pulmonary resuscitation) is disingenuous if the patient does not have sufficient cognitive capacity to experience harm (i.e., “to suffer”). Is this phenomenon unique to the United

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States (US), where - outside the Veterans Affairs system—the health care system operates on principles of market competition rather than government planning? The case of Charlie Gard allows for comparison, as Charlie was born in the United Kingdom (UK) and his health care was provided through the UK’s National Health Service (NHS). Charlie’s case gained international recognition after referral to the Family Division of UK’s High Court, where after numerous appeals, justices ultimately sided with doctors who opined that Charlie’s condition (a rare form of mitochondrial DNA depletion syndrome, or “MDS”) was incompatible with life. They determined it was not in his best interest to receive further treatment and recommended that he be removed from life support while receiving palliative care. Charlie’s parents wanted to take him to the US to try experimental treatment with an oral drug thought to replace what Charlie’s body couldn’t produce. Potential financial conflict of interest was not at issue here because neither the hospital nor the staff stood to gain financially based on what happened to Charlie. Also, money had been raised through a GoFundMe campaign to cover the costs of travel and the experimental treatment, so there would be no cost to the NHS (although the hospital was willing to implement the experimental study protocol if they thought it might have benefitted Charlie). Presumably, the justices’ decision had nothing to do with the costs of Charlie’s care.

Here, the UK has an advantage over the US in that individuals there are on more equal footing

regarding access to health care services. Resource stewardship and fair resource allocation are integral components of the NHS, so endorsement of these ideals by health care providers and those they serve generally engenders broader public support. However, the issue of distributive justice was omitted from the court’s opinion. Still, some weighing in on social media were critical of the clinicians’ and justices’ motivations in “depriving” Charlie of “hope for a cure.” Interestingly, the US researchers offering to provide the experimental therapy to Charlie were not subjected to the same level of distrust, despite standing to gain financially if Charlie had been allowed to receive the experimental treatment they offered. Hammond-Browning reported:

...[I]t became apparent that two potential imperatives drive access to treatment, the first being the best interests and the other, the “experimental”/“financial.” The willingness of the U.S. doctor to provide this experimental therapy raises ethical questions of providing a treatment purely based on the availability of funding. At some point Charlie’s parents were allowed to believe that if they could simply raise the money to travel to the United States then their son would have hope, whereas the willingness to provide an untested therapy on the sole basis of raising the required money should have raised warning flags and prompted further questions around anticipated outcomes. (Hammond-Browning, 2017, p. 467)

Potential financial conflicts such as these and distributive justice issues such as Charlie occupying an

ICU bed that could benefit another patient were not part of the debate. Yet, Close and colleagues (2018) believe that best interest decisions are inherently value-laden, and there is danger in prioritizing one set of values (e.g., that it is not in a child's best interest to be maintained on life support in the face of impending death) over others (e.g., that life is of value regardless of a child's prognosis). Instead of distancing such cases from discussion of fair distribution of health care resources, they recommend that "[m]ore treatment limitation decisions could be based on rationing, and there would be less need to cloak rationing decisions as best interests ones." They propose quasi-judicial multi-member tribunals (as is done in other countries such as Australia) as alternatives to courts in resolving conflicts such as what treatments Charlie's parents could pursue for him.

Huxtable (2018) sees promise in UK's Clinical Ethics Network (UKCEN) and regional clinical ethics committees, as they are quicker to issue their advice, less costly, more inclusive, and less adversarial. Such committees could perhaps do a better job than the courts in acknowledging justice concerns while examining relevant facts and stakeholder perspectives. Huxtable acknowledges, however, that there is room for improvement. Such committees should see their role as not just supporting clinicians but also the public. They would need to be independent from the health care institution(s) where they work, and more transparent about their operating procedures, how members are selected and trained to ensure diversity and

competency, and how their services are evaluated and overseen.

Pope (2016) has studied "outlier" cases and how they are handled with regard to "futility" disputes. He has long been an advocate of regional ethics committees as a compromise between the transparency/due process advantage of courts and the efficiency of hospital ethics committees in resolving disagreements between family members and clinicians about when to withdraw non-beneficial medical interventions. He argues that such committees would provide an advantage over hospital ethics committees and courts, as long as they were properly composed (e.g., adequate representation from the community and marginalized groups) and thoughtful attention was paid to procedural standards, transparency, and oversight.

Could a different approach to resolving the conflict between Charlie's parents and the medical team have involved less stakeholder burden while preserving a fair conflict resolution process? It's reported that ethics consultants met with Charlie's parents, yet the case still went to court. The court proceedings took several months, and inflicted stress, privacy violations, and cost burdens on the parties. Mr. Justice Francis, the High Court judge overseeing Charlie's court case, commented on the benefits of attempting alternative means of dispute resolution in these kinds of cases. He stated:

...[I]t is my clear view that mediation should be attempted in all cases such as this one even if

all that it does is achieve a greater understanding by the parties of each other's positions. Few users of the court system will be in a greater state of turmoil and grief than parents in the position that these parents have been in and anything which helps them to understand the process and the viewpoint of the other side, even if they profoundly disagree with it, would in my judgment be of benefit and I hope that some lessons can therefore be taken from this tragic case which it has been my duty to oversee. (Public Law Today, 2017)

Indeed, there is tension between the efficiency provided by members of an institutional ethics committee mediating conflicts in such cases and the neutrality, transparency, and due process of a court. If the conflict is primarily grounded in stakeholder miscommunication, it makes sense to attempt to address the miscommunication before turning to the court. But many cases that go to court (whether in the US or the UK) are "outlier" cases, such as Charlie Gard or Jahi McMath. If the question at issue is whether a patient's or surrogate's demand for limited resources is reasonable, such as access to advanced life support, a court is not best situated to address this, and an institutional ethics committee faces the challenge of overcoming assertions of financial bias. Regional ethics committees could present a preferable conflict resolution process for such outlier cases.

In the end, some of the same challenges facing institutional ethics committees would be present in regional ethics committees: deter

mining who is competent to join, training and engaging members who are not compensated for their services, attracting a diverse membership (particularly community members, as well as medical specialists), and implementing fair and efficient procedural standards and oversight. But perhaps such a committee could achieve “economies of scale” by helping individual institutions achieve, collectively, what is much more difficult to achieve individually: contribution toward a fair process for handling conflicts about medical treatment rooted in a community standard of medical care. This could be particularly useful when stewardship of healthcare resources (such as an ICU bed or advanced life support technology) is at issue—even if that is not the central issue.

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DIFFERENCES BETWEEN HOW US AND UK COURTS RESOLVE CASES INVOLVING LIFE SUSTAINING TREATMENT



In “Ethics Committees vs. Courts – A Role for Regional Ethics Committees in Addressing Distributive Justice?,” Dr. Tarzian refers to the case of Charlie Gard, the case that captured the attention of the UK and many in the US during the summer of 2017. The case was perplexing for many American bioethicists and health lawyers likely because of some basic differences in the foundational law that undergirds similar cases in the US. For decision-making involving infants and children, both courts in the US and UK apply a best interest test, as an infant or young child innately lacks decision-making capacity. However, UK and US law differ in who determines what is in the child’s best interest. In the US, the US Supreme Court has determined that parents have a constitutional right to privacy regarding family matters. This

has been interpreted to mean that they have protection from government intrusion into their decision-making regarding health care for their children, absent a showing of abuse or neglect or statutes allowing a mature or emancipated minor to make certain decisions regarding their health. When parents disagree about a medical decision regarding their child, and the case goes to court in the US, the court will determine what is in the child’s best interest. This assessment generally includes the benefits and burdens of life with and without the treatment at issue.

In the UK, parents have no right to decide, but scholars have described the decision-making over life-sustaining treatment in these cases as a ‘joint decision’ between the child’s parents and his or her doctors (Close et al., 2018). When the child’s physicians and parents

are unable to agree, the parents or the hospital can apply to the courts for a decision as to whether it is in the child's best interests to provide life-sustaining therapy (Id.). In this decision, the parents' wishes are "wholly irrelevant" to the objective best interest test except to the extent they play into the "quality and value to the child of the child-parent relationship" (Mason & Laurie, 2013, p. 515).

Law between the jurisdictions also differs in decision-making for adults who lack decision-making capacity. In the US, virtually all states have adopted law through statute or case law that allows surrogate decision-making for an adult patient who lacks decision-making capacity. Surrogates can make decisions based first on what they believe the patient would have wanted, i.e., the substituted judgment test. If there is insufficient evidence of what the patient wanted, then the surrogate is to base his or her decision on what is in the patient's "best interest." Best interest in most states is defined by common law, although in Maryland it is spelled out in the Health Care Decisions Act (HCDA). Interestingly, in the UK, the courts have not adopted a substituted judgment test, rather under the Mental Capacity Act 2005, at least in England and Wales, the courts apply a modified best interests test that takes into account some of the attributes of the patient that might have affected his or her decision, i.e., the patient's previous wishes, beliefs and values. (This is actually similar to the definition of best interests in the HCDA.) Also, under the law in the UK, the decision-maker is not necessarily the patient's family

member but is the "carer responsible for [their] day-to-day care, or a professional such as a doctor, nurse or social worker where decisions about treatment, care arrangements or accommodation need to be made." (Mental Capacity Act 2005).

In both the UK and the US, the courts in these types of decisions do not generally consider the cost of continued life-sustaining treatment or use of limited medical resources for a patient. In the US, such decisions are thought not to be appropriate for the courts as they do not have the requisite knowledge about how health care resources are being used, they only have information about the case before them. This type of decision, most courts argue, is more appropriate for a legislative body that can collect the information necessary to make broader resource allocation decisions. The issue is a separation of powers argument about the relative expertise and role of each branch of government.

As the UK does not have a constitution and has no formal separation of powers doctrine, the argument does not apply to the same extent, but "courts usually refuse to intervene in resource allocation decisions, because they recognize they are poorly situated to make these prioritization decisions in the context of a single case" (Id.). While UK courts do not generally weigh in on the substantive issue of resource allocation, they will assess the decision-making process used by a health care institution to ensure that it is fair. Most of the resource allocation questions come to courts in the UK

when a patient or parent alleges that a health authority or institution has not allocated sufficient resources to a patient or family member. However, even in these cases, there must be an explicit rationing decision made by the health authority that the court is asked to review. There is nothing comparable in the US as there is no right to medical care, except a limited right to emergency medical treatment under the federal Emergency Medical Treatment and Labor Act. The closest analogy in the US might be appeals of Medicare or Medicaid coverage denial decisions in the context of health care or the appeal of a school system decision under the Individuals with Disabilities Education Act (IDEA), denying a student a free and appropriate education, in the context of education.

Upon reading about the Charlie Gard case last summer, individuals familiar with the law regarding medical decision-making in the US might have asked, why did the Gard case go to court? In the US, the parents could have simply enrolled their child in a research protocol without judicial approval. But maybe not. British health law experts explain that the case came to court at the request of the health care institution. The court was asked to affirm the medical decision that it was not in Charlie's best interest to be kept alive on the ventilator but also whether it was appropriate for Charlie to undergo experimental therapy.

As to the ventilatory support and experimental therapy, Justice Francis, who heard the case, determined that there was virtually no

benefit to either and that there was the potential for pain and suffering by exposing Charlie to the experimental therapy. Therefore, he determined that neither were in Charlie's best interest and that the hospital would be acting within the law to remove Charlie from the ventilator. In the US, it is conceivable that if Charlie was being cared for in a hospital and the physicians were aware that his parents were enrolling him in an experimental protocol that involved more than minimal risk, they might have taken the case to court arguing that such action was medical abuse, but such an argument would be much more difficult to make than whether or not the action was in the child's best interest.

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HARVARD REVISITS CRITERIA FOR DETERMINING DEATH



This year marks the 50-year anniversary of Harvard's ad hoc committee report establishing neurologic criteria for death (what lead author Henry Beecher termed "irreversible coma"). The report, published in 1968, informed the model definition of death that the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research developed in 1981 to address the problem of variation in how states defined death. This led to adoption by all states (in some form) of the Uniform Determination of Death Act (UDDA), which defines death as occurring after "irreversible cessation of circulatory or respiratory functions" or "irreversible cessation of all functions of the entire brain, including the brainstem" (UDDA, 2008).

Last April, Harvard convened experts to revisit criteria for determining death. Recent cases such as that of Jahi McMath have raised various questions and concerns, as summarized below.

UDDA WORDING

All functions of the entire brain. The UDDA specifies that death occurs when "all functions of the entire brain" irreversibly stop. Since then, we have seen cases of people declared dead based on neurologic criteria whose bodies have been preserved with ventilator support and nutrition/hydration via gastrostomy tube. We now know that a body can reach a kind of homeostasis after the brain ceases to function such that, with ventilatory support, the lungs, heart, kidneys, and liver can still function, and the gut can process tube-fed nutrients. Most neurologists and bioethicists have considered these bodily functions—absent a functioning brain—as insufficient for human existence, since

the brain is the integrating center and without it, a human cannot meaningfully exist in this world. However, the fact that McMath reportedly began menstruating after being declared brain dead has led others to conclude that part of her hypothalamus, which supports pituitary function, may have been functioning. If this were scientifically corroborated, then McMath would not have met the UDDA criteria for death, which requires that “all functions of the entire brain” have irreversibly ceased. Some have advocated for changing the wording in the UDDA to specify which functions of the brain must have permanently stopped, and to clarify which diagnostic tests would confirm this. Lawyer and futility blogger Thaddeus Pope predicts that more cases like these will challenge the discrepancies between the UDDA’s standard and the American Academy of Neurology (AAN) criteria.

Irreversible cessation of circulatory function. Given advances in cardiopulmonary resuscitation (CPR) since Harvard’s 1968 report, it’s not surprising that the UDDA may be outdated in its language. Some have argued that the term “irreversible” be replaced with “permanent” when referencing circulatory function, since some individuals who die by circulatory death could have their heart beat and circulation restarted but have opted for a “Do-Not-Attempt Resuscitation” (DNAR) order. In this case, circulatory function is permanently ceased because the DNAR order precludes attempts to restart the heart (that is, the stopping of the heart

may be reversible but since the decision was previously made not to try to restart it, its stopping is thus permanent). The question of what defines “permanent” circulatory cessation can be further nuanced in situations of organ donation after cardiac death (when an “arbitrary” time is established after the heart stops to declare death before organs are procured), and when patients are on cardiac bypass, such as extracorporeal membrane oxygenation (ECMO). ECMO-CPR, implemented in some locales such as France, is highlighting the complexity of establishing a specific time of death. Seema Shah, Associate Professor in the Division of Bioethics at the University of Washington School of Medicine, proposes that the UDDA’s definition of death be considered as a “legal fiction,” much like blindness (i.e., one doesn’t have to be completely blind to be considered “legally blind”).

CONFIRMING DEATH BY NEUROLOGIC CRITERIA

Which tests are confirmatory?

The UDDA establishes neurologic criteria for death as requiring the following over a 24-hour period, absent certain medications or conditions that could confound the testing:

- No response to stimuli
- No spontaneous movement or breathing
- No reflexes

However, the UDDA does not specify which tests must be done. It defers to “accepted medical standards” for confirming these criteria are met. A neurologic exam involves checking for absent

reflexes and confirming that no spontaneous respirations have occurred over a period of time (typically, ten minutes). Other ancillary tests may be done if needed (e.g., an electroencephalogram or cerebral angiogram). Some wonder whether other tests should be considered or developed that would reduce ambiguity or uncertainty, such as giving intravenous atropine to see if heart rate increases, or more precise types of blood flow studies.

Variable practices. Many point out that clinical practice varies from state to state and institution to institution. Greer and colleagues (2008) found major differences in brain death guidelines among the leading neurologic hospitals in the US, concluding that adherence to the AAN guidelines for determining death by neurologic criteria is inconsistent. Some wonder if having different guidelines for adults and children may add to the variable approaches. The AAN’s guidelines for adults can be found at <https://www.aan.com/Guidelines/home/GuidelineDetail/431>. The Pediatric Section of the Society of Critical Care Medicine’s (P-SCCM’s) guidelines for children and infants are available at https://www.aap.org/en-us/Documents/socc_pediatric_bd_guideline_tool.pdf.

Consent & refusal for apnea testing. Some clinicians, such as neurologist Alan Shewmon, have concluded that apnea testing to confirm neurologic death is unethical, as it may harm patients who retain some brain function. Others believe that clinicians should get consent to perform the apnea test. There is a small but

growing number of cases in which surrogates have refused to allow clinicians to perform an apnea test, thus precluding the declaration of death via neurologic criteria (since the apnea test is typically the last step before death is declared via neurologic criteria). Nevada recently passed a bill recognizing that the determination of death is a clinical decision made by a doctor in accordance with AAN's and P-SCCM's guidelines, and that surrogate consent is not required. However—Shewmon's position notwithstanding—others have suggested that physicians explain implications of the apnea test by providing a kind of “informed non-dissent” with the surrogate such that objectors could decline. In those cases, death would not be declared, but presumably, it would come eventually, for example, after a determination that further treatment was non-beneficial, since the patient could not survive outside of the intensive care unit.

In 1968, Henry Beecher referred to brain death as “irreversible coma.” Indeed, some believe those with higher brain function loss, such as Terri Schiavo, could be considered dead. Robert Veatch suggested that individuals be able to declare in an advance directive whether they considered themselves dead based on permanent whole brain, higher brain, or circulatory function loss. This would allow for organs to be procured in a way that respects individual variation in when they consider a person dead. In 2018, Robert Truog, Director of the Harvard Center for Bioethics, referred to Jahi McMath as being in a state of “irreversible apneic unconsciousness,” which evokes Beecher's reference. Truog chal-

lenged the mainstream consensus that the UDDA's definition of death is “good enough.” Time will tell whether we stick with the status quo and if not, what changes are on the horizon.

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MHECN ESTABLISHES ADVISORY BOARD



On July 2, 2018, MHECN staff held a roundtable on the future of the Network to which they invited twenty ethics committee representatives and thought leaders in the areas of bioethics, health policy and bioethics-related legal issues. At the roundtable, attendees explored the following questions: 1) is the Network continuing to provide members with valuable information and services; and 2) are there other types of initiatives or services that the Network could provide that would assist members in addressing ethical issues that arise in their institutions. Participants heard presentations from Diane Hoffmann, who convened the meeting, about the history of the Network and activities and initiatives it has undertaken ranging from delivering educational programs and providing information (e.g., The Mid-Atlantic Ethics Committee Newsletter) to engaging in research on such issues as the competency of ethics committee members, the views of ICU physicians and hospital legal counsel on the medically ineffective treatment provisions in the Health Care Decisions Act; and the implementa-

tion of the Maryland Orders for Life Sustaining Procedures Act. They also heard from Anita Tarzian, Coordinator of the Network, about what is happening at the national level with ethics committees, in particular efforts by the American Society of Bioethics in Healthcare (ASBH) to establish standards for clinical ethics consultation, and from Paul Ballard of the Maryland Office of the Attorney General, about initiatives of the State Advisory Council on Quality Care at the End of Life. These presentations were followed by comments from Cynda Rushton, Professor of Clinical Ethics, at the Berman Institute of Bioethics and School of Nursing at Johns Hopkins University; David Moller, Director of Health Care Ethics, Anne Arundel Medical Center; and Evan DeRenzo, Assistant Director, John J. Lynch, MD Center for Ethics, MedStar Washington Hospital Center. Each spoke about some of the programs and issues their committee had taken on or were struggling with. The remainder of the roundtable was spent hearing from each of the

attendees regarding their thoughts about the future of the Network. An outgrowth of the roundtable was the establishment of an Advisory Board for the Network to keep it current and make sure that it is providing a useful forum and services to its member institutions. Members of the Board include: Cynda Rushton (Johns Hopkins Hospital), Evan DeRenzo (MedStar Washington Hospital Center), David Moller (Anne Arundel Medical Center), Frederick Weinstein, Yoram Unguru (Sinai Hospital), Jack Schwartz (formerly with Maryland Office of the Attorney General), Jessica Schram (Living Legacy Foundation), Lee Schwab (Holy Cross Hospital), Wayne Brannock (Lorien Health Services), Marion Danis (NIH), Karen Rothenberg (University of Maryland School of Law), Shahid Aziz (formerly with Harbor Hospital), Dan Kleiner (Kennedy Kreiger), Jackie Dinterman (Frederick Regional Health Systems), and Henry Silverman (University of Maryland Medical Center). The first meeting of the Advisory Board was on October 1, 2018.



ASBH OFFERS FIRST CERTIFICATION EXAM FOR ETHICS CONSULTANTS

On June 10, 2018, the American Society for Bioethics and Humanities (ASBH) opened its application cycle for certification to practice clinical healthcare ethics consulting. Those who demonstrate the requisite practice experience and pass the certification exam will earn the HEC-C credential. The HEC-C program assesses core knowledge and skills in clinical healthcare ethics consulting. Eligible applicants are those who have a Bachelor's Degree (minimum) and at least 400 hours of healthcare ethics experience within the previous four years. The exam is administered during two, month-long test windows between November 1-30, 2018, and May 1-31, 2019. The application deadline date for the November testing window was September 10, and the application deadline date for the May testing window is March 10. The exam fee is \$450 for ASBH members and \$650 for non-members. To view the content outline for the exam with examples and to download an application, visit <http://www.asbh.org>.

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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.

CASE STUDY: When Physicians Lose Their Tempers: Apologizing and Moving Forward in the Care of a Dying Patient

The following case and first commentary are reprinted with permission from the Journal of Hospital Ethics, 2015, Volume 4, Issue 1, 33-34.

Mrs. C. is a 76-year-old woman brought to the hospital's Emergency Department (ED) after a sudden, unwitnessed cardiac arrest. EMS was called after she was found by her neighbors and they were unclear as to how long she had been down. Mrs. C. received extensive cardio-pulmonary resuscitation lasting over 40 minutes in the ED before establishing a stable cardiac rhythm sufficient for transfer to the cardiac intensive care unit (CICU).

After her admission to the CICU, the neurology team assessed the patient, concluding that she had suffered significant and likely irreversible neurological damage caused by her cardiac arrest. Both neurology and the CICU teams have determined that the patient has very little chance at any meaningful neurologic recovery and that her general

prognosis is poor. Mrs. C. has 4 adult children and a very involved son-in-law, but does not have an Advance Directive of any kind. Her family and the CICU team have been meeting regularly to discuss her circumstances and determine appropriate goals of care. These discussions have gone on for more than a week. The CICU attending physician has explained at each meeting that the patient's neurological condition has not changed, that she is hemodynamically stable, and so it will be up to the children whether or not they want the patient to receive a tracheostomy and percutaneous endoscopic gastrostomy (trach and peg) and be moved to a nursing home, or whether they want to shift to comfort measures only.

As the patient's care moves into the second week, Dr. W., the CICU attending physician who has been present at several of the previous family meetings, has grown increasingly frustrated as a result of the children's inability to decide what direction they want to take with their mother. It has been Dr. W.'s training that he is to lay out the options and let the family decide. But he has grown frustrated with their indecision and walks out of the next meeting throwing his hands in the air, declaring, "I don't care what they want, as long as they make a decision!" Both

family and medical team members who witnessed the display are left in various degrees of shock, confusion, and anger. Ethics is consulted in order to address the resulting tensions and distress.

CHART NOTE AND RECOMMENDATIONS

1. Dr. W. and the clinical ethicist should meet with the family so that Dr. W. can offer an apology for his frustration.
2. Dr. W. should make a clear recommendation about what he thinks would be best for Mrs. C. and why he thinks this would be the best approach to her future care.

REASONING

The attending physician has demonstrated an impulsive lack of appropriate professional demeanor and regard for the sensitive nature of the matters under discussion. His voiced frustration has resulted in additional distress to the family and the rest of the clinical team. After calming down and reflecting, Dr. W. tells the ethics consultant he regrets having blown up. He tells the consultant that his frustration comes not only from the family's indecision, but from the way in which he feels he has been trained and professionally conditioned to refrain in such circumstances from offering his own recommendation;

that he's just to lay out the options and let the family choose (Hutchinson & Veatch, 2015).

Frustration is no excuse when an emotional reaction gets the better of a clinician's behavior. When this happens, however, clinicians need to acknowledge that they've lost their temper and be sure to genuinely apologize. We've learned that a sincerely felt and given apology from a physician for a medical error goes a long way to reduce the distress physician mistakes cause to patients and families (Robbennolt, 2009).

There is no reason to think that an honest apology for losing one's temper can't have the same beneficial effects. One particular potential outcome, the building of trust, is particularly important here. Combining renewed trust and having the physician give a clear recommendation may help move the family forward. Separating Dr. W.'s frustrated outburst from the content of his remarks indicates that he has come to these meetings with an appropriate impartiality towards the outcome. When a patient is unstable and imminently dying, physicians should only offer indicated interventions. If patients or families ask for interventions that are not indicated on the basis of well-established standards of practice, ordinarily physicians should not provide such interventions (Bosslet, et al., 2015).

Where conflicts continue, transfer should be facilitated to the greatest degree medically feasible. But where a hospitalized patient, even a dying hospitalized patient, can be made stable to discharge, Dr. W.

appears to be rightly coming to the decision-making from a position impartial towards the outcome. That does not mean, however, that a physician ought not give a recommendation. Although this is a controversial point, we take the position that after presenting all medical options within reason, it remains the physician's responsibility to make a recommendation. Often this can help a family come to their own decision, whether in agreement with the physician or not. If, under these conditions, the family cannot come to a decision, it is incumbent on the physician to move to sustain the patient's life and ready the patient for discharge. If the physician and other clinicians can do this in a supportive rather than frustrated manner, whatever the decision, the hospital experience is likely to be less distressing for everyone.

The Editorial Group of the Center for Ethics, MedStar Washington Hospital Center, Washington, DC

REFERENCES

- Bosslet, G.T., Pope, T.M., Rubenfeld, G.D., et al. (2015). An official ATS/AACN/ACCP/ESICM/SCCM policy statement: Responding to requests for potentially inappropriate treatments in Intensive Care Units. *Am J Respir Crit Care Med*, 191(11), 1318-133.
- Hutchinson, P.J. & Veatch, R.M. (2015). Do physicians have a responsibility to provide recommendations regarding goals of care to surrogates of dying patients in the ICU? Point/Counterpoint. *Chest*, 147(6), 1453-1459.
- Robbennolt, J.K. (2009). Apologies and medical error. *Clin Orthop Relat Res*. 467(2), 376-382.

COMMENTS FROM AN ETHICS CONSULTANT

Some form of communication breakdown is present in most ethics case consultations. This case was prompted by an unfortunate incident in which the CICU attending physician failed to navigate the patient's care in a way that conveyed compassion and a clear direction to stakeholders. Ethics consultants are likely familiar with scenarios in which the medical team reports having repeatedly attempted to achieve consensus with family members on appropriate goals of care for an incapacitated patient but have been unsuccessful in achieving such consensus. Sometimes, best efforts were implemented to no avail. Often, however, the quality of the communication preceding the request for ethics consultation has been deficient. In this case, Dr. W.'s outburst is indicative of a clear breach in communication standards. How should the responding ethics consultant (or consultants – the plural “consultant” is used here for simplicity) respond to this breach of professional ethics?

The obvious step of gathering relevant facts in this case may be additionally challenged by the breakdown in trust (and perhaps medical team rapport) that resulted from Dr. W.'s inappropriate behavior. Wicks and Buck (2013) point out the importance of health care leaders modeling best practices for cultivating resilience, which they refer to as more than “bouncing back from stress” (p. 6) but “both recovering and deepening as a consequence of encountering stress in the right way with adequate inner

strength” (p. 7). They identify “becoming easily upset” as one red flag of possible burnout. Thus, one role for the ethics consultant may be to speak privately with Dr. W. to understand what prompted his frustration and if he has insight into his inability to regulate his emotional reaction in front of family and staff. If this is a recurring pattern with this particular provider, other interventions may be appropriate as a method of follow-up.

Shapiro and colleagues (2014) created the Center for Professionalism and Peer Support at Brigham and Women’s Hospital in Boston to educate staff about professionalism and to manage unprofessional behavior. They report that mandatory education sessions on professional development successfully engaged clinicians in developing a culture of “enhanced professionalism.” In particular, they have developed a process for responding to clinicians exhibiting repetitive unprofessional behavior that demonstrates successful outcomes in altering such behavior.

Whether Dr. W.’s outburst was an isolated incident or a pattern of unprofessional conduct, he should be steered in the right direction to correct his missteps. In this case, it would be appropriate for the ethics consultant to coach Dr. W. in how to make amends and redirect attention toward doing what’s right for the patient. If Dr. W. would not be open to such an intervention, that says something about the organizational culture.

It’s not uncommon for patients or family members to vent frustrations about members of the health care team to ethics consultants.

While ethics consultants can do their best to avoid taking sides in their efforts to reconstruct relevant perspectives, they should not be put in a position of enabling or apologizing for another provider’s unprofessional conduct.

*Anita J. Tarzian, PhD, RN
MHECN Program Coordinator*

REFERENCES

- Shapiro, J., Whittmore, A., & Tsen, L.C. (2014). Instituting a culture of professionalism: the establishment of a center for professionalism and peer support. *The Joint Commission Journal on Quality & Patient Safety*, 20(4), 168-77.
- Wicks, R.J. & Buck, T.C. (2013). Riding the dragon: Enhancing resilient leadership and sensible self-care in the healthcare executive. *Frontiers in Health Services Management*, 30(2), 3-13.

CALENDAR OF EVENTS

Fall 2018

OCTOBER

8-10

Aspen Ethical Leadership Program for Healthcare. Visit: <http://www.aspenethicalleadership.com>.

11

A Live Online Workshop on Disclosure and Apology after Medical Errors and Adverse Events.

Visit: <http://ipepweb.org/disclosure-and-apology>.

16

The 3rd Annual Ethics Symposium: Conscientious Objection, sponsored by the Clinical Ethics Department at Children's Hospitals and Clinics of Minnesota, Minneapolis, MN. Visit: www.childrensmn.org/conferences.

16-17

Pediatric ELNEC (End-of-Life Nursing Education Consortium), sponsored by the University of Maryland Children's Hospital, 110 S. Paca St., Baltimore, MD. Contact: professionaldevelopment@umm.edu; 410-328-6257.

17-18

ELNEC (End-of-Life Nursing Education Consortium) for Veterans, sponsored by Stella Maris, 2300 Dulaney Valley Rd, Timonium, MD. Visit: <https://www.stellamaris.org/news/events>.

18-21

The Future is Now: 20th Annual Meeting of the American Society for Bioethics and Humanities, Anaheim, CA. Visit: <http://www.asbh.org>.

NOVEMBER

2-5

The 14th Biannual Clinical Ethics Immersion, Center for Ethics at MedStar Washington Hospital Center, Washington, DC. Visit: <https://www.medstarwashington.org/our-hospital/center-for-ethics/clinical-ethics>.

8

5th Annual Interprofessional, Interfaith Ethics Forum: Exploring Mental Health from a Trauma-Informed Care Lens, SMC Campus Center, University of Maryland, Baltimore, MD (Co-sponsored by MHECN – DISCOUNT for MHECN members).

RECURRING EVENTS

Johns Hopkins Berman Institute of Bioethics Seminar Series, either at Feinstone Hall, E2030, Bloomberg School of Public Health (615 N. Wolfe St.) or JH Technology Ventures (1812 Ashland Ave), Baltimore, MD. 12N-1:15PM. Visit: <http://www.bioethicsinstitute.org/educationtraining-2/seminar-series>.

October 8: “Bioethics, Pain Medicine, and America’s Opioid Crisis,” Travis Rieder, PhD, Director of the Master of Bioethics degree program and Research Scholar, Berman Institute of Bioethics (JH Technology Ventures)

October 29: “Opportunity Pluralism and Children’s Health,” Matteo Bonotti, Lecturer, Department of Politics and International Relations, Monash University (Feinstone)

November 12: “Marked Men: In Case You Don’t Know About Tuskegee,” Peter Buxton (Feinstone)

November 26: “Moral Distress: A Time for Hope?” Alisa Carse, PhD, Associate Professor of Philosophy, Kennedy Institute of Ethics (Feinstone)

December 10: “Incidental Enhancements: The Challenge of Prevention for Human Gene Editing Governance,” Eric Juengst, PhD, Director, Center for Bioethics, University of North Carolina (Feinstone)

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 to act consistently with its mission statement;
- Fostering communication and information sharing among Network members;
- Providing educational programs for ethics committee members, other healthcare providers, and members of the general public on ethical issues in health care; and
- Conducting research to improve the functioning of ethics committees and ultimately the care of patients in Maryland.

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

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