

**May 2019**

**Volume 21, Number 5: E373-474**

## **Advanced Cardiopulmonary Care Ethics**

### **From the Editor**

- When Clinical Advances Outpace Ethics** 375  
Elizabeth A. Sonntag, MD

### **Case and Commentary**

- Should Physicians Offer a Ventricular Assist Device  
to a Pediatric Oncology Patient With a Poor Prognosis?** 380  
Angira Patel, MD, MPH, Anna Joong, MD,  
Efrat Lelkes, MD, and Jeffrey G. Gossett, MD
- How Should ECMO Initiation and Withdrawal Decisions Be Shared?** 387  
Carolina Jaramillo and Nicholas Braus, MD
- How Should Physicians Respond to Requests for LVAD Removal?** 394  
Larry A. Allen, MD, MHS
- Should Long-Term Life-Sustaining Care Be  
Started in Emergency Settings?** 401  
Ellen C. Meltzer, MD, MSc, Natalia S. Ivascu, MD, Mark K. Edwin, MD  
and Timothy J. Ingall, MBBS, MD, PhD

### **Medical Education**

- Educating Resident and Fellow Physicians  
on the Ethics of Mechanical Circulatory Support** 407  
Elizabeth A. Sonntag, MD, Keyur B. Shah, MD, and Jason N. Katz, MD

### **AMA Code Says**

- AMA Code of Medical Ethics' Opinions  
Related to Ethics of Life-Sustaining Technologies** 416  
Rachel F. Harbut

### **Policy Forum**

- What Should We Learn From Early Hemodialysis Allocation About How We Should Be Using ECMO?** 421  
Daniel Gutteridge, MD and Gabriel T. Bosslet, MD, MA

### **Medicine and Society**

- How Should Mechanical Circulatory Support Be Deactivated for Patients With Depression at the End of Life?** 429  
Stephan R. Weinland, PhD, MS and James Levenson, MD
- Palliative Care for Patients on Mechanical Circulatory Support** 435  
Sara E. Wordingham, MD and Colleen K. McIlvennan, DNP, ANP

### **History of Medicine**

- Will We Code for Default ECMO?** 443  
Daniel J. Brauner, MD and Christopher J. Zimmermann, MD

### **Art of Medicine**

- Sustaining the Lives of Art Objects** 450  
Sarah Molina
- Fading Mind of a Patient With Alzheimer's** 455  
Laci Hadorn
- Moral Distress Containment Through an Artist's and Art Psychotherapist's Lens** 457  
Georgina Morley, PhD, MSc, RN and Annie Sharon Fox, MA

### **Personal Narrative**

- How Can We Make Out-of-Hospital CPR More Family Centered?** 461  
Caroline Mawer, MRCP, MBBS, MSc, MFPH

### **Viewpoint**

- How Should One Live Everlasting Life?** 470  
Rachel F. Harbut

### **Podcast**

- When and How Should ECMO Be Initiated and Removed?**  
**An interview with Dr Daniel Brauner and Dr Nicholas Braus**

## FROM THE EDITOR

### When Clinical Advances Outpace Ethics

Elizabeth A. Sonntag, MD

In the United States, about 6.5 million adults are living with heart failure, and about half of those patients will die within 5 years of diagnosis.<sup>1</sup> For patients with advanced chronic heart failure or acute unrecoverable decompensation, heart transplantation offers a cure. However, the number of patients with end-stage heart failure is increasing while the availability of donor hearts is decreasing,<sup>2</sup> leaving clinicians to consider options such as mechanical circulatory support (MCS).

MCS emerged in the second half of the 20th century. In 1957, Willem J. Kolff (1911–2009) kept a dog alive for 90 minutes with an artificial heart.<sup>3</sup> In 1967, while the first heart transplant was being performed by Christiaan Barnard (1922–2001) in South Africa,<sup>4</sup> Kolff worked to develop an artificial heart for humans.<sup>3</sup> At the same time, Michael DeBakey (1908–2008) was developing the first external heart pump, now known as the left ventricular assist device (LVAD).<sup>5</sup> And in 1976, Robert Bartlett (1939–), inventor of extracorporeal membrane oxygenation (ECMO), reported his first neonatal survivor.<sup>6</sup> Today, more than 60 years after Kolff implanted a mechanical pump in the chest of a dog, MCS devices such as the total artificial heart, LVAD, and ECMO are widely used in humans. These therapies stave off death and have completely changed the landscape of how we die, demanding reexamination of the clinical and ethical appropriateness of the use of life-sustaining technology.

This theme issue of the *AMA Journal of Ethics* discusses historical and social aspects of MCS development, education required for clinicians to use these technologies judiciously, multidisciplinary approaches to promoting patient-centered care, and policies needed to guide clinicians and protect patients. While we physicians weigh the benefits of technological advancement against the risks of harm, we must keep our duties to patients at the forefront of our considerations.

MCS presents unique challenges for clinical practice. LVADs are used to pump blood from a failing left ventricle to the rest of a body. Historically used as a bridge to transplantation, LVADs are now used as destination therapy for a growing population of patients with heart failure who are not transplant candidates.<sup>7</sup> These patients will live their remaining years—and ultimately die—with their device in place, introducing complex questions about the initiation of therapy and the timing of device deactivation.

When considering LVAD therapy for a patient with heart failure, the patient's health as a whole must be carefully examined. Often a complicated risk-benefit analysis must be undertaken. LVAD therapy can prolong life in patients with advanced heart failure; therefore it should be used when the benefits outweigh the harms. Angira Patel, Anna Joong, Efrat Lelkes, and Jeffrey G. Gossett present the case of a child with a poor prognosis due to refractory leukemia and chemotherapy-induced heart failure whose parents [request LVAD implantation](#). The authors examine a question at the center of MCS implementation: Just because we can do something, should we?

Unlike other organs in the body, MCS devices can be turned off or deactivated. LVAD deactivation is often done in a hospital when a patient is critically and irreversibly ill.<sup>8</sup> However, some patients might request withdrawal to facilitate death when feeling overwhelmed by recurrent complications, for example. This scenario can be emotionally difficult for patients, families, and clinicians, as patients are more likely to be awake, alert, and have decision-making capacity when they request deactivation. Sara E. Wordingham and Colleen K. McIlvennan argue that [palliative care clinicians](#) should be involved in all phases of MCS care, including initiation, symptom management, and end of life.

Requests for LVAD withdrawal can be further complicated when a decision is motivated by concerns about quality of life, depression, and caregiver burden, which raise questions about the circumstances in which withdrawal of life-sustaining therapy, such as an LVAD, is ethically permissible. Responding to a case in which a patient wishes to deactivate an LVAD placed emergently without his consent, Larry A. Allen argues that, because LVAD therapy is complex and requires a period of [patient and caregiver adjustment](#), clinicians should focus on supporting patients and understanding their values as they navigate the difficulties of life-sustaining therapy. Stephan R. Weinland and James Levenson maintain that decisions to withdraw LVAD therapy should only be considered after a patient's [depressive symptoms and coping challenges](#) have been addressed and, when possible, resolved. They argue that though depression associated with chronic illness can complicate decisions to withdraw life-sustaining therapy, clinicians should consider quality of life as an important clinical outcome and remain committed to minimizing patient suffering.

ECMO presents different end of life decision making obstacles. As a means of last-resort life support, ECMO takes over for failing heart and/or lungs by circulating oxygenated blood. Used as a temporary bridge to heart or lung transplantation or recovery and sometimes as a mode of cardiopulmonary resuscitation (ECPR), application is complicated by the fact that indication and outcome data for ECMO as therapy in cardiac failure is lacking and its use varies widely across centers.<sup>9</sup> Furthermore, it is estimated that only about half of adult patients placed on ECMO for cardiac failure survive.<sup>9</sup> Two cases examine ethical implications of ECMO initiation and discontinuation. Carolina

Jaramillo and Nicholas Braus consider the role of [shared decision making](#) for patients without a bridge to definitive therapy; they explore the case of a patient who wishes to remain on ECMO but is no longer a candidate for heart transplantation. Ellen C. Meltzer, Natalia S. Ivascu, Mark K. Edwin, and Timothy J. Ingall explore ethical implications of ECPR initiation for an incapacitated, [unrepresented patient](#) with acute myocardial infarction and cardiac arrest. In either circumstance, when a patient's bridge to therapy crumbles, physicians and families grapple with emotionally challenging tasks of withdrawing life support in patients who might be awake, alert, and autonomous. These dilemmas evoke questions about the circumstances in which initiating and withdrawing life-sustaining therapy is ethically permissible and how to best serve patients with heart failure.

Use of MCS devices for life-sustaining therapy not only has ethical implications for patients but also contributes to distress experienced by patients, families, and clinicians. Georgina Morley and Annie Sharon Fox explore [moral distress](#) within the complex web of relationships between patients and clinicians through a series of portraits. Laci Hadorn explores the [fear and isolation](#) that patients and their families can feel during chronic illnesses through a puzzle graphic. Caroline Mawer's personal narrative explores a patient's family member's perceptions of [advocating for the patient](#) with the medical team. Within the context of technological advancements in medicine, these articles remind us of human aspects of care that bring meaning to the practice of medicine.

Physicians can feel underprepared to face the ethical and emotional dimensions of caring for patients with MCS devices. Currently, there is no structured ethics curriculum for trainees in the fields of cardiology, heart failure and transplantation, or cardiothoracic surgery. I, along with Keyur B. Shah and Jason N. Katz, call for integration of ethics curricula into [graduate medical education](#). We argue that concepts of patient best interest, respect for autonomy, informed consent, shared decision making, surrogate decision making, and end-of-life care are imperative to the practice of heart failure medicine and responsible use of MCS devices.

Many factors motivate the continued advancement and use of life-sustaining therapies. In an era of "do everything" medicine, the tendency to prolong life by whatever means necessary should be mitigated by caution in order to avoid inappropriate uses of these therapies for heart failure. Professional society guidelines are lacking, and hospital policies regarding the use of MCS vary widely. In this issue, contributors use the evolution of CPR and hemodialysis to illustrate the successes and warn of the pitfalls of ECMO. Daniel J. Brauner and Christopher J. Zimmermann draw parallels between the establishment of CPR as the default for all patients with cardiac arrest and the [current expansion of indications for ECMO](#). Daniel Gutteridge and Gabriel T. Bosslet examine the historical application of hemodialysis and suggest a prospective, [democratic process for guiding policy](#) making about uses of ECMO.

In addition to their practical implications, life-sustaining therapies have deep philosophical underpinnings that are worth exploring. Rachel F. Harbut considers issues of resource scarcity and justice that would likely arise were technologies to significantly [extend lifespan](#), while Sarah Molina examines broader [meanings of preservation](#) by considering art conservation practices at the Art Institute of Chicago.

As long as illness and disease plague patients, virtue and ingenuity can inspire physicians to propel medicine forward. Kolff, Barnard, DeBakey, and Bartlett could not have imagined the impact of their work on today's patients and physicians. This theme issue of the *AMA Journal of Ethics* explores clinical and ethical complexities of life-sustaining technologies, such as LVADs and ECMO, and offers a path forward. We must educate physicians, develop and refine policies, and promote interdisciplinary collaboration when caring for patients with heart failure.

## References

1. Benjamin EJ, Virani SS, Calaway CW, et al; American Heart Association Council of Epidemiology and Prevention Statistics Committee; Stroke Statistics Subcommittee. Heart disease and stroke statistics—2018 update. A report from the American Heart Association. *Circulation*. 2018;137(12):e67–e492.
2. Prinzing A, Herold U, Berkefeld A, Krane M, Lange R, Voss B. Left ventricular assist devices—current state and perspectives. *J Thorac Dis*. 2016;8(8):E660–E666.
3. Blakeslee S. Willem Kolff, doctor who invented kidney and heart machines, dies at 97. *New York Times*. February 12, 2009. <https://www.nytimes.com/2009/02/13/health/13kolff.html>. Accessed October 28, 2018.
4. History.com Editors. First human heart transplant. History. <https://www.history.com/this-day-in-history/first-human-heart-transplant>. Published July 21, 2010. Updated August 21, 2018. Accessed October 28, 2018.
5. DeBakey ME. Left ventricular bypass pump for cardiac assistance. *Am J Cardiol*. 1971;27(1):3–11.
6. Bartlett RH, Gazzaniga AB, Jefferies MR, Huxtable RF, Haiduc NJ, Fong SW. Extracorporeal membrane oxygenation (ECMO) cardiopulmonary support in infancy. *Trans Am Soc Artif Intern Organs*. 1976;22:90–93.
7. Shreenivas SS, Rame JE, Jessup M. Mechanical circulatory support as a bridge to transplant or for destination therapy. *Curr Heart Fail Rep*. 2010;7(4):159–166.
8. Mueller PS, Swetz KM, Freeman MR, et al. Ethical analysis of withdrawing ventricular assist device support. *Mayo Clin Proc*. 2010;85(9):791–797.
9. Abrams D, Garan AR, Abdelbary A, et al; International ECMO Network (ECMONet); Extracorporeal Life Support Organization (ELSO). Position paper for the

organization of ECMO programs for cardiac failure in adults. *Intensive Care Med.* 2018;44(6):717-729.

**Elizabeth A. Sonntag, MD** is a pulmonary and critical care fellow at the University of North Carolina (UNC) at Chapel Hill and an alumna of the MacLean Center for Clinical Medical Ethics at the University of Chicago. She serves on the UNC Hospitals Ethics Committee and teaches an elective in medical ethics at the UNC School of Medicine. Her clinical interests include pulmonary hypertension and critical care, and her research interests include end-of-life decisions, advanced life-sustaining therapies, clinician burnout, and development of medical ethics curricula.

#### **Citation**

*AMA J Ethics.* 2019;21(5):E375-379.

#### **DOI**

10.1001/amajethics.2019.375.

#### **Acknowledgements**

I wish to thank all the contributors to this theme issue and the editorial team at the *AMA Journal of Ethics* for their support in making this issue possible. In particular, I would like to thank my co-authors Jason N. Katz, MD, MHS and Keyur B. Shah, MD for contributing their expertise in the field of heart failure and mechanical circulatory support; and Arlene M. Davis, JD and James Levenson, MD for inspiration and mentorship in clinical ethics. I would also like to thank Shannon Carson, MD and Ashley G. Henderson, MD for giving me space to grow and encouraging me to build a career full of passion and purpose as well as my first career mentor, Sammy Pedram, MD, for his continued friendship. Finally, I would like to thank Gautham Kalahasty, MD for his truly unconditional and unwavering support.

#### **Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**Copyright 2019 American Medical Association. All rights reserved.  
ISSN 2376-6980**

## CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

### Should Physicians Offer a Ventricular Assist Device to a Pediatric Oncology Patient With a Poor Prognosis?

Angira Patel, MD, MPH, Anna Joong, MD, Efrat Lelkes, MD, and Jeffrey G. Gossett, MD

*To claim one AMA PRA Category 1 Credit™ for the CME activity associated with this article, you must do the following: (1) read this article in its entirety, (2) answer at least 80 percent of the quiz questions correctly, and (3) complete an evaluation. The quiz, evaluation, and form for claiming AMA PRA Category 1 Credit™ are available through the [AMA Ed Hub™](#).*

#### Abstract

A case is presented of a 10-year-old girl with refractory leukemia with poor prognosis and chemotherapy-induced heart failure. She is evaluated for a ventricular assist device (VAD), but the pediatric heart failure team views VAD as clinically inappropriate due to her active oncologic problems. This article examines ethical concerns that arise in deciding whether to offer and use this technology.

#### Case

BJ is a 25 kg, 10-year-old with acute myeloid leukemia who underwent 4 cycles of chemotherapy and a total of 350mg/m<sup>2</sup> of anthracyclines. She attained remission but relapsed within 2 months. The oncology team felt that her probability of cure was extremely low. They estimated her chance of recovery at less than 25% but acknowledged uncertainty. If remission were achieved, it would then be followed by stem cell transplantation necessary for the high-dose chemotherapy to improve the chance of remission.

BJ's cardiac function was normal prior to chemotherapy. However, after chemotherapy she had moderately depressed left ventricular function (30% ejection fraction). She is on submaximal heart failure medications, as increases are limited by symptomatic hypotension. She has had frequent hospital admissions for hemodynamically significant infections. Between these episodes, she has had New York Heart Association Class I and II symptoms.

BJ's family and her oncology team want her "to have every chance." They have heard there are "heart pumps, and that some kids get heart transplants after chemotherapy has hurt their heart." BJ is fearful of all medical interventions but defers to her parents



for decision making. Her family expressly desires that all medical avenues be explored to maximize BJ's life expectancy. The pediatric heart failure team is consulted about BJ's candidacy for placement of a ventricular assist device (VAD) and, in her case specifically, a left ventricular assist device (LVAD).

In BJ's case, the heart failure team has concerns about the success of VAD support at each phase of her care. There is a higher probability of VAD-related, life-threatening complications (eg, wound-healing problems, infection, bleeding, stroke) while undergoing the intensive chemotherapy regimen and subsequent stem cell transplantation. Given the paucity of data on and experience in pediatric destination therapy, combined with BJ's increased risk for complications, the heart failure team decides that she is not a candidate for chronic LVAD therapy. VAD support as bridge to transplant candidacy would similarly require long-term VAD support, with a minimum 1-year disease-free period after treatment in order to be considered for a heart transplant. Due to these concerns, the heart failure team members decide that they are not comfortable offering an LVAD. They acknowledge that this decision is informed by BJ's less-than-25% probability of cancer-free survival. They also acknowledge that they might offer device therapy (as a bridge to either recovery or heart transplantation) to a patient with a higher probability of oncologic cure. While the majority of the medical professionals agree with the heart failure team's assessment in the case, the family expresses dissent and enmity.

### **Commentary**

A VAD is a form of mechanical circulatory support for the failing heart, most commonly the left ventricle. LVADs are implanted in patients with end-stage heart failure as (1) a bridge to heart transplant, (2) destination therapy when patients are not heart transplant candidates, (3) a bridge to myocardial recovery, or (4) a bridge to decision when transplant candidacy has not yet been determined. More than 2500 LVADs are implanted in adults annually, of which almost 50% are for destination therapy.<sup>1</sup>

Adult LVADs are used off label in teenagers and young children, with 174 such implantations reported to a national registry from 42 hospitals between 2012 and 2016.<sup>2</sup> These primarily serve as a bridge to transplant, with only 8 in the registry reported as destination therapy and 23 as a bridge to recovery.<sup>2</sup> Complications are common, with 55% of pediatric patients experiencing at least 1 adverse event—most commonly infection, bleeding, neurologic dysfunction (including stroke), and device malfunction.<sup>3</sup> Chronic VAD therapy or destination therapy in children is an emerging area of interest, but it is currently limited in practice to case series and reports such as palliative implantation in those with muscular dystrophy.<sup>4,5</sup>

In pediatric oncology patients, there are reports of LVADs being used as a bridge to candidacy or recovery for anthracycline-induced cardiomyopathy, but there is no

literature on pediatric VAD destination therapy.<sup>6-9</sup> Adult VAD guidelines state that oncology patients with a “reasonable life-expectancy” may be considered for VAD implantation as destination therapy, but it should not be considered in patients with a life expectancy of less than 2 years.<sup>10</sup> In pediatrics, however, there are no accepted guidelines or criteria for VAD support, and experience with destination therapy remains limited and controversial. This article examines ethical concerns that arise in deciding whether to offer and use this technology.

### **Guidelines for Shared Decision Making About New Technology Use**

Parents and health professionals sometimes disagree about health decisions for children. Overriding parents’ decisions is particularly fraught with conflict as new treatments and technologies are introduced for diagnoses that are inherently uncertain and complex.<sup>11-14</sup> Pediatric ethical principles and guiding frameworks, though sometimes conflicting, can be applied to various clinical scenarios with young patients of various ages.<sup>15,16</sup> These include various formulations of the best interest standard, avoiding harm, constrained parental autonomy, shared family-centered decision making, clinically reasonable alternatives, responsible thinking, and rational decision making.<sup>17-22</sup> While these principles and frameworks have historically served as a guide for parental refusals of therapy, as technology advances and parental requests for therapies arise that a clinical team might consider inappropriate, these models will need to be repurposed to address parental requests.<sup>17</sup>

Examples of conflict involving innovative technology exist in pediatrics, such as with extracorporeal membrane oxygenation (ECMO). Unlike VADs, ECMO has typically been viewed as a short-term therapy for reversible processes or as a bridge to durable support.<sup>23</sup> Utilization of ECMO has resulted in ethical debates about [autonomy](#), nonmaleficence, informed consent, resource allocation, and the advancement of medicine.<sup>24,25</sup> ECMO now has an expanded role including—at times—for patients with active malignancies who need short-term support to recovery, but this role can necessitate discussions of withdrawal of ECMO support if there is no clinical improvement.<sup>26,27</sup>

A central ethical question in BJ’s case is how to express regard for the [child’s best interest](#) using emerging technology amidst disagreement between clinical team members and parental decision makers. The parents seem to be appropriate surrogate decision makers for BJ who are motivated by love and believe that maximizing life expectancy is in BJ’s best interest. However, the proposed treatment of implanting an LVAD has little chance of achieving the family’s goal of BJ’s long-term survival given BJ’s ongoing chemotherapy and underlying poor prognosis. As mentioned previously, for pediatric patients implanted with a VAD, the risk of complications from device infection, bleeding, and stroke are higher. The heart failure team is weighing the potential of

extending BJ's life against the higher-than-usual burdens of harm posed by therapy with little prospect of benefit.

In the United States, physicians are generally expected to share decision making. In this case, then, the parents' views of what is best for BJ needs to be considered as the clinical team defines goals and offers recommendations. Life prolongation is the overarching goal for BJ's parents. However, BJ's physicians believe placement of the VAD for the purpose of life prolongation to be a probable source of harm and that the VAD would require long-term management during BJ's chemotherapy and stem cell transplant. They believe the probability of harm outweighs the minimal chance of benefit. They further argue that a VAD could hasten BJ's death if there are complications.

In cases such as this, several principles and frameworks, as mentioned above, can be helpful for guiding decision making.<sup>15</sup> One approach entails constraining or limiting parental decisional autonomy. While acknowledging that parents are almost always acting in their child's best interest, as in BJ's case, physicians must occasionally weigh whether harms outweigh potential benefits of an emerging technology when considering whether to present that technology as an option. If a chance of cancer-free survival from use of an emerging technology is high, physicians would likely be justified in offering it more freely to parents as a treatment option to consider. We must also acknowledge that a decision to not offer a VAD in BJ's case could be seen by some as setting a precedent that could limit other patients' access to this technology.

Finally, given that off-label and emerging treatments are being considered, BJ's team has an obligation to effectively communicate this information to BJ's parents and other caregivers. It is incumbent on the team to take responsibility for leading thoughtful, compassionate discussions about [palliative care](#) as an alternative to LVAD placement.

## Conclusion

As VAD technology continues to evolve—and as VAD outcomes improve and complications diminish—its use as a chronic care option or destination therapy might become more commonplace in select pediatric patients. In BJ's case, a poor prognosis and the significant possibility of severe complications given her underlying acute myeloid leukemia should directly inform the physicians' consideration of whether to offer LVAD. If BJ's disease had a higher rate of cure with potential for disease-free status—such that she could be a heart transplant candidate—LVAD implantation as a bridge to transplant candidacy or recovery could be viewed as more compelling. As debate over appropriate uses of VAD technologies continue, thoughtful analysis and conversations are needed among clinicians, families, and patients.

## References

1. Kirklin JK, Pagani FD, Kormos RL, et al. Eighth annual INTERMACS report: special focus on framing the impact of adverse events. *J Heart Lung Transplant*. 2017;36(10):1080-1086.
2. Blume ED, VanderPluym C, Lorts A, et al. Second annual Pediatric Interagency Registry for Mechanical Circulatory Support (PediMACS) report: pre-implant characteristics and outcomes. *J Heart Lung Transplant*. 2018;37(1):38-45.
3. Rosenthal DN, Almond CS, Jaquiss RD, et al. Adverse events in children implanted with ventricular assist devices in the United States: data from the Pediatric Interagency Registry for Mechanical Circulatory Support (PediMACS). *J Heart Lung Transplant*. 2016;35(5):569-577.
4. Perri G, Filippelli S, Adorisio R, et al. Left ventricular assist device as destination therapy in cardiac end-stage dystrophinopathies: midterm results. *J Thorac Cardiovasc Surg*. 2017;153(3):669-674.
5. Adachi I. Continuous-flow ventricular assist device support in children: a paradigm change. *J Thorac Cardiovasc Surg*. 2017;154(4):1358-1361.
6. Freilich M, Stub D, Esmore D, et al. Recovery from anthracycline cardiomyopathy after long-term support with a continuous flow left ventricular assist device. *J Heart Lung Transplant*. 2009;28(1):101-103.
7. Cavigelli-Brunner A, Schweiger M, Knirsch W, et al. VAD as bridge to recovery in anthracycline-induced cardiomyopathy and HHV6 myocarditis. *Pediatrics*. 2014;134(3):e894-e899.
8. Krasnopero D, Asante-Korang A, Jacobs J, et al. Case report and review of the literature: the utilisation of a ventricular assist device as bridge to recovery for anthracycline-induced ventricular dysfunction. *Cardiol Young*. 2018;28(3):471-475.
9. Schweiger M, Dave H, Lemme F, et al. Acute chemotherapy-induced cardiomyopathy treated with intracorporeal left ventricular assist device in an 8-year-old child. *ASAIO J*. 2013;59(5):520-522.
10. Feldman D, Pamboukian SV, Teuteberg JJ, et al; International Society for Heart and Lung Transplantation. The 2013 International Society for Heart and Lung Transplantation guidelines for mechanical circulatory support: executive summary. *J Heart Lung Transplant*. 2013;32(2):157-187.
11. Coulson-Smith P, Fenwick A, Lucassen A. In defense of best interests: when parents and clinicians disagree. *Am J Bioeth*. 2018;18(8):67-69.
12. Weitzman CC, Schlegel S, Murphy N, Antommaria AH, Brosco JP, Stein MT. When clinicians and a parent disagree on the extent of medical care. *J Dev Behav Pediatr*. 2009;30(3)(suppl):242-243.
13. Manning M, Wilkinson D. Ethical complexity and precaution when parents and doctors disagree about treatment. *Am J Bioeth*. 2018;18(8):49-55.

14. Winters JP. When parents refuse: resolving entrenched disagreements between parents and clinicians in situations of uncertainty and complexity. *Am J Bioeth.* 2018;18(8):20-31.
15. Lantos JD. Best interest, harm, God's will, parental discretion, or utility. *Am J Bioeth.* 2018;18(8):7-8.
16. Paquette ET, Ross LF. Pediatric decision making requires both guidance and intervention principles. *Am J Bioeth.* 2018;18(8):44-46.
17. Marron JM. Not all disagreements are treatment refusals: the need for new paradigms for considering parental treatment requests. *Am J Bioeth.* 2018;18(8):56-58.
18. Kopelman LM. The best-interests standard as threshold, ideal, and standard of reasonableness. *J Med Philos.* 1997;22(3):271-289.
19. Diekema DS. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theor Med Bioeth.* 2004;25(4):243-264.
20. McDougall RJ, Notini L. Overriding parents' medical decisions for their children: a systematic review of normative literature. *J Med Ethics.* 2014;40(7):448-452.
21. American Academy of Pediatrics Committee on Bioethics. Informed consent in decision-making in pediatric practice. *Pediatrics.* 2016;138(2):e20161484.
22. Ross LF. *Children, Families, and Health Care Decision Making.* Oxford, UK: Clarendon Press; 1999.
23. Pillai AK, Bhatti Z, Bosserman AJ, Mathew MC, Vaidehi K, Kalva SP. Management of vascular complications of extra-corporeal membrane oxygenation. *Cardiovasc Diagn Ther.* 2018;8(3):372-377.
24. Kirsch R, Munson D. Ethical and end of life considerations for neonates requiring ECMO support. *Semin Perinatol.* 2018;42(2):129-137.
25. Courtwright AM, Robinson EM, Feins K, et al. Ethics committee consultation and extracorporeal membrane oxygenation. *Ann Am Thorac Soc.* 2016;13(9):1553-1558.
26. Shankar V, Costello JP, Peer SM, Klugman D, Nath DS. Ethical dilemma: offering short-term extracorporeal membrane oxygenation support for terminally ill children who are not candidates for long-term mechanical circulatory support or heart transplantation. *World J Pediatr Congenit Heart Surg.* 2014;5(2):311-314.
27. Gow KW, Heiss KF, Wulkan ML, et al. Extracorporeal life support for support of children with malignancy and respiratory or cardiac failure: the extracorporeal life support experience. *Crit Care Med.* 2009;37(4):1308-1316.

**Angira Patel, MD, MPH** is a pediatric and fetal cardiologist at the Ann and Robert H. Lurie Children's Hospital of Chicago in Illinois. She is interested in ethical issues in pediatric and fetal cardiology related to decision making and emerging technology.

**Anna Joong, MD** is a pediatric heart failure and transplant physician at the Ann and Robert H. Lurie Children's Hospital of Chicago in Illinois. Her academic research focuses on pediatric heart transplant outcomes and pediatric ventricular assist devices.

**Efrat Lelkes, MD** is a pediatric intensive care unit physician and palliative care specialist at the UCSF Benioff Children's Hospital San Francisco. She is interested in the intersection of bioethics with palliative care and critical care and its role in approaching moral distress.

**Jeffrey G. Gossett, MD** is the medical director of pediatric heart failure, mechanical circulatory support, and heart transplantation services at the UCSF Benioff Children's Hospital San Francisco. His interests include optimizing the long-term outcomes of children requiring heart transplantation and maximizing the equitable utilization of donor organs.

**Citation**

*AMA J Ethics.* 2019;21(5):E380-386.

**DOI**

10.1001/amajethics.2019.380.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**CASE AND COMMENTARY**

**How Should ECMO Initiation and Withdrawal Decisions Be Shared?**

Carolina Jaramillo and Nicholas Braus, MD

**Abstract**

Extracorporeal membrane oxygenation (ECMO) is a new technology used to rescue patients with severe circulatory or respiratory failure and help bridge them to recovery or to definitive therapies like device implantation or organ transplantation. The increasing availability and success of ECMO has generated numerous ethical questions about its use and potential misuse. This commentary on a case of a patient who is no longer a candidate for transplant but wishes to continue ECMO identifies strategies clinicians can use to reconcile competing responsibilities.

**Case**

JL is a 20-year-old man with progressive interstitial lung disease that developed after burning brush treated with fertilizer and weed spray. Four months after his initial diagnosis, he was referred to Dr M, a lung transplantation specialist. In the ensuing year, JL's lung disease progressed, and Dr M recommended listing him for transplantation.

Unfortunately, one week after being listed for transplant, JL developed parainfluenza pneumonia and was admitted to a medical intensive care unit. His condition rapidly deteriorated and he required intubation for mechanical ventilatory support. Dr M and the cardiothoracic surgery team recommended initiation of veno-venous extracorporeal membrane oxygenation (VV-ECMO) as a bridge to lung transplantation. They discussed the risks and benefits of ECMO with JL and his family and indicated that the goals of ECMO in JL's case were to liberate him from mechanical ventilatory support and allow him to participate in physical therapy while awaiting a transplant. They disclosed that he would only remain listed for transplant if his other organs remained healthy, he remained free of serious complications, and he could get out of bed and walk every day.

JL and his family consented to the procedure, and over the next several days he was successfully cannulated for VV-ECMO, weaned from mechanical ventilatory support, ambulated daily in the intensive care unit (ICU), and relisted for lung transplantation. Four days later, JL developed a black skin lesion on the nose, groin, and axilla. A biopsy showed invasive mucormycosis—a rare and difficult to treat fungal infection. This new diagnosis disqualified JL for transplantation.

Dr M reflected that since ECMO in JL's case was intended as a bridge to transplantation and this was no longer feasible, ECMO ought to be discontinued. When Dr M shared this opinion with JL and his family, JL stated: "I want to keep fighting, and I want more time with my family; do not turn off the machine." Observing that JL needed ECMO to stay alive but that he could not remain on ECMO indefinitely, Dr M and the ICU team wondered how to navigate the next steps with JL and his family.

### Commentary

ECMO is a form of mechanical circulatory support that involves continuously circulating a patient's blood through a circuit that oxygenates and decarboxylates blood using a semi-permeable membrane. In VV-ECMO, oxygenated blood is returned to the venous circulation and pumped through the arterial circulation by the patient's heart. A veno-arterial ECMO (VA-ECMO) circuit pumps blood directly into a patient's arterial circulation, allowing for both respiratory and cardiac support. This case of VV-ECMO raises important questions about how to best use this powerful technology in an ICU. When and how should ECMO be stopped when it is no longer deemed beneficial? How ought responsibility for a decision to discontinue ECMO be shared among patients, surrogates, and clinicians? In what follows, we consider duties that need be reconciled when a patient is "stranded" on ECMO and describe how shared decision making can motivate consensus about how to proceed.

### Bridge-to-Nowhere ECMO

Despite JL's relatively grim circumstances, there were several reasons Dr M's team recommended ECMO to JL. There is a growing body of literature supporting the efficacy of ECMO as a bridge to lung transplantation.<sup>1-3</sup> For example, a recent retrospective analysis of United Network for Organ Sharing (UNOS) data from 2005 to 2013 found that, among patients successfully transplanted, a [bridging strategy using ECMO](#) instead of mechanical ventilation might have actually conferred a survival advantage.<sup>4</sup> Had Dr M's team estimated JL's risk of mortality on VV-ECMO using one of the handful of published decision support tools,<sup>5,6</sup> they would have found his chances to be relatively good, given his young age, short duration of mechanical ventilatory support before ECMO initiation, immunocompetent status, and lack of extrapulmonary organ dysfunction. Dr M's team also had an opportunity to discuss risks of ECMO and to obtain informed consent before proceeding, which is not feasible when ECMO is initiated emergently. Yet even under these relatively favorable circumstances, the decision to start ECMO has led JL and the team to an impasse.

Dr M is correct that the sudden and unexpected diagnosis of mucormycosis has undermined the original indication for using ECMO by disqualifying JL from transplantation. This is an example of what has been described as a "bridge-to-nowhere" scenario, in which a patient on ECMO is not expected to recover and is not a candidate for transplant.<sup>7</sup> Unlike left ventricular assist device therapy, ECMO is limited to



an ICU setting and is not employed as a permanent or destination therapy. Prolonged treatment with ECMO is resource intensive, technically challenging, and often impeded by complications such as bloodstream infection, coagulopathic bleeding, neurologic injury, or catheter-related limb ischemia.<sup>8</sup> As a result, most patients bridging to transplant remain on ECMO for an average of 1 to 2 weeks, regardless of their outcome.<sup>3</sup> There are no well-defined limits regarding how long a patient should be treated with ECMO as a bridge, but a few centers have reported success using VV-ECMO for up to 155 days as a bridge to transplant and up to 193 days as a bridge to recovery from acute respiratory distress syndrome.<sup>9,10</sup>

Dr M is also not wrong to recommend discontinuing ECMO to JL and his family. Closely hewing to the indications and contraindications for any treatment promotes the ethical values of beneficence and nonmaleficence. Even an efficacious intervention (eg, limb amputation for sepsis) in an enthusiastically consenting patient might not be justified without a clear indication (eg, paronychia). Because ECMO is a [resource-intensive intervention](#), using it indiscriminately would run afoul of one's duty to promote justice and equitably distribute limited resources. A recent single-center survey of physician attitudes towards decisional authority when using VA-ECMO found that 54% of all respondents and 81% of those identifying as "knowledgeable" about ECMO cited cost as a rationale for restricting its use.<sup>11</sup> In the same study, 71% of responding pulmonologists felt that "surrogate consent should not be required to discontinue VA-ECMO," and 76% of respondents who self-identified as "knowledgeable" about ECMO indicated that "physicians should have the right to discontinue VA-ECMO treatment over surrogate objection."<sup>11</sup> Although the survey pertained specifically to VA-ECMO, the results suggest that Dr M would not be alone if she felt ethically obliged to discontinue ECMO (if permissible by state law and institutional policy), regardless of JL's and his family's reaction.

Yet a bridge-to-nowhere scenario is not on its own sufficient ethical grounds for a clinician to unilaterally discontinue life support. The values of beneficence, nonmaleficence, and allocating resources equitably must be reconciled with respect for patient autonomy. JL's capacity to make decisions means that discontinuing ECMO without his consent would violate his autonomy. But it also gives Dr M's team the opportunity to confirm JL's understanding of his situation; elicit what is most valuable to him; discuss which outcomes he would find preferable, tolerable, undesirable, or intolerable; and explore and disclose biases and competing considerations that could favor one decision or another.

When a patient lacks decision-making capacity, a medical team must rely on [surrogate decision makers](#) or an advanced directive. A surrogate's exercise of substituted judgment based on knowledge of the patient's values and preferences may permit clinicians some latitude in weighing competing duties to avoid harm and equitably allocate resources,

but it can also lead to disagreements or conflict over how a patient's values and preferences should be applied in particular decisions.

### **Responding to Requests to Continue Bridge-to-Nowhere ECMO**

JL's initial response to Dr M seems unambiguous: he wishes to continue ECMO so he can have more time with his family. If Dr M were to take his wish at face value, she might conclude that her team's options for responding to JL are to either acquiesce and continue ECMO indefinitely or refuse and move to unilaterally discontinue the circuit. Framing the issue as a choice between 2 binary options might seem like an efficient way to allocate decision-making authority—either it is retained entirely by the medical team or it is delegated entirely to the patient. Yet both options pose communication risk. An unconstrained clinician, for example, could overstep ethical or even legal bounds on the exercise of medical paternalism, while an unconstrained patient could be fettered by physical, emotional, or spiritual burdens of severe illness. What makes a binary approach seem efficient is also what makes it unlikely to be effective: it omits elements of communication necessary for clinicians and patients to effectively [share decision-making authority](#).

Shared decision making (SDM) is recommended by the American Thoracic Society and the American College of Critical Care Medicine as the default approach to defining goals of care and making major treatment decisions in an ICU.<sup>12</sup> SDM happens when clinicians share information and recommendations regarding a patient's circumstances and a patient or surrogate shares values, goals, and preferences in light of those circumstances. Patients and clinicians then decide together how to allocate responsibility for decision making and select a course of action. Clinical ethics or palliative medicine consultation should not be used as a substitute for SDM but can be helpful in difficult discussions or when consensus cannot be reached.<sup>13-15</sup>

Avoiding conflict and creating consensus has implications beyond individual clinicians and patients. Caring for a dying patient on ECMO can be [morally distressing](#) and professionally challenging for anyone involved in a patient's care, particularly when the patient is awake and interactive. Conflict, uncertainty, and poor communication can intensify feelings of distress. Observational studies in neonatal ICUs have described a residue effect in which distress experienced by a caregiver can linger and be transmitted to the care of other patients and to other interactions with colleagues over time.<sup>16,17</sup> This finding suggests that preventing conflict and improving the decision-making process in one case might mitigate distress and its impact in that case and in other cases.

In this case, Dr M's first step in responding to JL should be to invite him to elaborate on what it means for him to "keep fighting" or ask him to clarify what is most important for him to accomplish in the time he has left with his family. JL might consider the burdens of remaining on ECMO tolerable and even meaningful for him to endure as long as he

remains alert and able to converse with his family. Dr M could then explore whether JL would regard ECMO as no longer worth the burden if a complication left him unable to converse with his family. If so, JL might be open to organizing and prioritizing other important decisions around the specific goal of maximizing his ability to interact with his family for as long as possible rather than around the more general goal of prolonging life under any circumstances.

The goal of SDM is not to arrive at a specific answer but to guide clinicians and patients away from conflict and toward common goals. What if, for example, JL told Dr M that, in view of his circumstances, he wanted to continue ECMO until his 21st birthday in 3 weeks? Or his nephew's bar mitzvah next week? Or the Yankees game on Thursday? The specific nature of the destination does not in itself justify ECMO but rather motivates consensus around a medically feasible plan that respects a patient's goals and values. If the interval of ECMO support is feasible according to Dr M and does not pose undue burdens according to JL—and there is no scarcity of resources relative to demand—then it is ethically permissible for Dr M and JL to continue crossing the bridge together.

## References

1. Lehr CJ, Zaas DW, Cheifetz IM, Turner DA. Ambulatory extracorporeal membrane oxygenation as a bridge to lung transplantation: walking while waiting. *Chest*. 2015;147(5):1213-1218.
2. Fuehner T, Kuehn C, Hadem J, et al. Extracorporeal membrane oxygenation in awake patients as bridge to lung transplantation. *Am J Respir Crit Care Med*. 2012;185(7):763-768.
3. Biscotti M, Gannon WD, Agerstrand C, et al. Awake extracorporeal membrane oxygenation as bridge to lung transplantation: a 9-year experience. *Ann Thorac Surg*. 2017;104(2):412-419.
4. Schechter MA, Ganapathi AM, Englum BR, et al. Spontaneously breathing extracorporeal membrane oxygenation support provides the optimal bridge to lung transplantation. *Transplantation*. 2016;100(12):2699-2704.
5. Schmidt M, Bailey M, Sheldrake J, et al. Predicting survival after extracorporeal membrane oxygenation for severe acute respiratory failure. The Respiratory Extracorporeal Membrane Oxygenation Survival Prediction (RESP) score. *Am J Respir Crit Care Med*. 2014;189(11):1374-1382.
6. Hilder M, Herbstreit F, Adamzik M, et al. Comparison of mortality prediction models in acute respiratory distress syndrome undergoing extracorporeal membrane oxygenation and development of a novel prediction score: the PREdiction of Survival on ECMO Therapy-Score (PRESET-Score). *Crit Care*. 2017;21(1):301.
7. Abrams DC, Prager K, Blinderman CD, Burkart KM, Brodie D. Ethical dilemmas encountered with the use of extracorporeal membrane oxygenation in adults. *Chest*. 2014;145(4):876-882.

8. Ventetuolo CE, Muratore CS. Extracorporeal life support in critically ill adults. *Am J Respir Crit Care Med*. 2014;190(5):497-508.
9. Kon ZN, Dahi S, Evans CF, et al. Long-term venovenous extracorporeal membrane oxygenation support for acute respiratory distress syndrome. *Ann Thorac Surg*. 2015;100(6):2059-2063.
10. Akkanti B, Hussain R, Nathan S, et al. Prolonged veno-venous extracorporeal membrane oxygenation in a patient with acute respiratory distress syndrome. *ASAIO J*. 2016;62(2):e13-e14.
11. Meltzer EC, Ivascu NS, Stark M, et al. A survey of physicians' attitudes toward decision-making authority for initiating and withdrawing VA-ECMO. *J Clin Ethics*. 2016;27(4):281-289.
12. Kon AA, Davidson JE, Morrison W, Danis M, White DB; American College of Critical Care Medicine; American Thoracic Society. Shared decision making in ICUs: an American College of Critical Care Medicine and American Thoracic Society policy statement. *Crit Care Med*. 2016;44(1):188-201.
13. Courtwright AM, Robinson EM, Feins K, et al. Ethics committee consultation and extracorporeal membrane oxygenation. *Ann Am Thorac Soc*. 2016;13(9):1553-1558.
14. Schneiderman LJ, Gilmer T, Teetzel HD, et al. Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: a randomized controlled trial. *JAMA*. 2003;290(9):1166-1172.
15. Bosslet GT, Pope TM, Rubenfeld GD, et al; American Thoracic Society ad hoc Committee on Futile and Potentially Inappropriate Treatment; American Thoracic Society; American Association for Critical Care Nurses; American College of Chest Physicians; European Society for Intensive Care Medicine; Society of Critical Care. 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*. 2015;191(11):1318-1330.
16. Epstein EG, Hamric AB. Moral distress, moral residue, and the crescendo effect. *J Clin Ethics*. 2009;20(4):330-342.
17. Thomas TA, Thammasitboon S, Balmer DF, Roy K, McCullough LB. A qualitative study exploring moral distress among pediatric resuscitation team clinicians: challenges to professional integrity. *Pediatr Crit Care Med*. 2016;17(7):e303-e308.

**Carolina Jaramillo** is a first-year medical student at Harvard Medical School in Boston. She completed her undergraduate degree in biology at Williams College, after which she completed a postbaccalaureate research fellowship in the Biomedical Ethics Research Program at the Mayo Clinic. Her interests are in risk-benefit perception and shared decision making near the end of life.

**Nicholas Braus, MD** is a pulmonologist and critical care physician at the William S. Middleton Memorial Veterans Hospital in Madison, Wisconsin, where he is also a

member of the hospital clinical ethics committee. He attended medical school at the University of Rochester and then completed an internal medicine residency and chief residency at the University of Wisconsin Hospital and Clinics. He later completed a pulmonary and critical care fellowship at the Mayo Clinic and a fellowship at the MacLean Center for Clinical Medical Ethics at the University of Chicago. He has a research interest in the ethics of mechanical circulatory support near the end of life.

**Editor's Note**

The case to which this commentary is a response was developed by the editorial staff.

**Citation**

*AMA J Ethics.* 2019;21(5):E387-393.

**DOI**

10.1001/amajethics.2019.387.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**CASE AND COMMENTARY**

**How Should Physicians Respond to Requests for LVAD Removal?**

Larry A. Allen, MD, MHS

**Abstract**

Mechanical circulatory support devices, including left ventricular assist devices (LVADs), have become mainstream treatment for end-stage heart failure. LVADs are ethically and legally no different than other types of life support, for which patients have a right to decline or withdraw care consistent with the principle of respect for autonomy. However, the realities of LVAD complicate informed consent and shared decision making. LVAD candidates are often older and have multiple illnesses. And life with an LVAD requires a period of comprehension, adaptation, and reintegration. Therefore, clinicians must assess LVAD candidates' decision-making capacity, screen and possibly consult for depression, seek to understand whether being on LVAD is consistent with patients' values, consider temporary support options to allow for goals clarification, and ask for help from family and palliative care specialists.

**Case**

RM is a 71-year-old man in heart failure (an inability to maintain sufficient cardiac output). He has a history of tobacco use, type 2 diabetes mellitus, chronic kidney disease, and ischemic cardiomyopathy (one cause of his heart failure). After collapsing at home, RM was intubated (by emergency medical service personnel) and brought to the hospital.

RM's numerous symptoms suggested he should be started on dobutamine, and he was admitted by Dr C to the cardiovascular intensive care unit (ICU). Despite aggressive ICU therapy, RM continued to decompensate. Dr C's team approached RM's spouse to discuss implantation of a left ventricular assist device (LVAD) as a "destination therapy." The team explained that, due to RM's advanced age, he would not be a candidate for a heart transplant and that he would depend on the LVAD to live. Dr C explained that an LVAD requires lifelong anticoagulation and that RM's connection to the LVAD carried a high risk of infection, bleeding, and other complications. RM's spouse gave consent for the LVAD, stating, "I want him to live."

Shortly after LVAD implantation, RM experienced an arterial clot that led to ischemia in his left leg, which necessitated below-the-knee amputation. Eventually, though, RM's clinical status improved, he was weaned from the ventilator and extubated, and, several

days after extubation, he fully regained capacity to make decisions regarding his care. He emphasized to Dr C that he did not consent to LVAD placement, and he did not wish to live with the risks of LVAD complications or with an amputated leg. RM requested that the LVAD be removed, understanding that he would die shortly after its removal by way of left ventricular failure and cardiovascular collapse. Although Dr C wants to support and respect RM's wishes, he feels that removing the LVAD means that he would have a key role in RM's death. Dr C wonders what to say and do.

### Commentary

Situations like that of patient RM are becoming increasingly common in cardiovascular care.<sup>1</sup> Improved mechanical circulatory support technologies have expanded the routine use of durable LVADs in a wider range of patients, including people like RM who are not eligible for cardiac transplantation. Because an LVAD is generally reserved for patients with end-stage heart failure, patients might require emergent initiation of mechanical circulatory support in the setting of critical illness. Patients with heart failure proceed to LVAD surgery with significant medical problems; surgery is inherently dangerous; and complications afterwards occur in the majority of patients.<sup>2</sup> Thus, decisions to undergo LVAD implantation—and later to discontinue LVAD—can be horribly complex and emotionally distressing.<sup>3,4</sup>

### Judicial and Legal Considerations for LVAD Decision Making

Fundamentally, people have the [right to choose and refuse care](#). As my colleagues and I have written elsewhere,<sup>3</sup> “The rights of patients or duly appointed surrogates to choose their medical therapy from among reasonable options”—including no intervention and termination of intervention—are grounded in the ethical principle of respect for autonomy<sup>5</sup>; judicial decisions such as *Cruzan v Director, Missouri Department of Health*<sup>6</sup>; and legislative actions such as the Patient Self-Determination Act.<sup>7</sup> To choose, a patient or surrogate must be informed.

An informed patient is one who is aware of the diagnosis and prognosis, the nature of the proposed intervention, the risks and benefits of that intervention, and all reasonable alternatives and their associated risks and benefits. A major purpose of a high-functioning healthcare system is to provide the resources with which an activated, informed patient can engage in productive discussions with a proactive, prepared healthcare team.<sup>3</sup>

Because destination therapy LVAD involves surgical implantation of a durable pump that is intended to remain in place for the remainder of the patient's life and comes with a variety of burdens and lifestyle changes (in addition to commitment of significant resources), the stakes are particularly high. And the law does not distinguish varying degrees of dependence on therapies to be withdrawn.<sup>3</sup>

### **Ethical Considerations for LVAD Decision Making**

In contradistinction to euthanasia, deactivation of a previously implanted LVAD does not introduce new treatment or an additional surgical injury and thereby allows patients to die from their original disorder.<sup>8</sup> As such, withdrawal of LVAD support is not ethically different than withdrawal of other treatments. Nevertheless, as my colleagues and I have written elsewhere, “clinicians, patients, and families can consider scenarios in which withdrawal leads to direct and rapid patient demise as unique and emotionally difficult.”<sup>3</sup> LVAD withdrawal typically leads to death in less than an hour.<sup>9</sup> LVAD deactivation stands in contrast to turning off an implantable cardioverter defibrillator, which might not have obvious implications for survival until later, if at all.<sup>10</sup> While withdrawal of LVAD support has been likened to withdrawal of ventilatory support, patients with an LVAD are more likely than patients with endotracheal intubation to be alert and oriented at the time of device deactivation.<sup>11</sup>

One way to limit challenges of durable LVAD deactivation is to avoid implantation in the first place in patients for whom the device is not concordant with their values. In the setting of acute cardiogenic shock with loss of patient [decision-making capacity](#) (as was the case with RM), temporary mechanical circulatory support is usually preferred to going straight to durable LVAD, as did RM. Temporary treatment options can include percutaneous ventricular support and peripherally cannulated venoarterial extracorporeal membranous oxygenation (ECMO). Such an approach not only allows for more rapid and efficient stabilization of patients but also can allow time for other issues to declare themselves (eg, acute renal failure, anoxic brain injury) and for informed medical decision making to occur. In the case of RM, stabilization of the patient on temporary support might have allowed him to regain consciousness and discuss treatment decisions with his wife and family.

Moreover, the commitment of resources tends to be significantly less with temporary approaches than with durable LVAD. The relative gravity of some treatment decisions is illustrated by cardiac transplantation, in which a decision to implant a suitable donor heart takes a finite resource away from another likely deserving patient. Advanced heart failure programs that perform LVADs and transplants are graded on their outcomes, including short-term mortality, such that patient decisions not to “make the most” of their LVAD or transplant can put patients and clinicians at odds with each other.<sup>12</sup> Thus, creating opportunities to reasonably ensure patient and caregiver commitment prior to durable LVAD implantation might avoid downstream disappointment and conflict.

### **Responding to a Patient Who Requests LVAD Removal**

Given that patients have the right to refuse or discontinue therapy, RM’s case starkly illustrates how life-altering events can acutely challenge patients’ ability to accurately forecast their future, including their ability to cope with new medical realities, and thus impair their decision-making capacity. Knight and Emanuel maintain that people with



life-threatening illness experience “multiple, accumulating, and profound losses of functions, abilities, roles, and relationships” and therefore “have to adjust psychologically to these losses.”<sup>13</sup> Psychologically, waking up to find oneself dependent on an electrical heart pump and missing a leg is shocking; yet, sadly, many of us in the business of advanced heart failure and LVAD care have witnessed patients confronted with such scenarios. Traumatic medical events are often accompanied by patient and caregiver exhaustion, fear, and perceived loss of control.<sup>3</sup> Depression and anxiety are common in patients with advanced disease and can affect information processing, memory, and executive function.<sup>3</sup> When there are concerns that a patient’s decision-making capacity is impaired, that patient’s request for termination of life-supporting care can be deferred in order to work through a period of assessment, treatment, comprehension of and adaptation to one’s condition, and social reintegration, following Knight and Emanuel’s reintegration model.<sup>13</sup> An agreed-upon trial period of days to weeks might help provide structure, facilitating potential adjustment and subsequent reconsideration of withdrawal.<sup>14</sup> Meanwhile, screening for depression and anxiety, followed by pharmacological and nonpharmacological interventions (including psychological or psychiatric consultation), might be appropriate. Like most difficult situations in medicine, the optimal approach involves family members and various medical professionals working collaboratively to truly understand the patient’s state of mind, dominant values, and goals in order to best guide preference-sensitive decision making.

Assuming a patient like RM persists in requesting to withdraw care and the clinical team and family agree that he has adequate decision-making capacity, the obligation of the physician of record is to either directly help withdraw life-sustaining technology or find a proxy physician who will do so. Clinicians often bring their own cultural, religious, and personal overlay to these discussions.<sup>15</sup> When a clinician’s own religious or cultural beliefs differ from a patient’s, such that the clinician does not feel comfortable fulfilling the patient’s request—and the request of the patient is reasonable within the law—it is the clinician’s professional responsibility to transfer care to someone who can carry out the patient’s wishes.

Thus, in this case of RM, Dr C should consider the following actions:

1. Assess RM’s decision-making capacity, being attentive to the potential overlay of delirium or acute depression.
2. Involve RM’s designated health care proxy (presumably his spouse), as appropriate.
3. Listen to RM (or his proxy) with the aim of understanding his hopes and fears, and assess whether the decision to withdraw the device is concordant with his stated values and goals.
4. Engage palliative care specialists with specific training in withdrawal-of-care situations, if available.<sup>16</sup>

5. Consider psychiatry consultation if there is concern about significant overlay of depression or other psychological disorder.
6. Consider a timeline that includes a deferred decision to allow for a trial period living with the LVAD and amputation.
7. Consider an ethics consult if the process does not lead to a clear shared decision.<sup>17</sup>

If the patient has decision-making capacity and consistently articulates values that are not consistent with life on LVAD support, then arrangements for withdrawal should be made either by the physician or by a willing colleague. Protocols for turning off LVADs are available to limit unnecessary patient suffering, avoid anxiety-provoking alarms, and ease bereavement of family members.<sup>18</sup> Most LVAD deactivations occur in the hospital, but they can be performed at home.<sup>9</sup> In the end, whatever RM decides to do is the right thing to do, as long as a thoughtful process is followed that respects his complex medical, ethical, and emotional realities.

## References

1. Benjamin EJ, Muntner P, Alonso A, et al; American Heart Association Council on Epidemiology and Prevention Statistics Committee; Stroke Statistics Subcommittee. Heart disease and stroke statistics—2019 update: a report from the American Heart Association. *Circulation*. 2019;139(10):e56–e66.
2. McIlvennan CK, Magid KH, Ambardekar AV, Thompson JS, Matlock DD, Allen LA. Clinical outcomes after continuous-flow left ventricular assist device: a systematic review. *Circ Heart Fail*. 2014;7(6):1003–1013.
3. Allen LA, Stevenson LW, Grady KL, et al; American Heart Association; Council on Quality of Care and Outcomes Research; Council on Cardiovascular Nursing; Council on Clinical Cardiology; Council on Cardiovascular Radiology and Intervention; Council on Cardiovascular Surgery and Anesthesia. Decision making in advanced heart failure: a scientific statement from the American Heart Association. *Circulation*. 2012;125(15):1928–1952.
4. Makdisi T, Makdisi G. Ethical challenges and terminal deactivation of left ventricular assist device. *Ann Transl Med*. 2017;5(16):331.
5. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 7th ed. London, UK: Oxford University Press; 2013.
6. *Cruzan v Director, Missouri Department of Health*, 497 US 261 (1990).
7. Patient Self Determination Act of 1990, HR 4449, 101st Cong, 2nd Sess (1989–1990).
8. Shah KB, Levenson JL, Mehra MR. Emergent use of mechanical circulatory support devices: ethical dilemmas. *Curr Opin Cardiol*. 2014;29(3):281–284.
9. Dunlay SM, Strand JJ, Wordingham SE, Stulak JM, Luckhardt AJ, Swetz KM. Dying with a left ventricular assist device as destination therapy. *Circ Heart Fail*. 2016;9(10):e003096.

10. Matlock DD, Stevenson LW. Life-saving devices reach the end of life with heart failure. *Prog Cardiovasc Dis*. 2012;55(3):274-281.
11. LeMond L, Allen LA. Palliative care and hospice in advanced heart failure. *Prog Cardiovasc Dis*. 2011;54(2):168-178.
12. Jay C, Schold JD. Measuring transplant center performance: the goals are not controversial but the methods and consequences can be. *Curr Transplant Rep*. 2017;4(1):52-58.
13. Knight SJ, Emanuel L. Processes of adjustment to end-of-life losses: a reintegration model. *J Palliat Med*. 2007;10(5):1190-1198.
14. Wilkinson D, Savulescu J. A costly separation between withdrawing and withholding treatment in intensive care. *Bioethics*. 2012;28(3):127-137.
15. McIlvennan CK, Wordingham SE, Allen LA, et al. Deactivation of left ventricular assist devices: differing perspectives of cardiology and hospice/palliative medicine clinicians. *J Card Fail*. 2017;23(9):708-712.
16. Swetz KM, Freeman MR, AbouEzzeddine OF, et al. Palliative medicine consultation for preparedness planning in patients receiving left ventricular assist devices as destination therapy. *Mayo Clin Proc*. 2011;86(6):493-500.
17. Shuman AG, Montas SM, Barnosky AR, Smith LB, Fins JJ, McCabe MS. Clinical ethics consultation in oncology. *J Oncol Pract*. 2013;9(5):240-245.
18. Schaefer KG, Griffin L, Smith C, May CW, Stevenson LW. An interdisciplinary checklist for left ventricular assist device deactivation. *J Palliat Med*. 2014;17(1):4-5.

**Larry A. Allen, MD, MHS** is the associate division head for clinical affairs in cardiology and medical director of the Advanced Heart Failure Program at the University of Colorado Boulder. He also conducts research with the Colorado Program for Patient Centered Decisions. His work focuses on improving ability to anticipate progression into end-stage heart failure and helping patients make tough choices regarding invasive therapies and palliative options.

#### **Editor's Note**

The case to which this commentary is a response was developed by the editorial staff.

#### **Citation**

*AMA J Ethics*. 2019;21(5):E394-400.

#### **DOI**

10.1001/amajethics.2019.394.

**Conflict of Interest Disclosure**

Dr Allen has consulted for ACI Clinical, Abbott, Amgen/Cytokinetics, Boston Scientific, Duke Clinical Research Institute, and Janssen, and he has received research grants from PCORI, the National Heart, Lung, and Blood Institute of the National Institutes of Health, and the American Heart Association.

*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

## CASE AND COMMENTARY

### Should Long-Term Life-Sustaining Care Be Started in Emergency Settings?

Ellen C. Meltzer, MD, MSc, Natalia S. Ivascu, MD, Mark K. Edwin, MD, and Timothy J. Ingall, MBBS, MD, PhD

#### Abstract

Decision making on behalf of an incapacitated patient is challenging, particularly in the context of venoarterial extracorporeal membrane oxygenation (VA-ECMO), a medically complex, high-risk, and costly intervention that provides cardiopulmonary support. In the absence of a surrogate and an advance directive, the clinical team must make decisions for such patients. Because states vary in terms of which decisions clinicians can make, particularly at the end of life, the legal landscape is complicated. This commentary on a case of withdrawal of VA-ECMO in an unrepresented patient discusses Extracorporeal Life Support Organization guidelines for decision making, emphasizing the importance of proportionality in a benefits-to-burdens analysis.

#### Case

TM is a 42-year-old man who was brought by emergency medical service personnel to an emergency department in refractory ventricular tachycardia. After multiple rounds of cardiopulmonary resuscitation (CPR), defibrillations, and administration of antidysrhythmic drugs, TM, who does not have a surrogate or advance directive, is put on venoarterial extracorporeal membrane oxygenation (VA-ECMO) and admitted by Dr A to the hospital's cardiac intensive care unit.<sup>1,2</sup> Dr A's team learns little about TM's medical history and life, and Dr A decides that TM is not a candidate for heart transplantation or left ventricular assist device placement. Over the next days, Dr A's team members agree that TM is unlikely to recover from heart failure. They wonder whether and when to withdraw VA-ECMO support and how to decide.

#### Commentary

Making complex decisions for incapacitated, unrepresented patients presents both clinical and ethical challenges. The absence of an [advance directive](#) or surrogate means clinical team members must make decisions. States vary in terms of which decisions clinicians can make, particularly at the end of life,<sup>3</sup> so the legal landscape is complicated. The Extracorporeal Life Support Organization (ELSO) guidelines can help clinicians make decisions for patients like TM about whether to initiate or discontinue VA-ECMO, a type of extracorporeal life support.

### Initiation of VA-ECMO and Emergency Presumption of Consent

VA-ECMO provides mechanical cardiopulmonary support for patients with refractory cardiac arrest. (This differs from veno-venous ECMO, which provides pulmonary support.) VA-ECMO does not fix underlying cardiopulmonary pathology; rather, it is a temporizing measure that offers patients time for their heart to recover or—in the absence of recovery—for transition to long-term circulatory support, such as a ventricular assist device (VAD) or cardiac transplantation.<sup>4</sup> In a life-threatening situation, the emergency presumption of consent justifies caring for an incapacitated patient without consent from a surrogate.<sup>5</sup> Treatment is provided based on the assumption that a reasonable patient with decision-making capacity would consent to a life-saving intervention.

One ethical question is whether VA-ECMO should be considered different from other forms of life-sustaining therapy typically covered under the emergency presumption, such as intubation and mechanical ventilation.<sup>6</sup> VA-ECMO is a medically complex, high-risk, and costly therapy, so it could be argued that its use should be restricted and offered only to patients who will clearly benefit. A challenge is that it can be difficult to prognosticate in the midst of a crisis. Although clinical factors have been identified retrospectively that are associated with more favorable outcomes when VA-ECMO is implemented for refractory cardiac arrest,<sup>7</sup> discussion of this issue is beyond the scope of this article; prospective studies are needed to better predict outcomes. For now, ELSO suggests that VA-ECMO be considered as an aid to CPR if the patient has a reversible cause for the arrest and has had excellent CPR.<sup>8</sup>

When considering initiation of VA-ECMO in an emergency, irrespective of whether the patient has a surrogate, clinicians should use the same clinical judgment as they do when making decisions about other life-sustaining treatments. The team should reflect on the patient's clinical condition and expected prognosis.<sup>9</sup> *Proportionality* is one ethical value suggested by the ELSO guidelines; to apply it, clinicians should consider whether the potential benefits of VA-ECMO are likely to outweigh its risks or burdens, given the patient's clinical situation. They should also incorporate patient preferences when set forth in an advance directive or in prior interactions. Respecting a patient's wishes articulated when he or she had decision-making capacity is paramount to respecting that patient's autonomy when incapacitated. These wishes can then be used to guide clinicians and surrogates in determining goals and a plan of care.

The clinical and ethical appropriateness of VA-ECMO should be assessed similarly to that of other life-sustaining measures. It should be initiated when its potential to benefit a patient outweighs its potential to burden the patient and when it promotes reasonable goals of care. Additionally, like any other life-sustaining treatment, VA-ECMO should not be withheld from a patient who lacks decision-making capacity simply because there is no surrogate decision maker or advance directive.

### Continuing VA-ECMO

Regardless of whether there is a surrogate, decision making in emergencies, when time is short, often does not permit ethical deliberation as described above.<sup>6</sup> Once clinical team members understand a patient's diagnosis and a patient is stabilized, informed consent can be revisited. By informed consent in the context of VA-ECMO, we mean an ongoing process of frequent discussions with patients or surrogates about the prognosis, goals of care, and benefits and burdens of VA-ECMO.<sup>10</sup>

As a patient's clinical status evolves, newly emerging information can be used to guide goals-of-care discussions and decision making. Over time, a VA-ECMO patient's likelihood of cardiopulmonary recovery tends to become clearer, as does the presence or absence of renal impairment, neurologic injury, or other complications related to VA-ECMO.<sup>11</sup> Ongoing application of the ethical value of proportionality—that is, continued consideration of the relative benefits and burdens of VA-ECMO—is essential to a good ongoing consent process. Palliative care or clinical ethics consultations, depending on institutional availability, can also inform deliberations and help guide decision making. When benefits outweigh burdens, generally, it makes ethical and clinical sense to continue VA-ECMO for a patient.

### Discontinuing VA-ECMO

When patients do not recover on VA-ECMO and are not candidates for a VAD or cardiac transplantation, [terminal discontinuation](#) is most likely the only option. Unlike mechanical ventilation—which can be provided long term, via a tracheostomy, and outside intensive care settings—presently, there are no options for long-term VA-ECMO support. This is one reason ELSO recommends that VA-ECMO for refractory cardiac arrest “be discontinued promptly if there is no hope for healthy survival,” where healthy survival is defined as “three to five days of no cardiac function in a patient who is not a VAD or transplant candidate.”<sup>12</sup>

Decision making about discontinuation of ECMO can be complicated. When a patient has a surrogate, the clinical team can have an informed discussion with this person to consider the rationale for terminal discontinuation and, ideally, obtain consent to stop VA-ECMO. If—after a good faith effort to locate a patient's friends, family, or advance directive (and to document such efforts)—no surrogate is found when VA-ECMO is initiated for a patient, then palliative care, clinical ethics, social work, and chaplaincy colleagues, for example, should be formally included in thoughtful discussion and deliberation about next steps. An incapacitated patient is incredibly vulnerable, and inclusivity of deliberation can be essential to ensuring that the patient receives the standard of care. If all generally agree that the patient under consideration would not likely survive after VA-ECMO removal or could not be converted to long-term support (such as transplantation or implantable VAD), terminal discontinuation is most likely the only option. We suggest clinicians also seek guidance from hospital legal counsel about

proceeding with discontinuation in accordance with applicable state law. Once a decision to discontinue VA-ECMO is made, the clinical team should proceed expeditiously, as delays tend to prolong a patient's dying process. Prior to discontinuing VA-ECMO, clinicians should be prepared to manage any distressing symptoms a patient could experience between the time of separation from VA-ECMO and his or her death.<sup>13</sup>

Making VA-ECMO decisions on behalf of an incapacitated patient with no surrogate or advance directive tends to be **stressful** for clinicians; any decision will likely impact anyone who has cared for the patient. Postponing determination of goals of care or critical discussions about a patient's status or prognosis can be burdensome for team members, particularly if they are concerned about patient suffering, wasted resources, or continued care offering minimal or no benefit. Maintaining inclusivity in discussions and deliberations can help make members of a care team feel that their contributions to thoughtful consideration about the patient's care are important.

## Conclusion

In emergencies, VA-ECMO should probably be provided to all patients, regardless of whether they have a surrogate or advance directive, particularly when potential benefits are thought to outweigh potential burdens. If the patient fails to recover and is not a candidate for a VAD or cardiac transplantation, VA-ECMO should be discontinued when its burdens outweigh its benefits or potential benefits. How best to proceed respectfully with terminal VA-ECMO discontinuation will vary depending on state law. Clinicians should prioritize their duties to incapacitated patients with no surrogate due to their extreme vulnerability.

## References

1. Tsai FC, Wang YC, Huang YK, et al. Extracorporeal life support to terminate refractory ventricular tachycardia. *Crit Care Med*. 2007;35(7):1673-1676.
2. Bhandary SP, Joseph N, Hofmann JP, Saranteas T, Papadimos TJ. Extracorporeal life support for refractory ventricular tachycardia. *Ann Transl Med*. 2017;5(4):73.
3. Venkat A, Becker J. The effect of statutory limitations on the authority of substitute decision makers on the care of patients in the intensive care unit: case examples and review of state laws affecting withdrawing or withholding life-sustaining treatment. *J Intensive Care Med*. 2014;29(2):71-80.
4. Meltzer EC, Ivascu NS, Acres CA, Stark M, Furman RR, Fins JJ. Extracorporeal membrane oxygenation as a bridge to chemotherapy in an Orthodox Jewish patient. *Oncologist*. 2014;19(9):985-989.
5. Snyder L; American College of Physicians Ethics, Professionalism, Human Rights Committee. American College of Physicians ethics manual: sixth edition. *Ann Intern Med*. 2012;156(1, pt 2):73-104.
6. Peetz AB, Sadovnikoff N, O'Connor MF. Is informed consent for extracorporeal life support even possible? *AMA J Ethics*. 2015;17(3):236-242.



7. Schmidt M, Burrell A, Roberts L, et al. Predicting survival after ECMO for refractory cardiogenic shock: the survival after veno-arterial-ECMO (SAVE)-score. *Eur Heart J*. 2015;36(33):2246-2256.
8. Extracorporeal Life Support Organization (ELSO). Guidelines for ECPR cases. ELSO ECPR supplement to the ELSO guidelines. Version 1.3. <https://www.else.org/Portals/0/IGD/Archive/FileManager/6713186745cusersshyperdocumentselsoguidelinesforecprcases1.3.pdf>. Published December 2013. Accessed November 9, 2018.
9. Fins JJ, Bacchetta MD, Miller FG. Clinical pragmatism: a method of moral problem solving. *Kennedy Inst Ethics J*. 1997;7(2):129-145.
10. Meltzer EC, Ivascu NS, Acres CA, et al. Extracorporeal membrane oxygenation in adults: a brief review and ethical considerations for nonspecialist health providers and hospitalists. *J Hosp Med*. 2014;9(12):808-813.
11. Makdisi G, Wang IW. Extra corporeal membrane oxygenation (ECMO): review of a lifesaving technology. *J Thorac Dis*. 2015;7(7):E166-E176.
12. Extracorporeal Life Support Organization (ELSO). General guidelines for all ECLS cases. Version 1.4. [https://www.else.org/Portals/0/ELSO%20Guidelines%20General%20All%20ECLS%20Version%201\\_4.pdf](https://www.else.org/Portals/0/ELSO%20Guidelines%20General%20All%20ECLS%20Version%201_4.pdf). Published August 2017. Accessed November 9, 2018.
13. Fins JJ. *A Palliative Ethic of Care: Clinical Wisdom at Life's End*. Sudbury, MA: Jones and Bartlett; 2006.

**Ellen C. Meltzer, MD, MSc** is an internist and clinical ethicist at Mayo Clinic in Scottsdale, Arizona.

**Natalia S. Ivascu, MD** is the chief of critical care anesthesiology and the medical director of the Cardiothoracic Surgical Intensive Care Unit at New York-Presbyterian/Weill Cornell Medical Center in New York City.

**Mark K. Edwin, MD** is a palliative care physician and the medical director of Hospice of the Valley at Mayo Clinic in Phoenix, Arizona.

**Timothy J. Ingall, MBBS, MD, PhD** is a neurologist and the chair of the ethics subcommittee at Mayo Clinic in Phoenix, Arizona.

#### **Editor's Note**

The case to which this commentary is a response was developed by the editorial staff.

#### **Citation**

*AMA J Ethics*. 2019;21(5):E401-406.

**DOI**

10.1001/amajethics.2019.401.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

## MEDICAL EDUCATION

### Educating Resident and Fellow Physicians on the Ethics of Mechanical Circulatory Support

Elizabeth A. Sonntag, MD, Keyur B. Shah, MD, and Jason N. Katz, MD

#### Abstract

Mechanical circulatory support (MCS) such as extracorporeal membrane oxygenation, left ventricular assist devices and total artificial hearts have altered the natural history of heart failure, and specialists in the fields of cardiology and cardiothoracic surgery are faced with more complex ethical considerations than ever before. Residency and fellowship training programs, however, do not have formal curricula in medical ethics as it applies to MCS. In response, this article proposes that ethics be integrated into graduate medical education with a focus on the following 6 constructs: patient best interest, respect for autonomy, informed consent, shared decision making, surrogate decision making, and end-of-life care. Curricula should offer learning experiences that help physicians navigate common ethical challenges encountered in practice.

#### Ethical Dilemmas in Cardiology and Cardiothoracic Surgery

Important innovations in the fields of cardiology and cardiothoracic surgery have significantly prolonged survival in patients with heart failure (HF), changing the scope of practice for many physicians. Although mechanical circulatory support (MCS) therapies, including extracorporeal membrane oxygenation (ECMO), left ventricular assist devices (LVADs) and total artificial hearts (TAHs) have altered the natural history of previously fatal conditions, these devices are not free of complications and do not necessarily lessen the impact of severe comorbidities. Consequently, physicians tasked with providing sophisticated medical care to patients with escalating illness severity are faced with ethical dilemmas.

A prominent clinical ethicist, Mark Siegler, asserts that ethics should be continuously taught at all levels of medical school and residency<sup>1</sup>; however, this is not the case. Ethics curricula were established in most American medical schools by the 1970s<sup>1</sup> and are now typically offered only in classroom-based learning environments during the preclinical years. There are no explicit ethics requirements for residency or fellowship programs.<sup>2-4</sup> Thus, specialty physicians can lack training in bedside clinical ethics pertinent to their medical specialty. This gap also applies to cardiologists and cardiothoracic surgeons who provide MCS for patients with HF, as specific training in MCS therapies comes later in

fellowship training—generally 5 to 8 years after preclinical ethics education. Although there are specific training requirements for specialists in cardiology, HF, and cardiothoracic surgery (for example, exposure to advanced HF and MCS devices),<sup>2-4</sup> most will have no formal education in ethical issues related to life-sustaining therapies. Some physicians thus might feel unprepared to navigate ethical complexities concerning respect for patient autonomy, shared decision making, quality of life (QOL), and end-of-life (EOL) care. Therefore, preparing physicians to care well for patients with MCS devices should include integration of ethics into residency and fellowship training.

### **MCS for Treatment of HF**

HF is a clinical syndrome in which the heart is unable to effectively deliver oxygenated blood throughout the body due to myocardial infarction (ie, heart attack), arrhythmias, hypertension, viral infection, inherited diseases, or other conditions. Symptoms include fatigue, breathlessness, fluid retention, and activity intolerance. Despite standard therapy, HF is a progressive disease. The end stage of HF is marked by frequent hospitalizations and poor QOL.<sup>5</sup> While heart transplantation is a life-saving intervention, few patients are eligible.<sup>6</sup>

Implantable MCS devices offer an important alternative therapy for end-stage HF. An LVAD is a pump implanted in the patient's chest in order to augment blood flow. Patients can carry out many of their usual activities with an LVAD in place. Initially used as a bridge to heart transplantation, permanent implantation of LVADs has now been approved as a destination therapy and has been shown to improve survival and QOL in patients who are not transplant candidates.<sup>7</sup> ECMO, which takes over for failing heart and/or lungs by circulating oxygenated blood, is a last-resort therapy that takes place in an intensive care unit and is typically limited to use in managing potentially reversible conditions or as a bridge to definitive therapy. It can be utilized for acute HF or as part of the cardiopulmonary resuscitation (CPR) algorithm.<sup>8</sup>

Despite their promise, these technologies have limitations and complications. LVAD survival at 4 years postimplant is 49%; common complications include bleeding, stroke, infection, and continued HF.<sup>9</sup> Common ECMO complications include hemorrhage and neurological injury,<sup>10</sup> and it can be difficult to predict whether and to what extent a patient's underlying condition is modifiable or whether a patient will be a candidate for definitive therapy. These outcomes, in addition to considerations about QOL and caregiver burden, play a role in decisions about whether and when to use MCS.

Some ethical questions raised by these technologies include (1) How can we ensure a patient's best interest is upheld when risk-benefit analyses and predictions of QOL with new technologies are becoming increasingly complex? (2) How should shared decision making and informed consent happen when these therapies are implemented

emergently? (3) To whom should life-sustaining therapies be offered and according to which criteria? (4) When is it permissible to withdraw MCS devices?

### **Incorporating Ethics Education Into Cardiology Training**

Trainees in cardiovascular disease fellowships are required to train in centers with robust critical care and surgery programs to ensure exposure to advanced HF and MCS devices.<sup>2</sup> Surgeons and HF subspecialists respectively implant and manage MCS devices. The American College of Cardiology recommendations for training in adult cardiovascular medicine and the Accreditation Council for Graduate Medical Education program requirements for cardiovascular disease, heart failure and transplant cardiology, and thoracic surgery highlight many important ethical concepts (see [Supplementary Appendix](#) Tables S1 and S2).<sup>2-4,11</sup> However, neither body gives a comprehensive list of objectives that reflect the ethical complexity of problems trainees face in practice. For example, important constructs such as surrogate decision making and [withholding or withdrawing life-sustaining therapies](#) tend not to be addressed at all. Training programs are left to consider, with little guidance, how medical ethics should be integrated into their curriculum, which principles to teach, and who will do the teaching.

*Ethics content.* We propose that, before they practice independently, all trainees achieve competency in the following 6 areas: (1) patient best interest, beneficence, and nonmaleficence; (2) respect for autonomy; (3) shared decision making and [informed consent](#); (5) surrogate decision making; and (6) EOL care, including withholding and withdrawing life-sustaining therapy and palliative care. The phrase, *primum non nocere* (“first, do no harm”) is adapted from the Hippocratic Oath and captures the concept of nonmaleficence. Understanding clinical indications for and benefits of MCS must be balanced with anticipated outcomes and careful consideration of QOL to ensure no—or minimal—harm to a patient. Thus, trying to balance nonmaleficence against beneficence (doing good) can help a clinician to determine what is in a patient’s best interest. A physician’s role is to guide patients in shared decision making, which takes into consideration a patient’s values and preferences in addition to evidence-based recommendations and anticipated outcomes. Because MCS requires a procedural intervention, informed consent is also necessary. Informed consent, which has both a legal and an ethical justification, helps ensure that patients have needed information about risks and benefits of a particular treatment or procedure. In many cases, patients are critically ill or incapacitated prior to initiation of MCS, and clinicians must rely on advanced directives or [surrogate decision makers](#) to determine a patient’s values and preferences with a view to predicting how a patient might choose under the current set of circumstances (assuming an advanced directive is not available). Ultimately, MCS should be withheld if its application is not consistent with a patient’s health care goals or if its use is expected to cause more harm than good.

*Ethical dilemmas.* Understanding when it is ethically permissible to withdraw MCS is a complex and nuanced topic that requires consideration of social, psychological, and QOL factors. Even when MCS use is initially consistent with a patient's goals of care, stakeholders should be prepared for these goals to change, and physicians who offer life-sustaining therapies must be prepared to constantly re-evaluate the appropriateness of therapy. And even when patients give informed consent and engage in shared decision making, it is incredibly hard to prepare a patient for complications that can arise with an LVAD.<sup>12</sup> As circumstances change and complications set in, some patients might wish to have the device removed, and physicians must be prepared to manage requests for withdrawal. Likewise, unforeseen complications of ECMO can threaten a patient's transplant candidacy, and, in consequence, physicians can be tasked with difficult discussions about timing of ECMO discontinuation. Withdrawal of MCS devices is often disconcerting to stakeholders, as many patients are conversant and even ambulatory but are nonetheless likely to die within an hour of withdrawal.<sup>13</sup>

In fact, there has been considerable debate over whether removal of MCS devices is ethically permissible at all. Most argue that it is, as it follows the same moral algorithm of withdrawal of other life-sustaining devices (eg, withdrawal of invasive ventilatory support).<sup>14</sup> However, others argue that discontinuation of MCS is permissible only when a patient has another life-limiting illness and that discontinuation of MCS is akin to physician-assisted suicide (PAS).<sup>15</sup> A survey of physicians found that 60% of cardiologists (vs 2% of palliative care physicians) agreed a patient must be immediately dying in order to remove or deactivate an LVAD.<sup>16</sup> Furthermore, in the same study, 13% of cardiologists considered doing so to be a form of PAS or euthanasia.<sup>16</sup> The discrepancy between cardiologists' and palliative care physicians' perceptions might reflect differences in comfort with and training in EOL care.

Many clinicians are uncomfortable with EOL discussions.<sup>17</sup> Although the American Heart Association recommends that patients with HF have their values, goals, and preferences re-evaluated yearly,<sup>18</sup> physicians often fail to include discussion about advanced HF therapies like MCS in their EOL conversations with HF patients.<sup>17</sup> Furthermore, care of dying patients continues to be misaligned with their stated wishes,<sup>19</sup> suggesting that current practices are probably not adequate. Most clinicians are eager to acquire more skill in managing these conversations,<sup>17</sup> and we believe this need could be addressed with further graduate medical education. The goal of integrating ethics education into cardiology and cardiothoracic training programs is to prepare physicians to navigate ethical dilemmas specific to initiating, continuing, withholding, or withdrawing MCS.

*Skills for managing ethical dilemmas.* Trainees should be taught how to balance benefits and harms in ways that integrate patients' preferences and values with clinical judgment. They should be trained to recognize that each individual patient has his or her own set of motivating factors when it comes to making decisions about health care. For example,

given the high stakes of HF treatment, patients tend to err on the side of choosing life-prolonging therapy without fully understanding complication rates and potential impact on QOL.<sup>20</sup> Therefore, trainees should be prepared to address how fear and emotion affect patient decision making.<sup>20</sup> In addition, trainees should be aware of the emotional toll of having a loved one who is ill and, when working with surrogate decision makers, encourage them to use substituted judgment rather than making decisions based on fear, stress, or their own personal values.

They should also practice conducting conversations about initiation of MCS devices and adapting them to different clinical scenarios. For example, in discussions with patients or surrogates, physicians should be transparent about the fact that clinical outcomes for ECMO are still being evaluated and that consequences of its broader application, such as during standard CPR, remain unclear.<sup>10</sup> In order to care for patients undergoing treatment with MCS, trainees should be educated about the importance of regularly re-examining the appropriateness of therapy and goals of care. Throughout the care of patients with HF—and when considering withdrawal of MCS—expressing respect for patient autonomy should be a guiding principle. Further training in ethics and decision making at the end of life could help motivate ethically appropriate decision making about MCS<sup>21</sup> and help clinicians determine under which circumstances withdrawal of MCS devices is ethically permissible. Finally, steps should be taken to mitigate burnout and ensure trainees' well-being as they learn to navigate clinical and ethical complexities of caring for patients with HF at the end of life.

There are a number of ways ethics can be integrated into graduate medical education training. For example, ethics curricula for trainees in cardiology, HF, and cardiothoracic surgery could be didactic, case based, or bedside based. Whenever possible, ethics curricula should be taught by a physician with special training in ethics.<sup>4</sup> If needed, faculty development programs should be established within the specialty so attending physicians can become adept teachers.<sup>21</sup> Ethically challenging cases should be reviewed in the form of case conferences or morbidity and mortality meetings so that a large group of physicians can learn from a single case. Bedside application of clinical ethics could take many forms, including modeling of how to express respect for a patient's autonomy and how to facilitate informed consent and shared decision making in day-to-day encounters (see Table). Trainees should also be actively involved in selection meetings, decisions about specific patients' MCS candidacy, and advanced care planning with patients and their loved ones.

**Table.** Application of Ethical Constructs in Bedside Learning

Ethical Construct	Application
Best interest	<ul style="list-style-type: none"><li>• Understand medical indications for procedures, medications, and other treatments.</li><li>• Include quality of life considerations in your evaluation of what is best for the patient.</li><li>• Attend and be actively involved in selection meetings surrounding LVAD, ECMO, TAH and transplant candidacy.</li></ul>
Respect for autonomy	<ul style="list-style-type: none"><li>• Elicit patients' values through advanced care planning on a regular basis.</li><li>• Respect patients' choices as they pertain to their care plan.</li><li>• Avoid conflicts of interest.</li></ul>
Informed consent	<ul style="list-style-type: none"><li>• Obtain informed consent for all procedures.</li></ul>
Shared decision making	<ul style="list-style-type: none"><li>• Thoughtfully discuss indications, risks, benefits, and possible outcomes when making decisions about care.</li><li>• Elicit patient values in relation to treatment plan.</li></ul>
Surrogate decision making	<ul style="list-style-type: none"><li>• Counsel surrogate decision makers on the meaning and use of substituted judgment when making decisions for loved ones.</li><li>• Develop a physician-surrogate relationship similar to the patient-physician relationship.</li></ul>
End-of-life ethics	<ul style="list-style-type: none"><li>• Counsel patients on end-of-life issues, including withholding or withdrawing life-sustaining treatment and palliative care.</li><li>• Interact with palliative care consultation service and ethics consultation service regularly.</li></ul>
Abbreviations: ECMO, extracorporeal membrane oxygenation; LVAD, left ventricular assist device; TAH, total artificial heart.	

## Conclusion

As technology advances, applying ethics constructs to patient care seems to be increasingly complicated. More formalized curricula in ethics are needed to help physicians recognize and manage ethically challenging aspects of patient care.<sup>22</sup> It is important for this training to be woven into graduate medical education so that the concepts taught are specific and applicable to the trainees' future day-to-day practices. Curricula should aim to help physicians navigate most of the ethical issues they will confront in practice.<sup>23</sup>



## References

1. Siegler M. Training doctors for professionalism: some lessons from teaching clinical medical ethics. *Mt Sinai J Med*. 2002;69(6):404-409.
2. Accreditation Council for Graduate Medical Education. ACGME program requirements for graduate medical education in cardiovascular disease (internal medicine). [https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/141\\_cardiovascular\\_disease\\_2017-07-01.pdf](https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/141_cardiovascular_disease_2017-07-01.pdf). Published 2011. Accessed October 27, 2018.
3. Accreditation Council for Graduate Medical Education. ACGME program requirements for graduate medical education in advanced heart failure and transplant cardiology (internal medicine). [https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/159\\_advanced\\_heart\\_failure\\_transplant\\_cardiology\\_2017-07-01.pdf](https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/159_advanced_heart_failure_transplant_cardiology_2017-07-01.pdf). Published 2012. Accessed October 27, 2018.
4. Accreditation Council for Graduate Medical Education. ACGME program requirements for graduate medical education in thoracic surgery. <https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/460ThoracicSurgeryCore2018.pdf?ver=2018-06-18-083752-470>. Published 2018. Accessed October 27, 2018.
5. Goodlin SJ. Palliative care in congestive heart failure. *J Am Coll Cardiol*. 2009;54(5):386-396.
6. Torres MF, Perez-Villa F. Heart transplantation in patients with hypertrophic cardiomyopathy. *Glob Cardiol Sci Pract*. 2018;2018(3):32.
7. Rose EA, Gelijns AC, Moskowitz AJ, et al; Randomized Evaluation of Mechanical Assistance for the Treatment of Congestive Heart Failure (REMATCH) Study Group. Long-term mechanical left ventricular assistance for end-stage heart failure. *N Engl J Med*. 2001;345(20):1435-1443.
8. Mehta H, Eisen HJ, Cleveland JC Jr. Indications and complications for VA-ECMO for cardiac failure. *American College of Cardiology Perspectives and Analysis*. July 14, 2018. <https://www.acc.org/latest-in-cardiology/articles/2015/07/14/09/27/indications-and-complications-for-va-ecmo-for-cardiac-failure>. Accessed October 27, 2018.
9. Kirklin JK, Pagani FD, Kormos RL, et al. Eighth annual INTERMACS report: special focus on framing the impact of adverse events. *J Heart Lung Transplant*. 2017;36(10):1080-1086.
10. Makdisi G, Wang IW. Extra corporeal membrane oxygenation (ECMO): review of a lifesaving technology. *J Thorac Dis*. 2015;7(7):E166-E176.
11. Halperin JL, Williams ES, Fuster V, et al; ACC Competency Management Committee. ACC 2015 core cardiovascular training statement (COCATS 4) (Revision of COCATS 3). *J Am Coll Cardiol*. 2015;65(17):1721-1906.

12. McIlvennan C, Thompson J, Matlock D, et al. A multicenter trial of a shared decision support intervention for patients and their caregivers offered destination therapy for advanced heart failure: DECIDE-LVAD: rationale, design, and pilot data. *J Cardiovasc Nurs*. 2016;31(6):E8-E20.
13. Dunlay SM, Strand JJ, Wordingham SE, Stulak JM, Luckhardt AJ, Swetz KM. Dying with a left ventricular assist device as destination therapy. *Circ Heart Fail*. 2016;9(10):e003096.
14. Mueller PS, Swetz KM, Freeman MR, et al. Ethical analysis of withdrawing ventricular assist device support. *Mayo Clin Proc*. 2010;85(9):791-797.
15. Rady MY, Verheijde JL. Ethical challenges with deactivation of durable mechanical circulatory support at the end of life: left ventricular assist devices and total artificial hearts. *J Intensive Care Med*. 2014;29(1):3-12.
16. McIlvennan CK, Wordingham SE, Allen LA, et al. Deactivation of left ventricular assist devices: differing perspectives of cardiology and hospice/palliative medicine clinicians. *J Card Fail*. 2017;23(9):708-712.
17. Dunlay SM, Foxen JL, Cole T, et al. A survey of clinician attitudes and self-reported practices regarding end-of-life care in heart failure. *Palliat Med*. 2015;29(3):260-267.
18. Allen LA, Stevenson LW, Grady K, et al; American Heart Association; Council on Quality of Care and Outcomes Research; Council on Cardiovascular Nursing; Council on Clinical Cardiology; Council on Cardiovascular Radiology and Intervention; Council on Cardiovascular Surgery and Anesthesia. Decision making in advanced heart failure: a scientific statement from the American Heart Association. *Circulation*. 2012;125(15):1928-1952.
19. The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT) [published correction appears in *JAMA*. 1996;275(16):1232]. *JAMA*. 1995;274(20):1591-1598.
20. McIlvennan CK, Allen LA, Nowels C, Brieke A, Cleveland JC, Matlock DD. Decision making for destination therapy left ventricular assist devices: "there was no choice" versus "I thought about it an awful lot." *Circ Cardiovasc Qual Outcomes*. 2014;7(3):374-380.
21. Curtis JR, Vincent JL. Ethics and end-of-life care for adults in the intensive care unit. *Lancet*. 2010;376(9749):1347-1353.
22. Eckles RE, Meslin EM, Gaffney M, Helft PR. Medical ethics education: where are we? Where should we be going? A review. *Acad Med*. 2005;80(12):1143-1152.
23. Culver CM, Clouser KD, Gert B, et al. Basic curricular goals in medical ethics. *N Engl J Med*. 1985;312(4):253-256.

**Elizabeth A. Sonntag, MD** is a pulmonary and critical care fellow at the University of North Carolina (UNC) at Chapel Hill and an alumna of the MacLean Center for Clinical Medical Ethics at the University of Chicago. She serves on the UNC Hospitals Ethics Committee and teaches an elective in medical ethics at the UNC School of Medicine. Her clinical interests include pulmonary hypertension and critical care, and her research interests include end-of-life decisions, advanced life-sustaining therapies, clinician burnout, and development of medical ethics curricula.

**Keyur B. Shah, MD** is chief of the Section of Heart Failure and the medical director of the Mechanical Circulatory Support Program at the Virginia Commonwealth University Health Pauley Heart Center in Richmond, Virginia. His clinical and research foci include heart transplantation, amyloid cardiomyopathy, and mechanical circulatory support.

**Jason N. Katz, MD** is an associate professor of medicine and surgery as well as the director of the Cardiovascular Critical Care, Mechanical Circulatory Support, and Cardiogenic Shock Program at the University of North Carolina at Chapel Hill. His research interests include optimal models of care delivery for patients with cardiovascular critical illness and for those with end-stage heart disease.

#### **Citation**

*AMA J Ethics.* 2019;21(5):E407-415.

#### **DOI**

10.1001/amajethics.2019.407.

#### **Conflict of Interest Disclosure**

Dr Shah is a consultant for Medtronic and Syncardia. Drs Sonntag and Katz had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

## AMA CODE SAYS

### AMA Code of Medical Ethics' Opinions Related to Ethics of Life-Sustaining Technologies

Rachel F. Harbut

#### Abstract

Advances in science and technology have far-reaching potential for implementation in health care and must be considered from an ethics perspective. Physicians conducting research on such technologies must consider their duties to subjects and patients. The AMA *Code of Medical Ethics* offers guidance on research conduct and best practices for using innovation patents.

#### Life-Sustaining Technologies

As technological advances are made, the implications of their implementation in health care become increasingly complex, raising new ethical<sup>1</sup> and regulatory<sup>2</sup> concerns while complicating old issues, such as risk of confidentiality breaches.<sup>3</sup> While conversations about these topics tend to revolve around patient care,<sup>4</sup> advanced medical devices,<sup>5</sup> and genetic engineering,<sup>6</sup> some have questioned the ethical implications of novel technologies, such as genetic engineering techniques, designed to significantly prolong life<sup>7</sup> or to extend it indefinitely.<sup>8</sup> The American Medical Association (AMA) *Code of Medical Ethics* sets forth basic guidelines for how physicians can best conduct research on life-sustaining technologies to promote the advancement of medicine while protecting patient-physician relationships and improving outcomes.

#### Innovation and Research

The emergence of new technologies suggests the importance of clear guidelines and policies for researching, selling, and using such technologies.<sup>9</sup> The AMA *Code of Medical Ethics* offers guidance on how physician researchers can conduct ethical clinical research with the goal of advancing medical knowledge and expanding treatment options. Opinion 1.2.11, "Ethically Sound Innovation in Medical Practice,"<sup>10</sup> discusses how physician-researchers can assist in furthering innovation as individuals within a larger context. This opinion calls upon physician researchers to be aware of the costs, risks, and driving factors associated with the development of new technologies. Opinion 7.1.1, "Physician Involvement in Research,"<sup>11</sup> expands on this guidance, specifically outlining duties of physicians related to expertise, patient safety and well-being, research protocol, and quality standards when participating in research. Specifically, physicians should (a) restrict themselves to conducting research in their area of expertise, (b) ensure that proper [informed consent](#) has been obtained and that research protocols are scientifically

and ethically sound, (c) treat research subjects with the same respect as their patients (d), and (e) adhere to both scientific and ethical standards in research, including monitoring and [minimizing conflicts of interest](#).

Physicians' responsibilities in sharing the results of studies with the community are further explored in Opinion 7.2.1, "Principles for Disseminating Research Results."<sup>12</sup> This guidance focuses on best practices for public disclosure of research findings, advocating for the timely, transparent release of well-designed and peer-reviewed study results. Opinion 7.2.3, "Patents and Dissemination of Research Products,"<sup>13</sup> discusses a similar topic, examining more closely best practices for using [innovation patents](#) to protect the health and well-being of patients. Specifically, Opinion 7.2.3 calls for physicians not to use patents "to limit the availability of medical innovations" and, furthermore, to use such patents to "encourage the development of better medical technology." Finally, Opinion 7.3.9, "Commercial Use of Human Biological Materials,"<sup>14</sup> offers guidance to physicians whose research on new technologies and treatments<sup>15</sup> involves human biological materials<sup>16</sup> insofar as it addresses issues relating to protection of tissue donors. This opinion can be helpful in discussions of emerging technologies that promise to transform organ transplantation medicine,<sup>17</sup> among other life-prolonging treatments.

### **Health Care and Patient-Physician Relationships**

Health care professionals must consider how emerging and existing life-extending technologies might be integrated into patient care in such a way that their use does not negatively influence patient-physician relationships. The AMA *Code of Medical Ethics* Opinion 1.1.1, "Patient-Physician Relationships,"<sup>18</sup> describes the ethical responsibility of a physician to "use sound medical judgment on patients' behalf, and to advocate for their patients' welfare." Furthermore, Opinion 1.1.3, "Patient Rights,"<sup>19</sup> discusses the "mutually respectful alliance" between patients and physicians and emphasizes patients' fundamental right to collaborative, informed decision-making, laid out in Opinion 2.1.1, "Informed Consent."<sup>20</sup> These opinions call on physicians to share all treatment options with patients and, if patients wish, to discuss these options with them.

Physicians recruiting subjects for a clinical trial or helping a patient decide whether to pursue enrollment in a clinical trial should be guided by these opinions and Opinion 5.5, "Medically Ineffective Interventions."<sup>21</sup> Opinion 5.5 elaborates on the duty of physicians to support patients' informed decisions when appropriate, stating that they should:

only recommend and provide interventions that are medically appropriate—i.e., scientifically grounded—and that reflect the physician's considered medical judgment about the risks and likely benefits of available options in light of the patient's goals for care. Physicians are not required to offer or to provide interventions that, in their best medical judgment, cannot reasonably be expected to yield the intended clinical benefit or achieve agreed-on goals for care. Respecting patient autonomy does not mean that patients should receive specific interventions simply because they (or their surrogates) request them.<sup>21</sup>

Furthermore, Opinion 5.5 discusses policies on futile care, reminding physicians that “the meaning of the term ‘futile’ depends on the values and goals of a particular patient in specific clinical circumstances.”<sup>21</sup>

### **AMA Code Guidance in Context**

Ethical analyses often lag behind technological development. The medical use of some developing technologies, while scientifically feasible, has ethical implications that might not be immediately apparent.<sup>22</sup> Increasingly, as technology promises to lengthen patients’ lives, questions arise about the ethical line between extending life and prolonging death.<sup>23-26</sup> New and expanded treatment options could further blur this line and, as Haider Warraich notes,<sup>27</sup> amplify the need for advance directives (see Opinion 5.2, “Advance Directives”<sup>28</sup>) to help support patient autonomy. Opinion 11.1.2, “Physician Stewardship of Health Care Resources,”<sup>29</sup> examines how the use of novel, expensive treatments in achieving certain outcomes for individual patients might best be balanced against the obligation to promote public health and access to care.

### **References**

1. Al-Rodhan N. The many ethical implications of emerging technologies. *Scientific American*. March 13, 2015. <https://www.scientificamerican.com/article/the-many-ethical-implications-of-emerging-technologies/>. Accessed July 14, 2018.
2. Wadhwa V. Laws and ethics can’t keep pace with technology. *MIT Technology Review*. April 15, 2014. <https://www.technologyreview.com/s/526401/laws-and-ethics-cant-keep-pace-with-technology/>. Accessed October 26, 2018.
3. Banova B. The impact of technology on health care. *American Institute of Medical Sciences and Education Blog*. April 24, 2018. <https://www.aimseducation.edu/blog/the-impact-of-technology-on-healthcare/>. Accessed February 21, 2019.
4. Silverman E. The 5 most pressing ethical issues in biotech medicine. *Biotechnol Healthc*. 2004;1(6):41-46.
5. Walker MJ. Ethics and advanced medical devices: do we need a new approach? *Health Voices*. 2017;(21). <http://healthvoices.org.au/issues/november-2017/ethics-advanced-medical-devices-need-new-approach/>. Accessed October 26, 2018.
6. MacDonald GL. Ethical issues in genetic engineering and transgenics. *Actionbioscience*. June 2004. <http://www.actionbioscience.org/biotechnology/glenn.html>. Updated November 2013. Accessed October 26, 2018.
7. Partridge B, Underwood M, Lucke J, Bartlett H, Hall W. Ethical concerns in the community about technologies to extend human life span. *Am J Bioeth*. 2009;9(12):68-76.
8. Harris J; International Longevity Center-USA. Intimations of immortality: the ethics and justice of life-extending therapies. <http://www.ilc-alliance.org/images/uploads/publication-pdfs/IntimationsImmortality.pdf>. Published September 24, 2002. Accessed November 5, 2018.

9. Mytton OT, Velazquez A, Banken R, et al. Introducing new technology safely. *Qual Saf Health Care*. 2010;19(suppl 2):i9-i14.
10. American Medical Association. Opinion 1.2.11 Ethically sound innovation in medical practice. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/ethically-sound-innovation-medical-practice>. Published 2017. Accessed October 26, 2018.
11. American Medical Association. Opinion 7.1.1 Physician involvement in research. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/physician-involvement-research>. Published 2017. Accessed October 26, 2018.
12. American Medical Association. Opinion 7.2.1 Principles for disseminating research results. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/principles-disseminating-research-results>. Published 2017. Accessed October 26, 2018.
13. American Medical Association. Opinion 7.2.3 Patents and dissemination of research products. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/patents-dissemination-research-products>. Published 2017. Accessed October 26, 2018.
14. American Medical Association. Opinion 7.3.9 Commercial use of human biological materials. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/commercial-use-human-biological-materials>. Published 2017. Accessed October 26, 2018.
15. Franklin B. Top new medical technologies of 2014-2015. Medical Technology Schools. <https://www.medicaltechnologyschools.com/medical-lab-technician/top-new-health-technologies>. Accessed October 27, 2018.
16. Bledsoe MJ, Grizzle WE. Use of human specimens in research: the evolving United States regulatory, policy, and scientific landscape. *Diagn Histopathol (Oxf)*. 2013;19(9):322-330.
17. Giwa S, Lewis JK, Alvarez L, et al. The promise of organ and tissue preservation to transform medicine. *Nat Biotechnol*. 2017;35(6):530-542.
18. American Medical Association. Opinion 1.1.1 Patient-physician relationships. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/patient-physician-relationships>. Accessed October 26, 2018.
19. American Medical Association. Opinion 1.1.3 Patient rights. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/patient-rights>. Accessed October 26, 2018.
20. American Medical Association. Opinion 2.1.1 Informed consent. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/informed-consent>. Accessed October 26, 2018.
21. American Medical Association. Opinion 5.5 Medically ineffective interventions. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/medically-ineffective-interventions>. Accessed October 26, 2018.
22. Thimbleby H. Technology and the future of healthcare. *J Public Health Res*. 2013;2(3):e28.

23. McDermid RC, Bagshaw SM. Prolonging life and delaying death: the role of physicians in the context of limited intensive care resources. *Philos Ethics Humanit Med*. 2009;4:3.
24. Jones JW, McCullough LB. Extending life or prolonging death: when is enough actually too much? *J Vasc Surg*. 2014;60(2):521-522.
25. Malcolm AH. Extending life or prolonging death? *New York Times*. March 23, 1986. <https://www.nytimes.com/1986/03/23/weekinreview/extending-life-or-prolonging-death.html>. Accessed October 27, 2018.
26. Lee T. Medical technology prolongs lives. But is that a good thing? *MedCity News*. June 29, 2010. <https://medcitynews.com/2010/06/medical-technology-prolongs-lives-but-is-that-a-good-thing/>. Accessed October 27, 2018.
27. Doctor considers the pitfalls of extending life and prolonging death [transcript]. *Fresh Air*. National Public Radio. January 30, 2017. <https://www.npr.org/sections/health-shots/2017/01/30/512426568/doctor-considers-the-pitfalls-of-extending-life-and-prolonging-death>. Accessed October 27, 2018.
28. American Medical Association. Opinion 5.2 Advance directives. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/ethics/advance-directives>. Published 2017. Accessed October 26, 2018.
29. American Medical Association. Opinion 11.1.2 Physician stewardship of health care resources. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/physician-stewardship-health-care-resources>. Accessed October 26, 2018.

**Rachel F. Harbut** is a fourth-year undergraduate at Loyola University of Chicago in Chicago, Illinois, where she studies molecular and cellular neuroscience and philosophy with a concentration in bioethics. During the summer and fall of 2018, she was an intern for the American Medical Association's Ethics Group.

#### Citation

*AMA J Ethics*. 2019;21(5):E416-420.

#### DOI

10.1001/amajethics.2019.416.

#### Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



## POLICY FORUM

### What Should We Learn From Early Hemodialysis Allocation About How We Should Be Using ECMO?

Daniel Gutteridge, MD and Gabriel T. Bosslet, MD, MA

#### Abstract

Early hemodialysis allocation deliberations should inform our current considerations of what constitutes reasonable uses of extracorporeal membrane oxygenation. Deliberative democracy can be used as a strategy to gather a plurality of views, consider criteria, and guide policy making.

#### Introduction

Decision making about how to use new life-saving technologies, especially in life-or-death situations, is often fraught. Debate has long persisted about the appropriateness of hemodialysis (HD) for patients who are elderly and frail.<sup>1</sup> Decisions about use of extracorporeal membrane oxygenation (ECMO)—a machine-facilitated process that oxygenates and circulates blood for patients with impaired heart or lung function—are similarly clinically and ethically complex. In this article, we first examine the growth of ECMO and consider cautionary lessons of early HD allocation deliberations for current decision making about ECMO use. We then highlight a recent multisociety statement that calls for stakeholder input in defining the [boundaries of ECMO use](#) at the end of life. Finally, we suggest that a deliberative democratic process can provide a better way forward in decision making about deployment of new technologies in a health care environment in which costs continue to escalate.

#### ECMO in Its Adolescence

ECMO has been in clinical use for more than 40 years. In 1944, blood was first oxygenated while passing through cellophane artificial kidney membranes, and the idea of ECMO was born.<sup>2</sup> In 1972, ECMO was first successfully used to treat an adult with posttraumatic respiratory failure.<sup>3</sup> In its first decade of use, however, patients' survival rate was around 10%.<sup>3</sup> The next 40 years were a slow period of growth in use of ECMO.<sup>4</sup> Complications from bleeding, clotting, infections, and resource limitations impaired its regular use in adults until the mid-2000s.<sup>5</sup> Between 2002 and 2006, for example, fewer than 1000 adults annually received ECMO therapy.<sup>6</sup> Since 2009, there has been a considerable increase in adult ECMO use, with 18 684 patients receiving ECMO therapy between 2008 and 2014.<sup>7</sup>

Currently, ECMO is used as a bridge to surgical intervention (a temporary modality) or as a bridge to recovery from respiratory and cardiac conditions (even if that time is measured in years<sup>8</sup>) when traditional modalities have failed. Already in development is a small implantable ECMO for bridge to recovery or destination therapy,<sup>9</sup> so one can easily envision a time in the coming decades in which ECMO will be used increasingly as destination therapy.

### **Ethical Foundations of Clinical Criteria Used in HD Decision Making**

Growth in ECMO use was similar to that of HD between 1940 and 1960. Originally envisioned as a short-term organ support device that would bridge a patient to receiving an organ, HD is now commonly used to manage patients' care for years. In the 1930s and 1940s, HD for acute renal failure was to be complimented with dietary treatment.<sup>10</sup> It is unlikely that early "protonephrologists" envisioned treating end-stage renal disease (ESRD) with HD, as is currently done, but once repeated vascular access was developed in 1960,<sup>11</sup> HD became a feasible maintenance therapy. This breakthrough led to the establishment of the first outpatient dialysis center, the [Seattle Artificial Kidney Center](#) (now the Northwest Kidney Centers), in 1962.<sup>12</sup> HD use in treating chronic disease ballooned when Medicare funding for dialysis began in 1972.<sup>11</sup> As of 2015, 468 000 patients were maintained on chronic HD.<sup>13</sup>

At the Seattle Artificial Kidney Center, ethics committees helped determine how to allocate limited HD resources. First, a team of physicians (the Medical Advisory Committee) created screening criteria for assessing patients' eligibility for HD in terms of their comorbid conditions and risk factors. Patients who passed this phase of evaluation according to clinical criteria were then evaluated by the Admissions and Policy Committee (a group of Seattle area citizens comprising a lawyer, a clergyman, a housewife, a banker, a state official, and a surgeon), which sought to allocate HD access in terms of patients' *social worth*. This controversial second phase of decision making was one of the first times an organization formally drew upon community input to allocate a scarce resource.<sup>14</sup>

An article in *Life* magazine about this decision-making process sparked national debate about whether and how one's social worth should be used to allocate access to medical technologies.<sup>15</sup> At the time of this debate, the clinical criteria were generally seen as necessary and relatively uncontroversial. Since then, however, even the presumed objectivity of clinical criteria has been questioned. For example, challenges to neurological criteria for death have been raised.<sup>16</sup> In this context, deciding the medical appropriateness of treatment outside of true medical futility can be very controversial.

In 2015, the second author (GTB) collaborated on a multiple critical care societies statement to address "potentially inappropriate treatment" in intensive care units.<sup>17</sup> This document considered how clinicians and institutions should respond to patient or

surrogate requests for treatments that clinicians regard as medically inappropriate, an issue that has been a persistent source of clinical ethical complexity. In the 1960s, using HD to treat ESRD in patients with other life-limiting diseases would have been considered a potentially inappropriate treatment. Even today, there is support for the view that dialysis for certain populations is inappropriate.<sup>18</sup> Given the controversy around defining and responding to requests for inappropriate treatment, how should indications for ECMO be assessed and how should ECMO be used?

### **Democratic Deliberation About Health Technology Uses**

The 2015 multisociety statement called for the medical profession to “engage in efforts to influence opinion and develop policies and legislation about when life-prolonging technologies should not be used.”<sup>17</sup> This document further specified that such engagement requires diverse stakeholder input in order to be ethically acceptable in a pluralistic society. What would it look like to gather pluralistic stakeholder input about ECMO use?

Deliberative democracy (DD) is one model for gathering [stakeholder input](#) about value-laden and often controversial topics. Amy Gutmann and Dennis Thompson have defined DD as “a form of government in which free and equal citizens (and their representatives) ... justify decisions in a process in which they give one another reasons that are mutually acceptable and generally accessible, with the aim of reaching conclusions that are binding in the present on all citizens but open to challenge in the future.”<sup>19</sup> DD involves asking a small representative sample of stakeholders (selected by an organizing body for a given value-laden topic and a DD facilitator) to come together to agree upon a response to a controversial question or policy. DD requires a structured process that allows for open information sharing among all parties and requires a skilled facilitator in the DD process.<sup>19</sup>

Governments and large institutions have used DD to inform health policy. In Great Britain, the National Institute for Health and Care Excellence (NICE) has employed a Citizens Council.<sup>20</sup> This body of 30 members of the public represents the demographic makeup of Great Britain and is assembled to give input on topics that NICE has chosen.<sup>21</sup> (See Table for topics recently deliberated upon by the NICE Citizens Council.)

**Table.** Sampling of Topics Deliberated Upon by the National Institute for Health and Care Excellence Citizen Council

How should NICE assess future costs and health benefits? <sup>a</sup>
In what circumstances should NICE recommend interventions where the cost per QALY is above the threshold range of £20 000 to £30 000? <sup>b</sup>
Is there a preference to save the life of people in imminent danger of dying? <sup>c</sup>
Are there circumstances in which the age of a person should be taken into account when NICE is making a decision about how treatments should be used in the National Health Service? <sup>d</sup>
<p>Abbreviations: NICE, National Institute for Health and Care Excellence; QALY, quality-adjusted life year.</p> <p><sup>a</sup> From National Institute for Health and Care Excellence Citizens Council.<sup>22</sup></p> <p><sup>b</sup> From National Institute for Health and Care Excellence Citizens Council.<sup>23</sup></p> <p><sup>c</sup> From National Institute for Health and Care Excellence Citizens Council.<sup>24</sup></p> <p><sup>d</sup> From National Institute for Health and Care Excellence Citizens Council.<sup>25</sup></p>

In the early 2000s, the Romanow Commission on the Future of Health Care in Canada also convened a series of DD-based conversations with almost 500 representative Canadian citizens on health reform in Canada.<sup>26</sup> These sessions helped inform a final government report that recommended sweeping changes to encourage the sustainability of Canada's health care system.<sup>27</sup>

Although the strong centrally managed health care systems of Canada and Great Britain differ in important ways from the individualistic and decentralized health structures in the United States, these 2 examples of DD informing health policy align with the multisociety statement goal of "engag[ing] in efforts to influence opinion and develop policies and legislation about when life-prolonging technologies should not be used."<sup>17</sup> So how could a DD-based approach to ECMO use proceed in the United States?

### Operationalizing DD for ECMO

There is precedent in the United States for policy making concerning difficult value-laden health care decisions. The Organ Procurement and Transplantation Network (OPTN) coordinates organ allocation through the United Network for Organ Sharing (UNOS). OPTN allows public comment on proposed policy changes but does not use a true DD process in discussions regarding policy changes. Allocation of transplant organs is analogous to deployment of scarce technological resources like ECMO—both involve highly value-laden decisions with many stakeholders and life-or-death consequences.

The Extracorporeal Life Support Organization (ELSO) is "an international non-profit consortium of health care institutions who are dedicated to the development and evaluation of novel therapies for support of failing organ systems."<sup>28</sup> Its origins parallel

the early development of UNOS in that it consists of a registry “to support clinical research, support regulatory agencies, and support individual ELSO centers.”<sup>28</sup> ELSO could coordinate DD processes to inform policies regarding ECMO deployment by convening stakeholder participants (likely to include citizens, physicians, and payers) and a DD facilitator. Potential questions for DD facilitators to ask participants in a DD process could include the following:

1. Which, if any, comorbid conditions are absolute contraindications to ECMO use?
2. Should a quality-adjusted life year (QALY) analysis inform ECMO use?
3. Should ECMO use be limited to regional ECMO centers?

Establishing prospective criteria based on responses to these questions by participants in a DD process could help generate robust and thoughtful engagement regarding the clinically beneficial limits of ECMO; help avoid current idiosyncratic bedside clinical decision making about when to recommend ECMO; and be used as the basis for refining national professional guidelines for ECMO use. Such a process and the resultant guidelines could also be used to inform broader debates about the social and cultural relevance of technology use at the end of life.

### **ECMO Guidelines**

The rise of ECMO as extracorporeal organ support—with future potential for organ replacement therapy—shares many similarities with the rise of HD. Just as in the early days of HD, criteria for [appropriate use of ECMO](#) remain vague and undefined. Lessons from early decision making about HD use and subsequent shifts in social attitudes about intensive care suggest that set boundaries for new technology use in health care should be prospective and transparent, include multiple stakeholders or their representatives, and be open to challenge and revision as the technology matures and as clinical, social, and cultural norms evolve. As we have suggested here, DD-based approaches to policy making offer one strategy for including stakeholders’ voices in refining guidance for bedside clinicians about how and when to use ECMO. This technology is currently in its adolescence—rapidly growing, developing, and testing the boundaries of its potential—and ECMO policy making should be informed by many and applied broadly to help clinicians help patients.

### **References**

1. Akbar S, Moss AH. The ethics of offering dialysis for AKI to the older patient: time to re-evaluate? *Clin J Am Soc Nephrol*. 2014;9(9):1652-1656.
2. Kolff W, Berk HTJ, Welle NM, van Der Ley AJ, van Dijk EC, van Noordwijk J. The artificial kidney: a dialyser with a great area. *Acta Med Scand*. 1944;117(2):121-134.

3. Hill JD, O'Brien TG, Murray JJ, et al. Prolonged extracorporeal oxygenation for acute post-traumatic respiratory failure (shock-lung syndrome). Use of the Bramson membrane lung. *N Engl J Med*. 1972;286(12):629-634.
4. Extracorporeal Life Support Organization. ECLS registry report. <https://www.else.org/Registry/Statistics.aspx>. Published July 2018. Accessed December 3, 2018.
5. Vuylsteke A, Brodie D, Combes A, Fowles J, Peek G. *ECMO in the Adult Patient*. Cambridge, UK: Cambridge University Press; 2017.
6. McCarthy FH, McDermott KM, Kini V, et al. Trends in US extracorporeal membrane oxygenation use and outcomes: 2002–2012. *Semin Thorac Cardiovasc Surg*. 2015;27(2):81-88.
7. Bailey KL, Downey P, Sanaiha Y, et al. National trends in volume–outcome relationships for extracorporeal membrane oxygenation. *J Surg Res*. 2018;231:421-427.
8. Johns Hopkins Medicine. An ECMO record? <https://www.hopkinsmedicine.org/news/articles/an-ecmo-record>. Published September 7, 2016. Accessed February 13, 2019.
9. Bartlett RH. ECMO: the next ten years. *Egypt J Crit Care Med*. 2016;4(1):7-10.
10. Peitzman SJ. Origins and early reception of clinical dialysis. *Am J Nephrol*. 1997;17(3-4):299-303.
11. Butler CR, Mehrotra R, Tonelli MR, Lam DY. The evolving ethics of dialysis in the United States: a principlist bioethics approach. *Clin J Am Soc Nephrol*. 2016;11(4):704-709.
12. Blagg CR. The early history of dialysis for chronic renal failure in the United States: a view from Seattle. *Am J Kidney Dis*. 2007;49(3):482-496.
13. National Kidney Foundation. End stage renal disease in the United States. <https://www.kidney.org/news/newsroom/factsheets/End-Stage-Renal-Disease-in-the-US>. Updated January 2016. Accessed November 21, 2018.
14. Blagg CR. Development of ethical concepts in dialysis: Seattle in the 1960s. *Nephrology (Carlton)*. 1998;4(4):235-238.
15. Alexander S. They decide who lives, who dies. *Life*. November 9, 1962:102-125.
16. Lewis A, Pope TM. Physician power to declare death by neurologic criteria threatened. *Neurocrit Care*. 2017;26(3):446-449.
17. Bosslet GT, Pope TM, Rubenfeld GD, et al; American Thoracic Society ad hoc Committee on Futile and Potentially Inappropriate Treatment; American Thoracic Society; American Association for Critical Care Nurses; American College of Chest Physicians; European Society for Intensive Care Medicine; Society of Critical Care. 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*. 2015;191(11):1318-1330.

18. Germain MJ, Davison SN, Moss AH. When enough is enough: the nephrologist's responsibility in ordering dialysis treatments. *Am J Kidney Dis*. 2011;58(1):135-143.
19. Gutmann A, Thompson D. *Why Deliberative Democracy?* Princeton, NJ: Princeton University Press; 2004.
20. Rawlins MD, Culyer AJ. National Institute for Clinical Excellence and its value judgments. *BMJ*. 2004;329(7459):224.
21. NICE. (National Institute for Health and Care Excellence). Citizen Council. <https://www.nice.org.uk/get-involved/citizens-council>. Accessed February 22, 2019.
22. National Institute for Health and Care Excellence Citizens Council. How should NICE assess future cost and health benefits? <https://www.ncbi.nlm.nih.gov/books/NBK401699/>. Published November 4, 2011. Accessed January 28, 2019.
23. National Institute for Health and Care Excellence Citizens Council. Departing from the threshold. <https://www.ncbi.nlm.nih.gov/books/NBK401691/>. Published November 29, 2008. Accessed January 28, 2019.
24. National Institute for Health and Care Excellence Citizens Council. Rule of rescue. <https://www.nice.org.uk/Media/Default/Get-involved/Citizens-Council/Reports/CCReport06RuleOfRescue.pdf>. Published January 2006. Accessed February 13, 2019.
25. National Institute for Health and Care Excellence Citizens Council. NICE Citizens Council report on age. <https://www.ncbi.nlm.nih.gov/books/NBK401698/>. Published November 22, 2003. Accessed January 28, 2019.
26. Von Lieres B, Kahane D. Inclusion and representation in democratic deliberation: lessons from Canada's Romanow Commission. In: Cornwall A, Coelho VSP, eds. *Spaces for Change? The Politics of Citizen Participation in New Democratic Arenas*. London, UK: Zed; 2007:131-154. *Claiming Citizenship*; vol 4.
27. Commission on the Future of Health Care in Canada. *Building on Values: The Future of Health Care in Canada*. <http://publications.gc.ca/collections/Collection/CP32-85-2002E.pdf>. Published November 2002. Accessed February 10, 2019.
28. Extracorporeal Life Support Organization. Overview. <https://www.elseo.org/AboutUs/Overview.aspx>. Accessed November 21, 2018.

**Daniel Gutteridge, MD** is an assistant professor of clinical medicine in the Division of Pulmonary, Critical Care, Allergy, and Occupational Medicine at Indiana University School of Medicine in Indianapolis. He is a specialist in thoracic transplantation and has a special interest in extracorporeal membrane oxygenation and quality improvement.

**Gabriel T. Bosslet, MD, MA** is an associate professor of clinical medicine in the Division of Pulmonary, Critical Care, Allergy, and Occupational Medicine at Indiana University School of Medicine in Indianapolis, where he is also the fellowship director for pulmonary and

critical care medicine. In addition, he serves as an assistant dean for faculty affairs and professional development at Indiana University.

**Citation**

*AMA J Ethics.* 2019;21(5):E421-428.

**DOI**

10.1001/amajethics.2019.421.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



**MEDICINE AND SOCIETY**

**How Should Mechanical Circulatory Support Be Deactivated for Patients With Depression at the End of Life?**

Stephan R. Weinland, PhD, MS and James Levenson, MD

**Abstract**

Mechanical circulatory support (MCS) is an increasingly frequent treatment option for managing end-stage heart failure. Devices are implanted either as destination therapy or as bridge to transplant. Patients undergoing this treatment can experience significant symptoms of depression in addition to stresses associated with chronic illness. After implantation, some patients may decide that the burdens of an MCS device outweigh the benefits. Physician asked to assist in deactivating MCS devices in the face of depression must ensure appropriate assessment, informed consent, and multidisciplinary involvement to minimize suffering and maximize patient quality of life.

**Depression and Mechanical Circulatory Support**

With more than 2500 mechanical circulatory support (MCS) devices implanted per year, left ventricular assist devices (LVADs) and associated circulatory support devices are becoming an increasingly frequent method of bridging patients to transplant or prolonging life in the form of destination therapy.<sup>1</sup> When patients in the Interagency Registry for Mechanically Assisted Circulatory Support (INTERMACS) sample were asked about satisfaction with their decision to implant a device, more than 80% reported a favorable impression of their VAD experience during the first 2 years.<sup>1</sup> Quality of life also improved after VAD implantation in a majority of patients in the INTERMACS sample irrespective of preoperative disease severity.<sup>1</sup>

One important factor influencing quality of life in MCS patients is depression. Two studies have highlighted improvement in both depression and anxiety symptoms—largely due to functional improvements in activity level, sleep, and other symptoms—after device implantation.<sup>2,3</sup> Despite improvements in quality of life postimplantation for many patients, symptoms of depression can still be a common experience in patients with heart failure and MCS. Two studies, found that 29% and 43% of LVAD patients reported at least mild depressive symptoms while on the device.<sup>4</sup> Quality of life may decline in some MCS patients, and there is a bidirectional relationship in MCS patients between depression and poorer quality of life<sup>5</sup> (as is common with other chronic diseases<sup>6</sup>). Physical symptoms associated with heart disease can mirror those seen in

patients with depression, and it can be difficult to determine whether some physical symptoms are attributable to heart failure or clinical depression (eg, insomnia, fatigue, anorexia, poor concentration).<sup>2</sup>

Assessment by a psychiatrist or psychologist experienced with MCS patients can help clarify whether a patient has a true depressive disorder or is experiencing a period of depressed mood that can occur as part of a normal reaction or temporary adjustment to the stresses that often accompany advanced disease. Given that depression is prevalent preimplantation and postimplantation,<sup>4</sup> depressive symptoms should be identified as early as possible to enable evaluation and intervention, thereby allowing patients maximum time for stabilization or improvement in mood symptoms prior to implantation. The presence of clinical depression should never absolutely preclude MCS implantation; rather, clinical depression should be treated so as to ensure the highest likelihood of the patient's managing his or her care needs effectively postimplantation. Such an approach ensures that patients are at their most resilient in dealing with the upcoming stresses of a major medical procedure.<sup>7</sup>

Clinicians can thus expect that significant depressive symptoms frequently will be present when a patient expresses a desire to withdraw MCS care. When a patient's request to deactivate MCS appears to be influenced by depression, ethical uncertainty arises related to informed consent and medical [decision-making capacity](#), necessitating a comprehensive health assessment and multidisciplinary involvement to minimize suffering and maximize patient quality of life.

### **Informed Consent for Implantation and Preimplant Discussion**

Given that a medical decision to discontinue MCS can be made by a patient with decision-making capacity who is experiencing depression symptoms, preimplantation evaluation and [informed consent](#) become more critical. Comprehensive multidisciplinary assessment preimplantation can provide information about patients' past history of depression as well as how they have coped with significant prior medical challenges.<sup>8</sup> Routine informed consent includes not only informing patients of device risks and benefits and expectations for daily life with the device, but also discussion of end-of-life issues.<sup>7</sup> Specifically, patients should be informed of their right to disengage from MCS care from the time of initial evaluation and discussion, since patients with decision-making capacity are not required to receive therapy they no longer wish to receive.<sup>9</sup>

Capacitated adults' right to refuse life-sustaining treatment is both legal and ethical.<sup>10</sup> Discontinuation of MCS is considered equivalent to allowing natural death by restoring the patient's original heart failure trajectory.<sup>10</sup> It is ethically permissible if the aim of withdrawal is not to precipitate death.<sup>8</sup> Preimplantation discussion of patients' preferences is therefore highly desirable. The use of advance directives may serve as a starting point for such discussion but cannot substitute for in-depth exploration of how

patients view MCS benefits and burdens.<sup>11</sup> Even with appropriate preimplantation assessment and intervention, patients might choose at a later point to terminate use of their implanted MCS device.

### **Assessing a Request to Discontinue MCS in Light of the Patient's Health**

Clinicians should anticipate situations in which requests for discontinuing MCS are likely to arise.<sup>12</sup> Devices may be withdrawn if they become ineffective or too burdensome or are no longer desired.<sup>13,14</sup> Some patients may consider life with MCS “worse than death” because MCS can prolong the dying process. Clinicians should consider how depression might be affecting patients’ decision-making capacity, and clinicians and patients together should assess whether the device improves quality of life, not just length of life, as an extension of life that is accompanied by suffering may be experienced as an extension of the dying process.<sup>12</sup>

*Mood.* The clinical evaluation of the effect of depression on a patient’s capacity to make medical decisions is difficult for several reasons.<sup>15</sup> Depression may seem a normal response to serious medical illness. It can distort decision making on a spectrum from subtle pessimism to extreme nihilism. Ultimately, a diagnosis of major depression is neither necessary nor sufficient to determine if the patient’s medical decision making is impaired. Put differently, the diagnosis of a psychiatric disorder does not necessarily compromise a patient’s ability to consent to or **refuse treatment**. Even most psychiatric inpatients retain decision-making capacity, and the rate of incapacity for psychiatric patients closely mirrors the rate for medical inpatients.<sup>16</sup> Early identification and treatment of depression may prevent its incursion into later decisions. When it remains uncertain whether depression has undermined decision-making capacity in a patient requesting discontinuation of MCS, consultation with psychiatry and ethics is advisable.

*Coping.* Physical suffering or limitations imposed by devices can affect patients’ ability to think accurately about how they are managing. Assessing patient coping by asking questions such as “If you had less pain would you still want to turn off your device?” or “If you were able to unplug from the wall and be more active with batteries would you still want to proceed with deactivation?” may help clarify patients’ motivation and identify issues that are modifiable with multidisciplinary team and support system involvement.

### **Decision Making Regarding Discontinuation of MCS**

When a patient wants to discontinue therapy but the treatment team determines that the patient does not have the capacity to make that decision, a surrogate would become the decider. Who should serve as the appropriate surrogate decision maker is determined in the United States by state law. If a guardian had been previously court appointed or the patient had previously designated a health care power of attorney (POA), that individual would be the surrogate. In the absence of a guardian or POA, in

most states the closest next-of-kin would serve as the surrogate decision maker. Surrogates are supposed to base their decisions on what is known regarding the patient's values and, if those are unknown, what is in the patient's best interests.<sup>17</sup> In circumstances in which the patient is actively protesting the surrogate's decision, consultation with risk management and hospital legal counsel is advisable to determine if judicial involvement is warranted. In talking with families, it is important to communicate transparently about the prognosis and the patient's wishes regarding treatment. Assessing how well patients and their families understand the benefits and burdens is important in this stage of care as well.<sup>13</sup>

Shah et al advise that the process of deactivation should be coordinated by an interdisciplinary team to maximize patient comfort and family support.<sup>18</sup> Particularly when there is a lack of consensus, consulting a hospital ethics committee may be advisable. Involvement of the palliative care service from preimplantation to deactivation has been shown to reduce overall hospital costs and shorten intensive care unit stays.<sup>18</sup> One study found that in an MCS program that utilized palliative care services, patients were more likely to die in a supportive hospice setting rather than in an intensive care unit.<sup>13</sup>

## Conclusion

Clinicians must plan for situations in which MCS is no longer medically appropriate or desired by patients, who have the right to decline or discontinue treatment if they have decision-making capacity.<sup>9</sup> End-of-life issues, including possible discontinuation of MCS, should be discussed prior to implantation. However, valid informed consent for implantation may be complicated by the presence of depression. Early identification and treatment of depression can enhance patients' capacity to make medical decisions, including future MCS discontinuation. More severe depression can impair patients' capacity to make such decisions but does not necessarily obviate it. When depression appears to impair decision-making capacity, psychiatric consultation should be obtained. Decisions to discontinue MCS should be multidisciplinary and involve patients' families. When there is a lack of consensus, involvement of an ethics committee and palliative care team can be helpful.

## References

1. Kirklin JK, Pagani FD, Kormos RL, et al. Eighth annual INTERMACS report: special focus on framing the impact of adverse events. *J Heart Lung Transplant*. 2017;36(10):1080-1086.
2. Eisele M, Boczor S, Rakebrandt A, et al; RECODE-HF Study Group. General practitioners' awareness of depressive symptomatology is not associated with quality of life in heart failure patients—cross-sectional results of the observational RECODE-HF Study. *BMC Fam Pract*. 2017;18(1):100.

3. Yost G, Bhat G, Mahoney E, Tatrooles A. Reduced anxiety and depression in patients with advanced heart failure after left ventricular assist device implantation. *Psychosomatics*. 2017;58(4):406-414.
4. Reynard AK, Butler RS, McKee MG, Starling RC, Gorodeski EZ. Frequency of depression and anxiety before and after insertion of a continuous flow left ventricular assist device. *Am J Cardiol*. 2014;114(3):433-440.
5. Lundgren S, Lowes BD, Zolty R, et al. Do psychosocial factors have any impact on outcomes after left ventricular assist device implantation? *ASAIO J*. 2018;64(4):e43-e47.
6. Alzoubi A, Abunaser R, Khassawneh A, Alfaqih M, Khasawneh A, Abdo N. The bidirectional relationship between diabetes and depression: a literature review. *Korean J Fam Med*. 2018;39(3):137-146.
7. Caro MA, Rosenthal JL, Kendall K, Pozuelo L, Funk MC. What the psychiatrist needs to know about ventricular assist devices: a comprehensive review. *Psychosomatics*. 2016;57(3):229-237.
8. Rady MY, Verheijde JL. Ethical challenges with deactivation of durable mechanical circulatory support at the end of life: left ventricular assist devices and total artificial hearts. *J Intensive Care Med*. 2014;29(1):3-12.
9. Chamsi-Pasha H, Chamsi-Pasha MA, Albar MA. Ethical challenges of deactivation of cardiac devices in advanced heart failure. *Curr Heart Fail Rep*. 2014;11(2):119-125.
10. Guidry-Grimes L, Sederstrom N. Expectation and suffering with LVAD deactivation. *Am J Bioeth*. 2015;15(7):74-76.
11. Bramstedt KA, Wenger NS. When withdrawal of life-sustaining care does more than allow death to take its course: the dilemma of left ventricular assist devices. *J Heart Lung Transplant*. 2001;20(5):544-548.
12. Wiegand DL, Kalowes PG. Withdrawal of cardiac medications and devices. *AACN Adv Crit Care*. 2007;18(4):415-425.
13. Nakagawa S, Garan AR, Takayama H, et al. End of life with left ventricular assist device in both bridge to transplant and destination therapy. *J Palliat Med*. 2018;21(9):1284-1289.
14. Powell TP, Oz MC. Discontinuing the LVAD: ethical considerations. *Ann Thorac Surg*. 1997;63(5):1223-1224.
15. Sullivan MD, Youngner SJ. Depression, competence, and the right to refuse lifesaving medical treatment. *Am J Psychiatry*. 1994;151(7):971-978.
16. Casida JM, Abshire M, Ghosh B, Yang JJ. The relationship of anxiety, depression, and quality of life in adults with left ventricular assist devices. *ASAIO J*. 2018;64(4):515-520.
17. Torke AM, Alexander GC, Lantos J. Substituted judgment: the limitations of autonomy in surrogate decision making. *J Gen Intern Med*. 2008;23(9):1514-1517.
18. Shah KB, Levenson JL, Mehra MR. Emergent use of mechanical circulatory support devices: ethical dilemmas. *Curr Opin Cardiol*. 2014;29(3):281-284.

**Stephan R. Weinland, PhD, MS** is an associate professor of psychiatry and surgery at VCU Medical Center in Richmond, Virginia. He is a clinical health psychologist who specializes in transplant psychosocial evaluation, and he works extensively with patients receiving mechanical circulatory support devices.

**James Levenson, MD** is a professor of psychiatry, medicine, and surgery at the Virginia Commonwealth University School of Medicine in Richmond, Virginia, where he is also the chair of the Division of Consultation-Liaison Psychiatry and vice chair for clinical affairs in the Department of Psychiatry.

**Citation**

*AMA J Ethics.* 2019;21(5):E429-434.

**DOI**

10.1001/amajethics.2019.429.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

Copyright 2019 American Medical Association. All rights reserved.  
ISSN 2376-6980

**MEDICINE AND SOCIETY**

**Palliative Care for Patients on Mechanical Circulatory Support**

Sara E. Wordingham, MD and Colleen K. McIlvennan, DNP, ANP

**Abstract**

Palliative care (PC) teams are primed to support patients with advanced illness, including patients with mechanical circulatory support (MCS), and are increasingly being called upon to help care for these patients.

Detailed guidelines for PC engagement are lacking despite key stakeholders' endorsements of collaboration. PC needs to encompass the decision-making period, the duration of therapy, and end-of-life care. PC teams can assist with symptom management, advance care planning, and communication across the continuum of MCS care. However, the current state of MCS and PC collaboration is variable and can be hindered by staffing challenges and clinician discomfort. To best care for patients who receive advanced cardiopulmonary life-sustaining therapies, meaningful engagement of PC during all phases of MCS is essential.

**Need for Palliative Care Partnerships**

Mechanical circulatory support (MCS) is increasingly being used to support patients with advanced heart failure.<sup>1</sup> In many tertiary hospitals, once foreign devices are now common, including left ventricular assist devices (LVAD), extracorporeal membrane oxygenation (ECMO), and total artificial hearts.<sup>1</sup> Initially developed and used as a bridge to other treatment options such as transplantation, advanced heart failure therapies now support patients with diverse goals of care and for variable periods of time, ranging from hours to years. For patients who ultimately progress to end of life with their device in situ or suffer from complications, issues concerning quality of life, mortality, psychosocial needs, and advance care planning can be complex. Palliative care (PC) teams are well equipped to support patients, families, and MCS teams throughout the continuum of MCS care.

In recent years, PC teams have been increasingly engaged in the care of patients with MCS. Collaboration between PC and MCS teams is supported by the International Society for Heart and Lung Transplantation guidelines for MCS, which include a class IIa recommendation for PC consultation during the evaluation or preimplantation phase for patients considering a destination therapy LVAD (DT-LVAD).<sup>2</sup> The Centers for Medicare and Medicaid Services and the Joint Commission further require that a PC specialist be a part of the core multidisciplinary MCS team.<sup>3</sup> Nonetheless, detailed guidelines and

guidance for the logistics of engagement are lacking despite these endorsements. The MCS-PC [partnership](#) could be further complicated by staffing challenges, variable PC clinician familiarity with MCS, and patients', clinicians', and hospital systems' misconceptions about the role of PC.

As guidelines and best practices emerge, individual patients and clinicians, MCS and PC teams, and administrators must wade through a complex collaboration. The intricacies and unknowns of this alliance beg the question of how the system as a whole should best support this unique patient population. In a landscape of highly variable health care and multiteam systems, PC teams, which are armed with [advanced skills in communication](#), shared decision making, psychosocial support, and symptom management, can serve as key partners in the care of patients with MCS. Here, we consider ways in which PC teams can meet the needs of MCS patients.

### **Decision-Making Support**

While candidate selection for emergent ECMO might be outside the scope of practice for a PC specialist, how to elicit and align the patient's goals, preferences, and values with treatment options during a prolonged ICU stay certainly is not. Common themes arise in the care of patients and families considering MCS, regardless of the device type or intent. Patients might feel there is not a choice when they consider advanced therapies such as an LVAD. This perception is likely multifactorial, related to clinicians framing discussions as "life or death" as well as patients' strong desire to live.<sup>4</sup> Furthermore, refractory shortness of breath, fatigue, or volume overload might steer patients towards advanced therapy options with any chance of improving their disease state and symptom burden. These factors underscore that patients require time for deliberation as well as solicitation of their values and goals during the decision-making period. Caregivers have expressed feeling tension during this time as well, wanting their loved ones to live but also wanting to respect their loved one's wishes.<sup>5</sup> PC can play a key role in the decision-making process by offering an additional perspective on treatment options and assisting with the documentation of specific treatment preferences, such as in a honed and disease-specific advance directive.<sup>6</sup> Given the Centers for Medicare and Medicaid Services and Joint Commission mandate, many heart failure centers consult PC teams during the candidate selection process, and some programs have PC professionals present at their MCS selection meetings and fully engaged in patients' ongoing care.

Patient and clinician engagement in shared decision making is ideal for preference-sensitive decision making. This process should be iterative throughout the continuum of MCS care and can be supported by any team or team member with expertise in shared decision making. MCS and PC teams should collaborate to ensure concordance of the plan of care with the patient's values and preferences when considering LVAD therapy, during LVAD support, and when approaching end of life or potential withdrawal of LVAD support. To facilitate shared decision making preimplantation, a decision aid has been



developed for patients considering DT-LVAD to assist with solicitation of patient preferences.<sup>7</sup> Use of this decision aid increased patient knowledge and the concordance between patient values and patient-reported treatment choice.<sup>7</sup> In other words, patients' decisions about treatment aligned with their values and goals. Involvement of PC specialists early in consideration of LVAD placement is thus optimal to ensure the promotion of shared decision making.

### **Collaborative Care for the Duration of Treatment**

Studies exploring the role of PC in supporting the MCS patient population are lacking; however, there have been several studies in recent years describing PC involvement with patients with heart failure (HF). One PC-HF pilot study showed meaningful impact of PC on patient care as assessed by both HF and PC clinicians, especially for patients in a liminal state, such as those awaiting transplantation.<sup>8</sup> More recently, a randomized trial of 150 patients with advanced HF showed that a multidisciplinary PC intervention improved HF patients' "quality of life, anxiety, depression, and spiritual well-being" compared to usual care.<sup>9</sup> Additional large-scale trials of the effect of PC interventions on patient and caregiver quality-of-life outcomes are now ongoing, and hopefully higher-powered data to support the PC-HF collaboration will be forthcoming.<sup>10,11</sup>

Patients receiving MCS can experience high symptom burdens and have multifaceted advance care planning needs and complex end-of-life considerations that would benefit from ongoing PC-MCS collaboration. Patients with advanced illness often face a constellation of quality-of-life-limiting symptoms. For patients pursuing MCS, common physical symptoms may include dyspnea or pain. While the primary focus of symptom management should be addressing the underlying issues precipitating the symptoms, patients with advanced or refractory illness may require PC interventions directed at the symptom burden itself, such as weighing the risks and benefits of opioids for refractory pain or dyspnea, to promote quality of life. Furthermore, during MCS treatment, PC teams can add intentionally redundant layers of support to ensure that patients', families', and MCS team members' psychosocial needs are being met. This redundancy can be especially important for patients receiving prolonged MCS support or for patients facing complications from therapy when their needs escalate. PC clinicians are trained to assess psychological and social burdens of care in part by asking open-ended questions and soliciting social and emotional histories. Assessing both the physical and the nonphysical burdens of care takes time and skill, which may not be a part of a typical medical encounter with a subspecialty MCS clinician whose focus is appropriately on the detailed management of the patient's disease or device. PC social workers and chaplains can directly support the MCS team by offering their time and expertise in caring for both patients with advanced illness and their families in medical settings where patients' device, condition, or length of stay might render them outliers or otherwise in need of special consideration. The ideal of true interdisciplinary MCS-PC collaboration would likely include participation in daily inpatient rounds and embedment of PC clinicians

within the ambulatory MCS clinic, but likely remains a significant challenge at many institutions due to [resource limitations and challenges](#) in gaining clinician buy-in.

Despite limited data on the efficacy of PC in patients with MCS, thought leaders in the care of patients with LVADs have developed and put forth important tools that advance our collective understanding and ability to care for these patients. Preparedness planning toolkits, graphic representations of the clinical pathways from implantation to death with an LVAD, and patient and caregiver decision aids serve as critical pieces to the puzzle in orchestrating collaborative, quality-of-life-promoting care for this population across the care continuum.<sup>7,12-14</sup> Honed advance care planning, maximal symptom support, and addressing the psychosocial needs of patients and families are relevant to all patients with MCS, and perhaps PC involvement in these areas can inspire the development of tools that serve related but distinct populations.

### **End-of-Life Care**

PC specialists are frequently involved in the process of deactivation of MCS devices. Despite recommendations for early engagement of PC teams in patient selection and preimplantation decision-making support, device deactivation unfortunately might be the first introduction to PC of some patients and families. End-of-life care is more intricate in patients with MCS due to the nature of the devices themselves (eg, power cords, implanted hardware) and the close relationships between patients, caregivers, and clinical teams.<sup>15</sup> Patients and caregivers have described the device deactivation process as confusing, complex, and multifaceted. While the legal and ethical principles involved are similar in deactivation of MCS devices and withdrawal of other life-sustaining treatments,<sup>16</sup> patients, caregivers, and MCS team members might still consider MCS device deactivation to be an act of euthanasia or assisted suicide.<sup>17</sup>

PC specialists can support end-of-life care in various ways. As experts in communication, they can help allay concerns about end-of-life matters. Additionally, PC teams can assist with the transition to hospice care, if indicated, prior to a planned withdrawal of MCS support or following the withdrawal of MCS support if a patient's goal is to die outside the hospital and resources are in place to assist with this transition. Indeed, some patients may live up to 26 hours following device deactivation.<sup>12</sup> Furthermore, PC teams can assist with comfort-oriented care and symptom management for patients approaching end of life, including during planned MCS deactivation. Ideally, however, integration of PC specialists would happen prior to device implantation—and thus prior to consideration of device deactivation—in order to foster trust and PC teams' relationships with patients and caregivers as well as clinical teams.

### **Integrating PC Specialists Into MCS Teams**

The intricacies of care for patients being considered for, receiving, or approaching end of life with advanced circulatory support are substantial. The time and workforce required

to meet these needs is not insignificant. It is estimated that nearly 150 000 to 250 000 patients annually may be eligible for DT-LVAD.<sup>18</sup> The ability of PC teams to help support quality of life, excellent communication, and shared decision making cannot, however, serve as a justification for other clinicians and teams to shy away from patient-centered care and primary palliative medicine. Care models and triage systems should be in place that distinguish the need for subspecialty PC consultations and primary PC, with medical specialties such as cardiology and cardiothoracic surgery delineating basic skills of PC and opportunities for primary PC to be delivered by their members.<sup>19</sup> The decision is not about the appropriateness of PC; the decision is about which patients require subspecialty PC clinician consultation and when. Allen et al have outlined the critical role of shared decision making in the American Heart Association scientific statement on decision making in advanced HF<sup>20</sup>; however, they also recognize there is uneven access to clinicians with adequate expertise in HF and PC. Furthermore, there will be significant challenges in implementing true shared decision making without fundamental changes to how the health care system currently values and incentivizes such a model.<sup>20</sup> Questions concerning what the ideal HF-PC collaboration should look like and the perceived value of such a collaboration remain as we move forward in our understanding of the care needs of MCS patients.

DT-LVAD might be one of the most aggressive forms of palliation that we have in medicine. Device implantation and management in this setting are undeniably technical and intricate but fundamentally without curative intent. Rather, they are undertaken primarily to address quality-of-life burdens in advanced illness.

## **Conclusions**

To best care for patients who receive advanced cardiopulmonary life-sustaining therapies, we must finally transcend the idea of PC teams as end-of-life teams and genuinely promote them as quality-of-life teams tasked with helping support patients, families, teams, and systems across the continuum of care. Patients receiving MCS face innumerable challenges—both anticipated and unplanned—that range from surgical and device complications to caregiver catastrophes and intricate end-of-life considerations during the course of therapy. Accordingly, patients and clinicians are best served when we can support the entirety of patients' medical care and their personhood. Hospital policies can help support MCS-PC collaboration as partnerships develop or deepen but would be unlikely to encourage meaningful collaboration if, for example, a PC clinician is only vaguely familiar with MCS technology or a cardiothoracic surgeon is reluctant to allow PC engagement. To bolster patient-centered MCS care, subspecialty PC must be promoted at all levels; time and the development of trust will hopefully allow for increasingly meaningful ongoing collaborative engagement.

The current state of MCS-PC collaboration remains highly variable and ranges from the consistent use of embedded, highly specialized PC teams to general consultation driven

by engagement of a PC team member. MCS and PC teams practicing in settings where any type of MCS can be utilized should seek to collaborate for the best interest of the patient, caregiver, and health care system. PC teams should seek to gain detailed understanding of MCS support, outcomes, complications, and device-specific continuums of care. MCS teams should seek to augment primary PC skills, practice shared decision making, and work to address unmet psychosocial needs. Without true engagement and collaboration, each side risks misunderstanding the other and missing opportunities to deliver high-quality, high-value, patient-centered care.

## References

1. Kirklin JK, Pagani FD, Kormos RL, et al. Eighth annual INTERMACS report: special focus on framing the impact of adverse events. *J Heart Lung Transplant*. 2017;36(10):1080-1086.
2. Feldman D, Pamboukian SV, Teuteberg JJ, et al; International Society for Heart and Lung Transplantation. The 2013 International Society for Heart and Lung Transplantation guidelines for mechanical circulatory support: executive summary. *J Heart Lung Transplant*. 2013;32(2):157-187.
3. Centers for Medicare and Medicaid Services. Decision memo for ventricular assist devices for bridge-to-transplant and destination therapy (CAG-00432R). <https://www.cms.gov/medicare-coverage-database/details/nca-decision-memo.aspx?NCAId=268>. Published October 30, 2013. Accessed July 28, 2017.
4. McIlvennan CK, Allen LA, Nowels C, Brieke A, Cleveland JC, Matlock DD. Decision making for destination therapy left ventricular assist devices: "there was no choice" versus "I thought about it an awful lot." *Circ Cardiovasc Qual Outcomes*. 2014;7(3):374-380.
5. McIlvennan CK, Jones J, Allen LA, et al. Decision-making for destination therapy left ventricular assist devices: implications for caregivers. *Circ Cardiovasc Qual Outcomes*. 2015;8(2):172-178.
6. Swetz KM, Freeman MR, AbouEzzeddine OF, et al. Palliative medicine consultation for preparedness planning in patients receiving left ventricular assist devices as destination therapy. *May Clin Proc*. 2011;86(6):493-500.
7. Allen LA, McIlvennan CK, Thompson JS, et al. Effectiveness of an intervention supporting shared decision making for destination therapy left ventricular assist device: the DECIDE-LVAD randomized clinical trial. *JAMA Intern Med*. 2018;178(4):520-529.
8. Schwarz ER, Baraghoush A, Morrissey RP, et al. Pilot study of palliative care consultation in patients with advanced heart failure referred for cardiac transplantation. *J Palliat Med*. 2012;15(1):12-15.
9. Rogers JG, Patel CB, Mentz RJ, et al. Palliative care in heart failure: the PAL-HF randomized, controlled clinical trial. *J Am Coll Cardiol*. 2017;70(3):331-341.
10. Bakitas M, Dionne-Odom JN, Pamboukian SV, et al. Engaging patients and families to create a feasible clinical trial integrating palliative and heart failure

care: results of the ENABLE CHF-PC pilot clinical trial. *BMC Palliat Care*. 2017;16(1):45.

11. ClinicalTrials.gov. ENABLE CHF-PC (Comprehensive heartcare for patients and caregivers) [study]. <https://ClinicalTrials.gov/show/NCT02505425>. Published July 22, 2015. Updated May 23, 2018. Accessed November 16, 2018.
12. Dunlay SM, Strand JJ, Wordingham SE, Stulak JM, Luckhardt AJ, Swetz KM. Dying with a left ventricular assist device as destination therapy. *Circ Heart Fail*. 2016;9(10):e003096.
13. Swetz KM, Kamal AH, Matlock DD, et al. Preparedness planning before mechanical circulatory support: a "how-to" guide for palliative medicine clinicians. *J Pain Symptom Manage*. 2014;47(5):926-935.e6.
14. Wordingham SE, Woodburn J, Hollenbach S, Williamson S. Defining the disease in DT-LVAD: a comprehensive approach to a complex continuum of care (SA501). *J Pain Symptom Manage*. 2018;55(2):637-638.
15. Blume ED, Hauptman PJ, Gauvreau K, et al. Deactivation of ventricular assist devices: perspectives and experiences of adult cardiovascular providers. *J Card Fail*. 2017;23(6):485-486.
16. Mueller PS, Swetz KM, Freeman MR, et al. Ethical analysis of withdrawing ventricular assist device support. *Mayo Clin Proc*. 2010;85(9):791-797.
17. McIlvennan CK, Wordingham SE, Allen LA, et al. Deactivation of left ventricular assist devices: differing perspectives of cardiology and hospice/palliative medicine clinicians. *J Card Fail*. 2017;23(9):708-712.
18. Miller LW, Guglin M. Patient selection for ventricular assist devices: a moving target. *J Am Coll Cardiol*. 2013;61(12):1209-1221.
19. Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. *N Engl J Med*. 2013;368(13):1173-1175.
20. Allen LA, Stevenson LW, Grady KL, et al; American Heart Association; Council on Quality of Care and Outcomes Research; Council on Cardiovascular Nursing; Council on Clinical Cardiology; Council on Cardiovascular Radiology and Intervention; Council on Cardiovascular Surgery and Anesthesia. Decision making in advanced heart failure: a scientific statement from the American Heart Association. *Circulation*. 2012;125(15):1928-1952.

**Sara E. Wordingham, MD** is a consultant with the Center for Palliative Medicine and an assistant professor of medicine in the College of Medicine and Science at the Mayo Clinic in Phoenix, Arizona, where she is also the vice-chair of the Ethics Subcommittee and a member of the Cardiac Transplantation Selection Committee. Her primary focus is the augmentation of access and delivery of palliative care to advanced heart failure and mechanical circulatory support patients.

**Colleen K. McIlvennan, DNP, ANP** is an assistant professor of medicine in the Division of Cardiology at the University of Colorado Boulder. She serves as the lead nurse

practitioner in the Section of Advanced Heart Failure and Transplantation, and she performs research within the Adult and Child Consortium for Health Outcomes Research and Delivery Science. Her research interests include improving decision making and end-of-life processes for patients with left ventricular assist devices and their caregivers.

**Citation**

*AMA J Ethics.* 2019;21(5):E435-442.

**DOI**

10.1001/amajethics.2019.435.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

## HISTORY OF MEDICINE

### Will We Code for Default ECMO?

Daniel J. Brauner, MD and Christopher J. Zimmermann, MD

#### Abstract

Cardiopulmonary resuscitation has become the default treatment for all patients who suffer cardiac arrest. The history of how this came to be suggests the clinical and ethical importance of establishing more humane and appropriate indications for extracorporeal membrane oxygenation and other aggressive therapies for patients at the end of life.

#### Doing Everything

Development of new medical technologies has potential to greatly improve patients' lives but also raises questions about how to establish standards of care for applying them. Increasing application of extracorporeal membrane oxygenation (ECMO)—especially as an adjunct to cardiopulmonary resuscitation (CPR), termed ECPR—presents us with an opportunity to establish sensitive and humane use standards. Such standards would pose a stark contrast to using CPR and other “life-saving” procedures to treat cardiac arrest in all critically ill and dying patients without a do-not-resuscitate (DNR) order. CPR became the default treatment for cardiac arrest in hospitals in the early 1970s and established a precedent for the current standard of “doing everything”—that is, applying all indicated procedures, regardless of whether they are expected to help a specific patient. It was only later that [DNR orders](#) were established, placing the onus on patients or surrogates to opt out. The do-everything precedent, however, suggests that as ECMO becomes increasingly accessible, it, too, will likely be added to the list of what is included in everything physicians do by default and that patients come to expect, perhaps prompting the need for do-not-ECMO orders.

This article examines parallels between the early history of CPR and ECMO. We argue that similar forces that led to CPR becoming indicated in all cases of cardiac arrest are currently driving the expansion of indications for ECMO. Understanding these forces is essential to establishing more humane and appropriate indications for these aggressive therapies and may prevent them from becoming “default” treatments for all dying patients.

#### A Brief History of ECMO

ECMO is a life-supporting treatment that supplants the function of the lungs, the heart, or both, typically applied when patients' illnesses are refractory to other standard procedures. ECMO's earliest incarnation was referred to as the “mechanical heart and

lung.”<sup>1</sup> First successfully applied in the 1950s to bypass a patient’s heart, thereby revolutionizing cardiac surgery, ECMO was initially confined to operating rooms.<sup>1</sup> After development of a compact portable battery-operated “roller pump” in the 1960s, ECMO could be used outside operating rooms, and its indications expanded to include acute respiratory distress syndrome, bridge to transplant, sepsis, and resuscitation.<sup>2</sup> The first successes of ECMO as an adjunct to CPR in select cases of cardiac arrest were reported in 1976.<sup>3</sup> Although use of ECPR has increased in the last decade, 2 recent meta-analyses of the procedure suggest that ECMO should be used as an adjunct to CPR or as an alternative to resuscitation alone in patients with reversible etiologies for their arrest (ie, not at the terminus of diseases expected to end in death).<sup>4,5</sup> This limited indication for ECPR appears to be fairly well established and was echoed in an editorial commenting on 12 years of data from the Extracorporeal Life Support Organization,<sup>6</sup> which defined ECPR as “implantation of veno-arterial extracorporeal membrane oxygenation (VA-ECMO) in a patient who experienced a sudden and unexpected pulseless condition attributable to cessation of cardiac mechanical activity.”<sup>7</sup>

### **Innovating CPR Protocol?**

Although current standards for ECPR stipulate limited indications and specific locations, experts cannot help but wonder about where and for whom the procedure should be used. This concern was articulated in an editorial titled “ECPR: Are We Ready for Primetime?,”<sup>8</sup> which accompanied a previously mentioned meta-analysis. In addition to implying that the indications for and application of ECPR had expanded, the title of the editorial raises an unspoken question: Should ECPR become part of the CPR protocol? Although the meta-analysis reported overall greater survival to hospital discharge for ECPR compared to conventional CPR,<sup>4</sup> a reasonable answer to this question, for the time being, is “not yet.” The authors of the editorial suggested that the meta-analysis included too few publications, was “incomplete,” and that “ECPR should only be performed in selected circumstances and in those institutions that have 24-hours-a-day extracorporeal support systems in place.”<sup>8</sup> The authors also stipulate, as do many articles on ECPR, that “Ethical considerations as to who should receive ECPR, and who should not get it, need to be properly addressed.”<sup>8</sup>

What should be the role of ethics in establishing [standards for ECPR](#)? Responses to this question have included calls for more evidence about benefits and risks, for evaluating potential patients’ preferences, and for consideration of economics.<sup>9</sup> Establishing default CPR for all cardiac arrest meant that many patients, the vast majority of whom died in hospitals, underwent the procedure despite its not offering hope of meaningful life extension. The parallel early histories of CPR and ECMO suggest that the forces that contributed to CPR’s expanding indications and that ultimately led to its default application are also driving ECMO’s use trajectory.



## History of Default Care for Cardiac Arrest

Treatment of cardiac arrest was mostly confined to the operating room until the 1950s when a few bold surgeons encouraged applying the technique, which involved open cardiac massage, in other areas of the hospital and beyond. This development meant that, until 1950, cardiac arrest was for the most part only diagnosed in the operating room because it was there that the procedure to treat the condition could be applied. The definition of cardiac arrest and, with it, the indications for resuscitation, greatly expanded when the much-less-invasive closed method of resuscitation was developed in the late 1950s.

When the originators of CPR, which combined the closed method with mouth-to-mouth ventilation, convened for a roundtable discussion at the *Chest* meetings in 1962, they began by defining indications for the new therapy.<sup>10</sup> Peter Safar, a developer of and advocate for mouth-to-mouth ventilation, opened the roundtable by posing a definition of cardiac arrest as an indication for the new technique: "I would like to define cardiac arrest as the clinical picture of cessation of circulation in a patient who was not expected to die at the time."<sup>10</sup> He then asked James Jude if he agreed with his definition. Jude, one of the developers of external cardiac massage at the Johns Hopkins University School of Medicine and the sole physician on the first article on the technique, published in 1960,<sup>11</sup> replied, "It's a very good one."<sup>10</sup> The markedly diminished burdens of CPR compared to the more invasive open technique that it replaced led to an expansion of CPR's indications throughout the 1960s, but the limits of the procedure were still appreciated by many and guided practice in those hospitals accordingly.<sup>12</sup>

Evidence that CPR had not yet become the default treatment for cardiac arrest during the 1960s comes from several sources. Jude, along with James Elam, another developer of CPR also at the 1962 *Chest* conference roundtable, published the first CPR manual in 1965, *The Fundamentals of Cardiopulmonary Resuscitation*. The manual begins with a description of patients for whom CPR is indicated: "The patient must be salvable ... resuscitative measures on terminal patients will, at best, return them to the dying state."<sup>13</sup> Three years later, in an article about uses of life-saving treatments such as cardiac resuscitation, the attorney John Fletcher states:

The moral of our circular journey is that doctors are in a position to fashion their own law to deal with cases of prolongation of life. By establishing customary standards, they may determine the expectations of their patients and thus regulate the understanding and the relationship between doctor and patient. And by regulating that relationship, they may control their legal obligations to render aid to doomed patients.<sup>14</sup>

Fletcher's call for developing "customary standards" for cardiac resuscitation speaks to the lack of an established standard at the time. It was only after CPR was established as the default treatment for cardiac arrest that DNR orders became necessary. The first mention of the DNR order does not appear in the medical literature until 1972,<sup>15</sup> and it was formally codified by the American Heart Association in 1974.<sup>16</sup> The standard of default CPR thus was not established before 1970 (see Table).

**Table.** History of Default CPR Becoming the Standard Care

Pre-default Event	
1965	Jude and Elam publish <i>The Fundamentals of Cardiopulmonary Resuscitation</i> , which began, “The patient must be salvable ... resuscitative measures on terminal patients will, at best, return them to the dying state.” <sup>a</sup>
1968	Fletcher argues for the development of sensitive and humane standards for the care of patients who are clearly dying, implying a standard is not yet in place. <sup>b</sup>
Post-default Event	
1972	First mention of “Do Not Resuscitate” orders appears in the medical literature in a perspectives piece on patient death. <sup>c</sup>
1974	The American Heart Association officially codifies the “Order not to Resuscitate.” <sup>d</sup>
<sup>a</sup> Quoted from Jude and Elam. <sup>13</sup> <sup>b</sup> From Fletcher. <sup>14</sup> <sup>c</sup> From Janes. <sup>15</sup> <sup>d</sup> From “Standards for Cardiopulmonary Resuscitation (CPR) and Emergency Cardiac Care (ECC).” <sup>16</sup>	

Proponents of ECPR are to be congratulated for their prudence to date in limiting its indications, but the parallels between ECPR and CPR more than half a century earlier are startling: ECPR appears poised to follow in CPR’s footsteps by becoming the default treatment for cardiac arrest—an example of the *technological imperative*.

### **The Technological Imperative and Coding CPR as a Billable Procedure**

The technological imperative—the overapplication of technological solutions to an increasing range of problems—has been appreciated in medicine since at least the 1980s, when Howard Spiro discussed it at an eponymous conference. Spiro, then chief of general internal medicine at Yale University, identified the force driving the ever-increasing application of technological procedures when he remarked:

We are all encouraged to do more in the way of technological activities today than 10 or 30 years ago simply because the third-party payers pay for technology and not for thinking. When you talk with the officials, they point out that it is easy to assess the costs of the procedures but difficult to assess the cost of a thought.<sup>17</sup>

The truth of Spiro’s remarks is manifest in the temporal relationship between CPR becoming the default option for all patients who died in hospitals in the early 1970s and its listing as a billable procedure in the second edition of the *Current Procedural Terminology* (CPT) manual, published in 1970 by the American Medical Association (AMA).<sup>18</sup>

In 1966 the AMA published the first CPT manual, which was much smaller and narrower in scope than the second edition, so that physicians and administrators could begin billing Medicare for procedures.<sup>19</sup> The new 1970 CPT code read “CPR for Cardiac Arrest ... 96000” and, very soon, cardiac arrest came to mean all cases of cessation of circulation, regardless of the context of the patient. The default application of CPR thus became the standard of care.

A brief overview of the CPT codes for ECMO highlights an important difference between ECMO and CPR codes. The first instance of CPT coding for ECMO occurs in the 4th edition, published in 1977: “33960 ... Prolonged extracorporeal circulation for cardiopulmonary insufficiency.”<sup>20</sup> After several revisions, the current CPT codes for ECMO were established in 2015,<sup>21</sup> with 16 different codes referring to specific aspects of the procedure: placement, repositioning, and removal of peripheral or central cannulas, for example, are further subdivided into open or percutaneous approaches. Of note, these various CPT codes are not linked to specific indications, as were CPR codes for cardiac arrest. This history suggests that one way to avoid ECPR becoming the default treatment for all cardiac arrest would be not to create a CPT code that links it to cardiac arrest.

### Other Lessons

The gauntlet has already been thrown down for hospitals to provide around-the-clock ECMO teams before they will be sanctioned to provide ECPR, paralleling the creation of code teams for CPR in the 1960s.<sup>22</sup> Although American Heart Association guidelines state that “[t]here is insufficient evidence to recommend the routine use of ECPR for patients with cardiac arrest,”<sup>23</sup> it is likely only a matter of time before data will be collected that incontrovertibly show ECPR to be superior to CCPR, but only in select patients. One lesson from the history of CPR is this: cardiac arrest that includes all cases of cessation of blood flow should never be a blanket indication for ECPR. Another is that patients should not be forced to become do-not-ECMO to avoid the harms of ECPR. Instead, physicians need to make judgments about who would likely benefit from the procedure and decide with patients and families if this is something they would want. The history of CPR suggests the importance of defining the limits of any kind of resuscitation. By raising the stakes of resuscitation, ECPR also pushes us to better define these limits. By illuminating the temporal link between CPT codes and standards of care for CPR, this history also raises the question of CPT codes’ influence on other procedures and their standards.

### References

1. Gibbon JH Jr. Application of a mechanical heart and lung apparatus to cardiac surgery. *Minn Med.* 1954;37(3):171-185.
2. Makdisi G, Wang IW. Extra corporeal membrane oxygenation (ECMO): review of a lifesaving technology. *J Thorac Dis.* 2015;7(7):E166-E176.

3. Mattox KL, Beall AC Jr. Resuscitation of the moribund patient using portable cardiopulmonary bypass. *Ann Thorac Surg.* 1976;22(5):436-442.
4. Kim SJ, Kim HJ, Lee HY, Ahn HS, Lee SW. Comparing extracorporeal cardiopulmonary resuscitation with conventional cardiopulmonary resuscitation: a meta-analysis. *Resuscitation.* 2016;103:106-116.
5. Ahn C, Kim W, Cho Y, Choi KS, Jang BH, Lim TH. Efficacy of extracorporeal cardiopulmonary resuscitation compared to conventional cardiopulmonary resuscitation for adult cardiac arrest patients: a systematic review and meta-analysis. *Sci Rep.* 2016;6:34208.
6. Richardson AS, Schmidt M, Bailey M, Pellegrino VA, Rycus PT, Pilcher DV. ECMO cardio-pulmonary resuscitation (ECPR), trends in survival from an international multicentre cohort study over 12-years. *Resuscitation.* 2017;112:34-40.
7. Pappalardo F, Montisci A. What is extracorporeal cardiopulmonary resuscitation? *J Thorac Dis.* 2017;9(6):1415-1419.
8. Ocegueda-Pacheco C, Varon J. ECPR: are we ready for primetime? *Resuscitation.* 2016;103:A6-A7.
9. Riggs KR, Becker LB, Sugarman J. Ethics in the use of extracorporeal cardiopulmonary resuscitation in adults. *Resuscitation.* 2015;91:73-75.
10. Safar P, Elam JO, Jude JR, Wilder RJ, Zoll PM. Resuscitative principles for sudden cardiopulmonary collapse. *Dis Chest.* 1963;43:34-49.
11. Kouwenhoven WB, Jude JR, Knickerbocker GG. Closed-chest cardiac massage. *JAMA.* 1960;173(10):1064-1067.
12. Jude JR, Kouwenhoven WB, Knickerbocker GG. External cardiac resuscitation. *Monogr Surg Sci.* 1964;1:59-117.
13. Jude JR, Elam JO. *Fundamentals of Cardiopulmonary Resuscitation.* Philadelphia, PA: FA Davis; 1965.
14. Fletcher GP. Legal aspects of the decision not to prolong life. *JAMA.* 1968;203(1):65-68.
15. Janes RG. A clinical perspective on dying. *Can Med Assoc J.* 1972;107(5):425-427.
16. Standards for cardiopulmonary resuscitation (CPR) and emergency cardiac care (ECC). V. Medicolegal considerations and recommendations. *JAMA.* 1974;227(7)(suppl):864-868.
17. Wolf S, Berle BB, eds. *The Technological Imperative in Medicine.* New York, NY: Plenum Press; 1981.
18. Gordon BL, ed. *Physicians' Current Procedural Terminology.* 2nd ed. Chicago, IL: American Medical Association; 1970.
19. Gordon BL, ed. *Current Procedural Terminology.* Chicago, IL: American Medical Association; 1966.
20. American Medical Association. *Physicians' Current Procedural Terminology.* 4th ed. Chicago, IL: American Medical Association; 1977.
21. American Medical Association. *CPT 2015 Professional Edition.* Chicago, IL: American Medical Association; 2015.

22. Jung MA, Selby A, Johnson JR, Beanlands DS, Lenkei SC. Value of a cardiac arrest team in a university hospital: results in a series of 100 patients. *Can Med Assoc J*. 1968;98(2):74-78.
23. Link MS, Berkow LC, Kudenchuk PJ, et al. Part 7: Adult advanced cardiovascular life support: 2015 American Heart Association guidelines update for cardiopulmonary resuscitation and emergency cardiovascular care. *Circulation*. 2015;132(18)(suppl 2):S444-S464.

**Daniel J. Brauner, MD** is an associate professor of medicine in the Section of Geriatrics and Palliative Medicine at the University of Chicago, where he is also the co-director of the MacLean Center for Clinical Medical Ethics Consultation Service. He cares for patients in the nursing home, clinic, and hospital and is writing a book on the history of resuscitation and its impact on current standards of care that seeks to offer solutions to the crisis in medicine today.

**Christopher J. Zimmermann, MD** is a general surgery resident at the School of Medicine and Public Health in the Department of Surgery at the University of Wisconsin-Madison and an American College of Surgeons-MacLean Center surgical ethics fellow. His research interests include the ethics of brain death and organ donation, shared decision making for older adults facing high-risk surgery, drivers of nonbeneficial surgery, and increasing access to palliative care for surgical patients.

#### **Citation**

*AMA J Ethics*. 2019;21(5):E443-449.

#### **DOI**

10.1001/amajethics.2019.443.

#### **Acknowledgements**

The authors would like to thank the MacLean Center for Clinical Medical Ethics at the University of Chicago for encouraging collaboration on this project. Dr Zimmerman is supported by training grant 2T32HL11083-06 from the National Institutes of Health.

#### **Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

## ART OF MEDICINE

### Sustaining the Lives of Art Objects

Sarah Molina

#### Abstract

This article explores the complex process of sustaining the lives of art objects and considers ways in which conservation efforts in art museums parallel cultural humility cultivation among health care professionals. Conservators and scientists at the Art Institute of Chicago grapple with a number of ethical questions that emerge when preserving and caring for objects with complicated histories and entangled networks of stakeholders. What follows is an examination of these issues in relation to objects in the Art Institute's collection and the larger histories of art museums and medicine.

#### Conserving Art Objects

The mission of the Art Institute of Chicago (AIC) includes 3 critical endeavors: to collect, to preserve, and to interpret works of art. The endeavor to preserve artwork, the focus of this essay, manifests in ways both visible and invisible to visitors' eyes. Museum lights are adjusted at precise levels to decelerate the natural deterioration of art objects, hygrothermographs—mechanical instruments discreetly placed in corners of galleries—monitor humidity, and various written invocations to look but not touch underscore the vulnerability of artworks to contact with human bodies. Other elements of preservation are less visible to visitors. The AIC's Department of Conservation and Science<sup>1</sup> maintains behind-the-scenes storage systems designed to maximize objects' longevity, analyzes works in the collection to better understand their physical properties, and undertakes careful treatments of damaged and deteriorated artworks.

Some parallels between the fields of medicine and art conservation are direct, such as the use of advanced technologies to improve methods of care and to develop [close observation skills](#). Historically, conservators and physicians have adapted tools from science, like x-radiography, to look beyond an art object's surface to its internal structure.<sup>2,3</sup> Other comparisons are more abstract. Cybele Tom,<sup>4</sup> Andrew W. Mellon Fellow in Objects Conservation, has offered her perspective on conservation as related to the anthropomorphization of art objects and their lived histories.

Artworks are not breathing, metabolizing bodies, but, like human beings, they bear both material and immaterial<sup>5</sup> characteristics that shift, accumulate, and fade.... They acquire meaning; they give rise to other

creative acts. So if you think of life not only as a characteristic of biologically living bodies, but as a feature of entities and systems that are dynamic in that they change and grow in response to external stimuli and are even generative, then conservation very much endeavors to sustain the “life” of artworks. Its technology is to combine visual acuity, historical and cultural knowledge, and analytical science to make that happen (C. Tom, written communication, September 28, 2018).

### **Caring for Sacred Objects**

Just as ethical decisions about whether and when to use life-sustaining technologies in health care are rife with complicated issues, sustaining the lives of artworks is rarely straightforward. Quandaries and dilemmas arise within the complex and at times conflicted network of stakeholders invested in an object’s life. These stakeholders can include an artwork’s original creator(s), museum curators tasked with overall care for collections, the conservator responsible for preservation, and communities linked to objects through shared artistic practice, heritage, identity, or spirituality.

Take, for instance, a helmet [mask](#) possibly made in the early-to-mid-1900s in West Africa. This object shaped like the head of a wild animal was intended to be worn only by members of Kono, a secret society based in Mali that was responsible for guiding the community’s moral codes. Designed to be used during specific rituals that allowed Kono members to identify solutions for problems in their communities, the helmet mask contains material references to both the terrestrial and the supernatural. Its base has been crafted from wood and covered with a mud-like layer; attached horns and quills render an image of a powerful, polymorphous animal. The helmet mask has also been covered with a thick, supernaturally charged crust, sometimes called a sacrificial patination.<sup>6</sup> Objects such as these were never meant to be studied or exposed to the wider world. But now in the collection of the AIC, the helmet mask has raised questions about display and preservation. Conservators often work in collaboration with scientists to identify an object’s materials and physical properties, which then helps direct a plan for preservation or treatment. However, the desire to examine—with the aim of preserving—the helmet mask might be at odds with the object’s original purpose and its sacred dimensions, prompting a re-evaluation of what and who should constitute ethical conservation practices.

Conservators and art historians have approached the preservation of West African helmet masks from a variety of perspectives. They have solicited feedback from members of living communities and secret societies who venerate these objects, devised minimally invasive approaches to examining helmet masks, and carried out treatments while expressing ethical values of humility and respect.<sup>7</sup> Yet queries about competing values remain. Tom, who was tasked with examining the helmet mask and extracting a small sample for analysis, commented on cultural and ethical tensions in the process of studying and preserving non-Western ritual objects.

For many of these artifacts, the process and materials of their making are guarded secrets, and their handling and viewing is highly controlled. Is it then ethical ... to apply a conservator's or scientist's methods—which can involve invasive sampling of material with a scalpel (albeit microscopic amounts), x-radiography, or other technical imaging that reveals things unseen to the naked eye—to the study of an object whose secrets are surely to be exposed as a result? Do these acts, usually lauded in our society as a kind of noble act done in the name of knowledge and education, become acts of cultural colonialism? It's very complicated and messy. It is also a false assumption to say that all people from the originating culture are of homogeneous opinion. Such issues are a part of what makes close work with objects of cultural heritage fascinating (C. Tom, written communication, September 28, 2018).

### **Lessons From Art Musea for Medicine**

Accusations of neocolonialism should not be ignored. Encyclopedic museums like the AIC were founded upon ideals of the Western European Enlightenment, which fostered scientific discovery and humanistic progress, as well as ushering in an era that normalized ideas and practices supporting the worst of human practices: slavery and colonization. In the fields of medicine and anthropology, scientists produced “empirical” studies to justify European racial superiority and [colonialism](#).<sup>8</sup> Encyclopedic art and natural history museums were established to collect, classify, and showcase cultures of the world, with objects like West African helmet masks entering a new context of display. From the perspective of colonized communities, conserving these works can perpetuate colonialism's legacy, but preserving material culture might also be read as an act of subverting imperialist ideologies.

Historically, humanities scholars have prized written records as markers of great civilizations: Greek poetry, Egyptian hieroglyphics, Babylonian law inscribed in stone. Western scholars in the 18th and 19th centuries often regarded civilizations that encoded ancestral knowledge through nonwritten methods, like oral history, as primitive. Yet we know that civilizations like those in the Andes also developed complex nonwritten processes of recording history.<sup>9</sup> In some Andean cultures, about which much remains to be learned, extant materials like textiles and ceramics tell stories of their makers. Rather than sustaining the lives of these civilizations primarily through the writings of Spanish conquistadors who colonized the Andes, prioritizing artifacts' preservation asserts an ethical discourse of objecthood that provides an alternative to colonizers' written records. But even reifying the ethical value of a particular object through its preservation requires care. That is, while championing the value of preservation, musea must also acknowledge the relationship between historic objects and their living communities, as well as the potential for well-intentioned preservation efforts to be experienced by members of these living communities as a neocolonialist source of cultural trauma.

In the context of health care, patients, too, benefit from their professional caregivers' awareness of their power in patient-clinician relationships. Just as the same tools can be used in both medicine and art conservation, physicians' and conservators' practices of care and humility can aid both patients and museum visitors in making meaning of their experiences.



Ultimately, health care professionals and conservators are engaged in practices of sustaining lives. By preserving and studying the materiality of an art object, conservation functions as a crucial agent in sustaining the lives of objects and their lived histories. As Tom notes,

If not cared for, studied, and documented, these unique objects can very quickly slide into physical incoherence and dissolution of meaning. Some change is inevitable—again, mirroring human life.... Conservation is about weighing competing values and making decisions that are intended to let the artwork continue to be authentically experienced. There is not a single right way.... The field of conservation has itself changed in recent decades. We no longer think of our role in terms of halting change and preserving an artwork in time but as managing and documenting change to help it endure, with all its history, through time (C. Tom, written communication, September 28, 2018).

The Art Institute's mission to preserve and care for the material embodiments of people potentially silenced by time and history remains critical—as does the medical field's call for greater cultural competence<sup>10</sup> in understanding multilayered ethical debates about the uses of life-sustaining technologies.<sup>11</sup>

## References

1. Art Institute Chicago. Conservation and science. <https://www.artic.edu/about-us/departments/conservation-and-science-2>. Accessed November 26, 2018.
2. Stoner JH. Changing approaches in art conservation: 1925 to the present. In: *Scientific Examination of Art: Modern Techniques in Conservation and Analysis*. Washington, DC: National Academies Press; 2005:40-57.
3. Howell JD. Early clinical use of the x-ray. *Trans Am Clin Climatol Assoc*. 2016;127:341-349.
4. Tom C, Sutherland K. Overpaint removal from a quattrocento polychrome bas-relief: challenges in interpreting painted sculpture. Paper presented at: 18th Triennial Conference of the International Council of Museums—Committee for Conservation; Copenhagen, Denmark; September 4-8, 2017. <https://www.icom-cc-publications-online.org/PublicationDetail.aspx?cid=53de6230-aa60-4e78-8c07-670eca0748e5>. Accessed November 26, 2018.
5. Balachandran S. Race, diversity, and politics in conservation: our 21st century crisis. *AIC Blog*. May 25, 2016. <http://www.conservators-converse.org/2016/05/race-diversity-and-politics-in-conservation-our-21st-century-crisis-sanchita-balachandran/>. Accessed November 26, 2018.
6. Mellor SP. The exhibition and conservation of African objects: considering the nontangible. *J Am Inst Conserv*. 1992;31(1):3-16.
7. O'Hern R, Pearlstein E, Gagliardi SE. Beyond the surface: when cultural contexts and scientific analyses meet in museum conservation of West African power association helmet masks. *Mus Anthropol*. 2016;38(1):70-86.
8. Curran A. *The Anatomy of Blackness: Science and Slavery in an Age of Enlightenment*. Baltimore, MD: John Hopkins University Press; 2011.

9. Hyland S. Writing with twisted cords: the inscriptive capacity of Andean *quipus*. *Curr Anthropol*. 2017;58(3):412-419.
10. Lubimir KT, Wen AB. Towards cultural competency in end-of-life communication training. *Hawaii Med J*. 2011;70(11):239-241.
11. Abrams DC, Prager K, Blinderman CD, Burkart K, Brodie D. The appropriate use of increasingly sophisticated life-sustaining technology. *Virtual Mentor*. 2013;13(12):1050-1055.

**Sarah Molina** is the National Science Foundation Fellow at the Art Institute of Chicago, where she has previously held positions funded by the Andrew W. Mellon Foundation and the Samuel H. Kress Foundation.

#### **Editor's Note**

Visit the Art Institute of Chicago [website](#) or contact Sam Anderson-Ramos at [sramos@artic.edu](mailto:sramos@artic.edu) to learn more about the museum's medicine and art programming. Browse the *AMA Journal of Ethics* [Art Gallery](#) for more Art of Medicine content and for more about the journal's partnership with the Art Institute of Chicago.

#### **Citation**

*AMA J Ethics*. 2019;21(5):E450-454.

#### **DOI**

10.1001/amajethics.2019.450.

#### **Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

## ART OF MEDICINE

### Fading Mind of a Patient With Alzheimer's

Laci Hadorn

#### Abstract

Alzheimer's can be a devastating disease to observe in others. From a patient's perspective, it can be frightening, too, as memories fade away. This puzzle graphic considers the physical and emotional experiences of brain deterioration.

**Figure.** *The Fading Mind of a Patient With Alzheimer's*



#### Media

Pencil drawing.

Working closely with many nursing home residents with Alzheimer's disease allowed me to see what they and their families endure. Patients with Alzheimer's often do not have insight into how their minds disassemble; this puzzle graphic explores this phenomenon explicitly and starkly, using vividly contrasting black,

white, and gray shading. It is important to encourage patients with Alzheimer's to connect with others. Meeting persons with Alzheimer's where they are in the present moment and assuring them that they need not face their disease progression alone is critical.

**Laci Hadorn** is a second-year medical student at Kansas City University of Medicine and Biosciences in Kansas City, Missouri. Inspired by working with patients with Alzheimer's throughout her undergraduate years, she is passionate about making a difference both through her artwork and her career.

**Citation**

*AMA J Ethics.* 2019;21(5):E455-456.

**DOI**

10.1001/amajethics.2019.455.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

## ART OF MEDICINE

### Moral Distress Containment Through an Artist's and Art Psychotherapist's Lens

Georgina Morley, PhD, MSc, RN and Annie Sharon Fox, MA

#### Abstract

This series of 3 paintings of figures in a bath explores emotional responses of persons experiencing or responding to others' moral distress. Intricately tied together and connected through time and space, the bodies represented suggest a complex web of relationships between clinicians and patients.

**Figure 1.** *Containment 1*





**Figure 2.** *Containment 2*



**Figure 3.** *Containment 3*



## Media

Oil paint on clear Perspex®.

The first contributor (GM) commissioned the second contributor (ASF), an artist and art psychotherapist, to paint a series of works representing GM's doctoral explorations of moral distress based on interviews with critical care nurses. The series of paintings was commissioned to visually augment the "encounters with experience"<sup>1</sup> the nurses offered. The visuals provide a nontextual way to explore themes of balance, relationships, and responsibility that recurred in the interviews, which informed the nurses' conceptions of moral distress.

In a bath, the figures balance one another and work together to avoid sinking. The figures represent clinicians, patients, and family members intimately connected in professional and personal relationships that exert various pulls of responsibility. Portrait form is used to help convey the figures' vulnerability, most directly represented in their nakedness, paralleling the interviewees' vulnerability in retelling their stories and navigating ethically complex experiences in health care settings.

## References

1. Ives J. "Encounters with experience": empirical bioethics and the future. *Health Care Anal.* 2008;16(1):1-6.

**Georgina Morley, PhD, MSc, RN** conducted the present work while a doctoral student at the University of Bristol Centre for Ethics in Medicine in the United Kingdom, where she earned a PhD in bioethics. Georgina is a critical care nurse and most recently worked in cardiac intensive care. She holds an MSc in nursing and BA in philosophy from King's College London.

**Annie Sharon Fox, MA** is a mixed-media artist based in Melbourne, Australia. Her artwork aims to capture and explore the vulnerability, truth, and beauty of human nature in idiosyncratic movements. She received a first-class honors degree in fine art from Aberystwyth University School of Art and a master's degree in art psychotherapy from the University of Roehampton.

### Citation

*AMA J Ethics.* 2019;21(5):E457-460.

### DOI

10.1001/amajethics.2019.457.

**Acknowledgements**

This work was supported by the Wellcome Trust (108640/Z/15/Z).

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



## PERSONAL NARRATIVE

### How Can We Make Out-of-Hospital CPR More Family Centered?

Caroline Mawer, MRCP, MBBS, MSc, MFPH

#### Abstract

This personal narrative examines what physicians owe patients in ways that might be just as novel as any new technology for cardiopulmonary resuscitation (CPR). The narrative uses the actual words of Linda (not her real name), a woman who had to lead CPR on her mother. Rather than concentrating only on CPR, the narrative also discusses what happens—and does not happen—before and after an out-of-hospital cardiac arrest. Linda's story suggests possible ways to take better care of terminally and chronically ill patients at home: by listening in different ways to patients and families.

#### Unsuccessful Cardiopulmonary Resuscitation at Home

Contrary to public expectations, cardiopulmonary resuscitation (CPR) after out-of-hospital cardiac arrest leads to long-term survival in only a small minority of people.<sup>1</sup> Sicker and frailer patients have even worse survival rates.<sup>2</sup> Research suggests that even doctors don't always accurately estimate cardiac arrest survival.<sup>3</sup> Perhaps this is why Americans talk about do-not-resuscitate (DNR) orders: these orders reinforce the "rescue fantasy"<sup>4</sup> that resuscitation will always be a possibility.

I'm a family physician in the United Kingdom (UK). Here we have perhaps more realistic do-not-attempt-cardiopulmonary-resuscitation (DNACPR) orders.<sup>5</sup> I think this shift in language can help patients, families, and doctors understand what's at stake. Even so, when I surveyed my colleagues, they also had limited knowledge of true survival rates after out-of-hospital CPR.<sup>6</sup>

I mainly work out of hours, and I most commonly encounter sequelae of CPR when I am asked to declare death after an unsuccessful resuscitation. I am typically invited into homes where I see frail, elderly, palliative care patients lying dead on the floor with their clothing in disarray and an intubation tube still protruding from their mouth. Some of these CPR attempts could have been predicted to be futile.<sup>7</sup> To me, it often feels that many are worse than futile. Family members are understandably distressed not only by what happened during the death itself but also afterwards, when it's difficult to say goodbye to a medicalized corpse. I am frequently told: "At least everything was done." I nod respectfully, but privately I sometimes think, "What about sitting with your relative,

holding hands, and telling her you love her?" That's surely another sort of "everything" that might have been done.<sup>8</sup>

With all this in mind, I wanted to expand on my clinician survey by exploring the views of patients and the public on out-of-hospital CPR. Therefore, when I was volunteering with a UK end-of-life charity,<sup>9</sup> the charity's supporters were emailed a modified version of my previous questionnaire. Of course, this convenience survey cannot produce quantitative results. However, it has suggested some key issues. Mirroring findings in a literature review,<sup>10</sup> my respondents' most common concern was that they might be subjected to CPR against their wishes. Several respondents also wanted to tell me what had happened to members of their family and how upsetting these deaths had been. I focus here on one response, from Linda (not her real name). Her story illuminates fundamental ethical principles at stake in out-of-hospital CPR. Specifically, it suggests that improving patient-clinician communication about end-of-life care and better respecting patient dignity at the end of life could support alternatives to futile CPR.

### **Linda's Story**

*I'm a trained first aider. My mum [mother] had lived alone since Dad died. She had always been independent, but she had 4 chest infections in a row last winter, so I was staying with her. The problems with her chest were getting her down. She told me she was fed up with life, so I asked for a nurse to come round to assess her. Anyway, she went to the toilet, and I felt she was gone too long. When I went to check, I found her collapsed.*

*Faced with that situation, instinct and training kicked in. I got her onto the floor, rang for the EMS [emergency medical services], and started CPR. I know I broke her ribs—I felt a horrible, sickening crunching as they snapped under my hands. It was nothing like the dummy we'd practiced on.*

*The doctors in the emergency room told me it was common in elderly people, but they never teach you that in first aid courses. And it was all so undignified, squashed in her hallway, and me knowing all the time that if I revived her she would probably never forgive me.*

*I don't know how long the EMS took to arrive, but it felt like forever. I was glad to hand Mum over to the professionals and did my best to pull her pants back up and try to restore at least a little dignity to her. They applied the paddles and got her heart beating. But I couldn't tell the EMS [staff] that I wanted to let her go. That I knew my mum. That I knew there was no way she would want to live the remainder of her life no longer capable of being independent.*

*She was unconscious, but they got her stable enough to transport her to hospital. I left in my car at the same time but arrived at the hospital before them. When they rushed her into the emergency room, the EMS staff told me that I'd given her the best possible chance of survival, but her heart had stopped again on the journey and they'd had to resuscitate her again.*

*The EMS staff were brilliant. But on the way there I'd had time to think. Mum had managed to plan her funeral—she'd even written down what she wanted to wear, what to place in her coffin, and the exact service she wanted because she'd been so impressed with Dad's funeral.*

*But we hadn't thought about the actual dying. And nobody teaches you the words to say when you want the doctors to let somebody go. Not to resuscitate them if their heart stops again. It was not an easy decision but I knew it was right. Your head is saying "let her go" but your gut is churning and you desperately don't want her to die. You also do worry about what the doctors will think of you—will they think you don't care? Will they try to persuade you to change your mind when it's already the most difficult decision you've ever had to make?*

*I could bear that the professionals might think badly of me. But I couldn't bear that my mum would hate me for keeping her alive without being fully restored to health and fitness, and I just knew no doctor could do that. They agreed to make her comfortable—to not try resuscitating her again—and see how she fared through the night.*

*I was called back to the hospital at 4:30 the next morning, as they thought the end was near. The doctors told me her body was shutting down. The decision to turn off the life support machines was easy, as was the decision to donate her corneas. If something good was going to come out of tragedy, that was a comfort. I held her hand as she passed away. But by the time I said the words I'd always wanted to say, my mum was unconscious. I've been told that hearing is the last sense to go so I like to think she did hear.*

*No one wants their mum to die. But who wants their mum to suffer? I loved my mum enough to try to save her. But I also loved her enough to let her go.*

### **Learning From Linda**

As a physician, I've been privileged to have heard many personal stories. Linda's narrative is exceptional. I felt that she was writing primarily as her mother's protective and loving daughter as well as implicitly reflecting on the almost-inevitable power imbalance in patient-physician relationships.

Linda wrote that this was the first time she had ever shared her story with anyone. Two years after the events she described, she was still worried that the ribs she had broken had contributed to, or even caused, her mother's death. I wrote back to her how sorry I was, not only about what happened to her mother but also that she had to do all this by herself. I reassured her about her mother's ribs. I told her that I admired her bravery both in trying to save her mother and—even more difficult—in letting her mother go.

We emailed back and forth several times, and Linda told me how keen she is on clinicians being able to learn from what happened to her and her mother. I have removed the most undignified parts of her story and made some small changes so that Linda and her mother cannot be identified. Otherwise, you have read Linda's own words.

### **Before, During, and After CPR**

Much of the literature ignores the harsh reality of many out-of-hospital cardiac arrests. Guidelines,<sup>11-13</sup> ethical analyses,<sup>14-18</sup> and the rest of the significant literature<sup>18-22</sup> primarily discuss autonomy issues concerning family involvement during CPR. Inevitably, though, family members are likely first responders.<sup>23</sup> Theoretical musings are pushed aside when, as Linda describes, “instinct ... kick[s] in.” This is almost inevitably the case when emergency situations have not previously been contemplated.

What happens after any return of spontaneous circulation (ROSC) is another unpleasant and rarely discussed reality.<sup>24</sup> There are few investigations of ROSC that do not focus simply on survival or the adverse effects of CPR. A rare Midwestern study of those whose death terminated a post-CPR admission found that roughly 84% of patients died either after life support was withdrawn or while it was ongoing. Median survival time after a heart was restarted was only 1.5 days.<sup>25</sup> Linda’s mother fits this pattern.

The time before the CPR, the years and months when chronic diseases or cancer become more burdensome and treatments become less curative, is an obvious opportunity for intervention.<sup>26</sup> Over the course of one winter with 4 chest infections, Linda’s mother was given a range of medical treatments. Sadly, however, there was no effective consideration of advance care planning. Linda’s mother actually told Linda that she was “fed up with life,” implying that she might well have chosen a DNACPR if this option had been discussed.

Berry’s “imaginary inquiry” into an unsuccessful CPR attempt underlines how many physicians apparently think it is **not the right time** or that they are not the right person to start important conversations touching on death.<sup>27-29</sup> Although some physicians worry that these conversations are difficult,<sup>30,31</sup> consider how even more difficult it was for Linda, standing in an emergency room with her unconscious mother. Linda had to lead—in a situation that was extraordinarily challenging.

### **Applying Lessons Learned From Linda to Your Own Practice**

Linda’s story provides clues to some potential ways forward for clinicians when working with individual patients and their families on advance care planning.

Linda’s narrative of what it can be like for families during and after CPR underlines the importance of all clinicians using **guidelines for advance care planning** and decision making (including for DNR or DNACPR orders) and physician orders for life-sustaining treatments.<sup>32-35</sup> When we listen and respond to people who don’t want CPR, we can make out-of-hospital deaths more family centered. Linda’s worries about what happened when she attempted to resuscitate her mother should also prompt clinicians to actively listen for family members’ expressions of feeling traumatized and regretful after a CPR attempt.

Linda and many of my other respondents didn't even try to answer most of my questions. They were not interested in numbers, even though quantitative analyses are often a focal point for clinicians. Instead, my respondents focused on what was important to them. I think this practical focus underlines the limitations of some decision aids, even when supported by detailed data.<sup>36</sup> Using a scenario analysis to consider the best, worst, and most likely cases may offer a useful alternative approach to emergency care planning for individuals and families.<sup>37</sup>

Returning specifically to Linda, her biggest regret was not her mother's medical care but that she hadn't said what she'd "always wanted to say." This sort of thing can't be assured even with the best guideline or advance directive, and it would not have been identified in any routine audit of the CPR attempt. What Linda's story suggests is that we need to listen differently. For example, we could explore the times things go well, from a family point of view, in as much detail as we investigate problems from clinical or systems points of view. Thinking hard about what went as well as possible could help clinicians learn how to make things as good as possible (rather than merely reducing errors) in their end-of-life cases. One junior hospice physician, Nishma Manek, is already doing something similar by diminishing focus on "fixing what is in my control."<sup>38</sup> For example, instead of looking only at blood pressure, pulse, and lab results, Manek focused instead on understanding what was important to her patient when she worked out that the most valuable thing she could do was to get this patient a bucket of fried chicken. An emergency room physician, Andre Kumar, broke the algorithm rules when he asked a patient with recurrent chest pain what he wanted, then set up a system that avoided the revolving door of repeated admissions.<sup>39</sup>

As we acquire new and more technical skills, some of us might begin to devalue understanding, empathy, and imagination.<sup>40</sup> But we don't have to do this if we step back and listen in different ways to patients and families. We can listen and hear when people like Linda's mother are "fed up with life" and recognize that, however uncomfortable we might think talking is, we *are* the right person, and it *is* the right time to consider advance care planning. We can remember how Linda sat and held her mother's hand as she died. And we ourselves can sit with those who have no loved ones to do this for and with them.<sup>41</sup> More fundamentally, we can look beyond Linda's regret and distress and help families and communities develop ambitions beyond Kellehear's "healthy dying."<sup>42</sup>

Death is an inevitable part of the cycle of life. Clinicians have a duty to at least not make death worse and preferably to make it better for patients and families. If we personalize our listening and really hear patients and families, we can help make deaths as personal and even good as lives can be.

## References

1. Field RA, Soar J, Nolan JP. Epidemiology and outcome of cardiac arrests reported in the lay-press: an observational study. *J R Soc Med*. 2011;104(12):525-531.
2. Sehatzadeh S. Cardiopulmonary resuscitation in patients with terminal illness: an evidence-based analysis. *Ont Health Technol Assess Ser*. 2014;14(15):1-38.
3. Jones K, Garg M, Bali D, Yang R, Compton S. The knowledge and perceptions of medical personnel relating to outcome after cardiac arrest. *Resuscitation*. 2006;69(2):235-239.
4. Hetzler PT, Dugdale LS. How do medicalization and rescue fantasy prevent healthy dying? *AMA J Ethics*. 2018;20(8):E766-E773.
5. Resuscitation Council (UK). DNACPR model forms and recommended standards for recording decisions. <https://www.resus.org.uk/dnacpr/do-not-attempt-cpr-model-forms/>. Accessed February 23, 2019.
6. Mawer C. Primary care staff knowledge of CPR survival rates. In: *Abstracts of the 9th World Research Congress of the European Association of Palliative Care (EAPC)*; June 9-11, 2016; Dublin, Ireland. Abstract P299. <https://journals.sagepub.com/doi/pdf/10.1177/0269216316646056>. Accessed November 20, 2018.
7. Kjørstad OJ, Haugen DF. Cardiopulmonary resuscitation in palliative care cancer patients. *Tidsskr Nor Laegeforen*. 2013;133(4):417-421.
8. Mawer C. Cardiopulmonary resuscitation can be futile and sometimes worse in dying patients. *BMJ*. 2014;349:g4584.
9. Compassion in Dying website. <https://compassionindying.org.uk>. Accessed August 23, 2018.
10. Perkins GD, Griffiths F, Slowther AM, et al. Do-not-attempt-cardiopulmonary-resuscitation decisions: an evidence synthesis. *Health Serv Deliv Res*. 2016;4(11):1-154.
11. Morrison LJ, Kierzek G, Diekema DS, et al. Part 3: ethics: 2010 American Heart Association Guidelines for cardiopulmonary resuscitation and emergency cardiovascular care. *Circulation*. 2010;122(18)(suppl 3):S665-S675.
12. Oczkowski SJW, Mazzetti I, Cupido C, Fox-Robichaud AE; Canadian Critical Care Society. Family presence during resuscitation: a Canadian Critical Care Society position paper. *Can Respir J*. 2015;22(4):201-205.
13. Lederman Z. Family presence during cardiopulmonary resuscitation: evidence-based guidelines? *Resuscitation*. 2016;105:e5-e6.
14. American Heart Association. Part 2: ethical aspects of CPR and ECC. *Circulation*. 2018;102(suppl 1):I-12-I-i-21.
15. Bossaert LL, Perkins GD, Askitopoulou H, et al; Ethics of Resuscitation and End-of-Life Decisions Section Collaborators. European Resuscitation Council guidelines for resuscitation 2015: section 11. The ethics of resuscitation and end-of-life decisions. *Resuscitation*. 2015;95:302-311.
16. Vincent C, Lederman Z. Family presence during resuscitation: extending ethical norms from paediatrics to adults. *J Med Ethics*. 2017;43(10):676-678.

17. Oczkowski S. Family presence during resuscitation: an ethical analysis. McMaster University.  
[http://www.royalcollege.ca/portal/pls/portal/!PWEB\\_PORTAL.wwwpob\\_page.show?\\_docname=2211900.PDF](http://www.royalcollege.ca/portal/pls/portal/!PWEB_PORTAL.wwwpob_page.show?_docname=2211900.PDF). Accessed November 20, 2018.
18. De Stefano C, Normand D, Jabre P, et al. Family presence during resuscitation: a qualitative analysis from a national multicenter randomized clinical trial. *PLoS One*. 2016;11(6):e0156100.
19. Lederman Z, Garasic M, Piperberg M. Family presence during cardiopulmonary resuscitation: who should decide? *J Med Ethics*. 2014;40(5):315-319.
20. Oczkowski SJ, Mazzetti I, Cupido C, Fox-Robichaud AE. The offering of family presence during resuscitation: a systematic review and meta-analysis. *J Intensive Care*. 2015;3(1):41.
21. Flanders SA, Strasen JH. Review of evidence about family presence during resuscitation. *Crit Care Nurs Clin North Am*. 2014;26(4):533-550.
22. Jabre P, Tazarourte K, Azoulay E, et al. Offering the opportunity for family to be present during cardiopulmonary resuscitation: 1-year assessment. *Intensive Care Med*. 2014;40(7):981-987.
23. Bhanji F, Finn JC, Lockey A, et al. 2015 International consensus on cardiopulmonary resuscitation and emergency cardiovascular care science with treatment recommendations. Part 8: education, implementation, and teams. *Circulation*. 2015;132(16)(suppl 1):S242-S268.
24. Shuvy M, Morrison LJ, Koh M, et al; Rescu Epistery Investigators. Long-term clinical outcomes and predictors for survivors of out-of-hospital cardiac arrest. *Resuscitation*. 2017;112:59-64.
25. Miller W, Levy P, Lamba S, Zalenski RJ, Compton S. Descriptive analysis of the in-hospital course of patients who initially survive out-of-hospital cardiac arrest but die in-hospital. *J Palliat Med*. 2010;13(1):19-22.
26. British Medical Association; Resuscitation Council; Royal College of Nursing. Decisions relating to cardiopulmonary resuscitation. Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing. 3rd ed (1st rev).  
<https://www.resus.org.uk/EasySiteWeb/GatewayLink.aspx?allid=16643>. Published 2016. Accessed November 20, 2018.
27. Berry P. Why did that man receive CPR?—an imaginary inquiry. *Illusions of Autonomy*. January 16, 2015.  
<https://illusionsofautonomy.wordpress.com/2015/01/16/why-did-that-man-receive-cpr-an-imaginary-inquiry/>. Accessed November 20, 2018.
28. Berry P. Why did that man receive CPR?—part 2. *Illusions of Autonomy*. January 22, 2015. <https://illusionsofautonomy.wordpress.com/2015/01/22/why-did-that-man-receive-cpr-part-2/>. Accessed November 20, 2018.
29. Berry P. Why did that man receive CPR?—part 3. *Illusions of Autonomy*. January 30, 2015. <https://illusionsofautonomy.wordpress.com/2015/01/30/why-did-that-man-receive-cpr-part-3/>. Accessed August 23, 2018.

30. Drazen JM, Yialamas MA. Certain about dying with uncertainty. *N Engl J Med*. 2017;377(3):208-209.
31. Ofri D. *What Doctors Feel: How Emotions Affect the Practice of Medicine*. Boston, MA: Beacon Press; 2013.
32. NHS Wales. Talk CPR—discuss DNACPR. <http://talkcpr.wales>. Accessed August 22, 2018.
33. National POLST paradigm. About. <http://polst.org/about/>. Accessed August 22, 2018.
34. Interior Health. Making the tough decisions. <https://www.interiorhealth.ca/YourCare/PalliativeCare/ToughDecisions/Pages/default.aspx>. Accessed August 22, 2018.
35. Resuscitation Council. ReSPECT: recommended summary plan for emergency care and treatment. <https://www.respectprocess.org.uk/>. Accessed August 22, 2018.
36. Venkatesan S, Saji S. Graphic medicine and the limits of biostatistics. *AMA J Ethics*. 2018;20(9):E897-E901.
37. Schwarze ML, Taylor LJ. Managing uncertainty—harnessing the power of scenario planning. *N Engl J Med*. 2017;377(3):206-208.
38. Manek N. One dying patient taught me that doing nothing can be brave. *Guardian*. September 22, 2016. <https://www.theguardian.com/healthcare-network/2016/sep/22/dying-patient-taught-me-doing-nothing-brave>. Accessed November 20, 2018.
39. Kumar A, Allaudeen N. To cure sometimes, to relieve often, to comfort always. *JAMA Intern Med*. 2016;176(6):731-732.
40. Day J. *Dr Kiernan Sweeney* [video]. <https://youtu.be/3TignNvHNx4?t=140>. Uploaded November 6, 2012. Accessed September 5, 2018.
41. Mawer C. Natural death: Patrick and Edith. *DrCaroMawer*. October 21, 2018. <http://drcaromawer.com/natural-death>. Accessed February 23, 2019.
42. Kellehear A. Is “healthy dying” a paradox? Revisiting an early Kastenbaum challenge. *Omega (Westport)*. 2014-2015;70(1):43-55.

**Caroline Mawer, MRCGP, MBBS, MSc, MFPH** is a physician and multimedia artist who has been interested in patients’ last years of life since her first job working with AIDS patients in the years before effective treatments were discovered. She has cared for patients in Siberian tuberculosis prisons, on the island of Montserrat, and in the United Kingdom. Time with her with her terminally ill father helped shape her orientation to practice.



**Citation**

*AMA J Ethics.* 2019;21(5):E461-469.

**DOI**

10.1001/amajethics.2019.461.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

## VIEWPOINT

### How Should One Live Everlasting Life?

Rachel F. Harbut

#### Abstract

New and emerging life-extension technologies require careful consideration of ethical implications related to resource scarcity and justice, prompting an analysis of what, if anything, is intrinsic to experiences we define as human. Furthermore, extended lifespans suggest the importance of reinterpreting traditional roles of health care professionals as the needs of patients, communities, and clinicians shift.

#### Reanimation and Life-Prolonging Technologies

In 2018, reputable news outlets and tabloids alike sensationalized a Yale School of Medicine neuroscience research group's project.<sup>1-5</sup> Described repeatedly as having developed a method for "reanimation," the group, led by Dr Nenad Sestan,<sup>6</sup> used pig brains from local slaughterhouses—not to restore formerly deceased neural tissue to fully functioning capacity but to further their research on a comprehensive, global map of neural connections.<sup>7</sup> While Yale's BrainEx technology is not currently intended to be used as a clinical intervention, other research groups are interested in human reanimation,<sup>8</sup> as just one of many methods being explored to prolong human lifespans.<sup>9,10</sup> More mainstream approaches aimed at achieving similar life-extending outcomes rely on pharmaceutical treatments and genetic therapies<sup>11</sup> to maintain and repair biological system functions, while other solutions envision longer lives in terms of various degrees of human-machine interfaces ranging from repair nanobots, which would live in the body,<sup>12</sup> to uploading brains to the digital cloud.<sup>13</sup>

Although the pursuit of eternal life is a long-standing, pervasive theme in folklore and entertainment, the clinical and ethical implications of significantly extended humans lifespans<sup>14</sup> are as complex as they are numerous. Some of these implications, especially those relating to issues of resource scarcity and distributive justice, suggest the importance of inquiry into whether and how traditional roles of health care professionals will change.

#### Select Ethical Implications of Life-Prolonging Technologies

*Resource scarcity.* Scarcity of resources, such as food and clean water, would likely only be exacerbated by the increasing demands of populations growing due to the adoption of life-prolonging technologies.<sup>15</sup> While some argue that these fears are unfounded,<sup>16,17</sup>

critics are more likely to present ways in which environmental pressures could be lessened or circumvented altogether. Some solutions propose balancing quality of life and quantity of life—by choosing between extending one’s own lifespan or producing offspring, for example.<sup>18</sup> Beyond these accommodation strategies, proponents of extension technologies offer solutions requiring the alteration of resource production and fully changing the structure of national economies.<sup>19</sup>

*Justice.* Critics of life-extending technologies might question how, if at all, their distribution would be regulated. This issue of *justice*,<sup>20</sup> which is particularly well imagined in science fiction,<sup>21</sup> asks us to consider which members of society should have access to these technologies. Critics cite current economic inequalities between less and more developed nations,<sup>20</sup> reminding us that life-extending technologies would most likely not be inexpensive interventions. High costs often associated with desirable novel technologies might restrict their access to the wealthiest and most powerful members of society, further widening divides between socioeconomic groups.<sup>22</sup> Many emerging life-extension technologies promise healthier—not merely longer—lives, allowing for fundamentally different ways of existing for those wealthy enough to be able to afford these interventions. As evidenced by the continuing debate over physician-assisted death,<sup>23</sup> modern medicine is deeply divided over how it understands and approaches care at the end of life. The medicalization of death<sup>24</sup> seeks often to escape the end of life at all costs<sup>25</sup>; it is possible to envision a culture in which wealthier populations with access to life-prolonging technologies might feasibly be able to delay death indefinitely. In such a scenario, society would have to consider questions of whether and how to potentially end indefinitely healthy lives.

### **Death and Spiritual Value**

Human lifespans extended beyond the *limits of what was once considered natural* necessarily call for reconsideration of traditional, cultural, and personal values and beliefs. We might, for example, take a utilitarian approach to life-extension technologies, considering the tensions among competing interests to gain insight into how to balance risks and benefits and thereby generate the most good for the most people. Such assessments would likely differ in terms of which circumstances or theories best inform us about how to optimize an individual’s life satisfaction or collective human benefit. Leon Kass argues that parts of human life—such as love, aspirations, suffering, and concepts of moral excellence—would necessarily be altered if there were no fear of mortality, because there would be no heightened sense of appreciation or urgency.<sup>26</sup> If postponing death altered our conception of death as a human experience, it would likely have implications for how we cope with death physically, ethically, and spiritually, for example. Given that a large proportion of the 76% of Americans<sup>27</sup> and 84% of the global population<sup>28</sup> who affiliate themselves with a religious tradition draw on religious ideas to attempt to explain death or the meaning of life in some way,<sup>29</sup> changes in our understandings of death’s inevitability would likely influence the roles faith systems play in helping us cope with it.

## Health Care as an Enterprise

If life-prolonging technologies, such as reanimation techniques, see widespread implementation, they would likely change public understanding not only of professional caregiving but also of the purpose and uses of health care. Over time, the focus of clinical roles could shift from emphasizing end-of-life care and chronic disease management to a more proactive approach relying heavily on early diagnostic testing and preventive interventions—from treating symptoms to curing underlying causes.<sup>30,31</sup> A lifespan unthreatened by health concerns associated with traditional age progression would probably require significant medical advances to reduce the likelihood of disease transmission. However, prolonged lifespans are a reminder that health care systems are already at their limits and that health care professionals are already overworked. Burnout would likely increase along with difficulties in achieving the minimum level of satisfaction required for professionals to faithfully uphold their responsibilities. These changes would likely impact patient-physician relationships as well as health outcomes.

## Conclusion

Ethical concerns about new and emerging technologies that could significantly extend human lifespans generally focus on their potential impact on individuals and the permissibility of providing such treatment options. Because these technologies might also prompt us to assess and balance interests of different individuals and groups, given resource and production limitations, life-extension technologies provoke profound conversations about the nature and value of traditional conceptions of humanity.

## References

1. Powell CS. Creepy “brain in a bucket” study spurs medical, ethical debates. *NBC News MACH*. May 16, 2018. <https://www.nbcnews.com/mach/science/creepy-brain-bucket-study-sparks-medical-ethical-debates-ncna874711>. Accessed July 9, 2018.
2. LaSane A. “A living hell” —critics fear Yale scientist’s breakthrough in brain reanimation. *Outer Places*. May 7, 2018. <https://www.outerplaces.com/science/item/18402-yale-brain-reanimation>. Accessed July 9, 2018.
3. Ghosh P. Ethics debate as pig brains kept alive without a body. *BBC News*. April 27, 2018. <https://www.bbc.com/news/science-environment-43928318>. Accessed July 9, 2018.
4. Johnson S. Scientists successfully reanimate the brains of decapitated pigs. *Big Think*. May 7, 2018. <https://bigthink.com/stephen-johnson/scientists-successfully-reanimate-the-brains-of-decapitated-pigs>. Accessed July 9, 2018.
5. Knapton S. Yale experiment to reanimate dead brains promises “living hell” for humans. *Telegraph*. May 6, 2018. <https://www.telegraph.co.uk/science/2018/05/06/yale-experiment-reanimate-dead-brains-promises-living-humans/>. Accessed July 9, 2018.

6. Yale School of Medicine. Sestan lab: research interests. <https://medicine.yale.edu/lab/sestan/research/>. Accessed October 12, 2018.
7. Stannard E. Yale neuroscientist keeps pigs' brains alive outside of bodies. *New Haven Register*. May 2, 2018. <https://www.nhregister.com/news/article/Yale-neuroscientist-keeps-pigs-brains-alive-12879376.php>. Accessed July 10, 2018.
8. ReAnima. About us. <https://reanima.tech/about/>. Accessed November 9, 2018.
9. Cha AE. Sparking fears of a zombie apocalypse: controversial study aims to "reanimate" the brain dead. *Washington Post*. May 24, 2016. [https://www.washingtonpost.com/news/to-your-health/wp/2016/05/24/sparking-fears-of-a-zombie-apocalypse-controversial-study-aims-to-reanimate-the-brain-dead/?noredirect=on&utm\\_term=.e89502425b0d](https://www.washingtonpost.com/news/to-your-health/wp/2016/05/24/sparking-fears-of-a-zombie-apocalypse-controversial-study-aims-to-reanimate-the-brain-dead/?noredirect=on&utm_term=.e89502425b0d). Accessed October 10, 2018.
10. Marshall J. Life extension research: an analysis of contemporary biological theories and ethical issues. *Med Health Care Philos*. 2006;9(1):87-96.
11. Lucke JC, Herbert D, Partridge B, Hall WD. Anticipating the use of life extension technologies. *EMBO Rep*. 2010;11(5):334-338.
12. Poutintsev F. Nanorobots might hold the key towards radically extended life span. *Predict*. August 4, 2018. <https://medium.com/predict/nanorobots-might-hold-the-key-towards-radically-extended-life-span-a4a0cbf10284>. Accessed February 20, 2019.
13. Regalado A. This startup wants to kill you and upload your brain to the cloud. *Business Insider*. March 13, 2018. <https://www.businessinsider.com/this-startup-wants-to-upload-your-brain-to-the-cloud-but-it-has-to-kill-you-first-2018-3>. Accessed February 20, 2019.
14. Dong X, Milholland B, Vijg J. Evidence for a limit to human lifespan. *Nature*. 2016;538(7624):257-259.
15. Cull A. Longevity will lead to overpopulation—we need to consider our options now. *Institute for Ethics and Emerging Technologies Blog*. July 4, 2015. <https://ieet.org/index.php/IEET2/more/cull20150704>. Accessed February 20, 2019.
16. Fight Aging. Overpopulation: not a problem now, and never will be. <https://www.fightingaging.org/archives/2006/09/overpopulation/>. Published February 24, 2017. Accessed October 12, 2018.
17. Gavrilov LA, Gavrilova NS. Demographic consequences of defeating aging. *Rejuvenation Res*. 2010;13(2-3):329-334.
18. Davis JK. Life-extension and the Malthusian objection. *J Med Philos*. 2005;30(1):27-44.
19. Rutherford D. Malthus and three approaches to solving the population problem. *Population*. 2007;62(2):213-237.
20. Pijnenburg MA, Leget C. Who wants to live forever? Three arguments against extending the human lifespan. *J Med Ethics*. 2007;33(10):585-587.

21. Overpopulation. *Science Fiction Encyclopedia*. <http://www.sf-encyclopedia.com/entry/overpopulation>. Published August 12, 2018. Accessed November 6, 2018.
22. Harris J. Essays on science and society: intimations of immortality. *Science*. 2000;288(5463):59.
23. Quill TE, Sussman B. Physician assisted death. Hastings Center Bioethics Briefings. <https://www.thehastingscenter.org/briefingbook/physician-assisted-death/>. Accessed February 20, 2019.
24. Hetzler PT 3rd, Dugdale LS. How do medicalization and rescue fantasy prevent healthy dying? *AMA J Ethics*. 2018;20(8):E766-773.
25. Waldrop DP. Denying and defying death: the culture of dying in 21st century America. *Gerontologist*. 2011;51(4):571-576.
26. Kass L. L'Chaim and its limits: why not immortality? *First Things*. 2001;(113):17-24.
27. Jones RP, Cox D. America's changing religious identity. *PRRI*. September 6, 2017. <https://www.prri.org/research/american-religious-landscape-christian-religiously-unaffiliated/>. Accessed November 4, 2018.
28. Liu J. The global religious landscape. *Pew Research Center Forum on Religion and Public Life*. December 18, 2012. <http://www.pewforum.org/2012/12/18/global-religious-landscape-exec/#>. Accessed November 4, 2018.
29. Varisco DM. The end of life, the ends of life: an anthropological view. *J IMA*. 2012;43(3):203-207.
30. Koshland DE Jr. Immortality and risk assessment. *Science*. 1987;236(4799):241.
31. Klatz R. The benefits of immortality. *Futurist*. 2002;36(1):49-51.

**Rachel F. Harbut** is a fourth-year undergraduate at Loyola University of Chicago in Chicago, Illinois, where she studies molecular and cellular neuroscience and philosophy with a concentration in bioethics. During the summer and fall of 2018, she was an intern for the American Medical Association's Ethics Group.

#### **Citation**

*AMA J Ethics*. 2019;21(5):E470-474.

#### **DOI**

10.1001/amajethics.2019.470.

#### **Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**Copyright 2019 American Medical Association. All rights reserved.  
ISSN 2376-6980**