

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.¹ 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,² 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.³ In 1967, while the first heart transplant was being performed by Christiaan Barnard (1922-2001) in South Africa,⁴ Kolff worked to develop an artificial heart for humans.³ At the same time, Michael DeBakey (1908-2008) was developing the first external heart pump, now known as the left ventricular assist device (LVAD).⁵ And in 1976, Robert Bartlett (1939-), inventor of extracorporeal membrane oxygenation (ECMO), reported his first neonatal survivor.⁶ 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.⁷ 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.⁸ 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.⁹ Furthermore, it is estimated that only about half of adult patients placed on ECMO for cardiac failure survive.⁹ 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.

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