AMA Journal of Ethics®

May 2019, Volume 21, Number 5: E387-393

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.[1-3] 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.[4] Had Dr M's team estimated JL's risk of mortality on VV-ECMO using one of the handful of published decision support tools,[5,6] 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.[7] 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.[8] As a result, most patients bridging to transplant remain on ECMO for an average of 1 to 2 weeks, regardless of their outcome.[3] 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.[9,10]

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.[11] 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."[11] 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.[12] 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.[13-15]

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.[16,17] 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.

ISSN 2376-6980