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Finding a Bridge to Somewhere: An Ethical Framework for Veno- Arterial Extracorporeal Membrane Oxygenation Decisions

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Abstract

Extracorporeal membrane oxygenation (ECMO) is an established therapy for the management of acute cardiopulmonary failure. A substantial concern when considering ECMO therapy is whether the patient will recover enough function to be weaned from support and survive to discharge. The concept of “a bridge to nowhere” is where a patient is supported on a therapy for which there is no hope for recovery and would, by definition, immediately die if support is discontinued—a somewhat unique concept in clinical medicine, but often considered when considering short-term mechanical support for acute heart and/or lung failure. Much like initiating mechanical ventilator support in patients who have no chance of meaningful recovery, there are concerns about embarking on or continuing with ECMO support in patients in whom recovery is unlikely. The purpose of this chapter is to review the ethical foundation and principles to support the clinical decision-making process when there are concerns regarding the initiation, continuation, or withdrawal of this highly invasive, resource-intensive life-support technology. Specific attention will be given to well-established principles of the ethical application of advanced life support and how to appropriately limit offering or continuing therapies for which meaningful outcomes are unlikely or further support is considered futile.

Keywords: ethics, ECMO, ECLS, extra-corporeal membrane oxygenation, palliative care, morality, end-of-life, futility

1. Introduction

Veno-arterial extracorporeal membrane oxygenation (VA-ECMO) has been widely described as a bridge to recovery for acute reversible illnesses, transplantation, ventricular assist devices (VADs), or when the prognosis of patients with cardiorespiratory failure is uncertain [1–4]. Advancement of this technology has increased accessibility of ECMO and mobile ECMO teams, leading to several ethical issues of VA-ECMO. Few authors in the ethics literature delineate veno-arterial (VA) from veno-venous (VV) extracorporeal membrane oxygenation (ECMO) given the similarities among these technologies and related ethical issues (e.g., when to initiate or withdraw ECMO). However, for purposes of this chapter, the focus will

be on ethical analyses particular to VA-ECMO situations, illustrated through cases and ethical dilemmas we have encountered in the clinical setting.

Because of the distinct feature of VA-ECMO in providing both gas exchange and circulatory support through central or peripheral cannulation, it bears inherent potential problems, including, but not limited to, “separate perfusion of the lower and upper part of the body (watershed phenomenon), distention of the left ventricle (LV), and resulting pulmonary edema due to increased afterload produced by ECMO” [5]. Although close monitoring, optimizing vasopressor and inotropic support, the use of multiple cannulas, fluid offloading, alternative circuit configurations [e.g., veno-venous-arterial (VVA)], and adherence to guidelines [e.g., extra-corporeal life support organization (ELSO)], can be beneficial for minimizing risks and maximizing peripheral and central VA-ECMO support, patients are nonetheless more susceptible to clinical risks, which contribute to further ethical examination. Some studies (particularly in the pediatric literature), however, have shown no difference in complication rates between VA-ECMO and VV-ECMO [6].

Although, as Pavlushkov et al. [5] describe, the use of *central* VA-ECMO, is a particularly invasive approach for cardiorespiratory support that contributes to heightened risks of infection, injury, and bleeding as it requires chest opening (sometimes for days) for providing optimal perfusion flow. As the authors note, this type of ECMO is reserved for those patients, who will imminently die. Given the invasiveness and inherent levels of risk of central and peripheral VA-ECMO, it is critical for healthcare providers, patients, and families to engage in shared decision-making based on a clear understanding of the treatment goals, and the values and interests of the patient regarding advance care planning.

Thus, an ethics coherence framework, and not simply a set of guidelines, principles, or policies, is required for evaluating the complex ethical issues of ECMO, while guiding critical decisions in its initiation, management, and withdrawal of this technology, particularly given the potential for serious risks and unanticipated events. Specifically, we will be utilizing a theoretical model that builds upon the work of Nelson and others, known as the Wide Reflective Equilibrium (WRE), while appropriately integrating narrative approaches within this model that enhances the WRE and other ethical models for reflection and decision-making.

To begin, it is critical to identify and understand the ethics of ECMO as presented in the literature and based on real clinical scenarios. And while there is consistency among authors who have written about this subject matter, this is not to say the types of ethical issues and dilemmas presented are exhaustive; as ECMO technology, research, and clinical care becomes more widespread and advanced, it is likely we will encounter ethical issues unidentified by current experts. The WRE, however, will be a useful model for when new information needs to be considered for ethical decision-making. The flexibility and ability to accommodate new information makes the WRE an attractive model for ethicists and healthcare professionals alike. Following a brief review of the literature and descriptions of the WRE, we will analyze two scenarios based on actual clinical cases to illustrate the value of the WRE for enhancing communication and decision-making among healthcare teams, patients, and their families.

2. A bridge to nowhere

Although ECMO is better known and valued among healthcare teams as a beneficial stabilizing technology that is able to prolong artificial cardiac and respiratory

support external to the body, allowing patients to heal, if not fully recover, from traumatic injuries and diseases, it can be beneficial for giving patients and families more time with each other and for collective decision-making. However, decision-making is at the heart of great ethical controversies from points of initiation to withdrawal of ECMO. Courtwright et al. [7] explain the most common ethical issues involving disagreements among and between healthcare teams, patients, family, and other surrogates, particularly when confronted with decisions about the continuation or withdrawal of ECMO.

When patients, who have started ECMO, are unable to be bridged to recovery, transplant, or destination device therapy, this “ethically challenging and emotionally charged situation is sometimes referred to as a ‘bridge to nowhere,’ with obvious implications for the patient, his or her family, the caregivers, the hospital, and the healthcare system” [1]. These ethical issues are further exacerbated by a need for evidence-based scientific research taking into account patients’ comorbidities and the use of ECMO, improved scoring systems for determinations of survivability, reliable and consistent brain death evaluation and neurological testing, comprehensive advanced care planning prior to initiating ECMO, and improved availability, accessibility, and management of ECMO resources, particularly for disadvantaged populations. Essentially, since patients can be kept “alive” almost indefinitely while on VA-ECMO (particularly, given the lack of key tools for medical decision-making—like determining brain death on ECMO), much emphasis is placed on determining those patients who have the greatest chance of survival, either being weaned or transitioned to transplant or a long-term support device. The primary goal of such scoring systems is not just to optimize the appropriate use of an expensive and resource intensive therapy, but to help decision-makers prevent initiation of therapy in those patients for whom there is fundamentally, no hope of meaningful survival. While such concepts can be vague and subjective, the approach is not all that much different than why certain therapies (i.e., major surgery) are not offered in patients with advanced cancers or end-stage heart disease. Basically, the progress is so poor, however, with ECMO, advances in therapy and experiences are occurring at such a rapid pace that such threshold is hard to define.

For example, Makdisi and Wang [2], citing Bartlett and Gattinoni [8] wrote “... some helpful and score systems have been presented to assess the probability of survival with extracorporeal life support, using multivariate analysis of comorbidity, the history of lung or cardiac failure, and additional organ dysfunction, unfortunately there is no definitive measure of heart or lung failure to identify 80% mortality risk.” Without definitive measurements, these places undue burdens on healthcare teams when trying to communicate prognosis and treatment options, including when treatment is no longer beneficial to the patient’s survivability. This lack of certainty has further implications for non-beneficial treatment policies, the process of informed consent, determinations of patient capacity for decision-making, palliative care resources, DNR orders, hospice care, and other spiritual, social, and emotional resources for patient and family and/or surrogate. Thus, the ethical issues are more complex than “simply” disagreements about continuing or stopping ECMO; there are several decisions to be made, and, in most cases, patients, family, and surrogates are not well-prepared for such decision-making due to several factors, including, but not limited to, poor advance care planning, miscommunication, and unexpected confounding issues (e.g., cardiac arrest, sepsis, etc.).

One of the greatest difficulties that families experience when faced with a loved one, who is doing poorly on ECMO, is helping healthcare providers understand what the limits of what care patient would want—how much they want to live. Providers try to remain objective and unbiased, but often their own experiences

and insights help pave a direction. For example, in the context of facing truly imminent death of a loved one, and often someone, who was previously perceived to be relatively young and healthy (which is why ECMO might have been offered in the first place), familiar members must very quickly prepare and come to terms with the reality that their loved one might not even survive. If a patient is on ECMO, especially if they are experiencing complications (which are quite common), then conversations about leg and digit amputations and major disfiguring surgery often occur. Even discussions about temporary therapies as further bridges to what can be perceived as a long and difficult recovery are unclear and difficult, such as the need for dialysis, feeding tubes, tracheostomies, prolonged stays for recovery in long-term care facilities, or nursing homes. Without a doubt, such conversations, time-sensitive and emotionally charged, and often financially difficult, topics can be very difficult to process and reconcile.

And, while the ethical issues would be less complex when patients are alert, and able to make their own decisions, there are instances where the “bridge to nowhere,” as Abrams et al. [1] describe, leave the patient in a type of limbo: without ECMO, they will not be able to interact with family and others with some quality of life at the end of life, yet ECMO is no longer beneficial for the patient’s transition to transplantation, VADs, or recovery and survivability. The question, then, is when should ECMO be withdrawn?

For Abrams et al. [1], it would be cruel and unethical to withdraw ECMO without the consent of the patient. But what if the patient will not consent to its withdrawal? What are the implications of using ECMO when it has no direct clinical benefits, but acutely sustains the quality of one’s life, as measured by human interactions and relationships, and the ability to buy more time to make end of life plans? While we agree with Abrams et al. [1], it would be cruel and unethical to simply withdraw ECMO in such cases where patients are alert, we also argue that the prolonged use of clinically non-beneficial ECMO does not always provide a quality of life or effectively aid the patient to make end of life preparations. When the patient is awake on non-beneficial ECMO, the reality is they are terminally ill, requiring pain management, and not necessarily in a position to make critical decisions. Furthermore, the patient’s quality of life may be misunderstood by family/surrogates and healthcare professionals at the bedside; their perceptions are contrary to the actual experiences and values of the patient. Thus, it is imperative that hospitals and ECMO facilities utilize comprehensive resources for providing:

1. grief counseling for patients and families;
2. access to end of life preparations (e.g., funeral homes, burial sites, family legal representatives, etc.);
3. ongoing and direct communication about the prolonged physical, cognitive, and emotional effects of ECMO on the patient (and family/surrogate), financial costs, and the scarcity of ECMO technologies, and;
4. palliative and spiritual care, to ease social, physical, and emotional pain and suffering and to accommodate the cultural, religious, and spiritual needs of the patient.

However, this assumes that such resources are available and accessible. By having such resources, not only the burdens of prolonged non-beneficial ECMO (including financial costs, inability to serve other patients in need, etc.) are

reduced, but healthcare teams can prepare patients and families/surrogates to withdraw support and accept death without fear or resistance. While it is difficult to determine the scope of this problem, what is clear is that as ECMO is being used more frequently—especially in extreme cases—there is a growing number of patients, who are awake and alert, but are being kept immediately alive by life support for which discontinuation would result in immediate death. Even patients who take themselves off of other forms of organ replacement therapies—such as dialysis and ventilators—can live for days (if not longer, depending on the circumstances) before slowly, and often painlessly, succumbing to the consequences of the lack of organ function. The facing of immediate death is what separates removing ECMO from removing other therapies such as dialysis or even medical therapies, like chemotherapy. While the literature is sparse in this area, many providers who are involved in the care of patients requiring long-term life support with mechanical cardiac support devices (i.e., ventricular assist devices) are intimately aware of cases in which patients clearly took themselves off of support, essentially committed suicide, by removing or not replacing the power sources that such devices are dependent upon.

2.1 When surrogates disagree with the healthcare team

Ramanathan et al. [9] wrote, “Potential conflicts occur when the next of kin or the patient’s proxies and physician do not agree on treatment options, when options are scarce or unavailable, and when the options themselves are unclear because of uncertainties about the effectiveness or the duration of treatment” [9, 10]. While such events are common in medicine, in the context of ECMO, while therapy can continue for a long-term, often in the absence of clearly defined decision-making, often the decisions will be made by themselves—frankly, patients often will develop life-threatening (or ending) complications that will define an outcome regardless of objective decision-making. Massive bleeding, neurologic catastrophes, overwhelming sepsis, and infections are common in the context of ECMO and often lead to the obvious discussions of the fact that “nothing else can be done.”

Howe [11], in considering what clinicians should do if patients and/or loved ones never agree to stop treatment, wrote, “hospital authorities would stop ECMO if patients, loved ones, and clinicians won’t” and confirms our own experiences that “[P]ediatricians have told me that when children have ECMO, clinicians may have more discretion” [11]. Hospital authorities may be justified to intervene for purposes of fair resource allocation; ECMO is unavailable to patients in need due to continued use among patients, who are no longer benefiting from this limited resource. However, decision-making should not simply be about fair resource allocation. While children are often considered much more resilient than adults, the survival rates on ECMO are not that much different between adults and children, and there must be early discussions with families regarding this reality to help better manage expectations. Similar models of care and discussions are often held in the context of young children, who otherwise appear to be very much “alive,” but who are, in fact, irreversibly neurologically devastated or even brain dead.

Makdisi and Makdisi [4] explain “It is important not to force the family into making decisions that are against their beliefs and to provide them with adequate psychological support through and after the process, it is also important to understand their emotional needs, and understand the program from their perspective” [1, 12]. However, Abrams et al. [1] argue, “a strong case can be made to discontinue the intervention, with appropriate concessions of timing to the surrogates. There is no issue of emotional or physical patient suffering in that case and it is even possible, if not probably that the patient would not want his or her life prolonged in

such circumstances” [1]. So, while the healthcare team should not force decisions without support, there are limits to the extent ECMO should be used for patients, who are no longer benefitting clinically, socially, or otherwise, and are kept alive for the sake of the surrogate(s) own interests. Ongoing communication and a robust informed consent process with detailed information (e.g., harmful outcomes of prolonged ECMO use) can contribute to improved family or surrogate understanding and decision-making that is in the best interests of the patient. Unfortunately, such a comprehensive approach is not always beneficial. Shah et al. [12] suggest:

“Conversely, some may offer ‘comprehensive’ explanations inundated with technical points and statistical data incomprehensible to family members. Often, medical care in such acute situations may shift to a less desirable ‘paternalistic model’ in which the clinician is directing care rather than partnering with the patient or family acting on his behalf. These ethical dilemmas stem from the uncertainty of the outcome as well as lack of clarity on the intended treatment direction, whether bridge or lifetime support” [12].

Meltzer and colleagues [13] describe a 40-year-old Hasidic Orthodox Jewish mother of four children, diagnosed with large B-cell lymphoma, which contributes to acute heart failure and the need for ECMO treatment. Prior to treatment, discussions surrounding the potential need to withdraw ECMO were discussed early on with the patient, her family, and their rabbi. The family agreed to stop ECMO when the need arises; however, when it became clear, ECMO was no longer providing beneficial treatment, the family refused to stop the treatment. In reflecting on this case, Howe [11] explains:

We do not know why the family changed their minds. Perhaps even they didn’t know, but primarily responded to their fear the patient would die. That the family changed how they felt illustrates how unsure shared decision-making can be. The family’s experiences convey the pain all those involved in deciding to stop ECMO may feel, whether clinicians decide on their own or share the decision-making [11].

This and other similar situations reveal not only simple changes in a patient’s story or a change of mind among family and surrogates, but also how the narrative continues and develops over time with decisions and courses of action that are informed by new experiences, moral thinking, clinical information, emerging feelings of hope, and so forth. Religious, racial, cultural, emotional, and ethnic themes are common in such conflicts and must be recognized very early in the discussions. In addition, every healthcare provider who needs to be involved with such critical family (and patient) conversations must acknowledge, and prepare, for the reality that thoughts about continuing life-sustaining therapies is very much different when one is dealing with the abstract (i.e., your mother might not survive therapy and we might need to stop support) versus the impending and immediate reality (i.e., your mother is not going to survive therapy and we must consider stopping support *right now*).

Furthermore, from the example illustrated by Howe [11], it is important to understand that the patient and her family are situated in different points of time with a new set of ethical considerations. A patient and family could be well-informed and prepared for future decision-making, however, that information does not necessarily carry any meaning until a critical decision is required. The life story of the patient merely continues and is not “re-written” and the family or surrogate is not simply “changing their minds,” but are acquiring new information, i.e., the impending death of their loved one, which transforms their thoughts,

emotions, and behaviors such that decisions to forgo or withdraw treatment can be difficult and any future hope for survival is lost. Early discussions, hypothetical scenarios, and some shared decision-making (e.g., DNR orders) might prepare some patients and families, but even with such preparations they are not—at *that time*—required to make life-altering decisions or give up hope. Certainly, it may be the case that shared decision-making might be “unsure” because the healthcare team and family did maintain ongoing communication or a mutual understanding of each other’s values, thoughts, and overall interests.

However, even with the best communication, the moment treatment is no longer beneficial, it is the moment that family or surrogate decision-makers are receiving new information and expected to “do what is best or right” for the patient, despite their own emotional suffering and loss of hope. So, instead of thinking families and surrogates “change their minds,” which can elicit feelings of frustration among healthcare providers, understanding they are simply confronted with new information and need further guidance and support in decision-making (e.g., discussions about quality life *now* versus then) can alleviate frustration and lead to better outcomes. Caring for the family [8] and recognizing the difficulty of their predicament can effectively lead to a mutually supported ethical decision to withdraw ECMO and provide comfort care measures, allowing for a peaceful death of a loved one.

2.2 Disagreements among healthcare professionals and institutions

Besides the ethical difficulties of decision-making among surrogates, healthcare professionals may also encounter ethical dilemmas, when there are disagreements among team members or at the institutional level (e.g., policy disagreements). While many ethics cases focus on disagreements between the healthcare team and patients and/or family members, where miscommunication, misunderstanding, and conflicting values and interests contribute to these disagreements, similar problems can arise among healthcare professionals and institutions, particularly when new technologies or new uses for technologies emerge with unanticipated ethical issues and problems, and a lack of standards, policies, or laws to provide guidance toward resolution. Such disagreements might be motivated by or directly lead to burnout, moral distress, lack of healthcare professional autonomy, and disregard of team-based practices. Disagreements among the healthcare team involving the initiation or withdrawal of ECMO might also be related to a general lack of institutional guidance (procedures, processes, and policies), conflicts of diagnostic and prognostic opinions, and misinterpretations of patients’ cultural and moral values and interests. Ongoing communication, respect for healthcare team members, and collaborative contributions to the improvement of guidance measures (e.g., policy development), are essential for minimizing disagreements and those negative consequences that follow.

2.3 Extracorporeal CPR and DNR

Another ethical issue presented by Abrams et al. [1] involves VA-ECMO for extracorporeal CPR (ECPR), which is a more evasive and resource intensive intervention than traditional CPR that has the ability to cause undue suffering and harm to an already medically compromised patient. And ECMO, especially VA ECMO, “places the DNR order under severe conceptual strain both to the family and the physician” [9].

The prognosis for ECPR is uncertain during a cardiac arrest even when factors, such as the patient’s condition, available resources, expertise, and past patient experience of the healthcare team are known. Because the concept and application

of E-CPR (the focus of other areas of this book) are so rapidly evolving with large spectrums of potential outcomes based upon many complex circumstances, it is difficult to establish a timely and appropriate reference for objectively engaging in discussions about outcomes and prognosis. Abrams et al. [1] wrote “If the use of ECPR becomes even more widespread, there is a real concern that it would be an expected intervention for patients suffering acute cardiac arrest. If this occurs, physicians would need to incorporate ECPR into advance directive discussions, potentially requiring the development of a DNR with ECMO order.” Regardless of infrequent or limited occurrences of ECPR, it is the opinion of these authors to incorporate ECPR into advance directive discussions whenever the situation arises, including education, training, and policies that require ECPR to be a part of DNR orders or Medical Order of Life Saving Treatment (MOLST) orders. It is perplexing why healthcare teams would not be doing this advance care planning already when such planning can be reasonably done. Nevertheless, the rapid growth of the utilization of ECPR must prompt such conversations—especially, since it is a therapy that is currently not available widely, yet.

2.4 Organ preserving ECMO

Another set of ethical issues arise for those healthcare teams, who are using ECMO to preserve organs. Organ preserving extracorporeal membrane oxygenation (OP-ECMO) may be used for patients, who are already on ECMO and who become brain dead. In such cases, vital organs can be preserved for transplantation, which have obvious benefits to others who are in need of organs for survival. Dalle Ave and authors wrote, “Organ-preserving extracorporeal membrane oxygenation can benefit society by fulfilling the wishes of those who wish to donate, by making more organs available for transplantation and by saving the lives of patients in need of organs.” [14]. From a utilitarian perspective, saving several people with the viable organs of an individual, who no longer has quality of life and has irreversible loss of brain function, is a valid ethical justification.

Dalle Ave et al. [14] suggest that OP-ECMO is analogous to the continuation of mechanical ventilator for purposes of procurement. However, as these authors have also pointed out, there are challenges, similar to patients supported by ventilator, in determining brain death. Such determinations may be even more difficult given that the oxygenation process of ECMO can compromise neurological testing. Nonetheless, despite its uncertainty, a declaration of brain death holds great ethical (and legal) value in ensuring that organs are not being procured from patients who categorically are still living. However, this leads to deeper philosophical discussions as to what counts as “living” and whether brain death criteria should be used for purposes of organ procurement from patients, let alone ECMO patients. Furthermore, there is evidence in the past decade or so that patients, who were initially declared brain dead based on neurological standards, narrowly “escaped” organ harvesting by waking up prior to or during operating room preparations [15–19] or had reversible “brain death” determinations [15, 19, 20]. Although these “narrow escape” cases are few, they should give healthcare professionals pause in relying on existing brain death criteria and neurological testing. Furthermore, Dalle Ave et al. [14] have explained that ECMO can increase the potential risks of intracranial bleeding, causing undue suffering among individuals, who may have some undetected brain activity and can hasten death [14].

Given the uncertainty of determining brain death among ECMO patients, the risks of the aforementioned issues may not adequately outweigh the potential benefits of having viable organs for procurement (and this is assuming the organs

will, in fact, be viable upon procurement). With further scientific data to validate clinical tests used with any brain-injured patient, as well as those specifically on ECMO for both acute and prolonged periods of time, as well as more consistency among medical professionals in determining brain death, the threshold of uncertainty may be reduced, thus minimizing, if not eliminating, potential direct harms to patients, and subsequent emotional, social, and financial harms to their families and potential organ recipients. Nguyen [15] also adds that there have been logical and scientific inconsistencies when reasoning brain death at the bedside, as well as a general lack of understanding of the pathophysiology of the brain, where an absence of evidence of brain functions is not necessarily the equivalent to irreversible loss or death of the brain.

Furthermore, in his brief ethical assessment of care for the patient with (possible) brain death, Nguyen [15] emphasizes the importance of the physician's moral attitudes and subsequent actions to reflect caring for the patient, motivated by the inherent value of the patient as person, and not by a set of ethical rules or principles. However, Nguyen, a Catholic physician, who is guided by non-secular ethics, also argues that brain death cannot be equated with the biological death of the person; harvesting organs from brain death donors, thus, "brings about their true and premature death." His attentiveness to the inconsistencies and inadequacies of brain death determination are valuable, as is his personal moral perspective, which aligns with the teachings of Catholicism. However, for those patients for whom we can identify as brain dead (or in the future with improved research, testing, and technologies), the definition and meaning of death should be left up to the healthcare team and surviving family; hence, the need to have advance care planning and conversations much earlier, if possible, prior to the urgency of patient care, and often, subsequent paternalistic decision-making. Further challenging this concept is the very concept that "brain death" is "death" and that any continuation of medical care is medically, ethically, and legally inappropriate. Even patients who have been appropriately declared "brain death" are often kept on support for prolonged periods of time for family members to completely understand the scope of the circumstances, and even waiting for a family member to come from out of town in a few days to "buy time" is not appropriate. Such events are not uncommon and are very dependent on experienced healthcare providers appropriately managing expectations and having open, honest, and transparent conversations with families from the onset of therapy.

3. Toward an integrated approach: the wide reflective equilibrium

Bein et al. [21] wrote, "At the end of the day, we are left alone with our own 'common moral.' However, there should be a method of finding a solution for the individual patient and for his dignity in a sensible and faithful way if we understand that the medical perspective is not the only one that needs to come to a decision." Howe [11] in reflecting on Meltzer and colleagues [22], places importance on shared decision-making among healthcare professionals, patients, and their loved ones when the withdrawal of ECMO results in the patient's death despite the fact some clinicians believe such decisions are theirs alone. Reasons why clinicians may want to make the decision to stop ECMO include "from wanting to spare patients and families the exceptional pain of making the decision to reasons that are less altruistic" such as alleviating suspected guilt among family and alleviating the burdens of decision-making, assuming family may simply want the physician to decide [11].

Nevertheless, the concept of shared decision-making, making sure that patients and families have an increased sense of ownership and responsibility to make their own medical decisions that will ultimately impact both the quality and quantity of life, is becoming more common. This is especially true in area of medicine in which it is unclear of what the “best” or most appropriate decision should be and the responsibility is then placed in the hands of the patient. Nevertheless, as discussed above, some patients and families become completely paralyzed by the inability to sometimes even make basic medical decisions and will often defer to the concept of “do everything” or “do whatever you think it best.”

Such authors suggest an integrated approach, however, they do not provide one that might appropriately guide ethical decision-making, while taking into account the complex values of the healthcare team, patient, and family, as well as, the healthcare organization or system. Thus, we propose using the Wide Reflective Equilibrium (WRE), a theoretical model that builds upon contemporary philosophical theories and considerations, including narrative ethics. In the discussion of two case studies (based on features of existing clinical cases), we apply this model and illustrate its benefits in guiding pragmatic and ethical decisions prior to and during the use of VA-ECMO technology for patient care.

3.1 The wide reflective equilibrium (WRE)

The WRE is a theoretical model developed by Nielsen [23, 24] by extending the work of Norman Daniels and political philosopher Rawls [25]. This method consists of working back and forth among our judgments about particular situations, beliefs about those principles or rules that guide them, and additional considerations and beliefs relevant to the situation. The aim to find coherence by testing our beliefs against other systems of belief, moral theories, and non-moral views, revising and refining them, in a process of moral deliberation. The WRE as a model for practical ethics can be a way to recognize the value of multiple, methodologies in ethics (e.g., principlism, casuistry, and narrative) such that specific cases, theories, principles, and context (of stories or situations) matter and can contribute to the interplay of the WRE framework.

By using the WRE with an ethical situation, we work back and forth between three elements, including our initial moral judgment, background beliefs, and theories (e.g., social theory, clinical information, and legal laws), and ethical theories and principles to achieve coherence. WRE is then continually re woven in light of new knowledge or circumstances, which may alter any or all elements of the WRE. Beauchamp and Childress [26] explain that “No matter how wide the pool of beliefs, we have no reason to anticipate that the process of pruning, adjusting, and rendering coherent will either come to an end or be perfected” ([27], p. 66). Joan McCarthy writes, “On this understanding, the processes of moral deliberation are akin to scientific processes: they involve the setting up of hypotheses that are tested and modified or rejected on the basis of reasoning and experience. In turn, the aim of unifying one’s moral beliefs and background commitments is analogous to the scientific goal of achieving theoretical consistency and unity” [27].

While McCarthy shows the value of the WRE that incorporates principles into ethical decision-making, she also identifies the benefits of a narrative ethic, which draws upon “narrative concepts and methodologies drawn from literary criticism and philosophy as tools of moral understanding and assessment,” [27] and is formulated through various approaches such that individual stories are closely read, or compared to, even woven within, other stories, giving context to existing moral theories and models, serving as a theory in and of itself, or promoting the emergence of new ethical thought. McCarthy suggests that one can test various personal

narratives against various criteria similar to the way moral rules or principles are tested through the process of reflective equilibrium, and, thus, proposes a Narrative Reflective Equilibrium (NRE) to challenge and modify first person narratives. This narrative approach can be particularly useful for end of life decision-making, especially when healthcare professionals, surrogates, and others try to make sense of an incompetent patient's life story, which can reveal multiple courses of actions that are compatible with and would be "meaningful and consistent with the patient's self-conception" if she were the one deciding [27].

McCarthy shows that both principlism and narrative ethics provide important, often overlapping, ethical skills that can reinforce each other through deliberative, reflective processes that aim to achieve coherence and shared understanding [27]. Yet, the NRE is unnecessary unless we give primacy to a narrative approach over other ethical approaches under consideration. That is, the WRE is able to be a valuable model that incorporates principlism, narrative ethics, among other methodologies without be reductive to one approach or another; thus, it is unnecessary to have such a coherence model distinct from WRE. The other elements of WRE, including initial moral judgments and background beliefs and theories, including clinical and scientific facts, legal laws and policies, religious and spiritual beliefs and perceptions, and so forth are significant for not only further understanding the context of patients', caregivers', and others' stories, but also may contribute to new information that have the power to create new stories, reveal multiple courses of action based on different interpretations of stories, including alternative ethical considerations. Such new information might even be an unconsidered personal narrative that requires coherence among not just other narratives, but also among the other elements of WRE. It is this WRE that embraces narrative, as well as other ethical theories and approaches (which are themselves often embedded in narratives), which may untangle some complex ethical issues, arriving at justifiable courses of action through ongoing revision and refinement. Because, we cannot ignore the clinical, social, legal, economical, and ethical elements of VA-ECMO, a framework that recognizes these elements, as well as, patient and caregiver stories, relationships, and values, will best guide shared decision-making and perhaps find a "bridge to somewhere."

4. Finding a bridge to somewhere

To illustrate how the WRE can be a beneficial model for shared decision-making, we present two cases, followed by our ethical analysis.

4.1 Case 1

A critically ill 67-year-old female patient, M.J. presents to the cardiology team with progressive heart disease, profound cardiogenic shock, as a result of a massive acute myocardial infarction secondary to long-standing known coronary artery disease in the setting of previous coronary artery bypass surgery (CABG). As a result of a recently diagnosed, but medically treated breast cancer, she is neither a candidate for a transplant nor is a long-term ventricular assist device a reasonable option. Due to her ability to breathe on her own without ventilator support, she is on VA-ECMO without having to be in a clinically induced coma. Thus, she is alert, at times able to interact with family, but unfortunately has a poor prognosis and would die without ongoing ECMO support. The support is non-beneficial in that it will not be an effective bridge to survival, but simply a means to temporarily sustain a terminal life. M.J. is scared of dying, and feels as though if she gives up now, she

will be a disappointment to her loved ones. Because of the patient's insistence to keep living as long as possible, the healthcare team, family, and those closest to the patient are uncomfortable with removing ECHO. The healthcare team sees current benefit in giving the patient time to make end of life plans and spend time with family despite the financial burdens of ECMO. The issue of this case, however, is that M.J. refuses to listen to the healthcare team about her impending prognosis and to consider end of life planning in the event she is no longer able to make decisions.

Although the case of M.J. involves the use of VA-ECMO for a "bridge to nowhere," the healthcare team would like to see this not as a futile endeavor but one that bridge to a peaceful closure to life. For the multitude of patients who do not get to choose their deaths, M.J. has an opportunity to make end of life plans based on her values and needs, and yet the healthcare team is struggling as to why she is not engaged in such planning. When looking at this case through the lens of WRE, the initial moral judgment of the healthcare team may look like "M.J. should remain on ECMO." And, as simply put, there is consensus that removing ECMO from M.J. at this point in time would be unethical given that it is providing benefit by caring for her end of life needs, e.g., seeing family; removing ECMO could lead to moral distress among healthcare professions, emotional and social harm to M.J. and her family, potential legal liability, and social distrust. Looking at the benefits versus the risks of financial burden for family, lack of ECMO access for other patients, and amount of teamwork required to sustain M.J.'s life (i.e., "manpower" hours), as well as institutional considerations that may require alternative actions, e.g., transfer of care, before enacting non-beneficial treatment policies for the withdrawal of ECMO.

4.1.1 Initial moral judgment

In the event M.J. becomes incapacitated, we may ask the question, "For how long should M.J. remain on ECMO?" This new scenario and question prompts new moral judgments and ethical, clinical, legal, and social considerations such that "M.J. should not remain on ECMO due to progression of disease and unavoidable harm." This judgment, loaded with clinical and social requirements, leads to concerns about surrogate decision-making and refusal of withdrawal, DNR and ECPR, and OP-ECMO. If M.J.'s family supports her decision for continuing life support even when she no longer has capacity, this will lead to a complex dilemma for the healthcare team and family. The initial moral judgment, then, for the healthcare team will be based on their ability to sustain a quality of life for M.J.

4.1.2 Background beliefs and theories

Before delving into the ethical theories and principles, an analysis of multiple factors, i.e., background beliefs, including existing policies, laws, family beliefs and social theory, clinical information, etc., is essential to work back and forth among the WRE elements. Healthcare professionals are not required to provide futile treatment, and thus, many institutions have non-beneficial treatment or futility policies. Of course, the notion of futility is highly debated and this case, in point, shows how the concept of what is or is not beneficial may depend on the context of the situation (i.e., alert patient, family at the bedside). These conceptual considerations are valuable when working through the WRE, as well as the pragmatic considerations such that medical evidence, laws, and policies are considered. If M.J.'s surrogate or next of kin refuses to withdraw ECMO, the healthcare team may enact a non-beneficial treatment policy with the option to transfer care to another facility that may accept M.J.

Here is where the WRE pushes the healthcare team, ethics committee, or general counsel to find out if transfer of care is even possible, i.e., willingness, accessibility, and availability of other institutions. That is, M.J. may not be mobile, facilities may be at full capacity, they may not take cases like M.J.'s, or they may not have the team to support ECMO. If transfer of care is not possible, legal action is most likely the next course of action. To further complicate the matter, decisions of DNR and whether ECPR should be initiated must also be considered. While ECPR may sustain life, even for a short time, M.J. is still terminal and such interventions will not lead to clinically beneficial results. DNR discussions are essential prior to patients becoming incapacitated; however, given that option is no longer viable, such discussions need to occur with M.J.'s surrogate decision-maker. These policies, standards, and theoretical concepts (e.g., futility), should be considered in light of ethical theories and principles under the WRE model.

4.1.3 Ethical theories and principles

In light of clinical facts, existing policies, and standards, the healthcare team feels that it is best to withdraw support based on ethical considerations. By keeping M.J. "alive" on ECMO (and equally its removal) can violate the ethical principle of non-maleficence ("do no harm"), as would initiating CPR. Quality of life was understood as M.J.'s ability to interact with her family although she understood that ECMO was a non-beneficial treatment. However, due to her current state, and progressive declining health, she no longer has quality of life, and may potentially suffer if she still has brain function with continued ECMO use. Thus, the healthcare team believes it is their ethical obligation to withdraw all support so as to do no harm, despite allowing death to occur, which, to some, is counter to the goals of medical care. In addition, there are justice issues with this scenario; it is unjust utilizing a needed public resource for a patient who is no longer benefitting from that resource, especially when availability and accessibility is limited. Furthermore, the family is accruing a potential financial burden, and may not be fully cognizant of the economic costs of keeping a person alive because they are not wanting to let her go or violate her autonomous wish to be kept alive. The economic burdens, in their mind, may not outweigh their unrelenting desire to keep her alive and abide by her wishes. Besides principle-based considerations, the narrative approach is also valuable in this scenario to better understand the family's interests and values, and whether they are genuinely aware of M.J.'s current state.

Furthermore, M.J.'s story may further reveal to the family/surrogate decision-maker and healthcare team that her autonomous wish to be kept alive was only intended to be limited for when she was alert and able to interact with her surroundings. If she and her family's insistence on "doing everything possible" with continued ECMO support and refusal of DNR orders (a concept that, in itself, is somewhat misleading since the patient is, by definition, full cardiopulmonary life-support. As such, the term DNR in the setting of ECMO is often used to place objective limitations on escalation of support—such as initiating or escalating doses of vasoactive medications, new antibiotics, or performing additional invasive procedures) is motivated by cultural, religious, spiritual, or philosophical beliefs, these beliefs would then be brought into the WRE framework and pushing us to move back and forth between these beliefs and ethical theories and principles. Narrative ethics pushes us deeper into the reasoning behind our patients' and surrogates' decisions and beliefs and contextualizing the aforementioned considerations for further reflection and refinement. With deeper understanding, the healthcare team may have to utilize more resources, and justify the use of those resources, e.g., chaplaincy service, while possibly postponing critical decisions and the alleviation of M.J.'s harm and suffering.

4.1.4 Revision, refinement, and reflection

There may be some compromises (not necessarily consensus) among patients, family, and the healthcare team as we move back and forth among these elements of the WRE. For example, the healthcare team may be able to educate the family or surrogate about M.J.'s poor prognosis and the possible suffering she might endure if prolonged on ECMO as supported by their ethical obligation to do no harm. The family or surrogate, possibly feeling guilt, fear, or any number emotions in confronting the death of a loved one, might not want to sacrifice M.J.'s welfare for a previously declared request for continued treatment, and decide to withdraw. Then again, they may compromise and ask to have some more time with MJ, but with the acceptance of a DNR order. They may also be motivated to withdraw or accept a DNR order by recognizing that patients with quality lives can survive if they have access to the ECMO technology that is currently being utilized by M.J. The context of the decisions by which the healthcare will support or reject the family's decision just may depend on the level of harm, whether there is a patient in need of the ECMO unit, or if a transfer of care is possible. Regardless, the WRE should not simply be a tool for just healthcare professionals to come to terms with their initial moral judgments; the WRE should involve the perspectives, stories, and values of all persons who have stake in the decisions to be made. That is, the WRE can be a useful tool for shared decision-making, where considerations are presented by multiple persons and parties.

Moreover, in any of the possible outcomes, the WRE shows us that there does not have to be a single decision, recommendation, or outcome; some outcomes may be ethically preferable than others, however, the best outcome is one that has been carefully vetted through the WRE framework. With new information, the decisions may change, the patient, family and/or surrogates may be understood more fully as stakeholders in a shared decision-making process, and the healthcare team will have recognized that medical decisions, policies, and even laws may be subjected to revision and refinement. More importantly, once more permanent decisions are made such that ECMO is withdrawn, it is important for such decisions to be reflected on, asking "what other considerations might we have failed to consider?"

4.2 Case 2

A 22-year-old, previously healthy, male patient presents with severe cardiac failure due to fulminant myocarditis associated with a viral infection. The patient, T.K. has been experiencing flu-like symptoms for over 3 weeks without seeking appropriate medical attention. After passing out at a fast food restaurant, paramedics arrived on the scene and suspected cardiogenic shock, which was confirmed by his healthcare team. Clinical tests further confirm tachycardia, hypotension, left ventricle dysfunction, severe respiratory failure, and rapidly evolving multi-organ failure. Furthermore, T.K. did not respond to mechanical ventilation. Currently, T.K. is on ECMO as a potential bridge to VAD, however, due to a significant embolic stroke sustained while on ECMO, it is unlikely that he will survive with meaningful quality of life. T.K. has already been resuscitated, and the healthcare team is questioning whether to continue ECMO treatment toward VAD, continue ECMO for a short time ("bridge to nowhere"), withdraw ECMO, or consider OP-ECMO. T.K. currently does not have decision-making capacity; his estranged father is at his bedside and trying to make sense of the situation.

4.2.1 Initial moral judgment

While there are several possible courses of actions, the healthcare team could take their initial moral judgment that is to avoid as much harm to the patient as

possible, while establishing a more accurate prognosis regarding T.K.'s quality of life. The team also believes that including T.K.'s father in ongoing discussions about his son's prognosis is ethically appropriate.

4.2.2 Background beliefs and theories

When considering the risks and benefits of the options presented by the healthcare team that are specific to T.K. and his current status, it is clear that without ECMO support, there is no hope of recovery. In regard to their "hope for recovery," the healthcare team reviews all of the clinical facts surrounding T.K.'s situation. For example, it is not uncommon for patients on ECMO to have neurological complications such as ischemic stroke, however, outcomes are limited to few reported cases [6]. The amount of neurological damage due to embolic stroke and quality of life is uncertain until the patient is able to move from critical care to a period of recovery, where further neurological assessment can be done along with rehabilitative interventions. Although, it is initially suspected that T.K. will have a poor quality of life if he survives, uncertainty gives the healthcare team pause. They have seen some patients recover, and others who had to be withdrawn from ECMO with no survivability. T.K.'s young age and prior health status contribute to the team's push to continue ECMO, while being mindful of the inherent and ongoing risks of continued treatment. The team can continue to try to manage the emerging multi-organ distress and provide medication therapy and other interventions to monitor and prevent further neurological damage, while also setting important limits to their efforts. As for using ECMO as a bridge to VAD, the uncertainty of the current health status of the patient prompts a more "wait and see" approach. With that, the team also should realistically consider the higher rates of long-term disability and morbidity and mortality rates with T.K.'s co-morbidities and the surmounting financial burdens to the patient, family, and/or healthcare institution. However, the team's decision should not be isolated from a surrogate decision-maker. Thus, they need to first establish who is the surrogate decision-maker before moving forward in providing continued ECMO support in a "wait and see" approach.

T.K. is unmarried, does not have a significant other in his life, and his only family is a distant cousin who lives three states away and his estranged father. His father left T.K. and his mother, when he was 15 years old. Since the time, T.K.'s mother passed away from metastatic ovarian cancer, and he has been putting himself through college, while working a full-time job as an apprentice carpenter. T.K. talked to his father a few times on the phone over the past 2 years (his father calls every birthday); they met once for coffee about 2 months prior to T.K.'s hospitalization. T.K.'s father wanted to be back in his son's life and has been at his bedside nearly every day since his hospitalization. Given this information, and the legal requirements for next of kin (i.e., parent), the team is comfortable with providing ongoing communication with the father and involving him in shared decision-making regarding his son.

T.K.'s father does not insist that "everything be done" but approaches the situation based on what he feels his son would want. He describes his son as a "fighter," who is resilient, physically and emotionally strong, and would not want to be in a position, where he would have no quality of life or possibility to "fight" for his independence. The father is hopeful for his son's recovery, and willing to put in the work to secure him the resources he needs, however, he has also requested that if nothing more can be done, to simply "let him rest in peace" without "being a guinea pig" for scientific discovery. His reason for leaving his wife was due to her reliance on homeopathic medicine, and for never giving Western medicine a chance. T.K.

resented both of his parents for their actions but was willing to rekindle his relationship with his father, as reported by his father.

4.2.3 Moral principles and theories

In considering the clinical narrative of T.K., his father's narrative, and the healthcare team's initial moral judgment, it would seem as though the initial decisions to continue ECMO and treat the existing co-morbid issues, while engaging T.K.'s father in ongoing conversations about treatments and prognosis aligns with the principles of beneficence and nonmaleficence. T.K.'s father, in considering his son's needs and interests first, recognizes the importance of quality of life, end of life decision-making that is in the best interests of the patient, and the difficult nature of this clinical situation, which could change at any moment. Both the healthcare team and T.K.'s father mutually supports the decision to continue ECMO, treat any underlying problems, monitor the neurological effects from the stroke, and determine next steps. If and when T.K. should continue to decline, and ECMO is no longer beneficial, the team has discussed further options with his father including removal of ECMO. Advance care planning is guided by a care ethics approach, which involves caring for T.K. and his father (e.g., bereavement counseling), as well as the promotion of T.K.'s autonomy through surrogate decision-making, i.e., decisions based on what T.K. would have wanted if he were able to decide for himself.

4.2.4 A need to refine the coherence framework with new information

T.K. continues to decline, including an LV distention and subsequent pulmonary edema, and the neurological effects of the embolic stroke have proven to be severe. T.K.'s father, distraught with the new information, and knowing this is the end for his sons, asks the team to continue ECMO support for purposes of organ procurement, as "my son was a giving person, and I believe he would want to be able to help others." However, with multi-organ failure, a viral infection, prior ischemic stroke, and pulmonary edema, the team suspects there are no viable organs despite recent success cases [28], and thus, the best decision is to remove ECMO and allow T.K. to have dignity at the end of his life. The inconclusive nature of brain death determinations on ECMO, the high probability of non-viable organs that would be otherwise discarded rather than donated, the lack of robust case presentations and evidence-based medicine regarding ECMO patients as organ donors, and the rapid decline of T.K., all contributed to the background belief that ECMO should be withdrawn without pursuing organ procurement. This belief or rather the facts of the case, thus support the initial moral judgment to reduce or avoid unnecessary harm and keep T.K.'s father well-informed. However, the "wait and see" approach needs to be refined given the new clinical information (i.e., T.K.'s new prognosis), and the meaning of "harm" can be elucidated with a deeper examination of the ethical theories and principles as well as the status of the medical interventions (i.e., ECMO is no longer beneficial).

4.2.5 Revision, refinement, and reflection

In considering the new information, the healthcare team discusses removal of ECMO support and the inability to procure viable organs at this time, despite the honorable and altruistic recommendation by T.K.'s father. The team openly discusses the relatively new approaches to organ procurement from patients, who

are on ECMO, and some of the ethical and pragmatic concerns with the father. T.K.'s father understands what the team is relaying and is in agreement that more harm than good can arise from organ procurement; however, he does question whether removal of ECMO is necessary, given that T.K. is rapidly declining and has no hope for survival anyways. The team then explains that because ECMO is no longer beneficial, if T.K. were to remain on this technology for any length of time, additional harms, i.e., damage to his body, are likely and the team does not want to contribute to those harms if they can prevent them. Of note, it is difficult for everyone who has cared about T.K. to see him continue without any benefit (moral distress). Even if a non-beneficial treatment policy were to be implemented by the healthcare team, which permits them to forgo treatment that is not a benefit to the patient when family or surrogates insist to continue treatment, having the honest and open conversation prior any discussion surrounding hospital policy is preferable. The team is able to share what they mean by "harm" and have an opportunity to understand the family or surrogate's point of view. Here, T.K.'s father understands that medicine cannot bring back his son, and collectively decides to withdraw ECMO support with the healthcare team. However, ethical considerations should not end simply with this decision; the healthcare team should reflect on the father's experiences: losing his wife who refused Western medicine and losing a son with the limitations of Western medicine. Further care such as grief counseling, support groups, or simply acknowledging this difficult time should be part of the WRE; all persons involved ought to be considered along with those decisions or recommendations that emerge from achieving coherence. That is, the WRE prompts us to see all issues or concerns of a case or situation that involve multiple persons (healthcare team, patients, and family/surrogate).

Part of the ethical framework also prompts the healthcare team, institutions, and others to think critically about future patients, policies, and guidelines that could open up the organ donor pool significantly while giving family and surrogates the opportunity to make such decisions. In the end, while T.K.'s father agrees to the withdraw of ECMO treatment, there is also the possibility of future family members or surrogates who insist on continuing ECMO support in the effort to hold onto hope. In such cases, the WRE can help guide healthcare teams and families to understand the limits of medical technology, the importance of deciding what the patient would have wanted, the harms of continuing non-beneficial treatment, and the resources available for bereavement and support when letting go of a loved one.

The case of T.K. could had a very different outcome; instead of a rapid decline and no benefit of ECMO, to improvement with continued ECMO support, but not without future extensive rehabilitation, and a loss of quality of life (i.e., T.K. no longer able to work, go to school, or have the same capabilities as he did prior to hospitalization). Such decisions, though, should ultimately be left up to the family or surrogate decision-maker as to whether to continue ECMO or to withdraw given the prognosis of a potentially poor quality of life and a lifetime of ongoing care. Advance care planning, then, is essential for patients and families confronted with these ECMO decisions, as is the understanding of "harms" and "quality of life" as every outcome does not lead to a complete recovery without complications. Each patient and family member or surrogate will have different values and interpretations that ultimately ought to be respected by the healthcare team following shared decision-making and a careful consideration of the elements of the WRE, especially as new information requires us to revise, refine, and reflect on previously held judgments and actions.

5. Concluding thoughts

Although our two patients, M.J. and T.K., do not have successful outcomes with ECMO, and are unable to utilize this technology as a bridge to recovery; this does not suggest ECMO for them is simply a “bridge to nowhere.” What ECMO became for them was a bridge for careful ethical considerations, meaningful family and surrogate engagement and support, shared decision-making with the healthcare team, and outcomes that preserved the quality of life at the end of life. While ECMO had to be withdrawn, it was not done hastily, and pushes the healthcare community, including clinical ethicists, to critically think about best practices, policies, and ethical guidance, and the future of ECMO for such opportunities as organ donation.

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