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ETHICS/PALLIATIVE CARE (S FEDSON, SECTION EDITOR)

Ethical Challenges in Care of Patients on Mechanical Circulatory Support at End-of-Life

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Abstract

Purpose of Review Although the utilization of mechanical circulatory support (MCS) devices is increasing, ethical dilemmas regarding device deactivation and dying process persist, potentially complicating delivery of optimal and compassionate care at end-of-life (EOL). This review aims to study EOL challenges, left ventricular assist devices (LVADs) as a nuanced life support treatment, legal history in the US impacting EOL care, and suggestions to improve EOL care for patients on MCS support.

Recent Findings Recent studies have demonstrated challenging aspects of EOL care for patients on LVAD support: low use of advanced directives, high rates of surrogate decision-making due to lack of patient capacity, difficult decision-making involving LVAD deactivation even with cooperating patients, and high rates of death in the hospital and ICU settings. Recent studies also suggest lack of consensus even among clinicians in approaching LVAD deactivation as beliefs equating LVAD deactivation with physician-assisted suicide and/or euthanasia remain. Optimal care at EOL will likely require collaborative efforts among multiple specialties, caregivers, and patients.

Summary In light of the complex medical, logistical, and ethical challenges in EOL care for LVAD patients, there is room for improvement by multidisciplinary efforts to reach consensus about LVAD deactivation and best practices for EOL care, development and implementation of LVAD-specific advance planning, and protocols for LVAD deactivation. Programmatic involvement of hospice and palliative care in the continuum of care of LVAD patients has the potential to increase and improve advance care planning, support surrogate decision-making, improve EOL compassionate care, and to support caregivers.

Keywords End-of-life care · Life support treatment · Mechanical circulatory support · Palliative care · Hospice

Introduction

Since the first FDA approval in 1984 for MCS for bridge to transplantation, surgical implantation of mechanical circulatory support (MCS) such as left ventricular assist devices (LVAD), biventricular assist devices, and total artificial heart (TAH) is increasingly performed in patients with end-stage heart failure with the intentions of increasing survival, improving quality of life, and increasing functional capacity [1, 2]. However, MCS-related complications can negatively impact quality of life for both patients and their caregivers. In addition, due to the longevity afforded by MCS, LVADs in particular, patients may experience decreased quality of life due to progression of other diseases such as cancer and overall frailty.

MCS alters the typical end-of-life (EOL) trajectory and complicates the dying process. Potential EOL scenarios for patients on MCS include early death within the post-operative period, death in the setting of an acute event, or death after terminal decline. Patients, caregivers, and multidisciplinary team members may encounter LVAD deactivation as a necessary component of the dying process. Despite the growing utilization of LVAD technology, unfamiliarity and discomfort with the dying process for patients on LVAD support persist, especially around the psychosocial, ethical, and logistical aspects of LVAD deactivation. In particular, there are ethical concerns in approaching the request for LVAD deactivation, surrogate decision-making, and the permissibility of LVAD

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deactivation, with some clinicians equating deactivation with physician-assisted suicide or euthanasia. As a result, it is not uncommon for clinicians, patients, and surrogate decision-makers of incapacitated individuals to suffer distress and confusion at EOL. This paper will review the following: potential EOL scenario challenges in promoting high-quality, comfort care for patients with LVADs; the nuances and challenges of defining LVADs as a novel life-sustaining technology; legal precedents impacting of EOL care in the USA; and suggestions for further study to promote compassionate dying for LVAD patients and decrease caregiver burden.

Potential End-of-Life Scenarios and Challenges in End-of-Life Care for LVAD Patients

The utilization of life-sustaining therapies such as LVAD alters the typical trajectory of heart failure and the technology itself may limit options for compassionate EOL care outside of the hospital setting (Fig. 1). The potential death trajectories for LVAD patients may include death in the early post-surgical period during the index hospitalization for LVAD implantation, death after an acute event in the months or years after implantation, or death after terminal decline. The most common causes of death for those with LVAD include multiorgan failure, hemorrhagic stroke, and progressive heart failure [3•]. LVAD deactivation may be requested as part of the dying process. A recent retrospective review found that 43.4% of LVAD patients' deaths involved LVAD deactivation. Only 22.5% of LVAD patients themselves were involved in the decision-making process for LVAD deactivation as many of these patients lost capacity due to stroke. The majority of the LVAD deactivations occurred in intensive care units, often in the setting of withdrawal of other life-sustaining therapies such as mechanical ventilation, renal replacement therapy, and vasopressors. Often after some delay in time after the initial request, 8.1% of patients had LVAD deactivation occur in inpatient hospice facilities. Notably, this paper reported no LVAD deactivations occurred in the home setting [4••].

The decision for LVAD deactivation requires agreement among multiple stakeholders including patients, surrogate decision-makers when patients lack capacity, and multidisciplinary clinician team members. As the majority of LVAD patients did not have capacity at EOL, critical decisions regarding LVAD deactivations and other life-sustaining treatment were made by surrogates and clinical team members [5••]. There are multiple potential areas of distress and discord in the decision-making process for LAD deactivation (Table 1). Surrogates and clinical team members must ascertain the patient's probable wishes and must ultimately agree with each other regarding LVAD deactivation when there is lack of patient capacity. Given the gravity of the decision of LVAD deactivation, it is important for surrogates and family members to be supported by clinical team members.

Even in situations with direct patient participation in discussions, there can be distress and difficulties in achieving consensus toward LVAD deactivation. There was significant time delay between request for LVAD deactivation and actual completion. More frequent palliative care involvement was noted, suggestive of the increased complexity and distress of reaching a consensus among patients, caregivers, and clinical members. The request for LVAD deactivation may be more emotionally charged for caregivers and clinicians when made by a patient with capacity. Declining functional status most commonly contributed to the patients' requests for

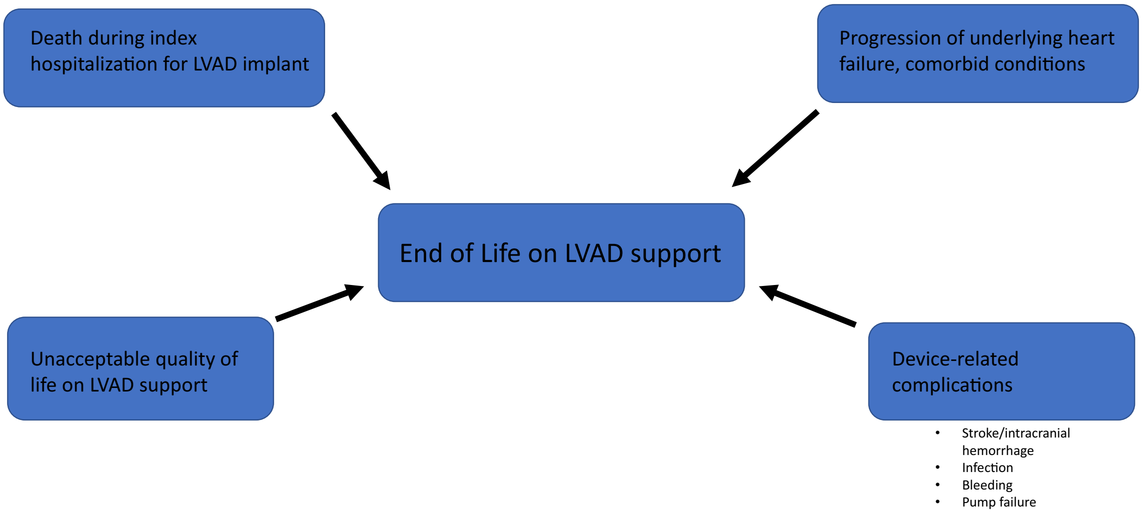

Fig. 1 Potential end-of-life scenarios for patients with left ventricular assist devices (LVADs)

Table 1 Ethical challenges in approach to LVAD deactivation

Participant	Ethical challenges
Clinician	LVAD deactivation as potential euthanasia
Patient	LVAD deactivation as potential suicide, burden of LVAD maintenance, possible LVAD-related complications
Family members/caregivers	Surrogate decision-making significant care and financial burden

LVAD deactivation [4••]. Depression, anxiety, and other psychiatric conditions in LVAD patients requesting LVAD deactivation present particular challenges in affirming and respecting patient autonomy [6].

Importantly, the logistical requirements for device deactivation and effective management of LVAD alarms may also complicate end-of-life decisions and care. Unfamiliarity with LVAD care or challenges in arranging for urgent LVAD care at EOL may add to the distress of end-of-life situations for patients, caregivers, and clinicians. Clinicians, in conjunction with LVAD coordinators, should be prepared to manage LVAD settings and alarms and to administer comfort-directed medication boluses prior to LVAD deactivation and halt in circulation [7•]. Management of anticoagulation and potential thrombotic complications can also add to medical complexity of EOL management [5••]. Protocols may be helpful in standardizing logistical considerations and processes. The delay between time of request and discharge to inpatient hospice facility may be reflective of the challenges in finding hospice agencies adept at VAD care at EOL [6]. Only through early coordination with, ongoing training of, and collaboration with hospice agencies to provide end-of-life LVAD care can we create capacity and locations where LVAD deactivation can occur in a compassionate and efficient manner.

In summary, end-of-life scenarios for patients with LVADs are medically complex due to multiple, concomitant life-sustaining therapies and often occur in an intensive care setting. The decision-making process can be charged and distressing for surrogates and clinicians even with patient capacity and direct participation. In particular, accepting request for LVAD deactivation from interactive patients may be ethically challenging to both family members and clinicians. However, past reviews have shown that, in the majority of deaths of LVAD patients, surrogates had to make decisions due to lack of capacity. Past studies have also shown the need for VAD specific advance directives [5••]. More upstream multidisciplinary collaboration prior to EOL with palliative care, psychiatry, and ethics can be helpful in achieving consensus among patients, surrogates, family members, and clinicians. The requirement of logistical comfort with VAD management may limit alternative healthcare and home settings as places of death.

LVADs as Nuanced Life-Sustaining Treatment

There is no legal precedent that specifically correlates to EOL care for MCS and LVAD deactivation. LVAD is a novel and nuanced life-sustaining therapy. It is internal, continuous, and constitutive as it replaces the function that the native heart can no longer provide [8], similar to mechanical ventilation and hemodialysis. Unlike mechanical ventilation and hemodialysis which are viewed as external to the body, LVADs are often considered distinctly by clinicians since LVADs are an internally implanted device. In LVAD deactivation, while the person performing the deactivation may not intend death, LVAD deactivation often leads to death within minutes [9]. In euthanasia, however, the intent is for termination of the patient's life and the clinician performing acts in an active way to cause the death. That contrasts with physician-assisted suicide (PAS also called medical aid in dying), a process in which patients self-administer a prescribed medication with the intent of terminating their lives. In both euthanasia and physician-assisted suicide, the cause of death relates to the new intervention, such as a prescribed medication that a patient takes or an intervention such as a medication or action directly administered by a physician [5••]. The often quick decline after LVAD deactivation may raise ethical and legal concerns about the true causality of death although the intention of the action, almost always related to reducing suffering and not prolonging dying, makes deactivation distinct from euthanasia or PAS.

US Legal History Around Life-Sustaining Treatment and Surrogate Decision-Making

Illegality of Physician-Assisted Suicide and Euthanasia

Ethical qualms with the dying process of LVAD patients and LVAD deactivation may stem from beliefs equating LVAD deactivation with physician-assisted suicide or euthanasia. The extension of the Equal Protection Clause of the 14th Amendment protects patients' rights to refuse unwanted medical treatment. However, the cases of Vacco vs. Quill [10] and Washington vs. Glucksberg [11] highlighted the difference between refusing life-saving treatment and expediting death via medications. Thus, with rare exceptions (i.e., Oregon Measure 16, a measure that legalized terminally ill patients to obtain prescriptions to end their lives [12]), physician-assisted suicide or euthanasia is not protected under the Equal Protection Clause. However, it can be argued that LVAD deactivation represents termination of treatment that is inhibiting the natural progression of end-stage heart failure rather than an active choice aimed at terminating a patient's life [13]. Thus, the cause of death is due to the progression of the underlying end-stage heart failure. The permissibility of LVAD deactivation rests on patient consent, determination of the burdens of continued LVAD treatment outweighing benefits, and the intention of patient and clinicians to terminate treatment although death is likely imminent. However, there remains much controversy within medical communities in regard to the permissibility of LVAD deactivation and its distinction from euthanasia.

Contrary to myths, there is no legal requirement for consultation with risk management or ethics committees prior to LVAD deactivation. Ethics committee may be helpful when there is discord among family members and/or among clinical team members. Risk management may be helpful when there is legal uncertainty [14]. Early palliative care involvement may provide assistance in clarification of preferences, in decision-making, and in mitigation of moral and ethical distress leading up to and during the end-of-life period. Unified resolution of ethical, legal, and religious concerns among the medical community in regard to LVAD deactivation may alleviate some of the anxiety clinicians may feel and enable them to act as better advocates for patients and family members.

Surrogate Decision-Making and Life-Sustaining Treatments

The legal background of surrogate decision-making is of particular interest as majority of LVAD patients' deaths occurred after they had lost capacity. The President's Commission Report in 1983 allowed for the legal and ethical withdrawal of life-sustaining treatment if patients have expressed their preferences through healthcare directives or via a healthcare proxy [15]. The ruling of Nancy Cruzan vs. Missouri Director of Department of Health in 1990 established the need for "clear and convincing evidence" of patient's wishes when third parties decide to terminate treatment for patients who lack capacity [16]. However, this ruling was not mandated for other states. In general, the national standard follows the "substituted judgment standard," which allows for patient's family members to make decisions on the basis of the patient's probable wishes [14]. Other important applications of the Cruzan case included the concept that death in the setting of withholding or withdrawing artificial nutrition in terminally ill patients was due to the patient's underlying condition. The Cruzan case also led to the Patient Self-Determination Act of 1991 and the interest in living wills and advance care planning. Given the complexities of LVADs as a life-sustaining therapy, the need for comprehensive and LVAD-specific advance care planning and support for surrogate decision-makers will be discussed further.

Areas for Further Study and Improvement

Need for Consensus in Legal and Ethical Considerations toward LVAD Deactivation Among Medical Communities

Despite the decades of utilization of LVADs since 1984, there continues to be unfamiliarity and lack of unified guidelines regarding the optimal care of MCS patients approaching death. There remains inconsistency in beliefs and attitudes regarding the permissibility of LVAD deactivation. A 2013 international survey of heart failure clinicians to assess attitudes and practices regarding LVAD deactivation in end-of-life showed significant variation in attitudes around LVAD deactivation and concern that LVAD deactivation may be a form of euthanasia [17]. Among even the two frontline specialties caring for LVAD patients in EOL, cardiology and hospice and palliative care, there was discordance in considerations for LVAD deactivation with cardiologists more likely to believe that a patient had to be imminently dying in order to deactivate LVADs and that LVAD deactivation was a form of euthanasia [18]. Consensus among clinical communities caring for patients on MCS is needed in order to prevent situations in which otherwise ethically sound decisions may be overridden by concern for legal protection. Intentional collaboration between multiple specialties including cardiology, palliative care, psychiatry, ethics, religion, and law as well as patient representatives will lead to helpful guidelines and frameworks in educating about and discussing LVAD deactivation to patients and their families. A cohesive multidisciplinary team allows for clinicians who may not be comfortable around LVAD deactivation to rely on other colleagues to help abide by patient and family wishes and preferences.

Need for Implementation and Study of VAD-Specific Advance Care Planning and Support for Surrogate Decision-Making

Given the often-unpredictable trajectory of advanced heart failure and risk of sudden cardiac death, all patients with heart failure would benefit from education regarding life-sustaining interventions and advance care planning. However, there is low utilization of advance directives in heart failure patients [19]. Given the transformational impact of LVAD in patients' lives and deaths, LVAD-specific advance care planning, such as preparedness planning, is needed to address LVAD-specific factors. Currently, commonly used advance directives, such as Five Wishes, often do not mention LVADs [4•]. Given the incidence of stroke, both ischemic and hemorrhagic, ranging from 12 to 29% [20, 21••] and the association between stroke in LVAD patients and loss of capacity, advance care planning, including designation of healthcare proxies and documentation of care preferences, is crucial for LVAD patients. Preparedness planning goes further to also discuss preferences in light of common LVAD-related complications and unacceptable conditions to the patient even if the LVAD is functioning well (Fig. 2) [22•]. There should be early documentation and frequent readdressing of preferences in order to help refine, confirm prior wishes, and identify transitions in life leading toward possible need for LVAD deactivation. Documentation of LVAD patient preferences and wishes has the potential to mitigate distress among clinicians and future potential surrogate decision-makers at EOL. The application of decision aids may also increase the quality of decisions and impact treatment [23]. The earlier introduction and completion of preparedness planning directives for LVAD patients may allow for more time for communication among not only family members but also clinical team members.

Responding to requests for LVAD deactivation from interactive patients is particularly challenging and potentially emotionally charged in respecting patient's autonomy. Clinicians should routinely screen for capacity and the presence of depression, anxiety, and other psychiatric conditions. Prior documentation of wishes may also help demonstrate consistency of patient's statements. Concomitant depression, anxiety, and other psychiatric conditions may raise concerns about patient capacity. Collaboration with other specialties, such as psychiatry and pain management, may help ensure all reversible detriments to a patient's quality of life and death are addressed [6]. Finding reversible conditions impacting a patient's quality of life may warrant deferring the request for LVAD deactivation to permit further assessment, treatment, and reassessment according to an agreed upon timeline [24]. Frequent assessment of patients' quality of life will help identify conditions causing distress and allow for early interventions and integration of other team members.

Thus, the ideal implementation of compassionate dying and LVAD deactivation is made possible on the foundation of multidisciplinary collaboration that occurs early and iteratively (Fig. 3). Patients and their caregivers would be given the opportunities to delineate, refine, and document their

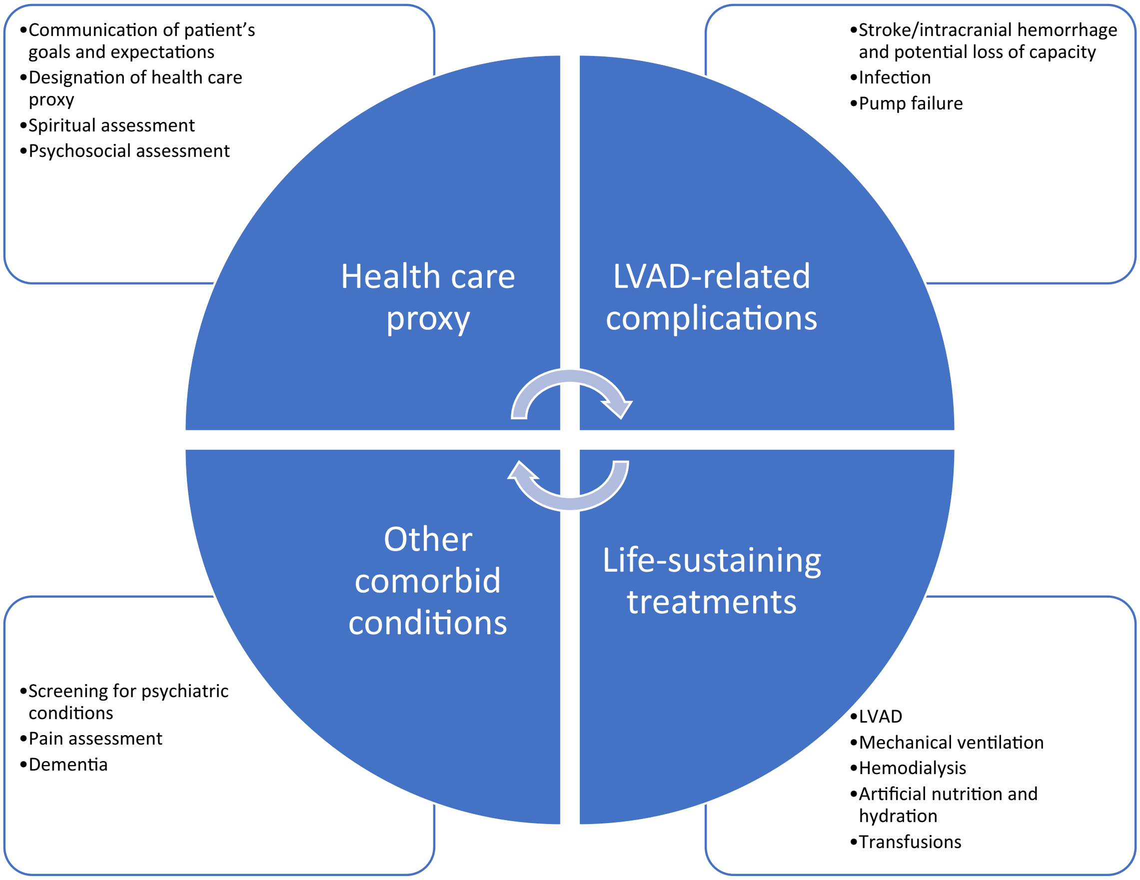

Fig. 2 LVAD-specific preparedness planning. Adapted from Swetz KM, et al. preparedness planning before mechanical circulatory support: A "How-To" guide for palliative medicine clinicians. J Pain Symptom Manage. 2014;47:926-935.e6

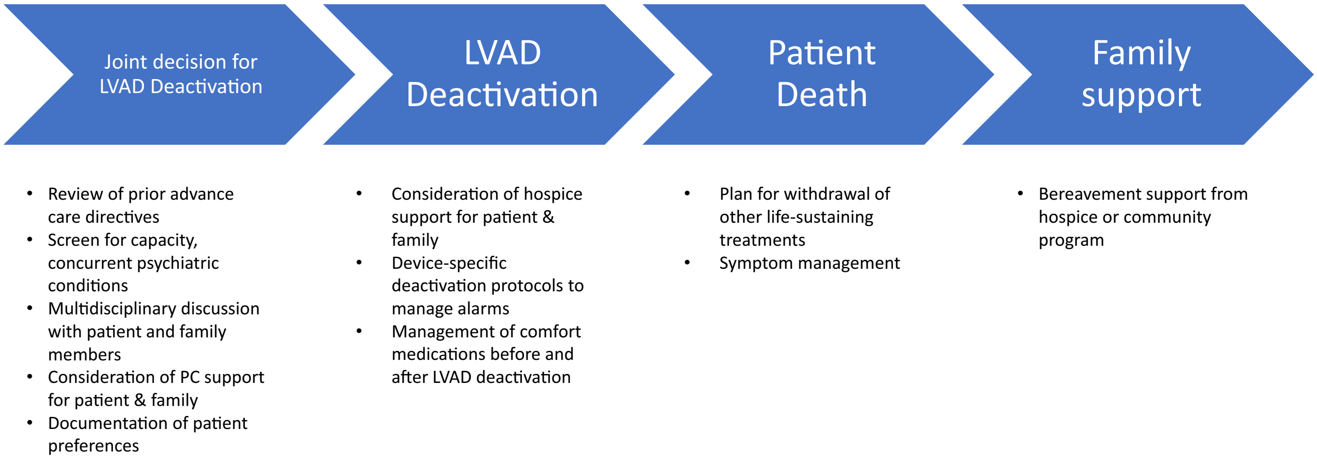

Fig. 3 LVAD deactivation process

preferences for EOL. Structured protocols and guidelines would help streamline carrying out of logistical requirements for LVAD deactivation. Plans would also be established in regard to other forms of life-sustaining treatment. Patients would have their symptoms adequately controlled throughout the dying process. Caregivers would also be provided bereavement support after the death of their loved ones.

Need for Meaningful Palliative Care (PC) Involvement in the Care Team of LVAD Patients

Contemporary trials have demonstrated the beneficial impact of PC involvement in high risk heart failure patients in improving quality of life, symptom control, and completion of advance care planning [25, 26]. Specialty Hospice and Palliative Care Medicine clinicians have much to offer in terms of nuanced support for LVAD patients at all stages of their journey, from patient selection to EOL support focused on helping with complex decision-making, LVAD-specific advance care planning, EOL care, and caregiver support. In 2009, the Centers for Medicaid and Medicare Services mandated the involvement of PC in the care team of patients for whom LVADs are implanted as destination therapy in recognition of the complexities of maintenance and EOL care. However, clinical courses at EOL of destination therapy and bridge to transplant can be similar, arguing for the role of PC for all patients for whom LVAD is considered [27]. PC team members provide support for complex medical decision-making, burdened caregivers, and advance care planning. As neutral members of the multidisciplinary team [28], PC members are well-poised to guide patients and caregivers through the preparedness planning specific for LVADs, ideally before implantation and iteratively post-implantation. Since "one size does not fit all" in advance care planning for LVAD patients, PC members can help to respond to the dynamic changes of LVAD patients and caregivers as integrated team members [29].

PC clinicians, ideally as part of the longitudinal care team, can help facilitate the important processes of shared decision-making and preparedness planning in light of the complexities of LVAD care and the presence of other comorbid conditions. Through more effective delineation and documentation of their wishes and preferences, it is hoped that patients, caregivers, and clinicians may be better prepared and prepared in advance to approach the dying process and LVAD deactivation. As a result, patients and caregivers are empowered to act as stronger advocates for their wishes and preferences. There is a great need for structured and integrated programmatic involvement of PC from patient selection to EOL care and study of outcomes in LVAD patients. A recent study has shown that a programmatic approach leads to improvement in quality of life for both patients and caregivers and completion of advanced care planning [30••].

A multidisciplinary team approach including PC allows for increasing and deepening comfort with the care and management of LVAD patients beyond the silos of cardiac surgery and cardiology to further enhance care at EOL. The ongoing interactions and collaboration with PC team members are crucial in training and further expanding skills for home PC and hospice agencies for LVAD patients. As the majority of deaths of LVAD patients occur in the hospital and ICU settings as mentioned previously rather than in the familiar home settings [3•], further study is needed to investigate specific end-of-life needs of LVAD patients and how to meet those needs. PC providers also demonstrated more comfort than cardiology providers in end-of-life care and LVAD deactivation [18]. The expertise of PC providers can ensure symptom control with comfort medications before and after LVAD deactivation. The promotion of effective and compassionate care of LVAD patients will require ongoing collaboration and coordination among cardiology, PC, and hospice agencies. Targeted end-of-life guidelines and protocols for

LVAD deactivation have the potential to both improve and streamline EOL care.

Programmatic involvement of PC may provide more support for caregivers throughout the entire MCS process, from patient selection to EOL. Caregivers are only informally inducted into the care team yet are the lynchpin for successful outcomes for LVAD patients. Caregiving requires an immense commitment in terms of time, resources, and finances. The ethical challenges in considering the large financial burden of LVAD, implantation, and care are beyond the scope of this paper, but certainly a prevalent factor in patients' lives and for society as a whole. Caregivers are often essential participants in medical decision-making and may be required as surrogate decision-makers when patients lack capacity during their pre-implant phase and at end-of-life [31, 32]. Related to the sacrifices, adjustments, and responsibility of daily care of LVAD patients, caregivers may experience anxiety and adverse health effects as much or more than the patients themselves [31]. Support from PC from the beginning in medical decision-making and education may alleviate distress and conflict at EOL.

Conclusion

Although surgical implantation of MCS and LVADs in particular are becoming increasingly common in the treatment of patients with advanced heart failure, there remain unresolved ethical challenges and unfamiliarity that may preclude and complicate optimal care of LVAD patients at end-of-life, most notably during LVAD deactivation. Consensus among experts in multiple disciplines including law and religion in regard to LVAD deactivation, development, and implementation of VAD-specific advance care planning, support for caregivers and surrogate decision-makers, and programmatic involvement of hospice and palliative care teams in LVAD care may help to address and resolve ethical challenges. As the majority of LVAD patients die in the hospital and ICU settings, there is much need to better understand specific needs of LVAD patients and caregivers and for development of multidisciplinary interventions at EOL to promote compassionate care at EOL.

Compliance with Ethical Standards

Conflict of Interest No potential conflicts of interest relevant to this article were reported.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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