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Usefulness of Palliative Care to Complement the Management of Patients on Left Ventricular Assist Devices

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Abstract

Within the last decade, advancements in left ventricular assist device (LVAD) therapy have allowed end-stage heart failure patients to live longer and with better quality of life. Like other life-saving interventions, however, there remains the risk of complications including infections, bleeding episodes, and stroke. The candidate for LVAD therapy faces complex challenges going forward, both physical and psychological, many of which may benefit from the application of palliative care principles by trained specialists. Despite these advantages, palliative care remains underused in many advanced heart failure programs. Here, we describe the benefits of palliative care, barriers to use within heart failure, and specific applications to the integrated care of patients on mechanical circulatory support.

Keywords

Advanced heart failure; LVAD; end-of-life; hospice

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At the most advanced stages of heart failure (HF), many patients are now offered a durable left ventricular assist device (LVAD). A multidisciplinary team is required to shepherd patients effectively through the complex and time-intensive discussions and decision-making processes related to LVAD therapy. While medical and surgical teams have traditionally addressed the initial evaluation and operative aspects, the integration of palliative care principles, including collaboration with a palliative care specialist, can further help to manage symptoms, set realistic expectations, and facilitate advance care planning. Current practice guidelines and consensus recommendations emphasize the integration of palliative care into the management of patients with advanced HF and mechanical circulatory support (MCS).^{1,2} In fact, in the United States, the Center for Medicare and Medicaid Services requires the involvement of a palliative care specialist to be a member of MCS destination therapy programs.³ This manuscript reviews the current literature on the integration between palliative medicine and HF, and provides recommendations on how palliative care may assist the MCS team with specific aspects of patient care.

Benefits of palliative care

Palliative care complements disease-modifying therapies, rather than supplanting them. A progressive palliative care management approach directs education and communication equally toward families and caregivers as much as patients, and helps patients better understand their illness, treatment options, and prognosis, and empowers them to make medical decisions consistent with achievable goals of care. To support these goals, a typical multidisciplinary team is composed of physicians, nurses, social workers, chaplains, physical therapists, and psychologists.⁴ Notably, there has been a historical misconception that palliative care is synonymous with hospice care. Hospice care is, in fact, the application of palliative services to the terminally ill patient with an expected survival of less than 6 months. In contrast, palliative care should be offered independent of prognosis and based on patient needs and an ability to offer benefit.⁴

Palliative care has historically been studied primarily in a cancer setting; reliable data for cohorts with cardiovascular disease are in a comparatively nascent stage. When integrated with oncology care, palliative care leads to improvements in quality of life, less aggressive end-of-life care, and even survival.^{5,6} An important component has been increased incidences of advance care planning, whereby patients—together with their health care clinicians and family members—make and document decisions about future health care goals and desired therapies.⁷ Advance care planning discussions increase the likelihood that the patient's wishes are followed at the end of life.^{7,8} Surviving relatives report that these strategies result in improved satisfaction, better communication, and reduced stress and anxiety.⁷ Almost 30% of elderly Americans require surrogate decision-making at the end of life; those with documented advance directives will have a higher likelihood of receiving the care they wanted.⁸ In HF patients, pilot studies have suggested similar benefits in quality of life, depression, and symptom control compared with cancer patients, but results from large-scale studies are still pending.⁹ The recent randomized controlled trial of Palliative Care in Heart Failure (PAL-HF), sponsored by the National Institute for Nursing Research, will provide empirical evidence for the potential benefits of a team-based palliative care intervention in conjunction with usual heart failure care on patient-reported quality of life.¹⁰

Traditional barriers to use in cardiology

Palliative care has also been underutilized in advanced HF patients compared with oncology, ranging from an estimated 2-20% versus over 50%, respectively.^{11,12} In HF populations, enrollment into hospice occurs comparatively late in the disease trajectory—a median of only 12 days before death compared to 20 days in cancer patients.¹² Additionally, hospice agencies have fewer options for patients with end-stage HF. While oral medications and opiates are commonly provided, few agencies can manage the expense of intravenous inotropes and/or diuretics within the limitations of a per-diem payment structure.¹³ And whether in inpatient or outpatient settings, relatively few hospice agencies around the country have experience managing end-of-life care for patients already on MCS.

There are several considerations that have limited the widespread adoption of palliative care in HF patients. Two key considerations are related to the uncertainty of disease progression (for both patients and providers) and real or perceived patient aversion to end-of-life planning. Unlike cancer, which more frequently follows a trajectory of progressive decline in the latter stages of disease, HF commonly follows a cyclical natural history. Periods of decompensation followed by periods of relative stability make it difficult to recognize when patients with HF are approaching terminal stages. Death from sudden arrhythmia can occur at any time, further compounding perceived unpredictability. As such, less than a quarter of physicians caring for HF patients are comfortable predicting a patient's 6-month mortality.¹⁴ Patients may not even fully comprehend HF's life-limiting nature.¹⁵ When there is significant uncertainty, timing discussions about advance care planning can be complicated, and as a result these conversations are routinely initiated too late in the course of disease.¹⁶

Even when symptoms stabilize or abate, both clinicians and patients may be reluctant to discuss prognosis and life expectancy. Patients' emotions including anxiety, depression, and denial may hamper adequate discussion and understanding. Depression is present in approximately 20% of patients with HF with a prevalence near 40% in those with the most advanced disease.¹⁷ Additionally, approximately 40% of patients with HF suffer from anxiety.¹⁸ On the other hand, data suggest that despite the high prevalence of comorbid mood disorders, patients with HF expect their physicians to initiate discussions on prognosis and have a strong desire to know the realities of their life expectancy.¹⁹ Although physicians may fear that discussing prognosis will cause patients to lose hope, acknowledging these issues has not been shown to adversely affect patients.^{19,20} Engaging in these difficult discussions earlier in the disease course aims to ease the difficult decisions of the future.

Role of palliative care in the management of patients with MCS

Palliative care principles can help target many aspects in support of patients with MCS, especially in those who may expect to live the rest of their lives on mechanical support. The management approaches of palliative care and practice methods of palliative care specialists integrate well into and reinforce the goals and messages of the medical MCS team. Figure 1 shows a graphical representation of the potential roles for integrating palliative care into the management of patient on MCS. At the initial discussion of advanced HF options, a palliative care team can further guide advance care planning and participatory decision-

making. They can explicitly address goals of therapy specific to MCS therapy and discuss care preferences in the event of undesired outcomes like poor quality of life or progression of a comorbid condition.²¹ After implantation, the team can reinforce symptom management and support for families and caregivers in the early post-operative period. Finally, the team can help the patient and his or her family with transition care and discussions of device deactivation by defining new goals of care. Although these conversations benefit from consistent reevaluation over the duration of MCS therapy, they are best initiated before surgery.

Empirical evidence and consensus statements suggest that advance care planning is beneficial to patients with HF and an essential part of quality health care.^{8,16} Beyond the designation of a health care proxy and the execution of a living will, advance care planning is, ideally, an iterative process that engages the patient, the family and surrogate decision maker, and the medical team. In a best-case scenario, these stakeholders meet to identify health care preferences, values, and goals of care, and document these findings in an advance directive.²¹ However, with respect to MCS therapy, most advance directive documents rarely provide concrete guidance for the nuanced and complex medical decisions that arise over the lifespan of an LVAD.²² Table 1 provides a general overview of the differences between traditional advance directives and one geared specifically for a patient contemplating LVAD therapy. Swetz et al. provides a detailed template document that can be completed by a patient during an advanced care planning session.²¹

Single center pilot studies highlight the value of these advanced care discussions in patients with LVADs. In 2011, Swetz et al. described how standardized integration of palliative care consultation led to increased completion of advance directives among patients with LVADs.²² These upfront discussions helped patients to better expect and overcome post-operative complications and, if required, empowered family surrogates and the medical care team to make difficult decisions regarding device deactivation.²² Similarly, another pilot study involving palliative care consults in patients referred for transplantation showed better understanding of treatment plans among patients and care more in line with their goals.²³ However, MCS programs around the country have integrated with palliative care to a variable degree. Recent analyses show palliative care consults for patients with LVADs ranging from 35-89%.^{24,25} Even in patients who completed a palliative care consultation, advanced directives were identified in approximately only 60% of patients.^{24,25} Certainly, there remain substantial opportunities to improve the integration of palliative care into the multidisciplinary care of a patient with MCS.

The decision to undergo mechanical circulatory support—especially in the form of permanent destination therapy—is complex and may be distressing to patients and families.²⁶ The patient journey to consider LVAD therapy may result in varying levels of anxiety, preparedness, and expectation of benefit. Supporting patients and families through this difficult decision process represents a key tenet of promoting patient-centered care.¹⁶ The ongoing LVAD-DECIDE study (clinicaltrials.gov NCT02344576) is evaluating the intervention of print and audiovisual decision aids in informing patients of the risks and benefits of LVAD therapy. CORA (Cardiac Outcomes Risk Assessment, NIH-1R01HL122639), a multicenter project sponsored by the National Institutes of Health,

aims to use data mining and machine learning to develop and evaluate a computerized decision support tool designed to assess a patient's individual risk/benefit ratio of undergoing LVAD therapy. Importantly, the role of a proactive palliative care consultation in this setting can help patients and caregivers understand their options, define values relating to quality of life, clarify their goals for LVAD therapy, and document end-of-life preferences in the event device deactivation becomes necessary.

Given the complexities of post-implant management and care, patients on MCS require close support, and, potentially around-the-clock care. The caregiver, typically a significant other or family member, must manage a complex medication regimen, change sterile dressings, monitor patient vitals and weights, and learn the LVAD's operation and management.²⁶ The burden on caregivers can be significant. In the early months, many caregivers describe "an overwhelming sense of fear and anxiety."²⁶ Caregivers describe sacrifices ranging from financial loss to deprioritizing their own health.²⁷ They may be required to demonstrate a tremendous amount of resilience in order to provide physical and emotional support for patients, but also must rely heavily on the healthcare team for education, preparation, and emotional support.²⁷

In most circumstances, the multidisciplinary support of the MCS team helps family members adjust to their responsibilities and build confidence in their skills. In extenuating circumstances, however, palliative care specialists with expertise on caregiver stress can help foster the positive attributes that facilitate coping and adaptation. In limited single center experiences, reports from LVAD patient families dealing with caregiver burnout and difficult end-of-life decisions describe positive experiences from the support and empowerment they received from the palliative care team.^{22,23} Once again, experience learned from oncology shows that the skills of coping, communication, and problem-solving can be taught.²⁸ Specific attention paid to caregivers can improve caregiver quality of life and reduce stress, resulting in patient benefits.²⁸

Most critically, palliative care support should be iterative in nature. As HF symptoms improve with LVAD support, patient preferences may change. Thus, the multidisciplinary LVAD team should periodically reevaluate patients' goals of care.²⁹ Conversely, if disabling complications occur or a co-morbidity becomes life-threatening, palliative care teams may assist with management of new symptoms. Together with other members of the MCS team, the palliative care practitioners' previously established relationship with the patient can facilitate renewed discussions regarding the achievable benefit versus burden of the device. The perspectives of the palliative care team may offer a balance to the patient and his or her family compared with the medical perspectives of the cardiology and surgical team members. When making difficult decisions, patients and families may rely on the continuity of existing strong relationships developed with both teams of providers.²² Continued and open dialogue is key to help patients and caregivers cope and adapt.

The vast majority of patients on destination LVAD therapy will die with the device in place. A catastrophic LVAD complication such as intracranial hemorrhage, end-stage progression of a new or recurrent malignancy, or advancing neurocognitive decline may prompt questions of device deactivation. Additionally, insidious insults such as progressive right HF,

refractory ventricular arrhythmias, deep infection, or refractory bleeding can similarly undermine quality of life and lead to renewed discussion of benefits of LVAD therapy. In these more ambiguous scenarios, disagreements and questions about futile care can easily arise among clinicians, furthering a sense of confusion for patients and families about an uncertain future. Identifying when care becomes futile is difficult in any circumstance, but once again, open communication and having explicitly defined—and realistically set—goals of therapy from a patient perspective can greatly prevent or resolve many such conflicts.³⁰

Deactivating a mechanical apparatus whose continuing operation staves off an otherwise terminal illness poses complex ethical questions.³¹⁻³³ Clinicians and researchers have questioned whether LVAD deactivation represents a form of euthanasia. Does the LVAD continue to support the values and goals of living even at the end of life, or is it merely prolonging a difficult death? The Patient Self-Determination Act protects patients' autonomy and their right to refuse or withdraw life-sustaining therapy they perceive as futile, or in their judgment, more burdensome than beneficial.³⁴ The goal is to allow natural death to occur. However, some physicians differentiate withdrawing LVAD support from withdrawing other life-sustaining therapies such as mechanical ventilation or vasopressor agents, suggesting a range of moral conflicts surrounding the dying patient on MCS.³⁵ While no physician may be compelled to perform an act or procedure to which he or she objects, consensus exists among the legal and ethical community that distinguishes killing from allowing to die.^{32,33,36} The crucial difference lies in the primary intention: termination of a life, versus termination of a therapy that inhibits the occurrence of an otherwise natural death from lethal disease. Routinely, death that follows withdrawal of LVAD support occurs from underlying HF.

In the context of withdrawing LVAD support, the palliative medicine team uniquely enhances the medical team. With its expertise in this arena, a palliative care team can guide these emotionally challenging and morally complex discussions. They can help patients and families clarify prior goals of care or define new ones, and empower decision making that serves these goals.³⁷ If particular symptoms are the primary driver of a poor quality of life, palliative care consultants may offer suggestions for relief that can allow the patient to continue living with quality. The presence of an existing relationship between the patient or family and provider establishes the basis for trust and rapport necessary for these difficult decisions.^{22,38}

When families accept the choice to allow natural death, the act of device deactivation may cause undue fear and distress. At this last stage of life for the patient on MCS, preparation, communication, and coordination are once again key tenets. In most patients, case evidence suggests unconsciousness and death ensues within twenty minutes of deactivating the pump.³⁸ However, some patients may survive for several days following LVAD deactivation, and this variability should be explained to families in preparation. The presence of the palliative care team provides assurance to family members that experts are available specifically to ensure the patient's comfort upon device deactivation and provide emotional support for grieving family members. Figure 2 describes an interdisciplinary checklist that explicitly outlines steps required at the time of device deactivation.

Conclusion

In the future, as MCS becomes less burdensome, more patients will likely elect this therapy at earlier stages of disease to alleviate symptoms. Current application of MCS has historically been advised in the sickest patients, which means that studies to date confound the efficacy of palliative care principles with advanced disease. In contrast, the preemptive role of a palliative care specialist is less clear in this scenario when prognosis of medical therapy is not as established. As the technology evolves, the role of palliative care will also need to evolve. Beyond well intentions, patients and families deserve high quality data from well-designed, multicenter clinical trials and carefully collected registries of patients and candidates requiring MCS. Objective data would shed light on patient concerns not currently addressed, outcomes important to them and to society, and the effectiveness of interventions.

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Figure 1A.

Figure 1A depicts: i) effort by medical/surgical team for implantation and symptom management over course of left ventricular assist device (LVAD) therapy; ii) integrated approach to palliative care, with emphasis on long-term relationship developed before implantation; iii) traditional approach to palliative care, with active involvement only close to end-of-life. **Figure 1B** depicts opportunities for a palliative care team to support patients throughout the LVAD process.

Figure 2.
Preparations for Left Ventricular Assist Device Deactivation.^{39,40}

Table 1**Advance Care Planning in Patients with Left Ventricular Assist Devices (LVAD)**

Traditional Advance Directives	Approach to Care	Preferences in Specific Care Situations
Health Care Power of Attorney Cardiopulmonary resuscitation Organ donation	Spiritual and/or religious preferences Review family dynamics Goals and expectations of LVAD Fears and worries about LVAD Acceptable measures for quality of life Understand alternative options	Perioperative morbidity Long-term role of antibiotics Artificial nutrition Blood transfusions Hemodialysis Mechanical ventilation Life threatening comorbidity Intracranial hemorrhage Stroke Device infection Device failure Operative device exchange