

The role of palliative care for patients with left ventricular assist devices: a narrative review

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Background and Objective: Left ventricular assist devices (LVADs) have revolutionized the care of patients with advanced heart failure (HF). Compared to guideline-directed medical and device therapies, LVAD technology improves quality of life and reduces mortality. Palliative care specialists have an important role to play in the pre-LVAD evaluation phase, in the post-operative longitudinal care phase, and at the end-of-life in patients with LVADs. The objective of this narrative review is to describe the evidence regarding the role of palliative care for patients with LVAD across the care continuum: pre-implantation, post-implantation, and at the end-of-life.

Methods: Clinical trials relevant to care of patients with HF, LVADs, and the role of palliative care were analyzed for this narrative review.

Key Content and Findings: Palliative care involvement in ‘preparedness planning’ has been described in the literature, though no standardized protocol for preparedness planning exists, to date. In the longitudinal care phase after LVAD implantation, the role of palliative care is less defined; depending on institutional culture and availability of palliative care, patients may be referred based on symptom-management needs or for advance care planning (ACP). At the end-of-life, either due to an acute event or a gradually worsening condition, palliative care is often engaged to participate in discussions regarding treatment preferences and to consider transitions in care from disease-directed treatments to comfort-focused treatments. Given the medical complexity of dying with LVADs, most patients with an LVAD die in hospital with support from palliative care teams for the physical, existential, and psychosocial distress that accompanies end-of-life and LVAD deactivation.

Conclusions: In this narrative review, we describe the integral role of palliative care throughout the care continuum of patients living with LVADs and suggest opportunities for further research.

Keywords: Left ventricular assist device (LVAD); heart failure (HF); palliative care; advance care planning (ACP); end-of-life care

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Introduction

Heart failure (HF) affects millions worldwide, with an estimated prevalence of 1–2% in the general population and up to 10% in those 70 years or older (1). In the United States, over six million adults have a diagnosis of HF, and the prevalence is rising (1). A subset will progress to stage D, advanced HF (AHF), defined as the presence of “marked HF symptoms that interfere with daily life and with recurrent hospitalizations despite attempts to optimize guideline-directed medical therapy (GDMT)” by the American Heart Association/American College of Cardiology/Heart Failure Society of America (AHA/ACC/HFSA) (2). Identification of AHF is crucial, as patients may benefit from surgical advanced therapies such as left ventricular assist device (LVAD), heart transplantation (HT), and concurrent palliative care (3).

Durable mechanical circulatory support in the form of LVAD therapy has revolutionized the care of patients with AHF. According to the Interagency Registry for Mechanically Assisted Circulatory Support (INTERMACS), over 27,000 patients underwent LVAD implantation between 2012 and 2021 (4). An LVAD supports the function of the failing left ventricle and augments cardiac output (5). The pump is implanted in the chest, with the driveline exiting the body and connecting to a power source. There are several indications for LVAD implantation: bridge to transplant (BTT) or short-term therapy; bridge to recovery (BTR), for a potentially reversible cause; lifelong or long-term therapy (formerly termed ‘destination therapy’ or ‘DT’), for patients who are unlikely to derive benefit from HT due to non-modifiable factors; and bridge to candidacy (BTC), for patients who have modifiable barriers to HT at time of implant and may derive benefit from HT in the future if those barriers are overcome (*Table 1*) (6). In 2021, 81.1% of implanted LVADs were classified as destination or long-term therapy, compared to 50.4% of patients in 2017 (4). With the advent of the fully magnetically levitated centrifugal flow HeartMate 3™, 5-year survival has increased to 54.0% compared to 29.7% 5-year survival experienced by recipients of the prior generation axial-flow HeartMate II™ (7). While LVADs offer significant improvements in survival and improvement in quality of life, the journey of patients undergoing this procedure is often complex and challenging. The increasing use of LVADs as long-term therapy, and the growing population of patients aging with their LVADs has resulted in more patients experiencing age-related illnesses such as cancer

and dementia.

Palliative care is a medical specialty focused on improvement of quality of life and reduction of suffering in patients with serious illness throughout their disease trajectory (8). A growing body of literature increasingly highlights the crucial role of palliative care services in the general HF population. For example, the Palliative Care in Heart Failure (PAL-HF) trial provided robust evidence in support of palliative care integration. In this prospective, single-center randomized controlled trial, patients who received palliative care had consistent and significant improvements in health-related quality of life, depression, anxiety, and spiritual distress scales compared to patients receiving usual care (9). A Delphi study of international experts on palliative care in HF identified six topic areas that should prompt consideration for specialist palliative care referral: support for complex decision making, high symptom burden, prognostication, frequent hospitalizations, complications from AHF or comorbidities, and consideration of AHF therapies such as LVAD, heart transplant, or continuous intravenous inotropic support (10).

Rationale and knowledge gap

Patients undergoing LVAD evaluation and implantation, and the caregivers that accompany patients through this journey, have significant care needs. Additionally, certain situations that arise at the end-of-life, especially surrounding LVAD deactivation, cause moral distress among clinicians. Palliative care specialists are frequently engaged, when available, to provide support to patients, caregivers, and clinicians in the care of patients with LVADs. However, the timing, frequency, and reason for referral of palliative care, especially in the pre-ventricular assist device (pre-VAD) and longitudinal care phase, is not well defined in the literature. We aim to review the unique challenges experienced by patients living with LVAD technology to lay the groundwork for future research.

Objective

In this review, we outline the contemporary role of palliative care across the LVAD care continuum: pre-implantation, post-implantation, and at the end-of-life. This review is aimed at palliative care clinicians who treat patients with AHF, specifically those considering, undergoing, or living with LVAD therapy. We present this article in accordance with the Narrative Review reporting checklist (available at

Table 1 Indications for LVAD therapy at time of initial LVAD implantation

LVAD indication	Description of LVAD indication
Short-term/BTT	LVAD implantation is expected to be followed by heart transplant after months to years
BTR	LVAD implantation is performed to provide time for myocardial recovery
Long-term/DT	Given non-modifiable barriers to heart transplant (e.g., age), patient is expected to remain on LVAD support for the remainder of their life
BTC	Once modifiable barriers are overcome (e.g., smoking, diabetes control, obesity), the patient may be considered for transplantation

LVAD, left ventricular assist device; BTT, bridge to transplant; BTR, bridge to recovery; DT, destination therapy; BTC, bridge to candidacy.

Table 2 The search strategy summary

Items	Specification
Date of search	June 1, 2023 through August 1, 2023
Databases and other sources searched	Ovid MEDLINE, PubMed
Search terms used	"Palliative care", "palliative medicine", "heart-assist devices", "ventricular assist device", "heart failure", "quality of life", "advance care planning", "prognosis", "communication", "preparedness planning", and "INTERMACS"
Timeframe	2000–August 1, 2023
Inclusion criteria	English-language articles of patients >18 years of age
Selection process	Original selection was independently performed by B.A. and A.R. Titles and abstracts were screened, and discrepancies were addressed in a manner that was conservative and inclusive so as to not erroneously exclude any potentially relevant publications

<https://apm.amegroups.com/article/view/10.21037/apm-23-551/rc>).

Methods

We used PubMed and Ovid MEDLINE to identify relevant articles from 2000 to 2023, published in English language, searching for relevant terms, including "palliative care", "palliative medicine", "heart-assist devices", "ventricular assist device", "heart failure", "quality of life", "advance care planning", "prognosis", "communication", "preparedness planning", and "INTERMACS". Relevant papers were reviewed by the authors. The review was structured to mirror the phases of involvement for palliative care for patients with LVADs: pre-LVAD implantation, living with LVAD, and end-of-life with an LVAD. The search strategy is summarized in *Table 2*.

Pre-LVAD implantation

Patients, caregivers, and clinicians view LVAD therapy

as a lifesaving procedure that can considerably improve health outcomes and quality of life of patients with AHF. Data from the INTERMACS registry demonstrated a large improvement in quality-of-life scores, such as the Kansas City Cardiomyopathy Questionnaire-12, in patients between pre-LVAD baseline scores and at 6-month and 3-year follow-up (11).

However, there are several risks including medical complications such as stroke, infection, gastrointestinal bleeding, and the possibility of device malfunction including pump thrombosis (12). The possibility of these potentially life-threatening events necessitates discussions about complex medical decision-making and end-of-life care. Because of this, thorough communication, realistic expectation-setting based on recipient risk, and planning regarding possible outcomes of the LVAD journey is especially important. LVAD decision aids have been studied and shown to improve concordance between stated values and treatment choice (13) and can be found online (14).

Advance care planning (ACP), or discussion of care preferences through the life cycle, is extremely beneficial to

patients. In a study by Detering and colleagues, ACP was shown to improve the quality of end-of-life care in elderly hospitalized patients, in addition to reducing symptoms of anxiety, stress, and depression in surviving relatives (15). In the intervention group who received palliative care, family members also reported higher satisfaction with end-of-life care (15). The ACC/AHA/HFSA HF guidelines recommend discussions regarding device deactivation from the time of initiation and throughout the continuum of care (COR:I, LOE:C-LD) (2).

In 2013, the Centers for Medicare & Medicaid Services mandated that teams caring for DT-LVAD patients must incorporate palliative care into their programs to be credentialed as a Medicare-approved facility. Moreover, it was suggested that palliative care specialists should be involved in the LVAD evaluation process but offered no specific guidance regarding what this consultation was expected to achieve (16).

Over time, evidence has accrued suggesting that when palliative care consultation is carried out before LVAD implantation, post-operative care planning and management of complications are more effectively handled by the LVAD team (17). Pre-VAD palliative care consultation can include symptom assessment, evaluating health-related quality of life, psychosocial and spiritual assessment, eliciting patient understanding of risks and benefits of LVAD and providing tailored education, determining patient goals of care, ACP including discussions of advance directive and surrogate decision maker, exploring patient perceptions regarding their minimally acceptable quality of life, and introducing nuances regarding end-of-life with an LVAD and device deactivation (18). Patient-specific risks should be considered to guide the discussion regarding treatment preferences (e.g., preferences regarding hemodialysis in a patient with advanced chronic kidney disease or the potential for medium-long term mechanical ventilation via tracheostomy in a patient with chronic lung disease or the interplay of psychiatric disease and substance use on outcomes) in concert with the counseling provided by the VAD team.

However, pre-implantation palliative care consultations, termed LVAD preparedness planning in the literature, lack standardization. In a qualitative analysis of 68 pre-implantation palliative care consults for patients undergoing DT-LVAD at a single center between 2013 and 2018, preparedness planning for device failure was discussed only 10% of the time; post-VAD quality of life with regards to health 54% of time; device complications 49% of the time; and the progression of comorbidities 12% of the time (19).

Building on the importance of a thorough and complete palliative care consultation before LVAD implantation, Nakagawa and colleagues conducted a study that found that when patients could articulate what is acceptable and unacceptable with regards to their well-being and care prior to LVAD implantation, they had more favorable outcomes at the end-of-life. In this study, patients who could clearly articulate conditions that would be unacceptable to them also died less frequently in the intensive care unit (ICU) compared to those who were unable to do so (20).

These studies highlight the importance and benefits of palliative care involvement during the LVAD evaluation process. However, there remain gaps in our understanding and consensus of what the optimal duration, frequency, and specific objectives of palliative care preparedness consultation, which must also be tailored to specific recipient medical and psychosocial circumstances and risk profile.

Living with an LVAD

Following LVAD implantation surgery, the majority of patients are able to be discharged from hospital to either rehabilitation or home. The 1-year survival in the contemporary era of LVAD technology is 83% (4). Patients are at risk of various medical complications, which may occur at unpredictable intervals, following LVAD implantation surgery. Gastrointestinal bleeding affects around 15–30% of patients (21). The infection rate for LVAD patients is around 42% for the first year (22), with driveline infections affecting 15–35% of patients (23). Ischemic and hemorrhagic strokes occur in 6.8% and 8.4% of patients, respectively (22). In an INTERMACS database analysis of 15,754 patients who received mechanical circulatory support from 2006 to 2014, 12.3% developed renal failure and required dialysis (24). In the long term, the development of right ventricular failure is a notable cause of morbidity and mortality in this population (25). The incidence of many serious adverse events including bleeding, stroke, and pump thrombosis is reduced with the HeartMate 3TM compared to the HeartMate IITM (7). The incidence of LVADs being implanted as DT-LVAD has been rapidly increasing. In 2019, a study by Woodburn and colleagues showed that a programmatic approach that standardized palliative care for DT-LVAD patients improved both patient outcomes and satisfaction, as well increased communication between the medical team and the patient/caregivers (26). This example highlights an opportunity where the quality of care in DT-LVAD patients

can be greatly improved by implementing a standardized approach to palliative care.

Many patients experience a loss of autonomy after LVAD implantation. This may result from worsening debility due to post-surgical deconditioning, loss of employment or financial independence with resulting strain, increased reliance on caregivers and stress surrounding the imposed burden on caregivers which can cause alterations family dynamics, anxiety related to managing the device including driveline exit site care and associated equipment, and fear of mortality (27). According to a study by Grady and colleagues, patients who were diagnosed with psychiatric or psychological issues, or cerebrovascular disease prior to LVAD implantation, were at a higher risk of poor outcomes due to their increased frequency of nonadherence to treatment recommendations after implantation (28). It is therefore crucial to assess patients' emotional and psychological preparedness, evaluate their degree of family and social support, and ensure the safety of their home environment prior to discharge.

In the recovery phase after LVAD, patients and caregivers must attend frequent clinic appointments to ensure that they are managing the LVAD appropriately and for the LVAD team to modify LVAD settings to attain optimal benefit. The frequency of LVAD appointments usually reduces over time, but some patients who experience chronic complications related to the LVAD may have the burden of attending additional appointments with specialists. Patients who are experiencing life-limiting complications of LVAD, such as chronic infection or neurocognitive impairments due to stroke or have an advanced illness diagnosis unrelated to the LVAD, such as cancer, may benefit from longitudinal follow up with palliative care.

Outpatient palliative care may be a limited resource or be unavailable in certain practice settings, hampering the ability of the care team to discuss ACP and treatment preferences specific to the natural history of their disease process. A recent survey of leaders of established cardiac palliative care programs identified challenges and facilitators to collaboration between cardiology and palliative care teams. This study demonstrated that the majority of programs, five out of the seven surveyed, provided outpatient services. However, availability of outpatient services was limited to a median of less than 1 day per week (29). Telehealth platforms may be a strategy to leverage and extend the limited palliative care workforce. Despite the inconsistent availability of comprehensive palliative care across the continuum of care, palliative care is recommended as part of

the multidisciplinary HF team to optimize patient outcomes and quality of life (30). An "annual heart failure review" incorporating palliative care specialists can normalize ACP and increase the frequency of these discussions (31).

End-of-life

For patients living with LVADs, several pathways leading to end-of-life exist. In some cases, patients may experience complications from the implantation surgery, leading to death during their initial hospital admission (32). In other instances, patients may struggle with persistent organ failure, such as renal, hepatic, or pulmonary insufficiency, thus requiring frequent and prolonged readmissions, and eventually leading to death. Many patients who derive improvement in their quality of life from an LVAD for months to years after implantation over time may experience either a gradual decline in health, leading to progressively worsening quality of life can lead to death, usually due to progression of HF, or a parallel progressive illness such as cancer. Others may experience an acute illness that results in morbidity and mortality such as a device malfunction, a cerebrovascular event, refractory ventricular arrhythmia, or sepsis (32). Palliative care and/or hospice may be considered at points depending on the illness trajectory, and the degree of involvement may wax and wane based on the clinical need and prognosis (*Figure 1*).

Regardless of a patient's clinical course, the topic of LVAD deactivation cannot be avoided as an LVAD must be deactivated to allow for death to proceed from a terminal process (18). In the United States, if an LVAD is no longer capable of maintaining an acceptable quality of life for the patient, its deactivation by either request of the patient or their surrogate decision maker is both morally and ethically permissible (33). Under these conditions, death following withdrawal of the LVAD is not considered euthanasia or a form of physician-assisted suicide, but rather death due to the natural course of the underlying illness (33).

Dying with an LVAD tends to be more medicalized; in a retrospective cohort study of patients dying with LVADs, the majority of patients died in the intensive care unit (34). A retrospective review of LVAD patients from the INTERMACS registry demonstrated that most patients died in a hospital setting (76.9%) (35). Notably, the further a patient was from their LVAD implantation date, the more likely they were to die outside of a hospital (37.4% in those greater than 12 months from LVAD implantation), while patients who were less than a month from their implantation

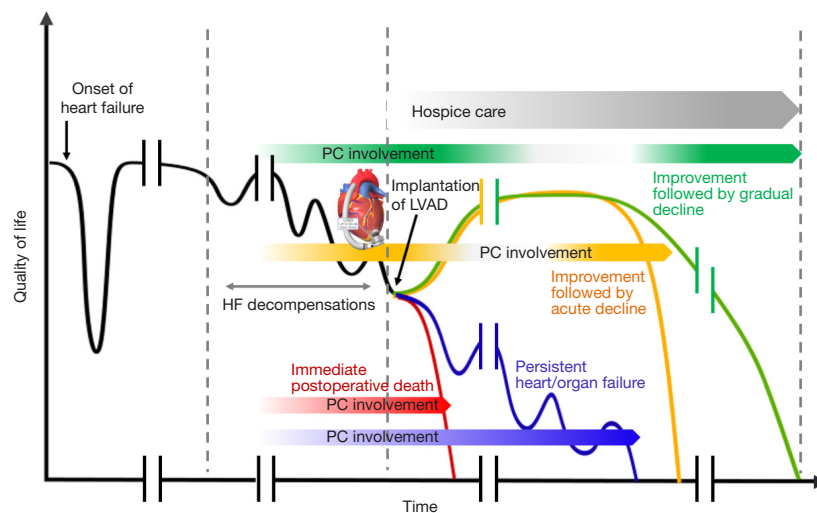


Figure 1 Schematic representation of the natural history of HF leading to the point of LVAD implantation. Post-LVAD trajectories were described by Dunlay and colleagues (32). Shaded bars represent PC and hospice involvement, with degree of shading intended to qualitatively reflect intensity of engagement. The parallel vertical lines are intended to represent the passage of “months-years” of time. PC, palliative care; LVAD, left ventricular assist device; HF, heart failure.

had a 2.3% chance of dying outside a hospital (35). Other factors including white race/ethnicity, advanced age, and a lower educational level were also associated with dying in the hospital. Complications such as infection, bleeding, psychiatric instability, and device malfunction were correlated with dying outside a hospital, whereas respiratory failure, neurologic abnormalities, and renal dysfunction were associated with an increased probability of dying in a hospital (35).

With adequate multidisciplinary support, the end-of-life experience of an LVAD patient can be made less distressing and more compassionate, thus improving quality of life for the patient, their family, and the care team (36). Training the care team to be adept at deactivating LVADs, including silencing alarms, may reduce the likelihood of errors that result in unnecessary distress; institutional checklists may aid in this effort (37,38). We published a checklist and detailed medication order set to aid clinicians through the process of LVAD deactivation (36). These checklists emphasize effective communication between the family and the interdisciplinary team and coordination between clinical specialists to assure a seamless deactivation. Defibrillator deactivation is also discussed as part of the process of preparing for LVAD deactivation (36). In a cohort of patients who died with DT-LVAD, one-third did not have their defibrillator deactivated prior to death, potentially exposing patients to the risk of defibrillator

discharges at the end-of-life (32). Treatment of dyspnea and other symptoms at the end-of-life are impacted by the acute cardiogenic shock that follows LVAD deactivation, resulting in impaired circulation and efficacy of symptom-focused treatments. The average duration of survival is 60 minutes following LVAD deactivation, though with significant patient-to-patient variability resulting in a survival range of minutes in some cases to days in others (34).

LVAD deactivation can be an emotionally turbulent experience for clinicians. According to Chuzi and colleagues, most clinicians are hesitant to broach the subject of end-of-life care before a patient is “actively dying”. Due to the unpredictable clinical course of LVAD therapy, providers admit that it can be difficult to optimally time end-of-life discussions (39). Clinicians also described deactivating an LVAD to be a very challenging act and viewed it to be very different from withdrawing other forms of life-sustaining care such as ventilators (39). In one survey, cardiologists were more likely than their palliative care colleagues to view LVAD deactivation as euthanasia, even when a concomitant terminal disease process was also present. McIlvennan and colleagues surveyed three different professional cardiology societies and one palliative medicine society to gather views on LVAD deactivation. Most clinicians who responded to the survey shared the view that an LVAD was a life-sustaining device (92% for cardiology,

and 81% for palliative medicine), however a majority (60%) of cardiology respondents believed that a patient should be actively dying before deactivating an LVAD, compared to only 2% of palliative medicine respondents holding the same view (40). These factors influence the discussions held between clinicians, patients, and caregivers as patients approach the end-of-life, as the discordant views between these two crucial pillars of the LVAD care team might lead to inconsistent and unclear goals of care for patients, which can be confusing and create undue distress.

A qualitative study of bereaved caregivers described confusion among caregivers about what dying with an LVAD would look like, concerns regarding the ethical and legal permissibility of LVAD deactivation, and worry that hospice staff were unfamiliar with LVAD technology (41). Chuzi and colleagues analyzed data from semi-structured interviews with bereaved caregivers and found that caregivers struggled with the uncertainty of the clinical course of their loved ones with LVADs and when to engage in discussions surrounding end-of-life (39). The perceived “invincibility” of the LVAD team was identified as another barrier to facing end-of-life discussions. The authors argued for improving communication curricula for LVAD clinicians, discussing ACP as a routine part of LVAD appointments, embedding palliative care within LVAD clinics, and providing support to clinicians experiencing psychological distress surrounding LVAD deactivation (39).

Hospice utilization is low in patients with LVADs; data from a large registry demonstrated that most patients with LVADs died in an acute care hospital in the United States (34). Patients with LVADs enrolled in hospice often experienced health crises that required emergency department visits or acute care hospitalizations (32). However, LVAD deactivation can be safely performed at home under the care of a hospice team (42). A retrospective study of patients who died after LVAD found that a minority of patients, 15%, died with hospice, with a median hospice length of stay of 11 days before death (32). The authors postulated that the low utilization of hospice services may reflect differences in preferences between LVAD patients and general HF populations, lack of comfort or training among hospice agencies and clinicians in caring for patients with LVADs, difficulties in prognostication, and the medical complexity involved in de-escalating LVADs and other life-sustaining medical therapies (32). Robust collaborations between hospice agencies and LVAD programs, including ‘just-in-time’ education for hospice care teams, are needed to support out-of-hospital care of patients with LVADs at the end-of-life (43,44).

Strengths and limitations

This review aims to summarize the literature in this niche but has several limitations: given the reliance on the INTERMACS registry for outcomes data, experiences with LVADs outside the United States are not represented. Additionally, the influence of Medicare national coverage determinants guidelines on the impetus for collaboration between HF and palliative care clinicians may not be mirrored in other countries. Nevertheless, we believe that the findings in this review are generalizable to international practice settings.

Conclusions

The importance of palliative care across the care continuum for patients with AHF cannot be understated. Research outside of the LVAD context has strongly established the benefits of palliative care in many aspects of patient care, ranging from managing symptoms, assisting with complex decision-making and the delineation of treatment preferences, to improving the quality of end-of-life care. As LVAD technology continues to evolve, there will be a growing need for palliative care specialists who are comfortable navigating the care needs, clinical trajectories, and ethical challenges for patients living with LVADs. At present, very little data exists to inform best practices in providing palliative care to patients with LVADs. More research is needed on the optimal timing, frequency, content, and location of palliative care consultation to optimize patient and caregiver outcomes.

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Footnote

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