Palliative Medicine Consultation for Preparedness Planning in Patients Receiving Left Ventricular Assist Devices as Destination Therapy

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OBJECTIVE: To assess the benefit of proactive palliative medicine consultation for delineation of goals of care and quality-of-life preferences before implantation of left ventricular assist devices as destination therapy (DT).

PATIENTS AND METHODS: We retrospectively reviewed the cases of patients who received DT between January 15, 2009, and January 1, 2010.

RESULTS: Of 19 patients identified, 13 (68%) received proactive palliative medicine consultation. Median time of palliative medicine consultation was 1 day before DT implantation (range, 5 days before to 16 days after). Thirteen patients (68%) completed advance directives. The DT implantation team and families reported that pre-implantation discussions and goals of care planning made postoperative care more clear and that adverse events were handled more effectively. Currently, palliative medicine involvement in patients receiving DT is viewed as routine by cardiac care specialists.

CONCLUSION: Proactive palliative medicine consultation for patients being considered for or being treated with DT improves advance care planning and thus contributes to better overall care of these patients. Our experience highlights focused advance care planning, thorough exploration of goals of care, and expert symptom management and end-of-life care when appropriate.

You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die.

Dame Cicely Saunders

The left ventricular assist device (LVAD) is a promising technology that supports circulation in patients with advanced heart failure. Originally developed to bridge patients to heart transplant, the LVAD is being used as destination therapy (DT) for patients who are not candidates for heart transplant. Compared with medical therapy, use of DT improves survival, quality of life (QOL), and functional status in appropriately selected patients with advanced heart failure.1-5 In our experience at Mayo Clinic, the 2-year survival rate of patients receiving DT is 75%.6 However, as a result of occasional adverse events (eg, stroke, infection, or multiorgan failure), some patients or their surrogate decision-makers may request withdrawal of LVAD support.7,8 In other situations, patients or caregivers may become overwhelmed with financial and psychosocial issues related to DT9-11 and are at risk of burnout and isolation because of outpatient needs and limited community support.11-14

Several analyses7,15,16 have concluded that goals of care of patients receiving DT are often undefined. Many patients either have inadequate advance directives that do not address potential problems (such as worsening comorbid conditions, complications, and worsening QOL) or simply lack advance care documents.7,16,17 Without clearly defined goals and/or explicit advance directives, DT may merely maintain circulation in a moribund patient, a situation referred to as “destination nowhere.”18 Also, protocols and processes regarding LVAD management and comfort at the end of life are often lacking7,17; hence, ethical quandaries (eg, withdrawal of device support) may arise.19,20

To avoid situations in which advance care wishes are unclear or unknown, palliative medicine (PM) consultation has been suggested8,17,21-23 to address end-of-life preferences, facilitate advance care planning, manage symptoms, and maximize QOL. Several authors have called for PM involvement in patients with advanced heart disease to improve health status and QOL,24-29 and a recent randomized study of early palliative care vs standard care in advanced lung cancer has demonstrated improved QOL, improved mood, and survival benefit.30 Herein, we describe our initial experience with proactive PM consultation in patients receiving DT.

PATIENTS AND METHODS

In January 2009, a multidisciplinary conference was held at our institution to discuss ethical dilemmas and longitu-
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Possible scenarios, such as device failure and complications that might adversely affect QOL but not necessarily threaten survival (eg, acute or chronic stroke, intracranial hemorrhage, incurable infection, or permanent renal failure), were discussed. Patients’ social situations and their spiritual and religious beliefs were explored. Finally, the PM team assisted with expectation setting. The aggregate documentation from the PM and social worker consultations, as well as previous or new advance directive documents incorporated into the patients’ electronic medical records, is what we collectively refer to as preparedness planning (Table 2 and Figure 1).

### TABLE 2. Common Differences Between Traditional Advance Directives and Preparedness Plans in Patients Receiving LVAD as Destination Therapy

<table>
<thead>
<tr>
<th>Measure to be considered</th>
<th>Advance directive</th>
<th>Preparedness plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antibiotics, long-term role</td>
<td>+</td>
<td>++</td>
</tr>
<tr>
<td>Artificial nutrition</td>
<td>+</td>
<td>++</td>
</tr>
<tr>
<td>Blood transfusions</td>
<td>+</td>
<td>++</td>
</tr>
<tr>
<td>Goals and expectations</td>
<td>−</td>
<td>++</td>
</tr>
<tr>
<td>Hemodialysis</td>
<td>+</td>
<td>++</td>
</tr>
<tr>
<td>Hydration</td>
<td>+</td>
<td>++</td>
</tr>
<tr>
<td>Intracranial hemorrhage</td>
<td>−</td>
<td>++</td>
</tr>
<tr>
<td>LVAD failure</td>
<td>−</td>
<td>++</td>
</tr>
<tr>
<td>LVAD infection</td>
<td>−</td>
<td>++</td>
</tr>
<tr>
<td>Organ donation</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Mechanical ventilation</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Postoperative plans for rehabilitation</td>
<td>−</td>
<td>++</td>
</tr>
<tr>
<td>Power of attorney appointed</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Psychosocial assessment</td>
<td>−</td>
<td>++</td>
</tr>
<tr>
<td>Review of perioperative morbidity and mortality</td>
<td>−</td>
<td>++</td>
</tr>
<tr>
<td>Social dynamics reviewed</td>
<td>−</td>
<td>++</td>
</tr>
<tr>
<td>Spiritual and/or religious preferences</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Stroke</td>
<td>−</td>
<td>++</td>
</tr>
</tbody>
</table>

− = not generally found in document; + = may be found in document; ++ = often found in document. LVAD = left ventricular assist device.

Follow-up Intervention

The PM team worked with patients after DT. When adverse events occurred, the PM team assisted with preparedness plan implementation, symptom management, and family- and patient-centered support. This intervention often included psychosocial support to family, assistance with interpretation of advance directives and surrogacy issues, and assurance of ethically appropriate comfort care if DT was withdrawn. In patients doing well clinically, the PM team focused on enhancement of QOL. This intervention often included ongoing symptom and QOL assessment and assertion that DT met the patients’ goals of care. The estab-

![Figure 1](image-url)
establishment of relationships during periods of relative well-being was aimed at building rapport to facilitate decision making should patients experience clinical deterioration or adverse events.

**RESULTS**

**SUMMARY OF THE PATIENT GROUP**

The characteristics of 19 patients (16 men and 3 women) and outcomes data are summarized in Table 1. The median (range) age of patients at the time of initial DT was 70.9 (55.3-78.1) years. All 19 patients had New York Heart Association class IIIB/IV symptoms, and the mean ± SD pre-LVAD left ventricular ejection fraction was 17%±5%. Ischemic cardiomyopathy was the most common cause of heart failure (12 patients [63%]). Median duration of heart failure was 60 months (mean ± SD, 71±51 months); 12 patients (63%) underwent prior sternotomy before LVAD. No patient required renal replacement therapy before DT, but 2 patients did after DT. Seventeen patients (89%) had implantable cardioverter-defibrillators (ICDs) before DT; 14 ICDs also had biventricular resynchronization function. All patients received a continuous flow LVAD (HeartMate II, Thoratec, Pleasanton, CA).

Thirteen patients (68%) received proactive PM consultation, with 6 being unable to complete consultation because of clinical factors (eg, emergency surgery or patient and/or family not available or agreeable to consultation). Median (range) time to PM consultation was 1 day before LVAD implantation (5 days before to 16 days after LVAD implantation). Five patients died after DT: 2 deaths were due to early DT-related adverse events, 1 due to cardiac arrhythmia, and 2 due to posttraumatic intracranial hemorrhage. Median (range) time from LVAD implantation to death in these 5 patients was 76 days (range, 1-161 days). During the intervention period, new or revised advance directive availability in the medical record was 68% (14/19). Of these 14 patients, 11 received PM consultation.

Comparison of the 13 patients who completed PM consultation with the 6 who did not revealed no significant differences in age (70.2±6.1 vs 67.6±7.4 years; \(P=.43\)), sex (85% vs 83% male; \(P>.99\)), ejection fraction (16.5%±3.8% vs 17.5%±7.7%; \(P=.70\)), or history of sternotomy (62% vs 67%; \(P>.99\)). Duration of heart failure demonstrated a trend toward longer duration (84±50 vs 42±43 months; \(P=.09\)) in the intervention group. Finally, 11 patients (85%) in the intervention group had documented advance directives compared with 3 patients (50%) in the group that did not undergo a PM consultation (\(P=.26\)). Considering the small sample size, the significance of this is unknown, yet the trend is noteworthy.

**ILLUSTRATIVE CASE REPORTS**

The case histories of 6 patients who were part of the study group are discussed subsequently. These 6 cases are described in detail because they exemplify unique aspects

![Image](https://example.com/image.png)
of preparedness planning or illustrate how palliative care could potentially contribute to improved outcomes. These cases are grouped into 4 care trajectories. The first 3 are end-of-life trajectories for patients who have died, as suggested by Rizzieri et al: (1) patients with improved functionality, survival, and QOL with no complications occurring before 90 days (Figure 2; line C); (2) patients with suboptimal or delayed recovery or debilitative comorbid conditions and poor QOL (no net survival or QOL benefit) (Figure 2; line B); and (3) patients with postoperative complications (within 90 days of procedure) and with relatively shortened survival (Figure 2; line A). The fourth group, line C+ (not shown on the graph), comprises patients who have improved QOL and functionality but have not had DT-related complications negatively affecting survival. They remain on the upswing of line C. The selected 6 cases (corresponding to patient case numbers listed in Table 1) are illustrative of case complexity.

**Line A Case: Case 3.** A 55-year-old woman with biventricular heart failure and left ventricular thrombus underwent DT evaluation. As a single woman with no children and limited family resources, she received social work assessment focusing on adequate support. The PM team worked with the patient on her written advance directive and helped her discuss potential complications with her mother and siblings. She underwent DT the next day, complicated by intraoperative coagulopathy, hemorrhagic shock, and multiorgan system failure. Despite heroic efforts, including transfusions and renal replacement therapy, the patient was moribund. The family was well informed regarding the patient’s wishes as outlined in her preparedness plan. The family felt supported because rapport was already built with the LVAD and PM teams, contributing to a smooth transition to comfort care only. The patient died on postoperative day 2 after life-sustaining measures, including LVAD support, were discontinued.

**Line B Case: Case 5.** A 73-year-old man had a complex medical history, including coronary artery disease with previous coronary artery bypass grafting and an embolic stroke. He later was diagnosed as having lymphoma, and anthracycline-based chemotherapy superimposed on ischemic heart disease led to inotropic-dependent heart failure. With refractory symptoms, advanced age, and comorbid conditions, DT was suggested. During preimplantation consultation with the social worker and PM team, the patient stated, “My wife knows what I want and she can make the decisions for me.” The patient exercised only a durable health care power of attorney and did not wish to further discuss preparedness planning. After DT, biliary sepsis developed, with progressive hepatic and renal dysfunction. The patient remained ventilator and vasopressor dependent with worsening cytopenias, but the LVAD otherwise functioned appropriately. Multidisciplinary meetings were held, without consensus regarding prognosis or care plan. Prognostic estimates ranged from extremely poor to 50-50. Although the family mentioned being discouraged by the patient’s clinical situation, they did not feel strongly about altering his care trajectory.

The PM team helped the patient’s family better understand his complex situation and how it portended poor QOL. The team encouraged the family to articulate their understanding of the patient’s wishes in lieu of a specific advance directive. A decision was made to not escalate care and to attempt to remove obtrusive interventions in which burden was greater than benefit. After continuous hemodialysis was switched to intermittent hemodialysis, the patient’s hemodynamics worsened. The family chose not to reescalate care, and the patient died in the presence of his family later that day after life-sustaining measures were stopped.

**Line C Cases. Case 1.** A 64-year-old man with advanced ischemic cardiomyopathy underwent peripheral artery bypass for critical leg ischemia. Postoperatively, fluid overload and renal failure developed despite diuresis, inotropes, vasopressors, intra-aortic balloon pump, and ultrafiltration. The patient was referred for DT.

The patient had good family support, which allowed for detailed advance care planning with social work and PM teams. However, the patient became depressed and displayed behavioral dyscontrol and nonadherence with a medical plan of care (thought to be due to multifactorial delirium and underlying personality traits). Given his dire prognosis, he underwent DT, with informed consent obtained from his surrogate.

Postoperatively, the patient’s behavioral dyscontrol escalated, and the patient displayed nonadherence in attempting to disconnect his LVAD and in injuring nurses. The PM team intervened with the psychiatric team to stabilize the patient’s clinical course. The patient’s behavior improved in the following weeks, and he was discharged home 2 months after DT, with his wife noting he displayed a “more positive demeanor than it had been in 25 years.” The LVAD and a clear plan for acceptable QOL helped the patient to enjoy a renewed life. Unfortunately, 1 month later the patient fell and sustained an intracranial hemorrhage; he died 2 days later after LVAD support was withdrawn because it was no longer consistent with his previously stated goals of care. The family’s ultimate decision to withdraw LVAD support reportedly helped with his preparedness planning, and rapport was established with the PM team before DT.

**Case 16.** A 73-year-old man with valvular cardiomyopathy developed heart failure with effort intolerance and worsening left ventricular indices; he received DT with-
out complication. Although the PM team was consulted postoperatively, the patient underwent preparedness planning focusing on longitudinal care provision. He asserted his wish to not continue life support measures if he “was completely dependent on others for care.” Initial recovery was uneventful, and he completed rehabilitation without incident. The patient was a determined, self-sufficient man who performed all LVAD-related care alone because his wife was disabled; his functional status improved during the next 3 months.

Three months after implantation, the patient fell and sustained a skull fracture with subarachnoid bleeding. His clinical status was precarious, but the patient survived without operative intervention. His LVAD and mechanical values functioned well despite anticoagulation withdrawal. However, the patient’s neurologic and cognitive status did not improve, and he exhibited progressive agitation, non-cooperation with care, and loss of inhibition due to frontal lobe injury.

Prognosis was discussed during multidisciplinary care conferences, and behavioral dyscontrol escalated such that sedation with midazolam and fentanyl was required to prevent harm to himself, the staff, or his LVAD. On the basis of the patient’s wishes in his preparedness plan, a collective decision was made by the patient’s family to withdraw LVAD support. Staff and family were “extremely appreciative of the presence and comfort offered to them and the patient” by the PM team, particularly in empowering the patient’s wife to make difficult decisions on her husband’s behalf and ensuring that the patient was comfortable and treated with dignity in his final days.

**Line C+ Cases. Case 8.** A 69-year-old man with ischemic cardiomyopathy and colon cancer (in remission) developed worsening dyspnea, fatigue, and frequent ICD firings, prompting referral for DT. The patient’s adult children and wife (whom he recently married) were supportive, although the couple held different religious beliefs. In his preparedness plan, the patient (a Roman Catholic) made his spiritual preferences known, including wishes regarding time-limited trials of advanced measures, such as hemodialysis and blood transfusion. This intervention allowed his wife (a Jehovah’s Witness) to avoid situations that could compromise her conscience. Since implantation, the patient has made an excellent recovery and reports substantially improved QOL and capacity for activity. Because of his gratitude for his new lease on life, the patient counsels other patients considering DT before implantation.

**Case 18.** A 77-year-old man with ischemic heart failure had progressive effort intolerance, dyspnea, and low output symptoms for 2 years before presentation. He worked actively as a barber, except when limited by his heart failure, and planned to go back to work after the procedure. He lived with his wife of 50 years, who was the primary caregiver. He underwent DT, and his postoperative course was complicated by bilateral pneumothoraces, limiting his ability to participate in physical therapy because of pain and dyspnea. These symptoms were effectively managed by the PM team, and he was eventually discharged to inpatient rehabilitation and then home. Two weeks later, the patient was readmitted for dehydration and failure to thrive due to dizziness and persistent nausea that limited oral intake. The patient’s wife was overwhelmed with the care the patient required and felt burned out. In this case, the social work and PM team worked together to address both the patient’s symptoms and his caregiver’s needs. Fortunately, the patient went from “wondering if he should have [agreed to the DT]” to feeling much better and looking forward to rehabilitation at home. His QOL improved with LVAD functioning but also with aggressive symptom and adverse effects management by the PM team.

**DISCUSSION**

In this report, we describe our initial experience with proactive PM consultation for patients receiving DT. To our knowledge, this is the first such report of a standardized and integrated PM approach to advance care preparedness planning for patients receiving DT. Despite impressive survival outcomes, some patients receiving DT have serious adverse events that may compromise patient and caregiver QOL. Our approach has encouraged development of preparedness plans congruent with patients’ goals. Financial and safety issues are proactively evaluated by the social worker if they could negatively affect post-DT care.

Advance directives are requested of patients receiving DT and are finalized with PM assistance. As reported elsewhere, our intervention has led to improved advance directive completion and availability in the electronic medical record compared with previous rates. This is a key outcome because advance directives can enhance patient autonomy and provide physicians and surrogates with insights into patients’ health care–related goals, values, and preferences.

Consultation with a PM specialist has facilitated the honing of advance directives into personalized preparedness plans. The preparedness plan is an expanded advance directive for patients with LVADs. It specifically addresses circumstances that arise when the circulatory system is mechanically supported, but medical conditions or functional limitations are such that significant long-term morbidity or impaired QOL persist. Consultation with a PM specialist inherently involves advance care plan clarification; documents now contain preparedness plan details regarding pa-
tient goals if DT does not improve outcomes as expected. This clarity has been valuable to the DT team, particularly if outcome is suboptimal.

Attempts at reverting to team-based social workers who are not familiar with the nuances of DT or omitting PM consultation have been suboptimal in our experience. Although no differences in survival or patient-reported satisfaction have been reported, a lack of clarity among caregivers regarding goals of care and disposition has been noted by health care professionals at our institution.

With preparedness planning, if adverse events or QOL issues arise, PM personnel are able to promptly intervene and do not have to focus on building rapport with the patient and family during times of crisis. This key outcome of our intervention has assisted with patient-centered outcomes consistent with a patient’s goals of care. Families, as well as primary care team members, have expressed gratitude that the PM consultant is able to assimilate into the patient’s care when adverse events or suboptimal outcomes occur. This positive feedback has generally taken on the form of thank you letters or verbal praise but has not been analyzed systematically to this point.

We recognize several limitations to the current study. This is a small, nonrandomized, observational pilot study at a single tertiary care center; hence, results may not be readily generalizable to other populations. We believe the findings demonstrate value-added and present available supporting data; however, our observations are lacking well-defined outcome measures or other metrics.

Several challenges arose during this initial experience with proactive PM consultation in patients receiving DT. Not all patients or caregivers understood what PM was and often confused it with comfort care, hospice, or not proceeding with aggressive care measures. This challenge, coupled with clinical factors (eg, emergency procedures), meant that not all DT patients at our institution received PM consultation. Nevertheless, during our first year, 13 (68%) of 19 received PM consultation, which is an improvement compared with our prior experience of 0 of 36 patients receiving proactive PM consultation. Before this endeavor, only 5 (14%) of 36 DT patients received PM consultation at any point in their care. This finding is despite the fact that half of these 36 patients had died since the first implantation, with a median survival of 172 days (range, 1-1030 days) for all deceased DT patients at our institution from March 2003 to January 2009. We believe that proactive PM consultation before DT or soon postoperatively is valuable in expectation setting and avoidance of possible ethical dilemmas. Ideally, preparedness planning would occur sooner, but late outside referrals and occasional emergent need for DT have sometimes interfered with a consistently early PM consultant presence.

Although the line A and B cases have completed outcomes through death, there are opportunities to intervene with the line C and C+ patients. We are continuing to define the intermediate- and long-term role of PM in working with the DT team. Optimum timing of PM follow-up (whether regular, routine visits or episodic follow-up visits when clinical changes occur) has yet to be ascertained. Currently, PM relies heavily on cardiologists to refer back to PM specialists if clinical or QOL changes are noted. We believe there may be ongoing benefit of longitudinal PM follow-up if goals of care change because of an LVAD-related complication or if secondary comorbid conditions occur or progress.

We recognize that a finite amount of work can be done shortly before DT when patients are critically ill. Even several months after DT, some patients only vaguely recall their preparedness planning. Patients tend to be seriously ill when DT is being discussed, and patient engagement with the PM team has been variable. Nonetheless, caregivers have articulated their appreciation (in the form of verbal feedback) for balanced information, have valued hearing about risks and benefits associated with DT, and did not negatively construe discussing these issues up front. Family members have reported that their perception of the postoperative course was less difficult by having information before or around the time of implantation.

Our DT team has consistently worked to articulate a primary goal of PM: symptom management and promotion of QOL in patients with life-limiting, life-threatening illness. Often, DT is used as a permanent means of palliation, with the goal of improving QOL when cure cannot be achieved. For patients with successful post-DT outcomes, the PM team has helped patients and caregivers cope with the transition from a terminal prognosis in the setting of end-stage heart failure to living well after DT implantation. The multidisciplinary DT team, including the PM team, continues to refine its role in promoting positive outcomes and improving survivorship by helping patients adapt to life after implantation.

Consultation with a PM specialist for patients receiving DT is now regarded as routine and integral by our cardiovascular teams. The DT multidisciplinary team is supportive of PM specialist involvement and looks to PM consultants for guidance and care suggestions regarding complex situations. Patients admitted to the heart failure hospital service before DT are cared for by heart failure cardiologists who recognize that PM consultation is adjunctive medical care, rather than resignation of optimism for these patients. Most notably, the PM team has the full support of the cardiothoracic surgeons who implant the devices. The teams work together collegially and provide input in terms of complex decision making to promote patient-centered outcomes.
CONCLUSION

Destination therapy is a lifesaving but life-altering therapy. Guidelines have been developed to address optimal clinical management of LVADs. Given medical complexities with DT, we conclude that improvements in QOL may be amplified with PM consultation throughout the patient’s course—both before DT for rapport building and after DT for longitudinal care provision and assertion of acceptable QOL. We view DT as a permanent palliative therapy for incurable heart failure—one that improves QOL and reduces symptom burden. Our experience with PM and DT highlights higher rates of advance directive completion, improved establishment of preparedness plans, and better working relations with cardiac care specialists. In tandem, these factors interplay to affect patients, families, and caregivers regardless of DT outcome.

REFERENCES