

**Special Article**

# Destination Therapy: Standardizing the Role of Palliative Medicine and Delineating the DT-LVAD Journey



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**Abstract**

**Context.** Destination therapy (DT) patients face significant challenges as they transition from chronic left ventricular assist device (LVAD) support to comfort-oriented care. Integration of palliative medicine (PM) into the multidisciplinary team is important to facilitate advanced care planning (ACP) and improve quality of life (QoL).

**Objectives.** We evaluated the impact of a structured programmatic approach to the end-of-life (EOL) process in DT patients as measured by QoL surveys and the utilization of ACP.

**Methods.** We instituted a four prong intervention approach: 1) delineated the path from implant to EOL by defining specific stages, including a *transitional phase* where care limits were agreed upon, 2) standardized the role of PM, 3) held transitional care meetings to support shared decision-making, and 4) held multidisciplinary team debriefings to facilitate communication. Preintervention and postintervention outcomes were measured for patients/caregivers by using the QUALE/QUAL-E (family) QoL instrument. Wilcoxon signed-ranks test compared nonparametric variables.

**Results.** All patients ( $n = 41$ )/caregivers ( $n = 28$ ) reported improved QoL measures (patient  $P = 0.035$ /caregiver  $P = 0.046$ ). Preparedness plans increased from 52% to 73% after implementation and advance directives increased from 71% to 83%. Fifty-nine percent of the patients completed an outpatient PM clinic visit; 51% completed/scheduled a second visit. Clinician outcomes improved including satisfaction with multidisciplinary team communication/expectations, ACP processes, and EOL management.

**Conclusion.** A programmatic approach that standardizes the role of PM and delineates the patient's path from implant to EOL improved quality outcomes and increased implementation of ACP. A defined communication process allowed the multidisciplinary team to have a clear patient management approach. *J Pain Symptom Manage* 2019;57:330–340. © 2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

**Key Words**

*Heart failure, ventricular assist device, end of life, advanced care planning, destination therapy*

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**Introduction**

The landmark REMATCH trial revealed that patients with advanced heart failure who received a left ventricular assist device (LVAD) could have a survival

benefit with an improved quality of life (QoL) compared with patients who were supported on medical therapy alone.<sup>1</sup> According to INTERMACS, between 2008 and 2014, 46% of LVADs were implanted

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as destination therapy (DT). In this group, survival rates of 76% at 1 year and 57% at 3 years are achievable but indicate the need for end-of-life (EOL) planning.<sup>2</sup> Although patients reported improved QoL and functional capacity with LVAD support,<sup>3,4</sup> they also reported that recovery from surgery was daunting and later found that decision-making during the liminal phase as death approached was fraught with caregiver burnout and difficulty understanding when the goals of care should transition from treatment to comfort care only.<sup>5–13</sup>

Historically, we know that standard advance directives and living will documents fail to guide goals of EOL care in patients who survive LVAD implant but suffer debilitating complications of LVAD therapy.<sup>14, 15</sup> Despite the development of a preparedness plan that is better suited to address LVAD-specific complications and EOL scenarios,<sup>16</sup> there still remains no standardized approach for advance care planning (ACP). Furthermore, even with the regulatory mandate from Centers of Medicare and Medicaid Services (CMS) and national guideline-based endorsement of palliative medicine (PM) involvement, there is no consistent approach for the partnership between PM teams and cardiothoracic surgery teams.<sup>17–19</sup> In heart failure medicine, there has been a recent movement calling for the need to integrate PM into clinical heart failure practice with the goal of functioning as a multidisciplinary team in a bidirectional fashion.<sup>20,21</sup>

At Mayo Clinic Arizona, we recognized a theme in DT care demonstrating that patients and caregivers encounter a unique set of challenges that correlate with his or her progression through the DT-LVAD advanced illness trajectory (Fig. 1). Therefore, we sought to first conceptualize the lived process that DT-LVAD patients and their caregivers experience throughout the DT journey from preimplant to EOL care and how we as clinicians interpret this. The phases are defined as follows: first is the *preimplant phase* where the preparedness plan is often created and warrants review after implant as many patients, and their caregivers, report being “overwhelmed,” or even forgetful, in this phase.<sup>22,23</sup> Next is the *recovery phase* where early engagement for symptom management can help minimize physical and existential distress.<sup>24</sup> Furthermore, there are unique challenges encountered in the recovery phase that tend to resolve after the first six months compared to what patients may encounter in other phases. Third is the post-LVAD implant phase during which the patient benefits the most from LVAD therapy from a QoL standpoint, however, patients are still subjected to multiple hospital admissions for LVAD-associated complications such as a gastrointestinal bleed, stroke, pump thrombus, etc. Fourth, we noticed that patients and caregivers

face specific challenges when no longer thriving on DT-LVAD support but not quite ready for hospice care. We collectively identified this as the *transitional phase*, where factors such as the natural aging process, onset of new disease, worsening of pre-existing comorbidities, or even advancement of heart failure tend to impede survival despite proper pump function. Finally, it is the *EOL phase* during which caregivers report uncertainty about what lies ahead<sup>25</sup> and primary cardiothoracic surgery teams express feeling out of their element with complicated EOL care.

With this DT-LVAD advanced illness trajectory framework in place, we sought to understand how will anticipatory guidance improve the patient and caregiver experience and clinical teams shared management approach? Therefore, we designed a single institution quality improvement project to fully standardize the ACP process at the system level and fully integrate PM clinicians as part of the core team. We developed an anticipatory guidance tool to cultivate the role of the multidisciplinary team and improve QoL at the EOL.

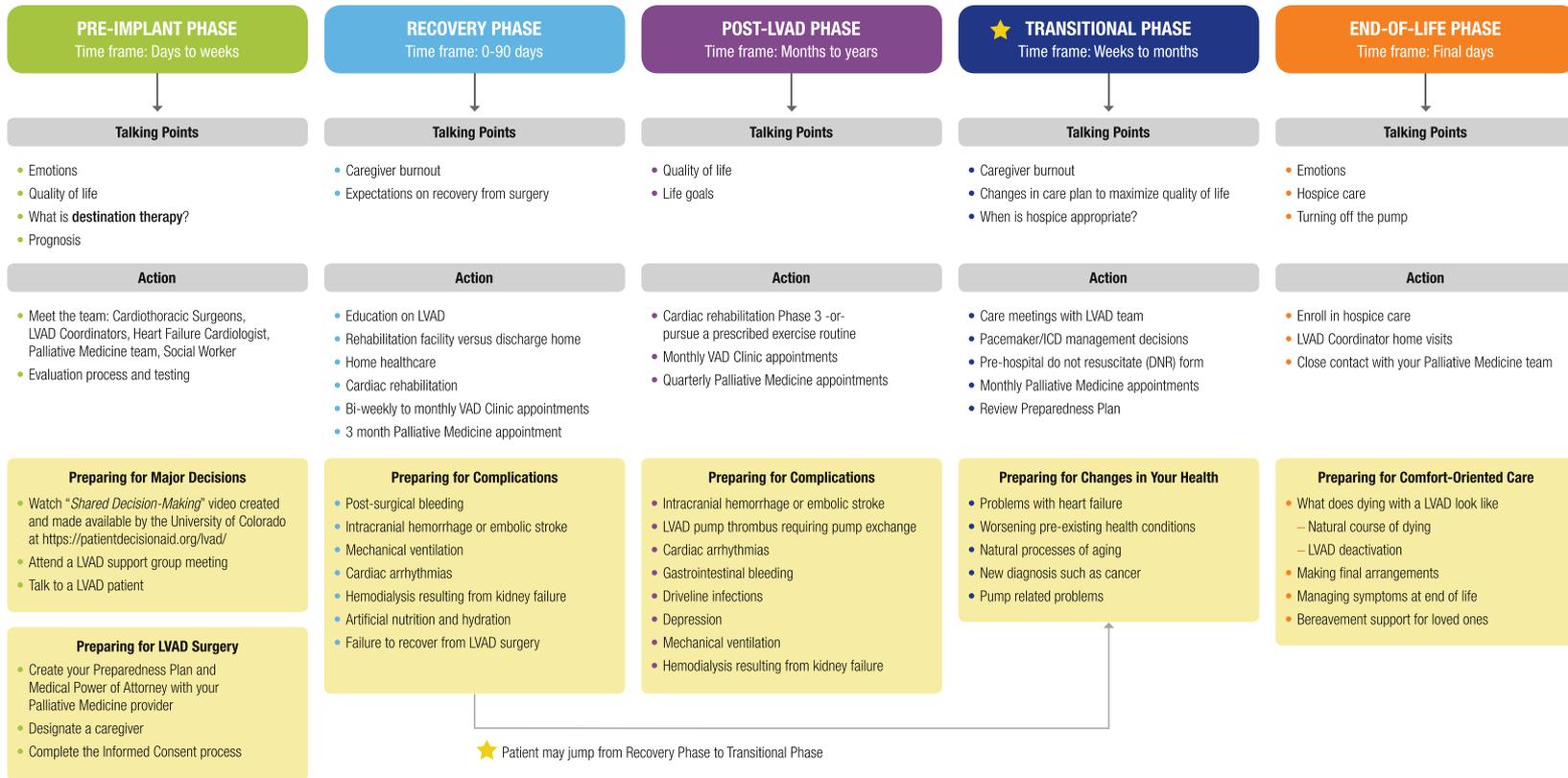
## Methods

This study was deemed exempt as quality improvement from the Mayo Clinic Institutional Review Board and Arizona State University Institutional Review Board. From September 2016 to February 2017, we instituted a multilevel intervention quality improvement initiative. All 41 patients and 28 caregivers seen during this period were included. The multidisciplinary team consisted of four cardiothoracic surgeons, four Advanced Practice Provider-VAD coordinators, five PM physicians, five heart failure cardiologists, one PM registered nurse, and one PM social worker. At the system level, three clinical departments were involved: cardiothoracic surgery, heart failure, and PM.

The outcomes measured are divided into subscales for each targeted population or process impacted: patient, caregiver, clinician, and system (Table 1). We used a four-prong intervention approach that cross-targeted all desired outcomes.

First, we created a novel tool that categorizes the DT-LVAD advanced illness trajectory (Fig. 1). The tool was developed as a way to frame and describe the clinical progression of illness that we were seeing in the DT-LVAD patient population. We interviewed members of the multidisciplinary team to elicit the five phases, and then feedback from stakeholder groups to refine the framework. Our goal was to use this framework tool to enhance clinician-clinician interaction by standardizing communication and creating a shared understanding of the expected progression of life with a DT-LVAD. In

# EXPECTED PROGRESSION OF LIFE WITH A LVAD AS A DESTINATION THERAPY PATIENT & CAREGIVER



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Fig. 1. Expected progression of life with a LVAD as a destination therapy patient and caregiver. LVAD = left ventricular assist device.

Table 1  
Outcomes Measured

Patient Outcomes Using QUAL-E <sup>26</sup>	Caregiver Outcomes Using QUAL-E (family) <sup>27</sup>
Symptom burden	Symptom impact
Relationship with health care provider	Relationship with health care provider
Preparation for end of life	Completion in relationship with patient
Completion with life	Preparation for patient end of life
Clinician Outcomes Using DT-LVAD Clinician Survey ( <i>Appendix 1</i> )	
Satisfaction with multidisciplinary communication and expectations	
Satisfaction with advance care planning	
Satisfaction with end-of-life management	
System Outcomes Pre to Post	
# of completed preparedness plans	
# of updated/reviewed preparedness plans	
# of documented advance directives	
# of outpatient palliative medicine appointments scheduled	
# of outpatient palliative medicine appointments completed	
# of transitional care meetings	
# of multidisciplinary team debriefings	

addition, we used the framework tool in patient/caregiver-to-clinician interactions during PM office visits, as well as in VAD clinic office visits to serve as a visual aid that provided anticipatory guidance, standardize common talking points for provider and patient/caregiver, and define appropriate actions for each of the stages.

Second, we standardized the role of PM with institutional policy development that provided outpatient and inpatient management recommendations and established routine outpatient care intervals for each of the five phases (*Appendix 2*). During the pilot intervention, each patient and their caregiver were given the opportunity to complete one to three PM outpatient clinic visits in which ACP documents would be reviewed, and interventions would focus on symptom management and QoL. Mutual buy-in from key stakeholders on the PM, heart failure, and cardiothoracic surgery teams was critical. Several department meetings were held before the pilot project period in which quality improvement project champions were designated from the PM and cardiothoracic surgery teams. The PM team and VAD coordinators were critical for scheduling and maintaining outpatient PM clinic appointments. Typically, patients and caregivers would follow up in clinic with whichever PM provider completed their consult in the hospital or at the preimplant clinic visit. If patients did not have an assigned PM provider then selection was based on appointment availability. All teams were invested in collaborating in the care of these patients and communicating to patients and caregivers that PM, and ongoing follow-up with the PM team, was integral to their ongoing care. Once it became an expectation that patients would follow up with PM, this became the norm for patients, caregivers, and providers. Fortunately, key stakeholders from all teams were adaptive and open to integrating PM into the core team.

Third, once patients were identified to be in the *transitional phase*, we aimed to hold regularly scheduled transitional care meetings with the multidisciplinary team to review goals of care, discuss implantable cardioverter-defibrillator management, and the timing for when a prehospital do-not-resuscitate (DNR) form would be indicated. This meeting was attended by the patient, caregiver, VAD coordinator, and heart failure attending and PM attending. Patients and caregivers most often interacted with the VAD coordinator. VAD clinic follow-up can range from three appointments a week to monthly or even bimonthly depending on how far the patient is from the date of implant and clinical stability. For example, patients in the recovery phase would be seen two to three times per week. The VAD clinic follow-up schedule was fairly stable before the pilot program. However, before pilot program, there was very little consistent follow-up with PM in the outpatient setting. In conjunction with standardized intervals of outpatient PM visits and facilitation of transitional care meetings our goal was to focus on helping patients and their caregivers transition goals of care in a shared decision making format.

Finally, we conducted monthly multidisciplinary team debriefings to facilitate and standardize communication to ensure the same plan of care was discussed with the patient/caregivers between all providers. The multidisciplinary team meetings were attended by cardiothoracic surgeons, VAD coordinators, the PM team attending, registered nurse and social worker, heart failure attendings, and the perfusion team. Participation in these meetings was not tracked as part of the pilot program data collection.

Before the interventions, multidisciplinary team meetings included a focus on educating clinicians on the quality improvement project and utilization of the DT-LVAD advanced illness trajectory tool. Our

central focus was more consistent follow-up in PM clinic. Therefore, the project team devoted significant energy to ensuring multidisciplinary buy-in for the workflow around scheduling orders.

#### Data Collection and Measurement Methods

We conducted preintervention and postintervention outcome measures using an exploratory approach. Patients and caregivers were interviewed in a face-to-face format using the QUAL-E and QUAL-E (family) instruments with demonstrated validity and reliability.<sup>26,27</sup> These tools were used because they provided similar outcome measures for both the patient and caregiver. Patients and caregivers participation was voluntary, and no consent process was required. A retrospective chart review was completed before interventions to obtain demographics and baseline data points for system-level measures. Deidentification methods were used to ensure that participants remained anonymous.

Despite a rigorous search for a validated and reliable measurement tool for clinician outcomes, no appropriate tool was found. Therefore, we created an eleven-question Likert-scale tool and undertook face validation with a relevant clinician population outside of the target clinician team for the pilot program (Appendix 3). The survey was administered via Qualtrics. All survey and interview responses were entered into Excel twice to ensure accuracy of the data transfer from Excel into SPSS for data analysis.

System-level measures were compared preintervention to postintervention. Statistical analysis was conducted using IBM SPSS Statistics for Windows, version 23 (IBM Corp., Armonk, NY). A *P* value of < 0.05 was set a priori. Data were not normally distributed. Wilcoxon signed-ranks test was used to compare nonparametric variables for patient and caregiver data. There was a reduction in sample size when running inferential statistics on paired subjects due to subject dropout. Clinician data were not paired to preserve participant anonymity and encourage clinician participation with honesty and transparency about the pilot program that included sensitive stakeholder buy-in. Therefore, Spearman's rho was used to look for significant correlations for clinician data. Descriptive statistics and frequencies reported on all unpaired samples.

#### Results

There were a total of 41 patients and 28 caregivers. Patient mean age was 66.7 (SD, ±13.2) years, and caregiver mean age was 63.4 (SD, ±13.9) years. Most patients were male (71%), and most caregivers were

female (75%). Fifty-one percent of patients were implanted after 2014.

All patient outcomes improved (Table 2). The patient relationship with health care provider (HCP) after intervention was significantly higher than the patient relationship with HCP before intervention ( $Z = -2.103$ ,  $P = 0.035$ ). A significant improvement in the patient's sense of control about their treatment decisions preintervention to postintervention was also found ( $Z = -1.999$ ,  $P = 0.046$ ) (Table 3). Of these patients, 79% had seen PM outpatients at some point since having an LVAD, and 79% had a completed preparedness plan. No correlation was found between a patient having a completed preparedness plan and preparation for EOL using a Spearman rho ( $P = 0.980$ ). Regarding symptom burden, 28% to 33% of patients denied symptoms; frequencies and type of symptoms are reported in Appendix 1.

All caregiver outcomes improved (Table 4). The caregiver relationship with HCP after intervention was significantly higher than the caregiver relationship with HCP before intervention ( $Z = -1.998$ ,  $P = 0.046$ ). There was also significant improvement in the degree to which caregivers were informed about what to expect as the patient illness progresses preintervention to postintervention ( $Z = -2.157$ ,  $P = 0.031$ ) (Table 5). Of these caregivers, the patients to whom they are matched with, 75% had seen PM outpatients at some point since having an LVAD, and 88% had a completed preparedness plan. No correlation was found between a patient having a completed preparedness plan and the caregiver preparation for patient EOL using a Spearman rho ( $P = 0.641$ ). Symptom impact, or perceptions of symptoms that patients struggle with, and their frequencies are reported in Appendix 1. Twenty-five percent denied symptom impact both before and after intervention.

Table 2  
Patient Outcomes Pre- to Post-QI Interventions Using QUAL-E<sup>26</sup>

Outcome/Survey Point	N	M/SD	Pvalue (n = 24)
Symptom burden <sup>a</sup>			0.169
Pre	31	9.48 ± 6.79	
Post	30	8.30 ± 6.40	
Relationship with health care provider			$Z = -2.103$ , $P = 0.035$
Pre	31	21.48 ± 3.17	
Post	30	22.13 ± 2.52	
Preparation for end of life <sup>a</sup>			0.342
Pre	31	13.61 ± 4.36	
Post	30	12.10 ± 4.05	
Completion with life			0.090
Pre	31	27.87 ± 4.12	
Post	30	28.53 ± 4.09	

M = mean.

<sup>a</sup>Reverse scored (lower score = improvement).

Table 3  
**QUAL-E<sup>26</sup> Patient Questions/Scores After Intervention (n = 30)**

Question	Range	Median	Mode
Although I cannot control certain aspects of my illness, I have a sense of control about my treatment decisions ( $Z = -1.999, P = 0.046$ )	2	4	4
I participate as much as I want in the decisions about my care	2	4	5
Beyond my illness, my doctor has a sense of who I am as a person	2	5	5
In general, I know what to expect about the course of my illness	2	4	4
As my illness progresses, I know where to get answers to my questions	2	5	5
I worry that my family is not prepared to cope with the future	4	3	3
I have regrets about the way I have lived my life	4	2	1
At times, I worry that I will be a burden to my family	4	3	3
Thoughts of dying frighten me	3	1.5	1
I worry about the financial strain caused by my illness	4	3	3
I have been able to say important things to those close to me	4	4	5
I make a positive difference in the lives of others	3	4	4
I have been able to help others through time together, gifts or wisdom	3	4	4
I have been able to share important things with my family	2	4	4
Despite my illness, I have a sense of meaning in my life	3	4	5
I feel at peace	3	4	5
There is someone in my life with whom I can share my deepest thoughts	2	5	5

Subscale scoring: 1 (not at all), 2 (a little bit), 3 (a moderate amount), 4 (quite a bit), 5 (completely).

Eighteen clinicians surveyed with a preintervention response rate of 56% and postintervention response rate of 44%. Clinician-level outcomes including overall satisfaction with multidisciplinary team communication and expectations improved from  $4.50 \pm 1.69$  to  $2.88 \pm 0.93$ ; ACP satisfaction improved from  $5 \pm 1.79$  to  $4.25 \pm 0.97$ , and EOL management from  $5.30 \pm 2.37$  to  $5.13 \pm 1.17$ . Clinicians consistently identified the recovery phase and *transitional phase* as the highest level of perceived caregiver burnout, and management of patient care most challenging in the *transitional phase*. Clinicians most often addressed prognosis when health status worsens and at the pre-implant visit. These findings did not change preintervention to postintervention.

System-level outcomes increased in all measures, including completed preparedness plans preintervention to postintervention (52% to 73%) with additional five-preparedness plans updated/reviewed. Refining the preparedness plans is imperative for effective

ACP because goals of care fluctuate over time. Documented advance directive increased (71% to 83%). Before intervention, 85% of patients had encountered PM (76% inpatient/59% outpatient), and 17% had scheduled ongoing appointments. In this six-month pilot, 100% of patients were successfully scheduled, and 59% completed one outpatient PM clinic visit. Of the 17 patients that did not complete a PM clinic visit, three expired before their appointment, five had scheduled appointments pending past pilot end date, two had seen PM before start of the pilot in which follow-up was scheduled further out, and seven patients canceled their appointments. Interestingly, the seven patients who canceled their appointments without rescheduling had their LVADs implanted between 2008 and 2013, which was prior to PM consultation becoming the standard of care at our institution as a component of the VAD implant evaluation. One patient transferred care from another facility without active PM involvement at their center. Six patients

Table 4  
**Caregiver Outcomes Pre- to Post-QI Interventions Using QUAL-E (Family)<sup>27</sup>**

Outcome/Survey Point	N	M/SD	P-value (n = 16)
Symptom impact			0.860
Pre	24	7.91 ± 5.53	
Post	20	8.55 ± 5.64	
Relationship with health care provider <sup>a</sup>			$Z = -1.998, P = 0.046$
Pre	24	6.91 ± 2.97	
Post	20	6.25 ± 2.75	
Completion in relationship with patient <sup>a</sup>			0.248
Pre	24	4.58 ± 1.81	
Post	20	4.30 ± 1.45	
Preparation for patient end of life <sup>a</sup>			0.580
Pre	24	9.50 ± 2.20	
Post	20	9.45 ± 2.16	

M = mean.

<sup>a</sup>Reverse scored (lower score = improvement).

Table 5  
**QUAL-E (Family)<sup>27</sup> Caregiver Questions/Scores After Intervention (n = 20)**

Question	Range	Median	Mode
How much have you been told about what to expect as the [patient's] illness progresses? ( $Z = -2.157, P = 0.031$ )	3	2	1
<sup>a</sup> How often does the health care team involve you in making decisions about the [patient's] care?	3	1	1
<sup>a</sup> How often does the health care team keep you informed about the [patient's] condition?	3	1	1
<sup>a</sup> How often does the health care team respond to your concerns about the [patient]?	2	1	1
How much of the time are you able to make a positive difference for the [patient]?	2	1.5	1
How much of the time are you able to have meaningful interaction with the [patient]?	1	1	1
How much of the time are you able to say important things to the [patient]?	2	1	1
How much do you feel financial strain related to the [patient's] illness?	4	3	3
How prepared are you emotionally for the future, no matter what happens?	4	2	2
How much do you feel at peace?	3	2	3
How much do you feel at peace about the [patients] care?	1	1	1

Subscale scoring: 1 (great deal), 2 (good bit), 3 (somewhat), 4 (only a little), 5 (not at all).

<sup>a</sup>Subscale scoring: 1 (always), 2 (usually), 3 (sometimes), 4 (rarely), 5 (never).

saw PM for the first time in the outpatient setting, and an additional 51% either completed, or scheduled, a second PM outpatient clinic visit. This demonstrated a change in practice, and mindset, on a patient and system level of adaptation to ongoing PM collaboration. Two transitional care meetings were completed (one outpatient/one inpatient). Of the one conducted in the outpatient setting, goals of care were reviewed, and shortly thereafter, a prehospital DNR form was provided and the patient was enrolled in hospice care at home. Three multidisciplinary team monthly debriefings were completed, and the focus remained on clinical management details, ACP, and QoL factors for our *transitional* and EOL phase patients. Regarding EOL, 75% of patients used hospice care (two enrolled in an inpatient hospice unit; one enrolled in hospice at home). Three of the four expired patients had completed a preparedness plan.

## Discussion

With this multidisciplinary care planning project for DT-LVAD patients, we have built on the framework of the landmark study by Swetz et al.<sup>15</sup> that improved ACP processes by integrating PM and further aimed to bridge gaps in care on a system and patient level to improve patient outcomes and reduce Medicare spending,<sup>28–31</sup> especially when performed in an iterative process that allows for patients and caregivers to develop a natural coping mechanism with their illness trajectory.<sup>32–34</sup> We addressed the barriers to ACP: difficulty of appropriately timing these conversations, provider and patient readiness to discuss EOL, the difficulty some patients have accepting their prognosis, and the fear that these conversations represent prematurely giving up hope.<sup>35–40</sup>

Outlining a DT-LVAD advanced illness trajectory that defines five distinct phases allows for patients, caregivers, and team members to have anticipatory guidance, specifically that of prognosis, expectations,

and potential complications across the expected progression of life with a DT-LVAD. The preimplant phase is one of the most critical phases in this trajectory because it establishes from the beginning that PM is a part of the team and expectations are established regarding ACP. From the LVAD team perspective, it is important to educate patients on the expectation of recovery. Cardiothoracic surgery and heart failure teams are vested in the patient's success, and often times, the consistent message given is that the first 90 days are going to be very hard, but we will help the patient get through it. Some patients do very well in this phase and are out of the hospital eight days after surgery. Others are discharged at the two-week mark and struggle with returning to baseline in those first three months. Finally, some patients fail to recover because of severe complications after implant that prevent a return to baseline or discharge from the hospital. Fortunately, failure to recover is rare, but when it occurs, it is critical that PM members are fully integrated to support the LVAD team, patient, and their caregiver, as it can be a daunting process.

Before implementation of PM as part of our mechanical circulatory support core team, it was very difficult for the PM team to engage after a DT patient had a serious adverse event. The integration of PM into the multidisciplinary team and engagement with patients during all phases of patient care allowed patients and caregivers to develop a trusting relationship with the PM team. This also worked in reverse in the sense that patients and caregivers would not feel abandoned by the primary cardiothoracic team when a patient was enrolled in hospice care, as the multidisciplinary team, presented a congruent front in this transition of goals of care. It allowed for specialty medicine experts to focus on specific needs of care at the appropriate time. Thus, direct and frequent conversations between PM and the patients and their caregivers enabled ACP to reflect patients' personal goals of care and EOL preferences. Early PM is known to improve QoL and symptom management, while reducing caregiver distress, as

well as offer clinical EOL expertise to help LVAD teams.<sup>41–45</sup> Literature suggests streamlining ACP with an innovative LVAD-specific advance directive approach.<sup>46</sup> Although this could be a useful approach, we found that the value of ongoing PM and the process of creating and refining the preparedness plan allows for the patient and caregiver to accept, process, cope, and adapt to their current health status. The ongoing relationship developed with the PM clinician not only helps patients and their caregivers but also alleviates burden from the primary LVAD team. At times, patients, caregivers, and even clinicians experience a negative reaction to merely the word “palliative” medicine. However, anxieties surrounding PM tend to resolve once patients have developed a rapport with a PM clinician. On a patient level, there is a need to create a longitudinal relationship from the beginning of LVAD therapy to the end. For example, shortcomings in ACP can occur when a patient and their caregiver encounter a PM provider for a preimplant consult and then have no further interaction with PM until the end of life phase or when enrolled in hospice. This breach in rapport does not allow for the patient and their caregiver to build a relationship and foster quality ACP goals.

The importance of building a comprehensive multidisciplinary team to break through ACP barriers is further highlighted by discrepancies in clinician involvement surrounding device deactivation and EOL care. It has previously been reported that only 26% of cardiologists were comfortable ordering LVAD deactivation when requested by the patient or surrogate decision-maker.<sup>47</sup> Other literature suggested that only 31% of clinicians reported a “high” or “very high” confidence level discussing EOL care or enrolling patients in hospice care with advanced heart failure.<sup>35</sup> Since 2012, there have been 65 new CMS-approved DT facilities across the U.S.<sup>48</sup> Although PM is required by the Joint Commission to be a part of the DT-LVAD care team,<sup>17</sup> the level of PM involvement is not clearly defined. Fortunately, various models of the multidisciplinary team partnership have become issues of heightened interest.<sup>21,49,50</sup>

The collaboration between our LVAD team and palliative care team stemmed from champions from both sides committing to this quality improvement project as meaningful engagement and wanting to follow the best practice guidelines with true incorporation of subspecialty palliative care. Despite clinical practice system constraints that may hinder the utilization of PM and develop the multidisciplinary team, it is imperative to establish routine PM care as DT-LVAD patients have a unique EOL experience that exceeds the scope of most heart failure/transplant teams alone. Following the DT-LVAD advanced illness trajectory tool can assist any clinical practice

in developing and fostering longitudinal relationships and provide sufficient ACP. Throughout this initiative, we recognized the existing barriers to multidisciplinary team collaboration within our own system. As we moved forward, we discovered that our multidisciplinary team debriefings provided an effective mechanism for bidirectional education from surgical practice preferences to considerations for QoL at the EOL.<sup>44</sup>

### Limitations

In reflecting on our experience, we note several limitations related to extant institutional experience, data collection, and administrative factors. Regarding institutional experience, this quality improvement pilot was not started at ground zero on an institutional level nor on a patient level. At an institutional level, our PM team already had engagement—albeit limited—with the LVAD team. At a patient level, some patients were in the *transitional phase*, whereas others were in the preimplant phase. Therefore, our experience and this quality improvement framework do not provide a blueprint for how to initiate a relationship for PM into a DT-LVAD program, but rather how to expand on a current program. For programs starting from the ground up, mutual buy-in and partnership between key stakeholders is vital. Future work with all patients starting at the preimplant phase and followed through to the EOL phase could have significant impact on ACP outcomes.

With regard to data collection, not all patients and caregivers were captured during the pilot project, which resulted in missing data. The QUAL-E (family) tool was not suitable for postintervention data gathering from grieving caregivers. Therefore, no postintervention data were collected from caregivers after a patient expired. There was no method established to track how often the DT-LVAD advanced illness trajectory tool was used. Various clinicians did document in the patient chart that the tool was discussed and reviewed in clinic, but this was not a consistent practice.

Regarding administrative factors, clinic scheduling was a major constraint. The highest success rate was when PM visits were scheduled same day as an LVAD clinic visit. Various clinician schedules impacted coordination of transitional care meetings.

### Conclusions

Establishing a clear framework and mechanisms for communication created a foundation of trust within the multidisciplinary team and allowed for in-depth appreciations of each other’s roles. We observed increased use of shared framework terminology (e.g., “transitional phase”) in both written and spoken

communication correlating with improved clinician satisfaction scores. We also noted improved patient and caregiver outcomes. Direct correlation between clinician satisfaction and patient/caregiver outcomes in this population merits further examination. Members of the team were able to express their priorities, worries, and inspirations in caring for DT patients and their caregivers during in-person meetings. Disseminating knowledge acquired in multidisciplinary team briefings to clinicians that could not attend will be a focus of further quality improvement work.

Based on our experience, we learned three key points. First, it is feasible to establish a shared understanding of the phases of progression of life with a LVAD for DT patients and their caregivers. This method can standardize the multidisciplinary team management approach and provide anticipatory guidance to increase patients' and caregivers' knowledge of the progression of life for the DT patient and the common adverse events that occur. Second, full integration of PM in the multidisciplinary team and routine outpatient care can improve the process of defining patient-centered goals of care throughout the continuum of care, create a refined and targeted approach to ACP in a shared decision-making format, and allow for early recognition of the *transitional phase* DT patient, thus allowing appropriate timing for EOL care. Finally, although it was challenging to coordinate transitional care meetings, we found that by expanding communication among the multidisciplinary care team, patient-centered communication can be bridged with multidisciplinary team debriefings. This allows for the multidisciplinary team to create an individualized plan of care to effectively guide the patient and their caregiver. Utilizing the DT-LVAD advanced illness trajectory tool allows the multidisciplinary team to have a standardized communication and approach in the management of DT-LVAD patients and their caregivers. We hope that this quality improvement work provides value to other DT-LVAD centers to standardize the role of PM and generate hypotheses for future work that strives to focus on patient-centered ACP.

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## Appendix 1

### DT-LVAD Clinician Survey

- 1) As a clinician caring for a DT-LVAD patient and their caregiver, I am satisfied with multidisciplinary team communication between Cardiothoracic Surgery, Congestive Heart Failure and Palliative Medicine departments
  - a) Extremely satisfied
  - b) Somewhat satisfied
  - c) Neither satisfied nor dissatisfied
  - d) Somewhat dissatisfied
  - e) Extremely dissatisfied
- 2) In 2014, the Centers for Medicare & Medicaid Services (CMS) mandated that a Palliative Medicine representative be a member of the multidisciplinary LVAD team. I believe that the role of Palliative Medicine is clearly defined in DT-LVAD patient management (inpatient and outpatient) at this institution.
  - a) Strongly agree
  - b) Somewhat agree
  - c) Neither agree nor disagree
  - d) Somewhat disagree
  - e) Strongly disagree
- 3) I perceive that completing a personalized preparedness plan helps a DT-LVAD patient and their caregiver to be aware of potential complications related to LVAD therapy.
  - a) Strongly agree
  - b) Somewhat agree
  - c) Neither agree nor disagree
  - d) Somewhat disagree
  - e) Strongly disagree
- 4) I believe that a personalized preparedness plan is useful in directing goals of care conversations with patients and caregivers.
  - a) Extremely useful
  - b) Very useful
  - c) Moderately useful
  - d) Slightly useful
  - e) Not at all useful
- 5) I believe that our multidisciplinary team does effective advance care planning with our DT-LVAD population.
  - a) Strongly agree
  - b) Somewhat agree
  - c) Neither agree nor disagree
  - d) Somewhat disagree
  - e) Strongly disagree
- 6) I perceive that a DT-LVAD caregiver experiences a high level of burnout in the following phase(s) of a patient's LVAD journey (select all that apply)
  - a) Preimplant phase
  - b) Recovery phase (day 0 to 90 days)
  - c) Post-LVAD phase (>3 months to years)
  - d) Transitional phase (when a patient is not ready for comfort-oriented care but no longer warrants disease-directed interventions)
  - e) End-of-life phase (final days)
  - f) Other (please explain)
- 7) As a clinician caring for a DT-LVAD patient and their caregiver, I address prognosis (select all that apply)
  - a) During the initial preimplant visit
  - b) On an annual basis
  - c) With every LVAD hospitalization
  - d) When their health status is worsening
  - e) I usually do not discuss prognosis
  - f) Other (please explain)

- 8) As a clinician caring for a DT-LVAD patient and their caregiver, when in the course of the patient's illness trajectory do you find challenging to manage care? (select all that apply)
  - a) Preimplant
  - b) Recovery phase (Day 0 to 90 days)
  - c) Postimplant phase (more than three months to years)
  - d) Transitional phase (when a patient is not ready for comfort-oriented care but no longer warrants disease-directed interventions)
  - e) End-of-life (final days)
  - f) Other (please explain)
- 9) I feel comfortable talking to a DT-LVAD patient and their caregiver about transitioning from a focus on disease-directed interventions to a care plan that maximizes quality of life interventions.
  - a) Extremely comfortable
  - b) Somewhat comfortable
  - c) Neither comfortable nor uncomfortable
  - d) Somewhat uncomfortable
  - e) Extremely uncomfortable
- 10) I feel that our multidisciplinary team effectively supports the patient and caregiver through the end-of-life phase.
  - a) Strongly agree
  - b) Somewhat agree
  - c) Neither agree nor disagree
  - d) Somewhat disagree
  - e) Strongly disagree
- 11) I feel comfortable talking with a DT-LVAD patient and their caregiver about what the end-of-life experience may look like with an LVAD (e.g., device deactivation, DNR status, transfer to hospice care)
  - a) Extremely comfortable
  - b) Somewhat comfortable
  - c) Neither comfortable nor uncomfortable
  - d) Somewhat uncomfortable
  - e) Extremely uncomfortable

*Appendix 2*

Caregiver Perception of Patient Symptoms	# Times Reported	Patient-Reported Symptom Burden
Pain	15	16
Fatigue	14	20
Dyspnea	12	13
Trouble sleeping	8	6
Confusion	4	2
Depression	4	2
Dizziness	4	4
Weakness	4	5
Device weight	2	5
Driveline infection	3	1
Driveline irritation	3	2
Allergies	3	—
Shower frustrations	—	3
Urinary problems	—	3
Edema	2	—
Mood	2	—
Nausea	2	3
Anxiety	1	3
No appetite	1	2
Neuropathy	1	2
Feeling of falling	1	1
Loss of independence	1	—
Management of batteries	1	—
Tremors	1	—
Atrial fibrillation	—	1
Gout	—	1

### Appendix 3

#### Strategy to Standardize the Role of Palliative Medicine

- 1) Preimplant consult
  - a) Can either be completed inpatient or outpatient clinic visit.
  - b) Complete preparedness plan (PP) as this visit; review, and ensure advance directive/living will are on file.
  - c) Sign off at the time of surgery or after the initial consult.
  - d) Ensure first palliative medicine (PM) follow-up appointment is scheduled within 60 days of discharge.
    - (1) This appointment is to be set by PM MD that completed the consult.
  - e) Re-engagement of PM is requested by ventricular assist device (VAD) team.
    - (1) Possible triggers for re-engagement: LOS > 30 days, ICU LOS > 14 days, and/or acute catastrophic change such as stroke.
- 2) Outpatient follow-up
  - a) Patient required to attend PM postimplant clinic visits at suggested time interval:
    - i) At six weeks (recovery phase visit), three months, six months, one year
    - ii) Q6 months until patient enters transitional phase
      - (1) Transitional phase determined by VAD team.
    - iii) Transitional Phase q 1–2 month(s)
  - b) Scheduling:
    - i) Palliative Medicine clinic visits will be made by the PM provider.
      - (1) VAD Coordinator to email PM Register Nurse (RN) if pt is not able to attend appointment due to hospitalization, etc ..., to assist with rescheduling—otherwise PM MD to order next f/u at time of visit.
    - ii) PM MD doing the initial consult will follow patient in the outpatient clinic.
- 3) Documentation and adherence of preparedness plan
  - a) Components of PP must include at a minimum a specific line for:
    - i) Goals and expectations of LVAD therapy, stroke, renal failure, pump thrombus, device failure, mechanical ventilation, long-term antibiotics, and blood transfusions
  - b) Document in EMR as an ACP note
- 4) Patient management
  - i) Management of chronic pain
    - (1) PM MD to determine appropriateness of opioid/benzodiazepine management on case-by-case basis—some patients may need to be referred to a chronic pain center or mental health providers.
    - (2) Best practice is for CTS to manage post-surgical pain up to three months.
  - ii) Review preparedness plan at three-month clinic visit; give patient/caregiver copy; or encourage patient to access via online portal
  - iii) Update/review preparedness plan every one to two years and upon entering transitional phase