

ORIGINAL RESEARCH

Perceptions of Bereaved Caregivers and Clinicians About End-of-Life Care for Patients With Destination Therapy Left Ventricular Assist Devices

Sarah Chuzi , MD; Adeboye Ogunseitan, MD; Kenzie A. Cameron , PhD, MPH; Kathleen Grady , PhD, RN; Lauren Schulze, MSN, FNP-BC; Jane E. Wilcox, MD, MSc

BACKGROUND: Patients with left ventricular assist devices (LVADs) implanted as destination therapy may receive suboptimal preparation for and care at the end of life, but there is limited understanding of the reasons for these shortcomings. Exploring perceptions of individuals (caregivers and clinicians) who are closely involved in the end-of-life experience with patients with destination therapy LVADs can help identify key opportunities for improving care.

METHODS AND RESULTS: We conducted semistructured qualitative interviews with 7 bereaved caregivers of patients with destination therapy LVADs and 10 interdisciplinary LVAD clinicians. Interviews explored perceptions of preparing for end of life, communicating about end of life, and providing and receiving end-of-life care, and were analyzed using a 2-step team-based inductive approach to coding and analysis. Six themes pertaining to end-of-life experiences were derived: (1) timing end-of-life discussions in the setting of unpredictable illness trajectories, (2) prioritizing end-of-life preparation and decision-making, (3) communicating uncertainty while providing support and hope, (4) lack of consensus on responsibility for end-of-life discussions, (5) perception of the LVAD team as invincible, and (6) divergent perceptions of LVAD withdrawal.

CONCLUSIONS: This study revealed 6 unique aspects of end-of-life care for patients with destination therapy LVADs as reported by clinicians and caregivers. Themes coalesced around communication, team-based care, and challenges unique to patients with LVADs at end of life. Programmatic changes may address some aspects, including training clinicians in LVAD-specific communication skills. Other aspects, such as standardizing the role of the palliative care team and developing practical interventions that enable timely advance care planning during LVAD care, will require multifaceted interventions.

Key Words: end-of-life care ■ palliative care ■ ventricular assist device

Left ventricular assist devices (LVADs) implanted as destination therapy (DT) improve survival, functional status, and health-related quality of life for most patients.^{1–3} Despite technological advancements, these devices are associated with significant adverse events, wherein over 70% of patients with an LVAD experience an infection, bleeding complication, device malfunction, or stroke within the first year following implantation.^{3,4} Furthermore, mortality among DT LVAD

recipients remains high,³ patients experience varied and unpredictable illness trajectories, and death may be sudden, with an estimated 40% of patients with DT LVADs suffering an acute event (eg, hemorrhagic stroke or device malfunction) that leads to demise within hours to days.⁵ Thus, patients with DT LVADs, their caregivers, and clinicians confront a unique paradox: whereas LVAD implantation is often pursued as a lifesaving intervention with the potential to dramatically

Correspondence to: Sarah Chuzi, MD, Division of Cardiology, Department of Medicine, Northwestern University Feinberg School of Medicine, 676 N. St. Clair Street, Suite 600, Chicago, IL 60611. E-mail: sarah-chuzi@northwestern.edu

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CLINICAL PERSPECTIVE

What Is New?

- Patients with destination therapy left ventricular assist devices (DT LVADs) receive suboptimal preparation for and care at end of life. There is limited understanding of the reasons for these shortcomings.
- Bereaved caregiver and clinician perspectives on end-of-life preparation and care for patients with DT LVADs have not been explored.
- This qualitative study of bereaved caregivers and clinicians identified 6 important themes pertaining to end-of-life preparation and care for patients with DT LVADs; challenges related to communication, team-based care, and unique barriers associated with providing end-of-life care to patients who elected to receive a life-saving technology were identified.

What Are the Clinical Implications?

- Efforts to improve end-of-life preparation and care for patients with DT LVADs will require multifaceted interventions that focus on enhancing LVAD-specific end-of-life communication skills, normalizing discussions about the end of life, and pursuing more longitudinal, consistent involvement of specialty palliative care across the DT LVAD trajectory.

Nonstandard Abbreviations and Acronyms

DT LVAD destination therapy left ventricular assist device

change the heart failure (HF) illness trajectory and improve health-related quality of life, recipients may also face device-related complications, complex end-of-life decisions, and ultimately death after implantation. Thus, planning for and communicating about end-of-life preferences and providing patient-centered care at end of life are critically important in this population.

Insights from the literature and clinical experience suggest that patients with DT LVADs may receive suboptimal planning for and care at end of life. Despite recommendations from regulatory bodies⁶⁻⁸ that clinicians engage patients with DT LVADs and their caregivers in advance care planning discussions and end-of-life decision-making from preimplantation through death, there is evidence that these discussions occur infrequently.^{9,10} Furthermore, patients with DT LVADs often receive aggressive interventions at end of life and rarely use hospice,⁵ bereaved caregivers of patients with

DT LVADs describe high levels of confusion at end of life,¹¹ and only 50% of patients with DT LVADs receive specialty palliative care services in the month before death.¹⁰

Although much attention has been paid to the logistical and ethical issues surrounding LVAD deactivation at end of life,¹¹⁻¹⁶ little is known about other challenges or salient aspects of the broader end-of-life experience for caregivers of patients with DT LVADs. Furthermore, clinician perspectives on end-of-life preparation and care are critically important but have not been explored. The purpose of this study was to understand bereaved caregiver and clinician perceptions of end-of-life discussions and care for patients with DT LVADs.

METHODS

Because of the sensitive nature of the data collected for this study, requests to access the data set from qualified researchers trained in human subject confidentiality protocols may be sent to Dr Chuzi at sarahchuzi@northwestern.edu.

We used an interpretive phenomenological approach to gather a diversity of opinions to create an understanding of both caregiver and clinician perceptions. This approach enables elicitation of rich information related to individual perceptions of issues and experiences with the goal of understanding the lived experiences of the participants.^{17,18} This study was approved by the Northwestern University Institutional Review Board.

Site and Sample

We recruited and interviewed (1) caregivers of patients who died after receiving DT LVADs at a large academic medical center with a mechanical circulatory support program, and (2) clinicians involved in the care of patients with DT LVADs. Criterion-based purposeful sampling was used in the selection of both caregivers and clinicians.¹⁹ Caregivers were identified through a REDCap (Research Electronic Data Capture) database of all LVAD-supported patients that is maintained by our mechanical circulatory support program. Caregivers were eligible if they were English speaking, older than 18 years, able to provide informed consent, were the primary caregiver for a patient with a DT LVAD who had died between 1 month and 5 years before recruitment, and were involved in the patient's care at end of life. Clinicians included advanced HF cardiologists, cardiac psychologists, cardiac surgeons, LVAD nurses, palliative care physicians, and social workers who provide care to patients with DT LVADs at our center.

Recruitment began in February 2019, with letters describing the study sent to a sample of bereaved caregivers. In an attempt to reduce unnecessary emotional

distress, we excluded caregivers if the patient's death had occurred within the month before recruitment; we further excluded caregivers if the patient's death had occurred >5 years before the start of the study. The letter provided a phone number for caregivers to call if they wished to opt out of receiving a recruitment phone call. A member of the study team placed a maximum of 3 phone calls, 4 days apart, to caregivers who did not call to opt out. For caregivers who were contacted and amenable to participation, a date and time were scheduled for completion of the consent and interview. Clinicians were recruited via email; those who did not opt out of the study received a follow-up email to schedule a time for provision of consent and the interview.

All interviews were digitally recorded. All participants provided written informed consent before participation. Caregivers received parking validation and a \$40 gift card as compensation; clinicians were not compensated. Interviews were conducted between February 2019 and November 2019.

Data Collection

A multidisciplinary team of clinicians and researchers with expertise in advanced HF, qualitative methods, palliative care, and patient-provider communication developed interview guides based on a review of the literature and the clinical expertise of the investigators. Separate guides were developed for caregivers and clinicians. Each guide sought to elicit participant perspectives on advance care planning and end-of-life care for patients with DT LVADs, including communication about end-of-life issues, logistical and emotional preparation for end of life, experiences and emotions pertaining to LVAD withdrawal, barriers and facilitators to end-of-life care for patients with LVADs, and suggestions for improvement (see Data S1 for the interview guides). Draft interview guides were reviewed and revised by the study team.

Semistructured, in-person interviews were conducted by the lead author (S.C.). Interviews lasted 30 to 90 minutes. Our process for conducting interviews was iterative: modifications to the interview guides (primarily adding probes) were made to further explore new views and perceptions based on previous interviews and ongoing analysis. We collected demographic information from all participants including age, sex, race, and ethnicity. Education level, relationship to the patient, and occupational status at the time of caregiving were collected from caregivers. Clinical experience, including palliative care training, was collected from clinicians.

Statistical Analysis

Digital recordings were transcribed verbatim by an external company (GMR Transcription, Tustin, CA);

all transcripts were deidentified. Analysis began after the first interview and continued concurrently throughout the interview process. We used a 2-step team-based inductive approach to coding and analysis.^{20,21} First, 6 authors (S.C., A.O., K.A.C., K.G., L.S., and J.E.W.) independently reviewed and coded 4 transcripts (2 clinicians and 2 caregivers) using line-by-line descriptive coding to develop a preliminary codebook.^{20,21} Two authors (S.C. and J.E.W.) then independently coded each of the remaining transcripts, identifying additional descriptive codes and adding to the codebook as necessary. The 2 coders met frequently during analysis, reconciling any coding disagreements through discussion. A detailed audit trail was used to track analytic decisions.²² In our second step, 2 authors (S.C. and A.O.) conducted focused coding, as described by Charmaz²³ and Saldana,²¹ through which we sought to refine a large number of descriptive codes into conceptual categories and further identify the most frequent or salient themes related to perceptions of end-of-life care for patients with DT LVADs. Constant comparison was used to compare responses across all participants and between caregivers and clinicians.^{24,25} Upon completion of this second-step coding and reconciling, the analyses and identified themes were presented to the larger research team (ie, all 6 authors) for critique and feedback. The use of multiple coders and larger team critique allows for a shared interpretation of the data and investigator triangulation,^{26,27} a process that maximizes reliability and confidence while establishing both trustworthiness and credibility.^{21,28} We opted to interview all clinicians in our initial recruited purposeful sample (n=10) to obtain a diversity of perspectives among clinicians who performed various professional roles and interacted with patients and caregivers throughout the LVAD implant experience. Analysis of these data demonstrated thematic saturation, the point of redundancy in data collection wherein subsequent interviews yield no additional information,^{29,30} and therefore additional clinicians were not recruited. Caregivers were recruited until thematic saturation was reached.

RESULTS

Participant Characteristics

Recruitment letters were sent to 21 caregivers: 5 caregivers opted out of the study, 9 were unable to be contacted, and 7 ultimately participated in the study. Caregivers were predominantly middle-aged, women, White, and spouses of the patients (Table 1). Six patients were implanted at the study site, whereas 1 patient was implanted at another institution and subsequently transferred care. Five of the patients died in

Table 1. Descriptive Characteristics of Caregivers and Clinicians

Characteristic	Value
Caregivers, n=7	
Age, y, mean±SD	59±16.5
Sex, % women	86
Race, % White	86
Relationship to patient, n	
Spouse or partner	4
Child	2
Parent	1
Time from patient death to caregiver interview, mo, mean±SD	19.6±14.6
Clinicians, n=10	
Age, y, mean±SD	41±7.6
Sex, % women	50
Race, % White	80
Current position, n	
Advanced HF cardiologist	2
Cardiac psychologist	1
Cardiac surgeon	2
LVAD nurse	2
Palliative care physician	2
Social worker	1
Years in practice, mean±SD	9±8.5
Self-reported formal training in providing end-of-life care	
Advanced HF cardiologist	CME course on breaking bad news
Advanced HF cardiologist	CME course on breaking bad news
Cardiac psychologist	None
Cardiac surgeon	None
Cardiac surgeon	None
LVAD nurse	None
LVAD nurse	None
Palliative care physician	Board certified in HAPM
Palliative care physician	Board certified in HAPM
Social worker	None

CME indicates Continuing Medical Education; HAPM, hospice and palliative medicine; HF, heart failure; and LVAD, left ventricular assist device.

the hospital, and 2 died at home with hospice services. The mean time from patient death to caregiver interview was 19.6 months (minimum time=4.8 months and maximum time=3.4 years).

Recruitment emails were sent to 10 clinicians, all of whom consented to participate. Clinicians were, on average, middle-aged, 50% women, and primarily White, and included 2 advanced HF cardiologists, 1 cardiac psychologist, 2 cardiac surgeons, 2 LVAD nurses, 2 palliative care physicians, and 1 social worker (Table 1).

Thematic Analysis

We identified 6 overarching themes pertaining to perceptions of end-of-life planning and care. Themes included: (1) timing end-of-life discussions in the setting of unpredictable illness trajectories, (2) prioritizing end-of-life preparation and decision-making, (3) communicating uncertainty while providing support and hope, (4) lack of consensus on responsibility for end-of-life discussions, (5) perception of the LVAD team as invincible, and (6) divergent perceptions of LVAD withdrawal. In addition to a description of each theme below, supplemental quotes for themes are presented in Table 2.

Timing End-of-Life Discussions in the Setting of Unpredictable Illness Trajectories

Many clinicians reflected a hesitancy to discuss end of life before the patient was “dying.” Some clinicians used the phrase “actively dying” to distinguish patients they perceived would clearly benefit from end-of-life discussions from those who may not.

“If someone is actively dying in the [intensive care unit], you have to talk about it, right? This is the issue at hand.”

(Advanced HF Cardiologist 1)

Other clinicians articulated that unpredictable patient clinical trajectories made it challenging to know when to broach end-of-life topics. One clinician (Advanced HF Cardiologist 2) described difficulty determining where patients with LVADs fell on a spectrum of “living” versus “dying,” using the word “limbo” to describe her perspective of the experience of many of her patients.

Caregivers echoed clinician sentiments about the uncertain clinical trajectories of patients with LVADs in the context of planning for end of life, noting that this uncertainty could lead to feeling unprepared to face the patient’s death. One caregiver described life with an LVAD as a series of ups and downs, expressing that previous rebound from critical illness made it challenging to accept that death was a possibility and that end-of-life discussions were warranted.

“I was hopeful, because he had always snapped back. You go down and down and down. You come up. You go down.”

(Caregiver 2)

Prioritizing End-of-Life Preparation and Decision-Making

Clinicians acknowledged that they did not prioritize discussions about end-of-life planning or care during

Table 2. Qualitative Results of Interviews

Theme	Representative Clinician Quotes	Representative Caregiver Quotes
Timing end-of-life discussions in the setting of unpredictable illness trajectories	“Whereas with some cancer diagnoses, you may know that this is probably curable or it’s not. You have this long to live. Whereas we’re so new, and we don’t know how people are going to do after LVAD.” (LVAD Nurse 1)	“I could see him deteriorating. His energy level was deteriorating. But did I suspect that he was doing to die? No. So was I prepared? No.” (Caregiver 4)
Prioritizing end-of-life preparation and decision-making	“I know that they’re overwhelmed...getting labs once a week, coming to LVAD clinic once a month. They’re overburdened already with health care in general, so I don’t know that they wanna come for one more appointment to discuss end of life or if we have the time.” (LVAD Nurse 1)	“We had phone conversations with nurses about his INR is International Normalized Ratio, his meds, what’s changing, and what should I do if... It was always more logistics, not this is what you should expect.” (Caregiver 3) “It would have been really good, I think, if someone had said I don’t want to take the wind out of your sails here...but we do want to spend some time just reminding you about some of these risks and offering some basic forms that might ease the pressure or stress on your family.” (Caregiver 1)
Communicating uncertainty while providing support and hope	“So not necessarily saying ‘this is what’s going to happen to you’ but helping them hold both preparation and hope at the same time.” (Cardiac Psychologist) “In medicine that’s our downfall. If you take away hope from patients, you’ve taken away everything.” (Palliative Care Physician 1)	“He was such a positive person in that regard, and I didn’t want to discuss that. I didn’t want to take away his hope.” (Caregiver 6)
Lack of consensus on responsibility for end-of-life discussions	“Ideally it [person who discusses end of life] would be a heart failure cardiologist, as opposed to a separate team that hasn’t really met our patients, doesn’t understand the breadth of heart failure.” (Cardiac Surgeon 1) “When they [the LVAD team] ask me ‘can you just try to tell them they’re dying?’ I say ‘I can, but they don’t know me, they don’t trust me.’ At the end of the day, they’re going to look to the doctors they have a relationship with to really understand what’s happening.” (Palliative Care Physician 1)	“And we wanted Dr. [advanced HF physician] because we knew her, we trusted her. She had been there from the beginning. And we needed to know from her what was going on [at end of life].” (Caregiver 1)
Perception of the LVAD team as invincible	“We’re the team that’s always been saying we’re going to save their life. So they really do think that we can do anything, and sometimes we just can’t make it better.” (LVAD Nurse 2)	“I believed in the team of doctors, and so far, they could do anything.” (Caregiver 1)
Divergent perceptions of LVAD withdrawal	“I try not to be [there when the LVAD is withdrawn]. It’s too raw for me.” (Cardiac Surgeon 1) “It feels weird to turn someone’s device off yourself. Extubating someone, turning off the ventilator... that’s fine. But it does feel weird to be the person to push that button and essentially end that person’s life.” (LVAD Nurse 2) “I discuss it similarly to how I discuss withdrawing any other life-sustaining treatment.” (Palliative Care Physician 2)	“I knew what the mechanics of it were, and I knew it’s not like he would instantly die, it just meant that the pump would stop, and so his own heart would then take over... I was surprised at how long it took, but it didn’t bother me to be there. It was just like it is what it is, so not it’s natural.” (Caregiver 3)

HF indicates heart failure; and LVAD, left ventricular assist device.

routine LVAD care, citing a focus on medical or logistical concerns, time constraints, and discomfort with the subject matter as reasons for not discussing end of life.

“We’re always focused on fixing the current problem. [Talking about end of life] is not the last thing on our list, but it’s close to the last thing on the list when it comes to taking care of your patient.... We know we can sort of kick the can down the road.”
(LVAD Nurse 2)

Caregivers agreed that prioritizing end-of-life topics was difficult, and some acknowledged their own focus on more logistical aspects of the care plan during LVAD care. None of the caregivers recalled discussing end-of-life preparation or care with members of the LVAD team

before the patient’s death. However, in contrast to clinicians, many caregivers reflected on the need for transparency from the care team and a greater emphasis on advance care planning:

“I just think that a little more communication one-on-one with me about—just be honest. Just be upfront. Nobody wants to say it, but you need to hear it.” (Caregiver 3)

Communicating Uncertainty While Providing Support and Hope

Clinicians acknowledged the importance of communicating with patients and caregivers about preparing for end of life, but appeared to struggle with how to communicate information on expected complications,

health-related quality of life, and prognosis. Fear of taking away hope was a frequently cited barrier to communication.

"If you say... 'oh by the way, you also might be dying, slowly, but not actively' that can be hard for patients to get their heads around. And it can be hard for us to communicate in a way that's not 'we're giving up on you'."
(Advanced HF Cardiologist 1)

Caregivers shared concerns about whether or not broaching or discussing end-of-life planning could be harmful to the well-being of the patient. One caregiver (Caregiver 6) commented that it would be too "depressing." Another said:

"[The patient] wanted to live so much, I wanted everything to be as positive as it could be for him."
(Caregiver 5)

Lack of Consensus on Responsibility for End-of-Life Discussions

Clinicians from across disciplines described conflicting feelings about their own role and others' roles with regard to preparing patients with LVADs for end of life, and there was a lack of agreement about who was responsible for these discussions.

"On the one hand, it should be our role. On the other hand, I think it would be better done by a palliative care doctor. Not just because they're better at it, but because it allows us to continue the role of being a [ventricular assist device] doctor and saying 'hey, we think you're doing really well.' Otherwise, people feel like we're giving up on them. I think that [more serious advance care planning] would hurt our doctor-patient relationship."
(Advanced HF Cardiologist 2)

Caregivers struggled to define their own role in the process of initiating end-of-life discussions with the LVAD patient, with one caregiver (Caregiver 6) remarking that this task "should not fall on the family." When asked whether they would have wanted a member of the LVAD team or another healthcare provider to discuss these topics, many caregivers were unsure. However, unlike most clinicians, caregivers emphasized the importance of the clinician-caregiver relationship, as opposed to the specific clinician role (eg, HF clinician, palliative care clinician),

in determining who should discuss end-of-life topics. A trusting relationship with a known provider was highlighted as essential, with one caregiver (Caregiver 7) remarking "you don't want to talk about death to some stranger."

Perception of the LVAD Team as Invincible

Caregivers expressed admiration toward the LVAD team who had provided this lifesaving therapy to the patient. Many caregivers believed that, because the patient had evaded death in the past with the help of the LVAD team, they could do so again. This belief in the invincibility of the LVAD team was cited as a barrier to facing end-of-life discussions.

"I didn't think about [the end of life] because [the LVAD team] had always rescued him."
(Caregiver 5)

Clinicians on the LVAD team reported similar reflections, citing their ability to "fight death" (Cardiac Surgeon 1). This perspective made it more difficult to broach end-of-life topics.

"I mean, you are giving a life-giving thing, and then all of a sudden that's not gone well, but you're so focused on life-giving."
(Social Worker)

Divergent Perceptions of LVAD Withdrawal

Caregivers and clinicians offered 2 main perceptions of LVAD withdrawal. Many caregivers and clinicians described turning off the LVAD as an extremely emotional process that differed from disconnecting alternative forms of life support (eg, a ventilator). One advanced HF cardiologist stated that LVAD withdrawal "feels like a very active killing process" (Advanced HF Cardiologist 2), whereas one caregiver remarked that "extubating him... in my mind that's a normal process. But to turn off the [ventricular assist device], that was his life" (Caregiver 2).

In contrast, some caregivers and clinicians (including an HF cardiologist and both palliative care physicians) described LVAD withdrawal from a more detached and mainly cognitive perspective. Some clinicians drew parallels between LVAD withdrawal and withdrawal of other forms of life support, whereas some caregivers described feeling a sense of curiosity about what LVAD withdrawal would look like.

"I was more curious. If they turn it off, what would happen to the heart? We knew it would stop, but I never really thought [the LVAD] was his lifeline." (Caregiver 4)

DISCUSSION

There is a paucity of literature exploring end-of-life planning and care for patients with DT LVADs. Although caregiver perceptions have been studied, the majority of articles are largely focused on LVAD deactivation,^{11–16} care provided to patients with LVADs in the final weeks before death,¹¹ or caregiver burden, strain, and decision-making.³¹ In contrast, little is known about caregiver perceptions of communicating about and preparing for end of life throughout the DT LVAD trajectory. Furthermore, clinician perceptions of end-of-life communication and care are critical but unexplored in the literature. In this article, we describe salient features of the end-of-life experience for clinicians and caregivers of patients with DT LVADs, as well as unique barriers to preparing for and providing end-of-life care not previously described. Themes coalesced around communication, team-based care, and unique challenges associated with providing end-of-life care to patients who have elected to receive potentially life-saving technology.

Communication was central to many of our themes: specifically, both caregivers and clinicians struggled to define when and how end of life should be discussed with patients with DT LVADs and their caregivers. Timing of end-of-life discussions was complicated by uncertainty about disease trajectory and life expectancy. This barrier has been described in the literature previously in other disease processes, particularly for nonmalignant terminal conditions in which risk stratification models have limited application in clinical practice.^{32–34} For example, in a Belgian study, general practitioners identified a lack of key moments in the HF disease trajectory as a barrier to initiating advance care planning discussions.³⁴ As a result, LVAD clinicians may choose to focus on aspects of care that are more immediate or pressing, such as laboratory results or medications. Both clinicians and caregivers acknowledged that the complexity of care served as a barrier to providing end-of-life discussions; however, many caregivers expressed that they wished these topics had been introduced earlier.

In addition to timing of end-of-life communication, most non-palliative care clinicians in our study expressed discomfort and uncertainty about how to discuss the end of life. Many cited a fear of destroying hope as a primary driver, especially for patients who were doing well. Not surprisingly, caregivers also worried that end-of-life discussions could cause

psychological harm to the patient. These findings are consistent with prior studies suggesting that conversations about prognosis and advance care planning happen infrequently in routine care, including cardiology practices,³⁵ and that many clinicians avoid these discussions because of fear of destroying hope or causing harm.^{32,34,36} One potential explanation for such discussion avoidance is that few cardiologists receive formal communication or palliative care training, as highlighted by clinicians' observations in our study. Furthermore, there is a conspicuous lack of communication or palliative care skills in cardiology training guidelines.³⁷

Although the importance of team-based care, especially the involvement of palliative care specialists, for patients with LVADs has been emphasized in multiple guidelines and by experts in the field,^{7,8,38,39} and both palliative and nonpalliative clinicians in our study articulated the challenges associated with this multidisciplinary effort not previously described. These clinicians spoke of uncertainty on the role of the palliative care team and which clinicians would be most appropriate to discuss end-of-life topics in the setting of existing patient-clinician relationships and trust. The issue of role tension has been explored in the literature⁴⁰ but not with regard to LVAD care. Thus, although multiple consensus statements highlight the importance of collaboration with palliative care in the care of patients with HF and LVADs, our findings underscore challenges that may come with such collaboration. Importantly, this theme highlights a key area of divergence for clinicians and caregivers: although clinicians were focused on which clinician was most appropriate to have these discussions based on their role on the team or skill set (eg, advanced HF cardiologist, palliative care physician), caregivers felt that these discussions should happen with the clinician with whom they had the strongest, most trusting relationship, regardless of their role on the clinical team.

Finally, our study also accentuates unique challenges in planning for and providing end-of-life care for patients with LVADs. First, both caregivers and clinicians described the LVAD team as invincible, using terms such as "rescue" and "lifesaving" to describe their efforts, which appeared to be a barrier to planning for end of life. The idea that advanced technology and the clinicians that provide it allow patients to avoid suffering and death has been called the "culture of rescue," whereby dying patients who cannot be rescued and the providers who cannot save them are often seen in our healthcare settings as having failed.⁴¹ Our study demonstrates that LVADs and the LVAD team are viewed in a similar way. The challenges inherent to withdrawal of such technology are also highlighted. Caregivers and clinicians in our study described 2 different perspectives of LVAD withdrawal. Interestingly, the clinicians at our institution who were most likely

to be present for or facilitate LVAD withdrawal (LVAD nurses) and the surgeons who implanted the LVADs tended to liken LVAD deactivation to an active killing process; whereas those clinicians who were generally not present for this process were more likely to view LVAD withdrawal in a manner similar to withdrawing other forms of life support.

Implications for Research and Clinical Practice

Findings from our study lay the groundwork for development of clinical, systems, and research initiatives to improve the end-of-life process for patients with DT LVADs and their caregivers. Strategies for improvement informed by our study findings, the clinical expertise of our team, and available evidence in non-LVAD populations are listed in Table 3. First, communication-skills training for LVAD clinicians is essential. Although structured communication-skills training has been shown to improve comfort and competency in domains such as breaking bad news,⁴²⁻⁴⁴ to our knowledge, LVAD-specific communication training, including content on end-of-life discussions, has not been developed. In particular, LVAD clinicians would benefit from understanding how to reframe the idea of hope, from focused hope, which centers on cure, to intrinsic

hope, which instead focuses on being present, and on cultivating the emotional skills that will be important at end of life.⁴⁵

Efforts to normalize conversations about end-of-life goals and wishes and the development of evidence-based interventions to incorporate these discussions into routine LVAD care are also essential. Many caregivers in our study expressed that efforts to introduce advance care planning into routine care would be valued and appreciated. Outpatient interventions using novel communication tools have been associated with increased occurrence and quality of goals-of-care communication in patients with serious illness,⁴⁶ but have not yet been applied in LVAD care. Furthermore, although palliative care teams may play a valuable role in the care of patients with DT LVADs, the field would benefit from more robust, evidence-based, and specific guidelines, perhaps developed by professional societies, about timing and goals of palliative care involvement. Although recent studies provide direction for integration of palliative care into evidence-based HF management,⁴⁷⁻⁴⁹ palliative care involvement in the setting of LVADs remains a nascent field.

Finally, our findings highlight that more education and debriefing opportunities for both clinicians and caregivers with regard to end of life would be beneficial.⁵⁰ Importantly, efforts to educate patients and caregivers about the logistical, physiological, and psychological aspects of LVAD withdrawal must be undertaken, whereas clinicians should be encouraged to engage in mindfulness, debriefing, and reflective practices after device deactivation. Future initiatives should focus on how to discuss this important issue with patients throughout the LVAD trajectory.

Table 3. Challenges to Optimal End-of-Life Preparation and Care for Patients With DT LVADs and Strategies for Improvement

Challenge	Strategies for Improvement
Communication barriers	<ul style="list-style-type: none"> Develop and implement LVAD-specific communication curricula for LVAD clinicians. Curricula content to include: <ul style="list-style-type: none"> Breaking bad news while providing support and hope Facilitating patient-centered discussions about LVAD deactivation
Uncertain timing of end-of-life discussions	<ul style="list-style-type: none"> Discuss advance care planning as a routine part of LVAD appointments, especially in the outpatient setting Recognize that LVAD-related adverse events provide an opportunity to address end-of-life discussions
Unclear roles and responsibilities of LVAD and palliative care clinicians at end of life	<ul style="list-style-type: none"> Explore embedding palliative care clinics within LVAD clinics to facilitate collaboration for patients with increased needs Develop expert consensus on involvement of palliative care clinicians throughout the DT LVAD trajectory, with clear triggers for referral
LVAD withdrawal may be challenging for clinicians and caregivers	<ul style="list-style-type: none"> Introduce the concept of LVAD withdrawal before LVAD implantation Educate patients and caregivers on the logistical, ethical, physiological, and psychological aspects of LVAD withdrawal during routine care Provide clinicians the opportunity to debrief or receive psychological services as needed after LVAD withdrawal

DT indicates destination therapy; and LVAD, left ventricular assist device.

Limitations

There are a few limitations to our study. The clinician sample size was relatively small and from a single institution. There may be variability among institutions in how end-of-life care is discussed and provided to patients with DT LVADs. However, we did include clinicians from multiple roles and achieved saturation in our clinician sample. Our sample of caregivers was also relatively homogeneous and small. Although the accrued caregiver sample reflects the population of LVAD caregivers, who tend to be White spouses (majority wives),⁵¹ the current findings may not be reflective of a more diverse patient with an LVAD and caregiver population. Although the size of our caregiver sample is similar to prior studies in homogeneous samples of LVAD caregivers,^{11,52} we recommend that our study be replicated in a larger, more diverse sample of caregivers, which may enhance generalizability of these findings. Finally, the average

bereavement time at interview was <2 years (longest time of 3.4 years), which is similar to recall time periods in other qualitative studies that investigated bereaved caregiver perspectives.^{11,53,54} However, findings in our study may have been influenced by caregiver recall bias.

CONCLUSIONS

Previous research demonstrated that patients with DT LVADs may receive suboptimal planning for and care at end of life.^{5,9–11} Our study identifies unique aspects of the end-of-life experience for patients with DT LVADs from the perspective of bereaved caregivers and clinicians, which provides insight into the reasons for suboptimal planning and care. Addressing these challenges will require multifaceted interventions that focus on bolstering LVAD-specific end-of-life communication skills, normalizing end-of-life discussions by embedding them into routine practice, and perhaps pursuing more longitudinal, consistent involvement of palliative care across the DT LVAD trajectory (Table 3). Research into the effects of such interventions on patient and caregiver quality of life, prognostic alignment, and documentation of advance care planning is needed and will inform future guidelines on patient-centered care for patients with DT LVADs.

ARTICLE INFORMATION

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Affiliations

Division of Cardiology, Department of Medicine, (S.C., K.G., J.E.W.), Division of Hospital Medicine (Palliative Care), Department of Medicine (A.O.), Division of General Internal Medicine and Geriatrics, Department of Medicine (K.A.C.) and Division of Cardiac Surgery, Department of Surgery (K.G., L.S.) Feinberg School of Medicine, Northwestern University, Chicago, IL.

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Supplementary Material

Data S1

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SUPPLEMENTAL MATERIAL

Data S1.

Semi-structured Interview Guides

Caregiver Interview Guide

Introduce self (interviewer)

Obtain written informed consent (see written informed consent document).

INTERVIEWER: Thank you for your willingness to participate in the interview today. I am going to start off by asking you to complete the following form that asks a few brief background questions about you. Your answers will be kept confidential. You are free to skip any questions that make you feel uncomfortable.

DEMOGRAPHICS

[Demographic items here – hand to participant for participant to fill out or offer to read out loud if preferred]

INTERVIEWER: Thank you.

I'm now going to ask you some questions about your and [patient name]'s experiences when [patient name] was at the end of [his/her] life. I'd first like to ask you about your own experience, and then we will turn to your perspective on [patient name]'s experience. We will ask questions about the time leading up to [patient name]'s death, which we will refer to as the "end of life," as well the day that [patient's name] died. I know that some of these questions might be difficult for you to answer. The purpose of this interview is to hear your story, and to learn how we can do things better. However, if at any point you would like to take a break or stop the interview, please let us know.

1. Thinking back, at what point did you know or realize that [patient name] was nearing the end of [his/her] life?

- How did you come to realize this?

2. Can you describe how you felt during this time, when [patient name] was nearing the end of [his/her] life?

My next questions are about how prepared you felt for the end of [patient name]'s life. Preparing for someone's end of life can mean different things to different people. Patients and caregivers have described one aspect of being prepared as more of a "logistical preparation," or having their "affairs in order"- such as determining end of life preferences, organizing finances, creating or finalizing legal documents, or making funeral arrangements. Another aspect of preparing for someone's death may be emotional preparation – this might include things like processing your emotions about death, resolving previous conflict, or being able to say goodbye in the way you wanted.

3. Describe how well, or not well, prepared you felt logistically for [patient name]'s death.
- Describe what discussions you had with [patient name] about this aspect of preparing for death.
 - Describe what discussions you had with your healthcare team about this aspect of preparing for death.
 - Probe if necessary: with which members of the healthcare team did you discuss this?
 - Probe if necessary: Would you have wanted your VAD team to discuss this with you?
 - Probe if necessary: Which healthcare provider would you have wanted to discuss this with?
 - How else do you feel you could have been better prepared logistically for [patient name]'s death?
 - What support if any did you have when it came to preparing logistically for [patient name]'s death?

Now I want to ask you about how prepared you felt emotionally for [patient name]'s death. Remember that I said emotional preparation for death might mean that you felt you had processed your emotions, and that you had time to say goodbye in the way that you wanted.

4. Can you describe for me how well, or not well, prepared you felt emotionally for [patient name]'s death.
- Describe what discussions you had with [patient name] about this aspect of preparing for death.
 - Describe what discussions you had with your healthcare team about this aspect of preparing for death.
 - Probe if necessary: with which members of the healthcare team did you discuss this?
 - Probe if necessary: Would you have wanted your VAD team to discuss this with you?
 - Probe if necessary: Which healthcare provider would you have wanted to discuss this with?
 - How else do you feel you could have been better prepared emotionally for [patient name]'s death?
 - What support if any did you have when it came to preparing emotionally for [patient name]'s death?
5. How important are spirituality and faith in your life?
- How were these supported or not supported during this period?

I realize this may be difficult to talk about, but I want to talk about the day that [patient name] died.

6. Where did [patient name] die? [Or, if has already been mentioned: You mentioned that [patient name] died (at home, in the hospital, in the intensive care unit)]. Would you be willing to share with me what happened during the last few hours before [patient name] died?

- Probe if necessary: Who if anyone guided you through what was happening and how?
- Probe if necessary: Can you describe what explanations you received about what was happening?
- Probe if necessary: Can you describe your understanding about what was happening?
- Probe if necessary: What symptoms did you observe and how were they managed?
- How could we have done a better job with supporting you through this?

7. How involved were you in the decision to turn off the VAD?

- What was explained to you about what it meant to turn off the VAD?
- What emotions did you experience during and after this decision was made?
- What was explained to you about what would happen once the VAD was turned off?
- How if at all did these emotions or feelings change when the VAD was actually turned off?

8. I've just asked you about your thoughts and feelings on [patient name]'s end of life and [his/her] death. Now, I'd like you to reflect, as much as possible, on what you think [patient name]'s experience was.

- Probe if necessary: What were [patient name]'s emotions towards the end of [his/her] life?
- Probe if necessary: What were [patient name]'s symptoms towards the end of [his/her] life?
 - How were these symptoms addressed and by whom?
- Probe if necessary: We talked about the different types of preparation earlier. How prepared do you think [patient name] was?
 - How were they or were they not prepared?
- How were [patient name]'s emotional and spiritual needs addressed during this time?
- What do you think was most useful or comforting for [patient name] as [he/she] approached the end of [his/her] life?

9. From your perspective, what are some important things caregivers and patients should know as they are approaching the end of life with a VAD? How about actually dying with a VAD?

10. How could the healthcare team have better supported you and [patient] as [patient] neared the end of [his/her] life? How about at the time the patient was dying.

11. As you remember, we are doing these interviews so we can better understand caregiver and patient perceptions of the end of life experience for patients with DT VADs and their caregivers. Is there anything else that you can tell us that you think is important for us to know? We want to make sure we don't miss anything that you feel is important.

Clinician Interview Guide

Introduce self (interviewer)

Obtain written informed consent (see written informed consent document)

INTERVIEWER: Thank you for your willingness to participate in the interview today. I am going to start off by asking you to complete the following form that asks a few brief background questions about you. Your answers will be kept confidential. You are free to skip any questions that you would prefer not to answer.

DEMOGRAPHICS

[Demographic items here – hand to participant for participant to fill out or offer to read out loud if preferred]

INTERVIEWER: Thank you.

Now I am going to ask you some questions about your experience caring for DT VAD patients. The purpose of this interview is to hear your perspective, and to learn how we can do things better. Additionally, there are no correct answers; we are just interested in your thoughts and experiences.

1. What is your role in the care of DT VAD patients?
 - How does your role change over time, from the evaluation stage for DT VAD to the patient's death?
2. How do you discuss the end of life with your DT VAD patients?
 - Probe if necessary: When do you start talking to your patients about the end of life?
 - Probe if necessary: How much or how often do you discuss the end of life?
 - What are some barriers to discussing the end of life with DT VAD patients?
 - What makes discussing the end of life with DT VAD patients easier?
3. How do you, yourself, prepare DT VAD patients for the end of life?
4. Can you describe the role you play caring for DT VAD patients at the end of life?
 - Probe if necessary: What role do you play?
 - What other roles would you want to play? How would this be possible?
 - Probe if necessary: What emotions do you experience when caring for DT VAD patients at the end of life?
5. What training did you have to prepare you for your role in end of life care for patients with DT VADs?

- What training do you wish you had?

Now I want to discuss your experiences talking about and caring for DT VAD patients who are actively dying. We are defining this as the day of or hours leading up to death.

6. How do you discuss dying with a VAD in place with your DT VAD patients?

- Probe if necessary: When do you start talking to your patients about dying with a VAD?
- Probe if necessary: How much or how often do you discuss dying with a VAD?
- What are some barriers to discussing dying with a VAD?
- What makes discussing dying with a VAD easier?

7. Can you describe your experiences caring for DT VAD patients as they are actively dying?

- Probe if necessary: What role do you play?
- What role do you wish you could play? How would this be possible?
- Probe if necessary: What emotions do you experience?
- Probe if necessary: What symptoms do you observe?
- Probe if necessary: What is difficult?
- Probe if necessary: What is rewarding?

8. What training did you have to prepare you for your role in the dying process for patients with DT VADs?

- What training do you wish you had?

9. Could you tell us about a *DT VAD* patient death that resonated with you that you think could have gone better?

- Probe if necessary: What felt bad about this experience?

10. Some people have an idea or perception about what it means to have a “good death.” Can you describe to me a patient death that felt like a “good death?”

- Probe if necessary: What aspects of this experience made it feel this way?

11. From your perspective, what are the most important things caregivers and patients should know as they are approaching the end of life with a VAD? How about dying with a VAD?

12. How can healthcare providers better support patients and their caregivers as they approach the end of life? How about as they are dying with a VAD?

- Probe if necessary: How can we improve the end of life process?

13. What is the role of the palliative care team in the end of life process for patients with DT VAD?

- Probe if necessary: How do you feel it is best to integrate palliative care?
- Probe if necessary: What kind of support do you wish you had from palliative care?

14. The last question is- What, if anything, did we not speak about today that you would want us to know?