In the United States, several thousand people are living with end-stage heart failure. Patients with stage D heart failure have heavy symptom burden at rest or minimal exertion, and heart transplant has been the standard treatment for these patients. However, many are optimal candidates for transplantation, and the demand for organs far exceeds supply. Given these limitations, patients may be considered for inotropic support and supportive care, hospice, or more recently, left ventricular assist devices (LVADs).

Initially, LVADs were developed as a bridge to transplantation, in which the device stabilized a patient until a donor heart was available for transplant. Because many patients are not acceptable candidates for transplant or do not desire it, the LVAD has been used as destination therapy (DT), in which the patient is supported by the LVAD for the rest of his or her life. The HeartMate II study, published in 2009, showed significant improvement in outcomes for patients with continuous-flow devices as DT versus pulsatile-flow devices as DT versus medical therapy. Nevertheless, although morbidity and mortality have improved with continuous-flow LVADs, adverse events such as stroke, bleeding, and infection still occur and can markedly decrease patients’ quality of life. Optimal outcomes require careful patient selection and an appreciation of the potential benefits and burdens of DT, especially in the setting of psychosocial concerns. The call for patient-centered heart failure is cogent in recent scientific statements that report a need for clinicians to work expertly with patients to tease out factors relevant to patients in terms of survival, quality of life, and costs.

At our institution, it has been routine that all patients who undergo DT implantation receive a palliative care consult. This is not to focus on end-of-life experience, rather to highlight potential benefits and challenges those patients and loved ones, and caregivers face can substantially affect the lives of patients who report improved survival.

Choices for Patients “Without a Choice”

Interviews With Patients Who Received a Left Ventricular Assist Device as Destination Therapy

Abigale L. Ottenberg, MA; Katlyn E. Cook, BA; Rachel J. Topazian; Luke A. Mueller, BA; Paul S. Mueller, MD, MPH; Keith M. Swetz, MD, MA

Background—Patients undergo major physical and psychological changes after implantation of a left ventricular assist device as destination therapy (DT). We sought to qualitatively study outcomes and attitudes of patients after DT.

Methods and Results—Ambulatory outpatients with DT at our institution were invited to be interviewed between June and August 2011. In-person interviews were audio-recorded, transcribed, and analyzed qualitatively using thematic analysis. The study included 12 patients (11 men) from the Midwestern United States with a median age of 71.5 years (range, 33–78 years). Interviews were conducted at a median (range) time of 1.37 (0.43–5.04) years after DT implantation. Most patients were white (n=11), married (n=10), and Christian (n=10). We identified 6 themes commonly discussed by the interviewees: preparedness planning, new lease on life, optimizing support networks, systemic limitations, reflections on time, and communication matters. Analysis revealed that most patients saw DT as their only choice, despite other alternatives.

Conclusions—Ambulatory patients reported varied experiences after DT but commonly reported gratitude for improved functional status and a perception of improved symptom burden. Recommendations for improving post-DT care include developing patient support systems, systematizing education for community providers, and expanding respite services. (Circ Cardiovasc Qual Outcomes. 2014;7:368-373.)

Key Words: advance care planning ■ decision making, shared ■ ethics, medical ■ heart-assist devices ■ palliative care
WHAT IS KNOWN

- Left ventricular assist devices, used as destination therapy in appropriately selected patients with advanced heart failure, often improve survival and patient-reported quality of life.
- Even in well-selected patients, some recipients of destination therapy may have suboptimal outcomes in terms of quality of life or survival.

WHAT THE STUDY ADDS

- Although most ambulatory patients reported gratitude for improved functional status and decreased symptom burden, many recipients of destination therapy report ongoing and unique challenges on returning to their home communities.
- Patients reported recalling only general information about the informed consent process before destination therapy because many reported being too unwell to have fully participated in the decision-making process.
- Communication between interdisciplinary care teams, external providers, and patients and their caregivers is crucial to optimizing patient satisfaction and best overall outcomes.

The detailed semi-structured interview guide was drafted by members of the research team (A.L.O., K.E.C., L.A.M., K.M.S.) and allowed for a thorough exploration of themes and the introduction of new topics, leading to sufficient data saturation. It included questions relating to the physical and psychosocial changes and challenges experienced by patients who received DT (Appendix in the Data Supplement). Patients were asked to provide background information to begin the discussion, including information about their current residence, family structure, and current health. Furthermore, the experience of being presented with the option of DT was explored. Patients were encouraged to discuss, in their own words, the diagnoses that led up to the DT consultation, including possible consideration of alternative treatments.

Interviewers also requested that patients share which factors weighed into their decision to proceed with implantation of an LVAD as DT. The patients’ experiences of care in the hospital were reviewed, including measures taken to prepare the patients to be discharged. Postimplantation life changes were discussed in depth. Patients were asked to share the memorable moments, adjustments to daily life, caregiver impact, and benefits and challenges they encountered. The interview concluded with patient reflection and advice.

Thematic analysis was performed by 4 analysts (A.L.O., K.E.C., R.J.T., K.M.S.) to determine major themes in the patients’ responses. Thematic analysis is defined as a method for identifying, analyzing, and reporting patterns (themes) within data and is used to construct and describe data sets in depth. Individual transcripts were reviewed by a member of the research team to ensure accuracy. All 4 analysts were trained to perform a detailed reading of each transcript and begin developing potential codes based on the text. Analysts were instructed to highlight important portions of the text on paper and write potential codes in the margins. Once potential codes were identified individually, the analysts met as a group to discuss their findings, categorize information, establish a final code book, and decide on themes. Instances of disagreement were resolved by consensus. Transcripts were reviewed, and themes were updated on each paper transcript according to the final codebook.

Results

Overall, 15 patients were invited to participate in the study with characteristics summarized in the Table. Three patients did not complete the study because of inpatient hospitalization during the study period (n=1), change of follow-up appointment to a date after August 13, 2011 (n=1), and no study staff member available at the time of the patient’s clinical appointments to complete the interview (n=1). The remaining 12 patients, all from the Midwestern United States, participated. Median (range) distance traveled from home was 175.8 (1.1–471.1) miles. Median (range) time from DT implantation to interview was 1.37 (0.43–5.04) years. The sample included 1 woman and 11 white men, 10 of whom were married and 10 identified as Christian (Table). Median (range) age was 71.5 (33–78) years. Six major themes formed the basis of the analysis and are discussed below: (1) preparedness planning, (2) new lease on life, (3) optimizing support networks, (4) systemic limitations, (5) reflections on time, and (6) communication matters.

Preparedness Planning

As mentioned earlier, our institution uses a standardized approach to DT patients in which palliative medicine clinicians augment the education, advance care planning, and expectation setting in the preimplantation period. The palliative medicine team also continues to follow along with patients during significant changes in clinical status where the LVAD
may or may not continue to help patients to achieve their goals of care.\textsuperscript{10,11} Although this approach was somewhat novel when previously described,\textsuperscript{8} we sought to assess potential effect of both palliative care providers and the multidisciplinary team on helping patients to be prepared for changes after DT.

Patients reflected on the experience of evaluating the choice of whether to proceed with DT and the preparatory education and training that was part of the consent process. The decision-making process was rooted in patients’ conversations with their healthcare team. Specifically, respondents noted that the LVAD coordinator was an important part of the process:

The availability of the LVAD coordinators to answer questions and help the patient plan for implantation helped to alleviate the fear of uncertainty. All patients mentioned the high volume of information delivered by multiple members of the healthcare team. Understandably, patients felt overwhelmed by the many considerations but generally reported satisfaction that all details were shared.

“They give you a lot of information on that first [visit], and they put it into a folder, and they treat you like a scared hog in a packing plant but they do it right.” (Patient 5)

In general, patients expressed confidence in the competency of the healthcare team and willingly followed the advice of their clinicians. Nevertheless, most patients mentioned that the decision to proceed with implantation was just the beginning.

Accessible members of the healthcare team, such as the LVAD coordinator, helped patients to mentally prepare for the transition. This included specific reference to written educational material, seeing the actual LVAD device and meeting patients with DT, reviewing video clips, completing advance directives, and discussions with both the LVAD coordinators and the palliative care clinicians. Chaplain support was also provided by the multidisciplinary team to help patients to appreciate the risks of DT but also to be at peace as much as able with their decision to proceed with DT implantation. Patients continually spoke of the value of having a dedicated caregiver throughout the care trajectory. A common sentiment among the patients was that the decision to assume the responsibilities of caregiver throughout the care trajectory. A common sentiment among the patients was that the decision to assume the responsibility of caregiver throughout the care trajectory. A common sentiment among the patients was that the decision to assume the responsibilities of care was balanced with restrictions on activities. Daily cares such as showering now required an extra measure of preparation to protect the device, particularly the driveline site. The outpatient postrecovery process was most challenging when patients often required caregiver support to meet their own basic needs. For example, site care was frequently performed by a dedicated family caregiver, usually a spouse. Efforts at supporting caregivers and patients with activities of daily living were spearheaded by bedside nurses and physical therapists. Over time, most patients absorbed the majority of self-care activities and found ways to flex caregiver time.

Overall, most patients subjectively noted improved quality of life after DT implantation. With DT, patients reported feeling relative improvements in breathing and circulation, with associated increased energy and personal well-being.

### New Lease on Life

After receiving DT, patients must adjust their expectations on what is normal in their new everyday life. Patients described their postimplantation experience as a new chapter, new beginning, or more specifically, a new lease on life. All of the patients with whom we spoke said they had no regrets about their decision to proceed with LVAD implantation.

All of the patients in our study recognized that the positive outcomes of living with DT were balanced with restrictions on activities. Daily cares such as showering now required an extra measure of preparation to protect the device, particularly the driveline site. The outpatient postrecovery process was most challenging when patients often required caregiver support to meet their own basic needs. For example, site care was frequently performed by a dedicated family caregiver, usually a spouse. Efforts at supporting caregivers and patients with activities of daily living were spearheaded by bedside nurses and physical therapists. Over time, most patients absorbed the majority of self-care activities and found ways to flex caregiver time.

Overall, most patients subjectively noted improved quality of life after DT implantation. With DT, patients reported feeling relative improvements in breathing and circulation, with associated increased energy and personal well-being.

For those patients who encountered barriers during the recovery process, their experience of living with DT was more disheartening. All patients agreed receiving DT requires reframing expectations for what constitutes good health. Patients report the need to keep in mind that having DT necessitates a balance to be achieved between the benefits and burdens of the treatment. Unlike other interventions, DT requires a high level of commitment on behalf of the patient and the caregiver to adapt.
Adapting to these changes and embracing one’s new lease on life require resilience. A positive attitude and a dedicated caregiver were the elements that were consistently reported to help patients bounce back, despite major life changes. Daily frustrations were tempered by an optimistic spirit and a willingness to be patient with the recovery process.

“…it’s getting better, but you got to learn to lift your feet and you got to learn not to make a fast turn.” (Patient 12)

Hope for a healthy future sustained patients throughout the recovery process. Spending time with loved ones energized patients and confirmed their decision to proceed with implantation.

“No, I don’t regret getting the LVAD because this past weekend I was able to see my granddaughters dance in a recital and my grandson play baseball. If I hadn’t gotten the LVAD, I probably would not have.” (Patient 4)

All patients agreed that receiving an LVAD provided them with a new lease on life. DT offered an opportunity to live better than before implantation but required perseverance, creativity, and realism. Focusing on the positive and enjoying the present helped patients to move forward, which was reported to be most successful when support systems were optimized.

Optimizing Support Networks
Proceeding with LVAD implantation is the choice of the patient, but succeeding with DT takes a network of support. The category optimizing support networks describes the contributions of caregivers, providers, community members, and others who contribute to the patient’s physical and emotional health. The tireless dedication of caregivers was cited repeatedly as the main factor for achieving a positive outcome.

Providers in the hospital, including nurses, chaplains, LVAD coordinators, and palliative medicine clinicians, became a valuable support network for caregivers who were charged with learning how to care for the patient. Nurses taught caregivers how to attend to the patient’s daily hygiene needs such as dressing changes, and LVAD coordinators connected caregivers to postdischarge resources in the community. During hospitalization, patients and their families often participated in the monthly LVAD Support Group held adjacent to the inpatient unit. Emotional support motivated patients in their recovery process, especially during the postimplant hospital stay. Visits from family, friends, and community members built patient confidence and provided a welcome distraction.

“We were up here 80 days…a vanload of people came up every weekend…It was always exciting that they would come and then Sunday afternoon they left…we had very good support and we still do.” (Patient 9)

Optimizing support networks aided patients in their recovery processes. Caregivers provided steadfast aid, and providers helped patients and caregivers prepare for life outside the hospital. Other family, friends, and community members offered encouragement and social stimulation, yet challenges living with DT and limitations outside the hospital setting were still encountered by many.

Systemic Challenges to Living With New Technology
Once patients left the hospital, they returned to communities with medical clinics where caring for a patient with an LVAD might be a new experience. Patients in our study spoke of what it feels like to live with an emerging technology that sometimes requires the patient to teach the provider. Regarding the need for Doppler ultrasonography to measure blood pressure, 1 patient noted:

“We had to educate quite a bit. I don’t know how many doctors don’t have a Doppler, just about everybody.” (Patient 4)

Overall, patients welcomed the opportunity to educate and share with providers. Many saw teaching as a natural consequence of receiving DT and enjoyed sharing about how the device has improved their lives.

The reality of life beyond their hospital stay was a concern. Knowing that rapid access to LVAD-trained providers would be limited, patients and caregivers often feared the worst.

“[Now] there are doctors within 2 minutes of your bed…there are doctors [at home] but they are not versed in the LVAD. So we are sitting going, ‘Okay, now what happens if something happens?’ There are resources, but you get worried. Even the paramedics are not familiar.” (Patient 6)

Caregivers quickly became their patient’s best advocate, often visiting local fire departments to develop contingency plans for power outages and educating paramedics on how to respond to emergencies for an LVAD patient.

Educating and preparing potential support in the community appeared to be the largest factor that positioned patients and caregivers to transition to life at home. Practice changing dressings and helping patients with showers built caregiver confidence in their ability to aid the patient. Small steps such as developing a communication plan to implement with local authorities alleviated the stress caused by the transition.

Reflections on Time
The concept of time took on a new meaning for patients awaiting implantation or going through recovery. The time between consent and implantation differed among the patients in our study. For some, once the decision was made to proceed with DT, it was not unusual to wait several days or months to receive the device.

Not being sick enough to get DT immediately was a mysterious concept for patients who indicated long wait times between their decision and LVAD implantation. Patients struggled to understand how they could be considered for the device but not be truly eligible until they showed certain signs of physical decline. A tension existed between wanting to be healthy but not so healthy as to exclude themselves from implantation. For other patients, delaying implantation was a good sign.

“Good, that means I am not going to die…so if it was going to take me 6 months to get to that point I was going to live for at least another 6 months.” (Patient 1)

Some patients reported that the time between consent and implantation was short. Typically in such cases, age, physical status, or a rapid clinical decline was the catalyst.

“Actually, one doctor says, well, probably you have 2 months to live because it was so bad. And so then they suggested me to check in on the LVAD because the doctors
were...here are your choices. And I said, well, I’ll go for the LVAD.” (Patient 11)

Time in the hospital recovering was skewed for some patients. It was not uncommon for patients to have differing relative perspectives of their length of hospitalization. Typically, interviewed patients underestimated their time in the hospital.

Patients also discussed the amount of time required to sustain life with DT. Patients were often astounded by the portion of time spent on follow-up appointments, especially for patients with complications after surgery. Looking at the number of hours expended each day to maintain the patient’s health was revealing.

Assessments of time were common when patients reflected on their motivations for proceeding with LVAD implantation. Patients remarked that a concrete improvement in length of survival and hope of improved prognosis with DT was convincing and a major impetus for moving forward with implantation. The focus on the specific duration of a prognosis continued over time.

Patients focused on time throughout the care trajectory. Every patient in our study knew how long it took to get DT, how long the patient was in the hospital, and what was considered typical in each of these circumstances. For patients, their focus seemed intensely on beating the odds of their prognosis. In each scenario from before to after implantation, every hour mattered. Time was the overarching metric for measuring success and keeping care on track.

Communication Issues
Talking to other patients who are living with DT was cited as the most valuable information one could receive. Communication with providers, family, and especially people living with DT mattered. Patients remarked that it was hard to grasp the idea of what it meant to live with DT without speaking to someone who had been through the same experience. Unexpected considerations such as how to prepare to take a shower, remembering to bring your backup batteries, or getting through airport security helped patients prepare for how life would change. One patient spoke about how he made speaking with new patients his mission.

“[One day] a couple of people stopped and they asked me about [my LVAD]. So I talked to my wife about it. We talked about how difficult it was for her not having anybody to talk to... She says it would really be nice if [we] had something to do with it. And I guess I just started going up and talking ... [The LVAD Coordinator] would say, ‘Hey, [Name], I got an LVAD [patient] down there and he has been crying every day and it is harder than he thought. Why don’t you talk to him?’ And it just started like that... I love to go down and talk to them because it is life-altering... I feel so good being able to help somebody through this.” (Patient 2)

For patients who decide to proceed with implantation, having a dedicated caregiver was thought to be essential. No patient in our study thought they could have recovered from surgery alone. During the recovery process, patients should assume increasing responsibility for their care over time to adapt to the circumstances of their new normal. Having an extended support network of friends and family and relying on faith can ease the process. Patients should encourage their caregivers to have outlets to relieve stress and to schedule time away.

All of the patients in our study remarked how helpful their care teams were in assisting with the decision to proceed with implantation and aiding in their recovery. Although physicians were praised, LVAD coordinators and nurse educators were frequently mentioned as clear communicators and critical to the patient’s success. Patients said it was important to not be afraid to call on providers and ask questions, citing the need for open dialogue and communication about the plan of care.

Most patients with whom we spoke described the decision to proceed with DT as not really a choice at all because there was no perceived future without the device. Patients described the decision to proceed with DT as choosing life over death.

Discussion
Prior studies of DT have explored survival benefits, assessed improvements in symptom burden and quality of life, and analyzed the adjustment of spouses as caregivers after DT implantation. However, the current study is, to our knowledge, the first qualitative approach to capturing patients’ experiences and perspectives relating to life after implantation of LVAD as DT.

Several findings are noteworthy. First, there is variability in the perceived benefit and post-DT recovery for ambulatory patients and their loved ones. Commonly, patients and their loved ones report gratitude for improvement in their heart failure–associated symptom burden, and these results are consistent with reported outcomes for patients discharged from the hospital after LVAD implantation.

Resilience and reassessment of expectations were similarly reported in interviews of spouses who care for loved ones after DT. To this end, it is recommended that post-DT care be improved by developing patient support systems, by systematizing education for providers within local communities, and by developing mechanisms to expand respite care for caregivers.

At our institution, we have evaluated the benefit of palliative care in terms of patient quality of life and highlighted the potential benefits of ongoing assessment of care goals given the potential burden of DT. In the interviews we conducted, several patients or loved ones recalled meeting with palliative care specialists, but primarily mentioned being overwhelmed with the amount of information they had received in the preimplant period. This is consistent with other reports related to LVAD therapy and also is consistent with the challenges of making such decisions when patients are acutely ill and hospitalized.

Two limitations of this study are the ambulatory status and the homogeneity of the patients. As mentioned, patients remember little about the details of palliative care consultation and preparedness planning. Many of our patients have been doing acceptably well, so reconsultation with palliative medicine specialists has been limited, and recurrent iterations of care goals may not have been necessary up to this point. Furthermore, these are patients who have survived to hospital discharge and note improved quality of life and gratitude for having the DT implanted. However, seriously ill patients with major complications may not leave the hospital or be in a position to be interviewed. Similar analysis of patients who have experienced prolonged hospitalization or persistent debility, or interviews with their loved ones, may provide further insights into other challenges of post-DT care. Further focus
on a more diverse population (both outcomes and demographics) may provide different results, and thus these findings may not be generalizable to all populations.

Nevertheless, we think the outcomes reported herein are important because they are consistent with general quality of life reports for ambulatory patients after LVAD implantation as DT. In addition, our results highlight patient-reported benefits of DT but also suggest a need for iterative assessment of patients’ goals of care and quality of life in a regular and standardized fashion, as these evolve over time. Although it is important for in-hospital healthcare providers to appreciate the benefit of DT, it is also important for all providers to appreciate when complications or suboptimal outcomes are occurring. Inpatient providers may predominantly be involved in the care of patients after implant, either perioperatively or during major complications that warrant hospitalization, and not fully appreciate the benefit of DT. Conversely, outpatient or nonacute clinicians may be tempted to focus on quantitative metrics such as laboratories and pump parameters and may miss opportunities to explore challenges on quality of life or opportunity costs to patients.

Conclusions

All patients agreed that understanding the risks and benefits of living with an LVAD was made easier by dedicated care teams, supportive caregivers, and, in the best scenarios, patients who were already living with an LVAD. Realistic expectations and a hopeful attitude helped patients and their caregivers balance benefits and burdens of care. Preparedness planning and a willingness to educate others helped patients and caregivers establish an environment of recovery. Keeping lines of communication open and free between care teams, external providers, family, and friends created a network of support to bolster patients’ independence. Recommendations for enhancing care include patient-to-patient education and systematized education for community providers. Palliative care specialist involvement is recommended to assess patient quality of life and ongoing goals of care. Ultimately, gratitude was the hallmark of every LVAD patient because of improved functional status or decreased symptom burden.

Sources of Funding

Funding has been provided by Mayo Clinic Department of Medicine, Rochester, MN.

Disclosures

Dr Mueller is a member of the Boston Scientific Patient Safety Advisory Board and an associate editor for Journal Watch General Medicine. The other authors report no conflicts.

References

Choices for Patients "Without a Choice": Interviews With Patients Who Received a Left Ventricular Assist Device as Destination Therapy

Circ Cardiovasc Qual Outcomes. 2014;7:368-373; originally published online May 13, 2014; doi: 10.1161/CIRCOUTCOMES.113.000660
Circulation: Cardiovascular Quality and Outcomes is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
Copyright © 2014 American Heart Association, Inc. All rights reserved.
Print ISSN: 1941-7705. Online ISSN: 1941-7713

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://circoutcomes.ahajournals.org/content/7/3/368

Permissions: Requests for permissions to reproduce figures, tables, or portions of articles originally published in Circulation: Cardiovascular Quality and Outcomes can be obtained via RightsLink, a service of the Copyright Clearance Center, not the Editorial Office. Once the online version of the published article for which permission is being requested is located, click Request Permissions in the middle column of the Web page under Services. Further information about this process is available in the Permissions and Rights Question and Answer document.

Reprints: Information about reprints can be found online at:
http://www.lww.com/reprints

Subscriptions: Information about subscribing to Circulation: Cardiovascular Quality and Outcomes is online at:
http://circoutcomes.ahajournals.org/subscriptions/