Decision-Making for Destination Therapy
Left Ventricular Assist Devices
Implications for Caregivers

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Background—Implanting centers often require the identification of a dedicated caregiver before destination therapy left ventricular assist device (DT LVAD) implantation; however, the caregiver experience surrounding this difficult decision is relatively unexplored.

Methods and Results—From October 2012 through July 2013, we conducted semistructured, in-depth interviews with caregivers of patients considering DT LVAD. Data were analyzed using a mixed inductive and deductive approach. We interviewed 17 caregivers: 10 caregivers of patients living with DT LVAD, 6 caregivers of patients who had died with DT LVAD, and 1 caregiver of a patient who had declined DT LVAD. The themes identified, which could also be considered dialectical tensions, are broadly interpreted under 3 domains mapping to decision context, process, and outcome: (1) the stark decision context, with tension between hope and reality; (2) the challenging decision process, with tension between wanting loved ones to live and wanting to respect loved ones’ wishes; and (3) the downstream decision outcome, with tension between gratitude and burden.

Conclusions—Decision-making surrounding DT LVAD should incorporate decision support for patients and caregivers. This should include a focus on caregiver burden and the predictable tensions that caregivers experience. (Circ Cardiovasc Qual Outcomes. 2015;8:00-00. DOI: 10.1161/CIRCOUTCOMES.114.001276.)

Key Words: heart failure ■ patient-centered care

Destination therapy (DT) left ventricular assist devices (LVADs) are a relatively new treatment option for end-stage heart failure patients who are ineligible for heart transplantation. The most common reasons for heart transplant ineligibility, and consequently DT status, are advanced age and noncardiac medical illness.1 DT LVAD use is becoming increasingly common, with over 1000 implanted in the United States in 2013 and an estimated 150000 to 250000 potentially eligible patients annually.2-5 Centers offering LVADs often require the identification of a caregiver before proceeding with the implant. A caregiver’s requirements and responsibilities vary according to the center; however, at a minimum, a caregiver is required to transport the patient and attend physician appointments, perform sterile driveline dressing changes, and learn the connections and mechanics of the LVAD equipment to troubleshoot in an emergency situation. The 2013 International Society for Heart and Lung Transplantation Guidelines for Mechanical Circulatory Support include recommendations that significant caregiver burden or lack of any caregiver is a relative contraindication to implantation of an LVAD.1

Several qualitative studies have detailed caregiver experiences of patients with LVADs.4,6 Common themes in these studies include the emotional rollercoaster that caregivers describe before the LVAD and the need to adapt to a transformed life after the LVAD. The majority of these studies only included bridge to transplant patients, and most of the interviews were performed after transplantation. Consequently, caregivers expressed the relief provided by the transplant as well as gratitude that their loved one was still alive. Only 2 studies have explored the unique perspectives of caregivers of patients with DT LVADs,6,11 and no study has explored the perspectives of bereaved caregivers or caregivers of patients who declined an LVAD.

DT LVAD patients are often older with significant comorbidities that preclude heart transplantation.32 As such, the
decision to get a DT LVAD is arguably more complicated than the decision to receive a temporary LVAD in anticipation of a transplant. Additionally, caregivers are commonly female spouses of DT LVAD patients, who are also older with comorbidities; understanding their perspective in DT LVAD decision-making is extremely important as they are at particular risk for experiencing stress and caregiver burden because of the increased demands on caregiving with DT LVAD. There is a paucity of literature exploring the decision-making process of caregivers of patients considering DT LVAD. The Ottawa Decision Support Framework is a prescriptive framework that guides the development and evaluation of decision support interventions. This framework states that participants’ decisional needs (eg, knowledge, values, support) will affect decisional quality (eg, informed, values concordant decisions).13 The decisional needs and decisional quality affect subsequent outcomes, such as emotions, regret, blame, and behavior. The framework asserts that decision support can improve decision quality by addressing unresolved decisional needs. Therefore, as part of a larger agenda to help both patients and caregivers navigate this complicated decision, we aimed to understand the caregivers’ experiences and identify their needs related to decision-making surrounding DT LVAD.

Methods

Study Design

We conducted a qualitative, descriptive study using in-depth, semi-structured interviews with caregivers of patients currently living with a DT LVAD, caregivers of patients who had died with a DT LVAD, and caregivers of patients who had refused a DT LVAD. A qualitative study design was chosen to gain a comprehensive understanding of a caregiver’s experience with decision-making surrounding DT LVAD and was especially appropriate, given the lack of existing data on the topic. The study was approved by the institutional review board at the University of Colorado. Written or verbal informed consent was obtained from all study participants. Participants were compensated $25 for their time.

Sampling and Recruitment

Caregivers of patients who were currently or had previously been cared for at the University of Colorado were eligible for the study. We interviewed a convenience sample of caregivers of both living and deceased DT LVAD patients who were willing to participate in the study. We also included caregivers of patients who had declined DT LVAD. Interviews were conducted until no new themes emerged.15–19 The principal investigator directly recruited caregivers using her established clinical relationships with both the patients and the caregivers. To identify caregivers, patients were asked to name a primary caregiver who had provided support during their decision and who assisted with their ongoing care. If >1 person was identified, the patient was asked to choose one caregiver who was functioning as the primary caregiver. Caregivers were excluded if the patient’s DT LVAD implant had occurred >5 years prior.

Data Collection

In-depth, semistructured interviews were conducted either in person or by phone by 2 trained research staff without a clinical relationship with the patients between October 2012 and July 2013. Given the potential for intense emotional response, a member of the study team with a social work background and expertise in qualitative research performed the interviews of bereaved caregivers. All caregivers were interviewed alone to allow them to speak as freely as possible regarding their experience. Consistent with study goals and established qualitative research methods,17–19 these in-depth, semistructured interviews used broad, open-ended questions to elicit personal thoughts and experiences regarding decision-making surrounding DT LVADs. Three interview guides were developed: (1) for caregivers of patients living with a DT LVAD, (2) for caregivers of patients who had died with a DT LVAD, and (3) for caregivers of patients who had refused DT LVAD (Data Supplement). The interview guides were based on the Ottawa Decision Support Framework.15 Domains addressed in all 3 interview guides included factors involved in the decision-making process, assessment of clinician interaction, future decisions, consideration of alternatives, and degree of satisfaction with the decision. The interview guides of patients who chose to pursue a DT LVAD included questions regarding the expectations of living with a DT LVAD and unexpected outcomes. The interviews were digitally recorded, professionally transcribed, and reviewed for accuracy. Caregivers also completed a short survey, including demographic questions to characterize the sample.

Qualitative Analysis

Transcripts were entered into ATLAS.ti 7.0® software, and data were analyzed using a mixed inductive and deductive approach.9,21–22 We began with a process of exploring each transcript for language and phrases used by participants to describe their decision-making experiences. Three members of the study team each reviewed a subset of interviews separately, meeting regularly to reach consensus on our codebook as well as emerging themes. Through an iterative, multidisciplinary team-based process, codes were reviewed and discussed to ensure their completeness and contextual authenticity. A multidisciplinary team-based approach was used to add depth to interpretation. Further, by using a multidisciplinary team representing the various facets of the decision-making process, we were able to ensure that one point of view did not dominate theme interpretation. We developed the final codebook incorporating both data-derived codes and formal domain codes defined a priori from the Ottawa Decision Support Framework.

WHAT IS KNOWN

• Centers often require a dedicated caregiver before implanting a destination therapy left ventricular assist device.
• End-of-life care has been shown to produce dialectical tensions, where caregivers use relational history as knowledge.

WHAT THE STUDY ADDS

• Bereaved caregivers contribute a unique perspective on the emotional complexity of the decision-making process.
• The dialectical tensions identified are broadly interpreted under 3 domains:
  1. The stark decision context with tension between hope and reality
  2. The challenging decision process with tension between wanting their loved ones to live and wanting to respect their loved ones’ wishes
  3. The downstream decision outcome with tension between gratitude and a feeling of burden.
• Decision-making surrounding destination left ventricular device therapy should incorporate decision support, including a focus on caregivers and the predictable tensions that caregivers experience.
Support Framework, consistent with our mixed inductive and deductive approach.13,22,23 A process of open coding was applied to the remainder of the interviews, concomitant with team discussion and data reimmersion, followed by axial coding in which we established links between the a priori and in vivo codes to provide a conceptual and thematic description.23 Confirming and disconfirming cases were discussed until consensus was reached. The entire study team determined thematic saturation was reached when additional interview data created little or no change to the codebook and no new patterns or themes emerged.14–17

We used several strategies to assure trustworthiness of the findings.24–26 To assure dependability, the primary coder kept an audit trail during the analytic phase of the project. To assure transferability, we have attempted to describe our sample in adequate detail so that others can determine how different populations compare. To assure credibility and confirmability, we triangulated our findings using a multidisciplinary study team23 consisting of 2 advanced heart failure and transplant cardiologists, a heart failure and transplant nurse practitioner, 2 palliative care physicians, and 2 qualitative experts. Throughout the data analysis, this team met to discuss the analytic process and emergent themes. Additionally, themes were presented to a cardiac health services research group to seek input regarding trustworthiness.

Results

Between October 2012 and July 2013, we interviewed a total of 17 caregivers: 16 caregivers of patients who had received a DT LVAD and 1 caregiver of a patient who had declined a DT LVAD. Duration of interviews ranged from 21 to 72 minutes. At the time of interview, 10 were caregivers of patients currently living with a DT LVAD and 7 were caregivers of patients who were deceased. The majority (n=12) were spouses or widows of the patients; in addition, there were 2 daughters, a mother, a sister, and a friend. One caregiver was male and was a friend of the patient. The age of caregivers ranged from 35 to 79. Nearly all caregivers spent >8 hours per week caring for their loved one (n=13), and the majority attended almost all medical appointments (n=14). Additional summary statistics are provided in Table 1.

Throughout the interviews, the overarching theme was that considering a DT LVAD is a complex decision-making process. The complexity and tensions coalesced around 3 domains: (1) the decision context, (2) the decision process, and (3) the decision outcome (Table 2).

Decision Context

Caregivers described a complicated decision context, in which being offered a DT was often preceded by years of poor health. The decision was then frequently marked by a sense of urgency and, for some, dashed hopes, as a result of being declined for heart transplantation.

Tension: Hope and Reality

In this stark decision context, caregivers experienced an underlying tension between hope and reality. Within the same interview, some caregivers expressed both hope for a future as well as the reality of their loved ones’ prognosis; however, they rarely verbalized the incongruity or tension between these 2 lenses. At the time of decision-making, most caregivers reported feeling the DT LVAD would offer the patient more time and improved quality of life. Less often articulated was the fear that the patient would not survive surgery or would experience persistent complications.

<table>
<thead>
<tr>
<th>Relationship to patient</th>
<th>n=17</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>12 (70%)</td>
</tr>
<tr>
<td>Daughter</td>
<td>2 (12%)</td>
</tr>
<tr>
<td>Mother</td>
<td>1 (6%)</td>
</tr>
<tr>
<td>Sister</td>
<td>1 (6%)</td>
</tr>
<tr>
<td>Friend</td>
<td>1 (6%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Demographics</th>
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</thead>
<tbody>
<tr>
<td>Age in years, median (range)</td>
</tr>
<tr>
<td>Female, n</td>
</tr>
<tr>
<td>Non-White, n</td>
</tr>
<tr>
<td>Family income, n</td>
</tr>
<tr>
<td>$15000–$30000</td>
</tr>
<tr>
<td>$30000–$60000</td>
</tr>
<tr>
<td>$60000–$100000</td>
</tr>
<tr>
<td>Education level, n</td>
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<tr>
<td>Some high school</td>
</tr>
<tr>
<td>High school graduate/GED</td>
</tr>
<tr>
<td>Some college</td>
</tr>
<tr>
<td>4-year college graduate</td>
</tr>
<tr>
<td>More than a 4-year degree</td>
</tr>
<tr>
<td>Time from declination/implant to interview</td>
</tr>
<tr>
<td>Declined, days</td>
</tr>
<tr>
<td>Living, days, median (range)</td>
</tr>
<tr>
<td>Bereaved, days, median (range)</td>
</tr>
<tr>
<td>Caregiver responsibilities</td>
</tr>
<tr>
<td>Hours per week spent caring for the patient</td>
</tr>
<tr>
<td>&lt;1 h per week</td>
</tr>
<tr>
<td>1–2 h per week</td>
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<tr>
<td>3–5 h per week</td>
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<tr>
<td>6–8 h per week</td>
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<tr>
<td>&gt;8 h per week</td>
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<tr>
<td>Frequency of attending medical appointments with patient</td>
</tr>
<tr>
<td>Never</td>
</tr>
<tr>
<td>Occasionally</td>
</tr>
<tr>
<td>Often</td>
</tr>
<tr>
<td>Almost all of time</td>
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</tbody>
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Years of Poor Health

Patients being considered for DT LVAD implantation often experienced an extended period of deteriorating health before their decision-making period. Caregivers reported that loved ones had struggled with heart failure and other comorbidities for lengthy periods of time, arriving at the DT LVAD decision point exhausted, physically and emotionally compromised, and often desperate for a chance to improve their quality of life.

| ...it [heart failure] was killing him. He had no strength. He had no quality of life. He was just existing. [Living] |

Sense of Urgency

Caregivers spoke of the need to make a decision quickly before their loved one became ineligible for a DT LVAD or died. Those who felt pressure to make a decision quickly because of
the patient’s deteriorating health recalled the subtheme of a narrow window. Several caregivers expressed that the DT LVAD should be offered earlier to patients. These caregivers felt the DT LVAD discussions had occurred at a point when their loved ones were almost too sick to survive the major surgery.

- He had gotten really sick...and they were like “This needs to be done like this week.” Like “If you are going to choose to do it, he needs to do it like right now.” [Bereaved] 

**Ineligibility for Transplant**

Several patients (n=4) whose caregivers were interviewed had been considered for a heart transplant before the DT LVAD evaluation. In these situations, the decision to proceed with a DT LVAD was strongly influenced by the inability to proceed with heart transplantation. Caregivers expressed that once the patient was deemed ineligible for a transplant, both the patients and caregivers realized the DT LVAD had become their only option.

- …when we first started out…we had hopes of a transplant...but once the lung function was done, and the kidneys...there was pretty much nothing. There was no hope other than the LVAD. [Living] 

**Decision Process**

The actual decision process was a time when caregivers felt mixed emotions, including uncertainty, and a desire to support their loved ones. Some caregivers acknowledged voicing their own preferences regarding DT LVAD to their loved one, with all but one caregiver in favor of implantation. Additionally, many caregivers noted that their relationship with the doctors was important in their decision-making.

**Tension: Wanting Loved One to Live and Wanting to Respect Their Wishes**

Caregivers’ narratives revealed an internal tension between wanting their loved one to live and wishing to respect their loved one’s decision regardless of his or her choice. As they recalled the decision process, many caregivers talked about a fear of losing their loved one or an intense desire for them to survive. Factors included apprehension about being widowed, a need for help with responsibilities, such as raising grandchildren, or the perceived inability of a family with other recent trauma to cope with further loss. In contrast, a few caregivers focused heavily on their belief that this was an extremely personal decision, and the patient should not be influenced by others’ opinions.

**Influence of Relationships With the Clinicians**

Several caregivers recalled their experiences with the clinical personnel when going through the DT LVAD decision-making process. Some were relieved to have their clinicians’ support, whereas others expressed frustration with the urgency of the decision and the pressure to pursue a DT LVAD.

- And it takes a big doctor to be able to let a patient go. To be able to say, you know, this is their wish and this is what they want...When you go through so much, I think it gets to a point...
where you need to listen to the patient, when he’s had enough. [Declined]

- Well, we both really loved Dr. X and really respected him. So I’m sure just feeling that he had suggested this, that you know, it was probably a good decision. [Bereaved]

Making the Decision

Several caregivers saw the DT LVAD as their loved one’s only option. For this reason, many did not seriously consider factors, such as the risks of surgery, complications, or burdens of living with a DT LVAD. Others stated they viewed it as a life or death decision.

- We really didn’t want to look at the negative side. [Bereaved]
- I felt that the decision we had to make was life and death. Not whether or not we were going to talk about whether or not we were going to have the implant you know? [Bereaved]

Decision Outcome

Decision outcome encompasses how caregivers felt about the decision after the fact and largely included satisfaction and regret. Notably, some caregivers expressed ongoing uneasiness with the decision. Caregivers whose loved one chose to pursue DT LVAD experienced both gratitude for extended life and a sense of burden. Some caregivers reflected on the decision itself with regret or feelings of unfulfilled expectations, whereas others had never given the decision a second thought.

Tension: Gratitude and a Feeling of Burden

As they reflected on the experience of their loved ones living with a DT LVAD, the caregivers spoke of tension between gratitude for the additional life afforded by the DT LVAD, but also a sense of burden related to caregiving, such as frequent hospitalizations. The subtheme of you do what you gotta do was common. The few who acknowledged a sense of burden were hesitant to express any misgivings and emphasized that, in spite of the onus, they would not wish for anything different. This balancing act between gratitude and sense of burden was dynamic, fluctuating between both the negative (eg, a new hospitalization) and the positive (eg, activities previously not possible).

Reflecting on the Decision

Living with a loved one with a DT LVAD for a period of time resulted in increased reflection about the decision-making process among caregivers. Although some expressed disappointment about what life was like with the DT LVAD, others focused on the life-prolonging benefit and improved quality of life afforded by a DT LVAD.

- Now that we’ve experienced it, I’ve thought “Was that the right decision?” [Living]
- I mean, if he would have told me he was going to still be sick [after the surgery],...then we’d have probably had a lot different way of thinking. [Living]

Discussion

For patients and their caregivers, decisions about whether to pursue invasive technologies in the setting of chronic progressive illness are arguably some of the most complicated in medicine. Although caregivers form a critical component of the care for patients with chronic disease, their role is particularly central to and formalized in the setting of DT LVADs. Lack of caregiver support is considered a relative contraindication for implanting an LVAD according to the current mechanical circulatory support guidelines.1 Most LVAD programs go to date as having a mandatory requirement for a dedicated and capable caregiver in order for a patient to be eligible for a DT LVAD. Therefore, it is critically important that we understand the caregiver’s perspective as patients consider this invasive technology. By using a multidisciplinary team-based approach for analysis and interpretation, the many facets of the decision-making process were represented. Multiple disciplinary perspectives allowed various possibilities to be explored in the interpretation of data and also assisted when informing possible solutions for the DT LVAD decision-making process. We consider the nuances of disciplines and practice as we offer potential solutions and implications. This continues to move the needs of the caregiver from the previous silos to interdisciplinary care.

Caregivers tend to place the needs of loved ones above their own, and the level of caregiver responsibility required for DT LVAD has the potential to intensify caregiver burdens.5,27 Several studies have focused on the difficulties of the post-LVAD caregiver experience,5,11,27 emphasizing the importance of a quality decision about whether to pursue DT LVAD in the first place. Our results and those of prior studies highlight the importance of the caregivers’ perspective in this decision process. As one of only a few studies to include caregivers of patients who have died, caregivers provided a unique perspective that comes with reflection on past experiences in a patient’s absence. Because of the dire nature of the DT LVAD decision, it may not even be possible to fully explore a caregiver’s perspectives when patients are still alive. A do or the mortality means caregivers may be unable to reflect on the decision process although still caring for their loved one. Additionally, unlike most other studies, our interviewers had no prior relationship with any of the caregivers.

We described tensions within each domain, though the word tension may oversimplify the state of the emotion. Each of these tensions could be described as dialectical tensions or 2 ideas being equally valid when considered alone but contradictory when paired.28 End-of-life of life care has been shown to produce dialectical tensions, where caregivers use relational history as knowledge.29 These tensions demonstrate not just than a duality in choices, but a situation steeped in uncertainty, doubt, ambivalence, uneasiness, and ambiguity.28,29

There continues to be a need to improve the framing around the decision process for all high-stakes, medically complex decisions, including DT LVAD. Interviews with patients have demonstrated that the complexity and related emotion surrounding chronic progressive illness contribute to patients’ fear of discussing alternatives or hearing about complications and burdens.30 Caregivers not only viewed DT LVAD as their loved ones’ only hope, but they also felt pressured to make a decision quickly—negating the chance for full and open consideration of risks, benefits, and burdens. Therefore, decision support in this context must be timely but also responsive to the emotions and coping strategies of patients and caregivers. Reframing DT LVAD as a potentially life-prolonging therapy rather than a life saving one better captures the ongoing medical issues as well as the >50% death rate over the next 4 years.2 This could facilitate caregivers’ understanding of DT LVAD as one option, not the only option.
A large amount of information is provided to patients and caregivers during the decision-making process. Although informed consent is essential, the current process and practices are not sufficient. Given the complex tradeoffs of DT LVAD, necessary components of shared decision-making must include optimal patient selection; extensive informed consent’s adequate time to review expected risks, benefits, and burdens; and a strong grounding in patients’ and caregivers’ goals and values.

Involving caregivers throughout the entire decision process can help manage expectations for life with or without a DT LVAD. Several interventions should be considered for caregivers of patients considering DT LVAD. First, to better prepare caregivers for the burdens of DT LVAD, LVAD programs should continue to invite caregivers to participate in the decision-making process. This helps to address caregivers’ concerns and works to further engage them as active participants. Second, DT LVAD caregiver-specific tools and resources should be developed to outline responsibilities and the effect on the caregiver’s life. Third, providing caregivers with tools, such as a decision aid, may help to manage expectations and relieve the potential for postdecision caregiver burden. It is important for programs to normalize the ambivalence felt by caregivers by informing them that others have experienced this as a complex decision. Fourth, ongoing caregiver support groups, separate from patient support groups, can assist in empowering caregivers as well as validating feelings and concerns.

Deciding whether to pursue a DT LVAD is just one decision of many, that patients and caregivers face. Future work surrounding caregivers of patients considering DT LVAD could explore the decision process prospectively. Additionally, future studies should investigate the potential correlations between caregivers and their propensity toward certain tensions (eg, which characteristics make caregivers more likely to have decision regret). This would lend itself to identifying caregivers who would benefit from tailored caregiver support or interventions, with some caregivers potentially needing no interventions at all.

Limitations
There are several limitations to our study that should be considered when interpreting our data. First, this study was performed at a single academic center with a relatively homogenous convenience sample, including only 1 male caregiver; however, this is one of the first studies to focus on the unique DT LVAD caregiver population. Second, the sample of bereaved caregivers was small, and we included only 1 caregiver of a patient who declined a DT LVAD. Currently, this is the only study that includes bereaved caregivers of DT LVAD patients, and our team intends to explore this population in future research. Finally, caregivers were interviewed after the decision about DT LVAD. This could bias the results as the caregivers would be influenced by the outcomes; however, we chose this strategy deliberately so as not to influence the DT LVAD decision-making process with our interviews.

Conclusion
Caregivers of patients considering DT LVAD face many complex issues, including interpreting the decision to implant a DT LVAD in the context of risks and benefits, balancing their needs and the needs of their loved one and managing feelings of caregiver burden. Interventions to improve caregiver experiences of decision-making with DT LVAD should focus on the involvement of the caregiver. Further, expectations of caregivers need to be honest and managed carefully, and LVAD programs should recognize caregiver involvement and provide ongoing support and skills training.

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Disclosures
None.

References


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SUPPLEMENTAL MATERIAL
INTERVIEW GUIDE

Primary Caregivers of Patients with DT LVADs

1) First, can you tell me your relationship with the patient? How long have you known the patient?

2) Some patients want their family member/caregiver to be very involved in helping them make the LVAD decision, while others prefer less involvement. To what degree have you been involved in the LVAD decision? (wait for response, then probe for the following)
   - Attend doctor’s appointments
   - Ask doctor questions?
   - Ask patient questions?
   - Give patient your opinion?
   - See information in other places (e.g. library, internet)
   - On a scale of 1-10, how involved would you say you are/were with the decision? (1=not at all involved, 10= totally involved)
   - How happy were you with the decision (if made)? 1-10 scale

3) What was most important to you in the decision? (if not mentioned, probe on the following)
   - Wish for the patient to live as long as possible
   - Desire for the patient to have a reasonable quality of life
   - Wish to follow the doctor’s advice
   - Desire to be in agreement with the patient’s wishes
   - What options do decision makers have?
   - What was difficult about the decisions? And what did you find easy about the decision?

4) How did you go about making this decision? “cognitive/head” vs “emotional/gut”

5) Can you tell me about the advantages and disadvantages? What did you think about these?

6) How do certain factors weigh in to your decision-making?
   i. Spirituality
   ii. Family
   iii. Finances

7) What other questions/concerns did you have about the pump and how it might affect you or the patient?

8) What has it been like for you since the LVAD implant? Any worries, concerns? Anything unexpected? Any changes in your relationship with the patient? Any changes in the patient’s behavior or mood?

9) What’s your impression of what it’s been like for the patient since the LVAD implant? Any worries, concerns? Anything unexpected?

10) Is there anything that you know NOW that would have been helpful to know before the patient made the decision to get the LVAD?

11) If you could tell patients who are considering an LVAD and their loved ones anything about what it’s like, what would you tell them? What’s most important for them to know in making the decision?

12) Is there anything else you think we need to know about this topic? Anything that we haven’t asked about?
INTERVIEW GUIDE

Caregivers of Patients who have Died with DT LVAD

(Honoring their grief/loss) Thank you so much for agreeing to interview with me today. I’m so sorry that name of patient has died. When did s/he die? (Allow time for them to tell about it if they wish.) How are you doing? (Allow time for them to tell you. Then, after you’ve listened and validated their feelings, move ahead with the interview.

1) (If not addressed in previous section): First, can you tell me your relationship with the patient? How long had you known the patient?

2) Now I have some questions about name of patient’s decision to get the LVAD. Some patients want their family member/caregiver to be very involved in helping them make the LVAD decision, while others prefer less involvement. Thinking back to the time when name of patient was making the decision about whether get the LVAD, in what ways were you involved in the LVAD decision? (wait for response. Probe for the following if not mentioned)
   a. Attend doctor’s appointments?
   b. Ask doctor questions?
   c. Ask patient questions?
   d. Give patient your opinion?
   e. Get or look at information from other places (e.g. library, internet, message boards, other people with LVADs)
   f. On a scale of 1-10, how involved would you say you are/were with the decision? (1=not at all involved, 10=totally involved)
   g. How happy were you with the decision (if made)? 1-10 scale?
      i. What would it take for you to rate it as a 10? Can you tell me more about that?

3) What was most important to you in the decision? (wait for response. Probe for the following if not mentioned:)
   a. Wish for the patient to live as long as possible
   b. Desire for the patient to have a reasonable quality of life
   c. Wish to follow the doctor’s advice
   d. Desire to be in agreement with the patient’s wishes
   e. What options do decision makers have?
   f. How do certain factors weigh in to your decision-making?
      i. Spirituality
      ii. Family
      iii. Finances
   g. How did you go about making this decision? “cognitive/head” vs “emotional/gut”
   h. Can you tell me about the advantages and disadvantages? What did you think about these?
   i. What was difficult about the decisions? And what did you find easy about the decision?
   j. Anything else?

4) What other questions or concerns did you have about the LVAD and how it might affect you or the patient? For example, some people wondered whether the patient would be able to continue with activities they previously enjoyed, like travel or physical activities like bowling or climbing stairs at sporting events, while others ask about things like sexual activity. What about you?

5) Thinking back to the time after name of patient made the decision to implant the LVAD, what worries or concerns did you have?
   - Did anything unexpected happen?
   - What about any changes in your relationship with the patient?
   - What about any changes in the patient’s behavior or mood?

6) What was your impression of what it was like name of patient after the LVAD implant?
- Any worries, concerns?
- Did anything unexpected happen?

7) Is there anything that you know NOW that would have been helpful to know before the patient made the decision to get the LVAD?

8) If you could tell patients who are considering an LVAD and their loved ones anything about what it’s like, what would you tell them? What’s most important for them to know in making the decision?

9) Is there anything else you think we need to know about this topic? Anything that we haven’t asked about?
INTERVIEW GUIDE

Caregivers of Patients who have Declined DT LVAD

1) First, can you tell me your relationship with the patient? How long have you known the patient?

2) Some patients want their family member/caregiver to be very involved in helping them make the LVAD decision, while others prefer less involvement. To what degree have you been involved in the LVAD decision:
   a. Attend doctor’s appointments
   b. Ask doctor questions?
   c. Ask patient questions?
   d. Give patient your opinion?
   e. See information in other places (e.g. library, internet)
   f. On a scale of 1-10, how involved would you say you are/were with the decision? (1=not at all involved, 10=totally involved)
   g. How happy were you with the decision (if made)? 1-10 scale

3) What was most important to you in the decision? (if not mentioned, probe on the following)
   a. Wish for the patient to live as long as possible
   b. Desire for the patient to have a reasonable quality of life
   c. Wish to follow the doctor’s advice
   d. Desire to be in agreement with the patient’s wishes
   e. What options do decision makers have?
   f. What was difficult about the decisions? And what did you find easy about the decision?

4) How did you go about making this decision? “cognitive/head” vs “emotional/gut”

5) Can you tell me about the advantages and disadvantages? What did you think about these?

6) How do certain factors weigh in to your decision-making?
   i. Spirituality
   ii. Family
   iii. Finances

7) What other questions/concerns did you have about the pump and how it might affect you or the patient?

8) What has it been like for you since the decision was made not to get an LVAD? Any worries, concerns? Anything unexpected? Any changes in your relationship with the patient? Any changes in the patient’s behavior or mood?

9) [if patient is alive] What’s your impression of what it’s been like for the patient deciding not to get an LVAD? Any worries, concerns? Anything unexpected?

10) Is there anything that you know NOW that would have been helpful to know before the patient made the decision to not get the LVAD?

11) If you could tell patients who are considering an LVAD and their loved ones anything about what it’s like, what would you tell them? What’s most important for them to know in making the decision?

12) Is there anything else you think we need to know about this topic? Anything that we haven’t asked about?
CAREGIVER SURVEY

Please answer the following questions. This is completely voluntary; you may skip any question that you do not want to answer.

1. What is your relationship to the patient? (circle one)
   1…………..Wife
   2…………. Husband
   3…………..Partner or Significant Other
   4…………..Daughter
   5…………..Son
   6…………..Daughter-in-law
   7…………..Son-in-law
   8…………..Other relative
   9…………..Neighbor
   10……….….Friend
   11………….Paid caregiver
   12………….Volunteer
   13………….Other (specify):

2. At this time do you and the patient live in the same household? (circle one)
   1………………………Yes
   0………………………No

3. How many hours per week do you spend caring for the patient? (circle one)
   1……………Less than 1 hour
   2…………..1 – 2 hours a week
   3………….3 – 5 hours a week
   4………….6 – 8 hours a week
   5……….…More than 8 hours a week

4. How often do you attend medical appointments with the patient? (circle one)
   1…………..Never
   2………….Occasionally
   3…………..Often
   4…………. Almost all the time
Reflect on the decision your loved one made about whether or not to have a Left Ventricular Assist Device (LVAD) or heart pump. Show how strongly you agree or disagree with these statements by checking the box that best fits your views about your loved one’s decision.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree Nor Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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</thead>
<tbody>
<tr>
<td>5. It was the right decision</td>
<td></td>
<td></td>
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<tr>
<td>6. I regret the choice that was made</td>
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<td>7. I would encourage my loved one to make the same choice if (s)he had to do it over again</td>
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<td>8. The choice did my loved one a lot of harm</td>
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<tr>
<td>9. The decision was a wise one</td>
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</table>

The next few questions are to give us a little information about you.

10. How old are you? ________

11. What is the highest grade or level of school that you have completed?
- [ ] 8th grade or less
- [ ] Some high school
- [ ] High school graduate/GED
- [ ] Some college
- [ ] 4-year college graduate
- [ ] More than a 4 year degree

12. Are you of Hispanic or Latino origin or descent?
- [ ] Yes, Hispanic or Latino
- [ ] No, not Hispanic or Latino
13. **How would you describe your race?**
   - American Indian or Alaskan Native
   - Asian or Pacific Islander
   - Black or African-American
   - White
   - Another race or multiracial

14. **What is your current family income?**
   - Less than $15,000
   - $15,000-30,000
   - $30,001-60,000
   - $60,001-100,000
   - Over $100,000

15. **Which best describes your marital status:**
   - Married
   - Divorced
   - Separated
   - Widowed
   - Single / Never married
   - Common law (living as married)
   - Other