

Appendix A: Interview Guides

**In-depth Interview Protocol -- PATIENTS** *Interview Guide*

DOMAINS	Questions	Prompts
<p>Values in Decision-Making</p>	<p>When did your <b>conversations with doctors</b> about your heart <b>first begin</b>?</p> <p>What <b>alternative options</b> to the VAD, if any, were you <b>considering</b> or were <b>presented to you</b>?</p> <p>What <b>questions</b> did you have about the VAD at first/what did you want to know?</p> <p>Was there a <b>time when</b> you heard about the VAD but <b>didn't pursue it</b> as a potential option? Any <b>negative factors</b> that almost kept you from getting the VAD?</p> <p>What were your <b>expectations or concerns</b> about <b>how the VAD might change your everyday life</b>? (<i>pos/neg expectations</i>)?</p> <p><b>How long did it take you to decide</b> whether or not to get a VAD? Did you <b>feel well-informed and prepared</b> to make this decision?</p> <p>What <b>didn't the education and doctor visits before LVAD</b> prepare you for?</p> <p>Tell me <b>how you could have been better prepared</b> (by docs, caregivers, etc.) for those things prior to your LVAD?</p>	<p><i>Were you ever interested in hearing about <b>end-of-life planning options</b> instead? (e.g. hospice)</i></p> <p><i>Did you want to know the "<b>gist</b>" of risk, or <b>actual figures</b> (e.g. 30% risk of stroke, etc.)</i></p> <p><i>Recovery?</i>  <i>Still short of breath?</i>  <i>Pain?</i>  <i>Having to take so many pills?</i>  <i># of procedures (like)?</i>  <i># of hospitalizations</i>  <i>Insurance/cost of medicines</i></p>

	<p>What about after getting the LVAD? What <b>could be improved about your transition to rehab / home?</b></p> <p>Did/do you see the VAD as a <b>bridge to transplant?</b> Where do you see yourself on this <b>trajectory?</b></p> <p>If you knew that getting the VAD might <b>change your status on the transplant list</b>, would you <b>still get it?</b></p>	
<p>Usual and Preferred Decision-Making Roles</p>	<p><b>Who</b>, if anyone, <b>helped you decide</b> whether or not to get the VAD?</p> <p>What <b>kinds and/or sources of information</b> did you find most useful in helping to make your decision?</p> <p>Were any of the information sources <b>hard to understand?</b> Why?</p> <p>At <b>what stage in the decision-making process did you receive or seek out</b> these other sources of <b>information?</b></p> <p>Was there a particular time, from the beginning of your medical assessment to the present, <b>when you wanted to hear more about what the doctors thought you should do?</b></p>	<p><i>Which <b>FORMAT</b> of conveying information do/did you find most useful?</i></p> <p><i>Text</i></p> <p><i>Video</i></p> <p><i>Patient testimonies</i></p> <p><i>Web-based</i></p> <p><i>Interactive...? Etc...</i></p>
<p>Decisional Barriers and Facilitators</p>	<p>What are <b>2-3 key messages</b> do you believe <b>every potential VAD candidate should know</b> before getting the VAD?</p> <p>What would have helped you feel ready for the LVAD/life with the LVAD once you made the decision?</p>	<p>- <i>Did you want to talk to someone about</i></p>

	<p>Tell me how this <b>transplant/evaluation process has been for you</b> over the past couple of weeks leading up to the procedure, as you've gone through the assessment.</p> <ul style="list-style-type: none"> <li>- Any areas for <b>improvement</b>?</li> <li>- Areas that were <b>confusing, overwhelming, or frustrating</b> to you.</li> </ul> <p>What was the degree of <b>overlap in info or questions among the various people</b> associated with the heart failure team during this process?</p> <p><b>Did financial concerns factor into your decision-making about the LVAD in any way?</b></p>	<p><i>insurance/home care?</i>  <i>- Did you want to talk to other patients?</i></p>
<p>Degree of Decision-Making Difficulty &amp; Contributing Factors (including psychosocial)</p>	<p>What was your <b>understanding of possible complications</b> that could arise? (free list).</p> <ul style="list-style-type: none"> <li>- Which of these were you willing to tolerate? Or not?</li> </ul> <p>Take me back to the <b>first few weeks or months</b> after you had the VAD placed. What were <b>your expectations for this period vs. what you experienced?</b></p>	<p><i>were you ever readmitted after surgery? What kind of further information do you think might have prevented readmission?</i></p>

Perceptions of Options, Outcomes and Probabilities	Do you have any <b>regrets about your decision</b> to get a VAD? (why/why not?)	
Other Suggestions		

**In-depth Interview Protocol -- Caregivers Interview Guide**

DOMAINS	Questions	Prompts
Usual and Preferred Decision-Making Roles	<p>How much were you <b>involved in the decision</b> for your partner/family member to get a VAD?</p> <p>What <b>questions</b> did you have about the VAD at first/what did you want to know?</p> <p>Were your opinions/outlooks <b>consistent with his/hers</b>?</p> <p>Were you ever interested in hearing about <b>end-of-life planning options instead?</b> (e.g. hospice)</p>	<p><i>Were you ever interested in hearing about <b>end-of-life planning options instead?</b> (e.g. hospice)</i></p>
Values in Decision-Making	<p>What is the <b>biggest change in quality of life</b> you and your partner have experience before vs. after surgery?</p> <p>Which <b>FORMAT</b> of conveying information did you <b>find most valuable</b> for you when helping to decide on a VAD?</p>	<ul style="list-style-type: none"> <li>■ <i>Seeing the VAD?</i></li> <li>■ <i>Reading about the VAD?</i></li> <li>■ <i>Videos?</i></li> <li>■ <i>Talking to other VAD patients?</i></li> <li>■ <i>Patient narratives?</i></li> <li>■ <i>Web/Internet?</i></li> </ul>
Degree of Decision-Making Difficulty & Contributing Factors	<p>How long was the decision-making process, and how <b>prepared/informed did you feel</b> by the time you and your partner made a decision?</p> <p>Were there any <b>competing obligations</b> interfering with your choice to accept a VAD?</p> <p>Were you <b>nudged</b> in any way in one direction or the other?</p>	

	<p>What kind of <b>influence (bias)</b> did you experience, if any, while deciding?</p> <p>What were your <b>partner's primary considerations</b> in whether or not to get a VAD? Were these the <b>same as yours</b>?</p> <p>If you experienced <b>anxiety</b> during the decision process, what was the <b>primary source</b>?</p> <p>Was there <b>anything you learned pre-surgery</b> that <b>alleviated or augmented your worries</b> about deciding on the VAD device?</p>	<p><i>Was there any <b>difference</b> in what you <b>expected</b> to happen, versus what <b>really did happen</b> during- and post-op?</i></p>
<p>Decisional Barriers and Facilitators</p>	<p>What <b>kinds of information</b> did you <b>receive before</b> deciding?</p> <p>What other information do you <b>wish you had received</b> before deciding?</p>	<p><i>From whom/where?</i></p>
<p>Perceptions of Options, Outcomes and Probabilities</p>	<p>What aspects of <b>life post-surgery</b> do you and your partner feel <b>most vs. least adapted</b> to?</p> <p>Do you and your partner have the <b>same or different perceptions</b> about the <b>surgery outcomes</b>?</p> <p>How do you <b>communicate your social/emotional/physical</b> needs to your husband/wife?</p> <ul style="list-style-type: none"> <li>- What do you do/say <b>when you need a break</b> from caregiving?</li> </ul> <p>Describe the recovery period for me. Was it marked by complications, disappointment, or happiness? Did this fluctuate?</p>	<p><i>QoL issues...</i></p>

	<p>Going into the surgery, when you visualized the “outcome,” the “end goal, “the finish line,” how did you visualize your life? What sorts of things could you do or not do in this vision? Did your experience map up with this vision?</p> <p>Can you describe any <b>difficulties</b> you or your partner may have had <b>adhering to the maintenance</b> regime suggested by your doctors?</p> <p>Is there anything <b>you wish you had known</b> that could have helped you to <b>better prepare yourself as a caretaker</b>?</p> <p>What other <b>sources of support</b> do the both of you have?</p>	<p><i>Before/during the time of your decision-making?</i></p> <p><i>Post-surgery?</i></p>
Suggestions	<p>Are there <b>any questions you wish that we could have asked</b> you to <b>better understand</b> your experience as a caregiver?</p>	

**In-depth Interview Protocol -- Candidates Interview Guide**

DOMAINS	Questions	Prompts
Values in Decision-Making	<p><b>How long</b> have you <b>known about your heart condition</b>?</p> <p><b>How long</b> have you <b>known about the VAD</b> as a viable option to you?</p> <p>Do you <b>consider yourself</b> on your way to getting a <b>transplant?</b> (i.e. BTT or DT?)</p> <p>Under <b>what conditions</b> might you say <b>“No”</b> to getting an LVAD?</p> <p>What <b>sources of information</b> about the VAD have been <b>most useful</b> to you so far?</p> <p>Have you <b>done any of your own research</b> on VADs?</p> <p>Were any of the information sources hard to understand? Why?</p>	<p><i>Which FORMAT of conveying information do/did you find most useful?</i></p> <p><i>Text</i></p> <p><i>Video</i></p> <p><i>Patient testimonies</i></p> <p><i>Web-based</i></p> <p><i>Interactive...? Etc...</i></p>
Usual and Preferred Decision-Making Roles	<p>Is there anyone else close to you <b>involved in your decision</b> of whether or not to get a VAD?</p> <p>What <b>kinds of things</b> does <b>this person helps you to think about</b>?</p>	<p><i>Who? How many people?</i></p>
Degree of Decision-Making Difficulty & Contributing Factors	<p>How <b>prepared/informed do you feel</b> to make this decision?</p> <p>Do you feel <b>nudged</b> in any way in one direction or the other?</p> <p><b>Do you feel any anxiety</b> about making this decision? If so,</p>	<p><i>If so, by whom?</i></p>

	<p>what is the <b>primary source of your concerns?</b></p> <p>What kind of information, if <b>anything, might help to prepare you for the possibility of getting the VAD?</b></p>	
Decisional Barriers and Facilitators	<p>What <b>kinds of information</b> do you <b>wish you had right now to better inform your decision?</b></p> <p><b>Do financial concerns factor into your decision-making about the LVAD in any way?</b></p>	<i>Where would you expect this information to come from?</i>
Perceptions of Options, Outcomes and Probabilities	<p>What is the <b>biggest change in quality of life</b> you <b>expect to occur</b> after surgery? (<i>pos/neg expectations?</i>)</p> <p>Could you see yourself <b>living with the VAD forever?</b> (i.e. never getting a heart transplant?) – How would you feel about that?</p> <p>How easy/<b>difficult</b> do you think it would be to <b>adhere to the maintenance</b> regime suggested by the doctors?</p> <p>What <b>kinds of information</b> about your heart condition, or about the kinds of treatment options available to you, do <b>you wish you had known earlier?</b></p>	<i>When you visualized the “outcome,” the “end goal,” “the finish line,” of your treatment plan, what sorts of things do you include in this vision?</i>
Suggestions	<p>Are there <b>any questions you wish that we could have asked</b> you to <b>better understand</b> your experience as a candidate for a VAD?</p>	