

Appendix A: Interview Guides

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

DOMAINS	Questions	Prompts
<p>Values in Decision-Making</p>	<p>When did your conversations with doctors about your heart first begin?</p> <p>What alternative options to the VAD, if any, were you considering or were presented to you?</p> <p>What questions did you have about the VAD at first/what did you want to know?</p> <p>Was there a time when you heard about the VAD but didn't pursue it as a potential option? Any negative factors that almost kept you from getting the VAD?</p> <p>What were your expectations or concerns about how the VAD might change your everyday life? (<i>pos/neg expectations</i>)?</p> <p>How long did it take you to decide whether or not to get a VAD? Did you feel well-informed and prepared to make this decision?</p> <p>What didn't the education and doctor visits before LVAD prepare you for?</p> <p>Tell me how you could have been better prepared (by docs, caregivers, etc.) for those things prior to your LVAD?</p>	<p><i>Were you ever interested in hearing about end-of-life planning options instead? (e.g. hospice)</i></p> <p><i>Did you want to know the "gist" of risk, or actual figures (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 could be improved about your transition to rehab / home?</p> <p>Did/do you see the VAD as a bridge to transplant? Where do you see yourself on this trajectory?</p> <p>If you knew that getting the VAD might change your status on the transplant list, would you still get it?</p>	
<p>Usual and Preferred Decision-Making Roles</p>	<p>Who, if anyone, helped you decide whether or not to get the VAD?</p> <p>What kinds and/or sources of information did you find most useful in helping to make your decision?</p> <p>Were any of the information sources hard to understand? Why?</p> <p>At what stage in the decision-making process did you receive or seek out these other sources of information?</p> <p>Was there a particular time, from the beginning of your medical assessment to the present, when you wanted to hear more about what the doctors thought you should do?</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>
<p>Decisional Barriers and Facilitators</p>	<p>What are 2-3 key messages do you believe every potential VAD candidate should know 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 transplant/evaluation process has been for you 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"> - Any areas for improvement? - Areas that were confusing, overwhelming, or frustrating to you. <p>What was the degree of overlap in info or questions among the various people associated with the heart failure team during this process?</p> <p>Did financial concerns factor into your decision-making about the LVAD in any way?</p>	<p><i>insurance/home care?</i> <i>- Did you want to talk to other patients?</i></p>
<p>Degree of Decision-Making Difficulty & Contributing Factors (including psychosocial)</p>	<p>What was your understanding of possible complications that could arise? (free list).</p> <ul style="list-style-type: none"> - Which of these were you willing to tolerate? Or not? <p>Take me back to the first few weeks or months after you had the VAD placed. What were your expectations for this period vs. what you experienced?</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 regrets about your decision 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 involved in the decision for your partner/family member to get a VAD?</p> <p>What questions did you have about the VAD at first/what did you want to know?</p> <p>Were your opinions/outlooks consistent with his/hers?</p> <p>Were you ever interested in hearing about end-of-life planning options instead? (e.g. hospice)</p>	<p><i>Were you ever interested in hearing about end-of-life planning options instead? (e.g. hospice)</i></p>
Values in Decision-Making	<p>What is the biggest change in quality of life you and your partner have experience before vs. after surgery?</p> <p>Which FORMAT of conveying information did you find most valuable for you when helping to decide on a VAD?</p>	<ul style="list-style-type: none"> ■ <i>Seeing the VAD?</i> ■ <i>Reading about the VAD?</i> ■ <i>Videos?</i> ■ <i>Talking to other VAD patients?</i> ■ <i>Patient narratives?</i> ■ <i>Web/Internet?</i>
Degree of Decision-Making Difficulty & Contributing Factors	<p>How long was the decision-making process, and how prepared/informed did you feel by the time you and your partner made a decision?</p> <p>Were there any competing obligations interfering with your choice to accept a VAD?</p> <p>Were you nudged in any way in one direction or the other?</p>	

	<p>What kind of influence (bias) did you experience, if any, while deciding?</p> <p>What were your partner's primary considerations in whether or not to get a VAD? Were these the same as yours?</p> <p>If you experienced anxiety during the decision process, what was the primary source?</p> <p>Was there anything you learned pre-surgery that alleviated or augmented your worries about deciding on the VAD device?</p>	<p><i>Was there any difference in what you expected to happen, versus what really did happen during- and post-op?</i></p>
<p>Decisional Barriers and Facilitators</p>	<p>What kinds of information did you receive before deciding?</p> <p>What other information do you wish you had received before deciding?</p>	<p><i>From whom/where?</i></p>
<p>Perceptions of Options, Outcomes and Probabilities</p>	<p>What aspects of life post-surgery do you and your partner feel most vs. least adapted to?</p> <p>Do you and your partner have the same or different perceptions about the surgery outcomes?</p> <p>How do you communicate your social/emotional/physical needs to your husband/wife?</p> <ul style="list-style-type: none"> - What do you do/say when you need a break from caregiving? <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 difficulties you or your partner may have had adhering to the maintenance regime suggested by your doctors?</p> <p>Is there anything you wish you had known that could have helped you to better prepare yourself as a caretaker?</p> <p>What other sources of support 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 any questions you wish that we could have asked you to better understand your experience as a caregiver?</p>	

In-depth Interview Protocol -- Candidates Interview Guide

DOMAINS	Questions	Prompts
Values in Decision-Making	<p>How long have you known about your heart condition?</p> <p>How long have you known about the VAD as a viable option to you?</p> <p>Do you consider yourself on your way to getting a transplant? (i.e. BTT or DT?)</p> <p>Under what conditions might you say “No” to getting an LVAD?</p> <p>What sources of information about the VAD have been most useful to you so far?</p> <p>Have you done any of your own research 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 involved in your decision of whether or not to get a VAD?</p> <p>What kinds of things does this person helps you to think about?</p>	<p><i>Who? How many people?</i></p>
Degree of Decision-Making Difficulty & Contributing Factors	<p>How prepared/informed do you feel to make this decision?</p> <p>Do you feel nudged in any way in one direction or the other?</p> <p>Do you feel any anxiety about making this decision? If so,</p>	<p><i>If so, by whom?</i></p>

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