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“Talking Around It:” A Qualitative Study Exploring Dyadic Congruence in Managing the Uncertainty of Living with a Ventricular Assist Device

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Introduction

Implantation with a ventricular assist device (VAD) signals hope for improved functional status and quality of life for people with advanced heart failure.^{1–3} Although there is potential of prolonged survival, the VAD journey can be wrought with uncertainty, complications, and challenges.⁴ Despite improved quality of life and fewer heart failure symptoms following VAD implant,^{5,6} there are unique considerations surrounding end-of-life planning with a VAD, like how the patient will die with the device in place and the need for device deactivation.⁴ Additionally, patients and caregivers report feeling unprepared for what to expect as end of life approaches.⁷ When bereaved caregivers reflect on their experience of caregiving, they describe confusion and distress surrounding end-of-life processes.⁸ Due to this, the International Society for Heart and Lung Transplantation Guidelines for mechanical circulatory support and the Centers for Medicaid and Medicare Services recommend palliative care consultation prior to implant to assess quality of life, elicit goals of care, and discuss end-of-life preferences, especially if implanted as destination therapy.⁹ Once the patient has been implanted with a VAD, palliative care services should continue for the duration of device therapy, and are particularly important during periods of instability (e.g. hospitalization) or decline.⁴

Vital components of communicating goals of care include eliciting the patient and caregiver’s definition of quality of life, exploring uncertainty regarding end of life, and understanding how they draw meaning from their experiences.⁸ Quality of life is multidimensional and includes consideration of physical, social, and psychological elements.¹⁰ Uncertainty regarding end of life is also multi-faceted. In the present study, the construct of uncertainty includes the inability to predict when and how death will occur in addition to ambiguity and complexity surrounding end of life with a VAD.¹¹ Drawing meaning from what one endures in life, both suffering and pleasure, is associated with improved quality of life.¹² Theoretically, the construct of meaning has three elements: the ability to find patterns and significance from events, the motivation and goals that direct

actions, and the emotional feeling of satisfaction or fulfillment.¹³ Those with higher reported meaning or purpose in life are more likely to use adaptive coping strategies essential to managing the stresses associated with managing a VAD.^{2,14}

Although current literature suggests framing end-of-life conversations through the lens of meaning and quality of life, there is limited literature exploring dyadic congruence surrounding these important constructs.⁹ This is important for several reasons, as caregivers are often surrogate decision makers for VAD patients as they approach end of life, and patients and caregivers do not always share the same perspectives. Incongruence of values, beliefs, and expectations between patients and caregivers about end-of-life topics is common, and there is a need to improve communication to prepare patients and caregivers for the end of life with a VAD.^{5,7,15} However, few studies have explored dyadic perspectives and congruence on managing the uncertainty of living with a VAD with patients and their caregivers. Therefore, the purpose of this study is to explore congruence of VAD patient and caregiver perspectives regarding end of life, definitions of quality of life, and meaning in life while managing the uncertainty of living with a VAD.

Methods

Design

The present study reports qualitative analysis and findings from a series of a priori questions that are part of a larger convergent mixed methods study designed to describe the context of caregiving for persons living with a VAD. We conducted individual, semi-structured interviews with a purposive sample of VAD patients and their caregivers representing a range of dyadic relationships, perspectives, and VAD experiences.¹⁶ Data were analyzed using thematic analysis including a mix of inductive and deductive coding to refine concepts and categories.¹⁷

Theoretical Framework

Two related theoretical frameworks influenced this study. The Individual and Family Self-Management Theory posits that both proximal and distal outcomes are influenced by contextual factors (condition-specific, environmental, individual and family factors) which influence the process of self-management (knowledge and beliefs, self-regulation skills, and social facilitation).¹⁸ Lyons and Lee proposed a more inclusive model of self-management in which a dyadic view of context, appraisal, and behaviors are interconnected and influence the health outcomes of both members of the dyad.¹⁹ These important theories informed the exploration of perspectives from patients and caregivers, but also the importance of considering dyadic congruence. This study focuses on the process of self-management or appraisal aspects of the aforementioned theories.

Data Collection and Sample

The study team recruited a purposive sample of patients with continuous flow VADs and their caregivers from the Johns Hopkins Mechanical Circulatory Support Clinic. Patients were included if they were 3 to 12 months post VAD implant or were >12 months post-implant but had experienced a hospitalization within the past 30 days. Including patients >12

months post-implant with recent hospitalization allowed for inclusion of perspectives from longer term VAD dyads who may have experienced new or prolonged uncertainty related to clinical stability. Relevant to our study purpose, VAD patients who are less stable and require hospitalization typically discuss quality of life issues with their healthcare providers during this time, and may revisit goals of care or end-of-life planning.^{4,20,21} Including patients 3–12 months post-implant allowed for inclusion of perspectives from dyads outside of the immediate post-implantation adjustment phase, but who still may have increased uncertainty, clinical events, and caregiving needs compared to those who had been on VAD support longer than a year without hospitalization.^{22,23} Caregivers had to be identified by the VAD patient as the primary informal caregiver. For inclusion in the study, both patients and caregivers had to be 21 years or older and English speaking. Patients and caregivers were screened for cognitive impairment using the Montreal Cognitive Assessment and were excluded if they scored <17, as they may not have been able to reliably self-report.^{24–27} This study was approved by the Johns Hopkins School of Medicine Institutional Review Board (IRB00170548), and the study team obtained written informed consent from all participants.

Interview Guide Development

The study team developed a semi-structured interview guide with open-ended questions informed by previous literature and the theoretical framework (Figure 1). A panel of expert VAD clinicians reviewed the interview guide for appropriateness, match of study purpose, and completeness. Questions were designed to elicit patient and caregiver perspectives in order to explore congruence regarding each topic.¹⁶ Review of transcripts during research team meetings ensured questions elicited rich data. The study team adjusted the questionnaire in order to facilitate rapport building by starting with more accessible questions and progressing to more complex or challenging questions. Interviewers used probes as needed to elicit richer data.¹⁶

Interviews

During a single visit to the patient's home, individual interviews were conducted with the patient and caregiver separately in order to explore alignment and congruence between members of the dyad.²⁸ Semi-structured interviews were recorded, immediately uploaded to a secure file on the Johns Hopkins network and transcribed verbatim using a transcription service. The study team listened to each interview to adjust the interview guide as needed.

Qualitative Data Analysis

De-identified transcripts were uploaded into F4analyze 2.5.2 to assist in data management, organization, and qualitative analysis. To begin, the study team read all transcripts to understand the content of interviews and confirmed transcription accuracy. For initial coding, a research assistant with training in qualitative analysis used a deductive approach to apply the categories of uncertainty and worry, end of life, meaning and purpose in life, and quality of life to relevant content in all transcripts. Following this, the principal investigator (MA) and research assistants (LD, LL) used an open coding approach to create codes from the data and an initial codebook. The study team created analytic memos throughout the process to facilitate iterative code development and comparison between transcripts.²⁹ The study team conducted regular coding discussions to refine the codebook and review memos.

Trustworthiness was achieved through audit trail documentation and continual review of the codebook and themes by the study team. After the codebook was finalized, all transcripts were coded by two or three study team members and meetings were held to reach consensus on a final version of coding. Data saturation was determined by the study team when no new perspectives came from the interviews. Saturation was reached after 10 dyadic interviews.¹⁶

Dyadic congruence was defined as a shared understanding or aligned perspectives regarding a particular topic between the patient and caregiver.^{15,19,30} We examined congruence in two ways. First, we compared the patient group to the caregiver group to see if the two shared a perspective overall. Then, we examined each individual dyad to examine within-dyad congruence regarding a topic. For instance, patients may have had a different perspective regarding quality of life than caregivers on the whole, but a specific patient-caregiver dyad may share a similar view of quality of life. In this case, we considered view of quality of life to be different between patients and caregivers as a group but found congruence in views within dyads. We evaluated congruence for each major theme with independent evaluations by each of the three coders followed by discussion and consensus during team meetings.

Results

Participant Characteristics

In the final sample of ten patients and ten caregivers (mean age 55.8 and 52.6 years, respectively) most patients were male, white, married, and disabled, retired, or unemployed and received a VAD as destination therapy. Caregivers were primarily disabled, retired, or unemployed, and most were female, white, and the patient's spouse or partner. The majority of caregivers and patients graduated high school. Less than half had a bachelor's degree or higher.

Qualitative Findings

Three major themes were identified when discussing quality of life, meaning in life, and uncertainty about end of life among patients and caregivers: 1) differing trajectories of uncertainty and worry, 2) a spectrum of end-of-life perspectives, and 3) enjoying everyday moments and independence. Key themes are defined and supported with representative quotations.

“You get used to it” vs “I’m on alert all the time:” Differing Trajectories of Uncertainty and Worry

The majority of patients and caregivers experienced uncertainty and worry when living with a VAD, but the trajectory and sources of this uncertainty and worry differed for patients versus caregivers. In the first several weeks to months with the VAD, many patients were constantly worried about managing the VAD:

“That first couple of days there, I still felt nervous. I felt like a first-time mom...I was scared the alarm was going to go off and I would not know what to do, although I had been trained, and I was scared my niece wasn't going to wake up, so that was the most fearful part. That something was going to go off and I wouldn't

know what to do. You know how you panic -- you know what to do but then when the situation arises it's just like oh my god what do I do?"

(VAD Patient 015).

However, patients described increased confidence and self-efficacy over time as they acclimated to living with the device:

"The first couple months was just like you're kind of nervous. You're kind of scared to move around too much, or you just got to lay there kind of. You think, 'Oh, man, this is really bad.' This machine's pumping your heart. But as it goes, again, the last four months have been fine... Yeah, I was kind of worried about that in the beginning, so at first I was like 'Oh, man, I don't know if I can do anything.' I was laying down mostly and making sure it didn't bend or fold, but again as you get used to it it's pretty durable"

(VAD Patient 003).

Unlike the patients they cared for, caregivers experienced a constant undercurrent of worry and uncertainty even after the initial adjustment period:

"And even though one day can be good and the next day he's not feeling good so it's like I just -- I guess I'm on alert all the time... I probably worry all the time... I mean, I feel like I don't have any down time because I'm kind of like, 'What's today going to be like?'"

(VAD Caregiver 002).

Although both patients and caregivers experienced worry and uncertainty surrounding the VAD, there was incongruence in the trajectory of worry and uncertainty both between patients and caregivers and within dyads. As patients gained confidence and self-efficacy in VAD management, their worry and uncertainty decreased. However, caregivers continued to feel the weight of uncertainty and constantly worried even after the initial adjustment period of living with and managing the VAD.

Spectrum of End-of-Life Perspectives

There were three types of responses that appeared to fall along a spectrum when patients and caregivers were asked, "Do you think about the end of [the patient's] life?" (Figure 2). Some patients and caregivers stated they do not think about end of life at all:

Interviewer: "Do you ever think about the end of his life? Caregiver: No, I don't.

Interviewer: Do you ever think about how you might handle life without him?

Caregiver: No, I don't"

(VAD Caregiver 014).

A more moderate place on the spectrum of responses included participants who stated they could speak about end of life but preferred to "talk around it." These participants provided thoughtful reasons for minimizing end-of-life discussions, demonstrating they had clearly considered end of life.

The first reason for talking around end of life was because they chose to accept the lack of control over when death will occur, focusing instead on living day by day:

“I don’t think about that and, I mean, even though it can happen, but I just think about that, you know I mean, because it, like I said, if it’s my time, it’s my time... But long as my kids know that I love them, my mother know that I love them, my nieces and that I love them, so can’t do nothing about that. I’m fine with it”

(VAD Patient 005).

“I just try and take stuff day by day...I don’t want to try and look so far ahead, because then I stress myself out. So it’s like, I just take on things according to how they come”

(VAD Caregiver 014).

Secondly, some patients and caregivers talked around it by discussing practicalities such as living wills or burial preferences:

“We’ve discussed, you know, we’ve talked around it a couple of times. But never really talked about it. I mean, you know, I think she realizes it could happen at any time”

(VAD Patient 002).

“There’s some things I should do because I have a burial plot that I got to get transferred to my name that my parents bought”

(VAD Patient 009).

Third, some participants talked around it because the emotional discussions were overwhelming:

Interviewer “Do you think about the end of your wife’s life and how you would handle it?”

Caregiver: “I wouldn’t handle it. <cries> I’m sorry...my wife’s almost like a part of me. I don’t think I could do very well on my own. I really don’t. I don’t know what I would do. I don’t have any idea, but thankfully for now I don’t have to think about that, and that’s the way I look at that question. For the moment everything’s okay”

(VAD Caregiver 013).

Finally, the furthest end of the spectrum included the few participants who stated they do think about end of life. These participants had near-death experiences, causing them to face the reality that death is inevitable:

“Yeah, of course. Yeah, sometimes, yeah, mainly for the kids and my wife I worry about, so make sure that my parents know what the situation is, my brother does just in case. What’s going to happen if I do die? Because you don’t really think about that beforehand, but after the LVAD I do. And then I died. I had cardiac arrest after the surgery. Three days after I died and then came back, so it was even more in my mind”

(VAD Patient 003).

“Yeah, I felt like that when I first seen her after her operation, because she looked like my mom laying in the bed, and it just had like, a flashback so much that once I seen her I left, and it took me like, two days to come back”

(VAD Caregiver 015).

When evaluating within-dyad congruence regarding end-of-life perspectives, approximately half of the dyads had congruent responses to how they think about end of life:

“No... I mean, I don't think about that. You know, I'm one of those people that, you know, takes care of his funeral services tomorrow and if tomorrow isn't here... you know”

(VAD Patient 010).

“No, because to me my experience for as long as I can remember has been it happens, you do what you have to do, and you get through it, and that's how it is”

(VAD Caregiver 010).

However, several dyads had incongruent responses to the question. In some cases, the patient had reflected more deeply about the end of life while the caregiver was uncertain and fearful:

“I have to be a little bit more careful about life. It's a little bit more precious than it was before, because I didn't know it was that-- people always said like, 'Life's short,' or, 'You could die at any time,' this and that, a car accident, whatever, but you never really think about it, but after you've done what I've been through then you're like, 'All right. It's true you can die anytime,' so then that changed me”

(VAD Patient 003).

“Well, I thought about it before. I really thought about it while I was kind of scared. I didn't know what to do. Just that's kind of tough. I don't know”

(VAD Caregiver 003).

When asked if patients and caregivers talk with anyone about end-of-life concerns, there was less within-dyad congruence in dyads regarding discussing death with others. Most patients and caregivers did not discuss death together, opting to discuss it with other family members or friends or not talk about it at all. Additionally, some dyads described an unspoken understanding about end-of-life plans:

“My mother know how I feel. My family know how pretty much, they know how I am and how I feel. They know what I want, they know what I expect”

(VAD Patient 005).

Enjoying Everyday Moments and Independence

Patients and caregivers emphasized spending time with family and having independence as indicators of a good quality of life. For patients, quality of life meant having the

independence and ability to enjoy everyday moments with loved ones and not “being a burden” to anyone:

“I think the most pleasure I get is doing things with my wife. Going places, just joking. Sometimes we can have a good time just sitting around and talking to each other.”

(VAD Patient 002).

“I’m independent, on my own. I do everything on my own. I try-- if I can’t do it. I’m going to try to do it, because I want it back to where I used to be. Like, that’s how I am. I will-- I’m not used to nobody taking care of me. I’m not that type of person. I don’t want to just lay around and be a burden to no one”

(VAD Patient 005).

Caregivers described good quality of life as having resources and freedom to be comfortable and do things they enjoy:

“A good quality of life, one that you have good health. To a large extent you can do all the things that you want to do. You have access to when you have problems you have access to solutions”

(VAD Caregiver 004).

“Good quality of life would be able to live the American dream. Go to work every day. Come home have enough money to be comfortable with and be able to get up and go if you want to and just freedom”

(VAD Caregiver 009).

Of all of the themes, within-dyad congruence was strongest when discussing meaning and quality of life:

“Good quality of life? I would describe that as just comfortable money management-wise and then kids being happy and healthy and my wife being healthy, me getting healthy. Now I know that health is more important these days than anything else”

(VAD Patient 003).

“For now, healthy, healthy... the most important thing, healthy family”

(VAD Caregiver 003).

Discussion

In this study, patient-caregiver dyads experienced improved quality of life and the ability to regain a sense of normalcy despite the challenges of living with a VAD. However, many also experienced uncertainty and worry about the end of life. For patients, this uncertainty and worry dissipated as they gained self-efficacy in managing their VAD. In contrast, caregivers experienced a constant undercurrent of worry regarding the possible failure of the device and the uncertainty surrounding how long the patient may be able to live with the VAD. Despite this, both patients and caregivers found it difficult to have in-depth end-of-life discussions.

Both caregivers and patients chose to focus on enjoying the extended time and improved quality of life the VAD provided them. Findings from our study contribute to the existing evidence base with important implications for clinical practice and future research.

For many patients and caregivers, newfound anxieties fluctuated as patients and caregivers adapted to life with a VAD. In alignment with existing literature, caregivers in the present study experienced prolonged worry and hypervigilance following implant.³¹ One of the core drivers of this hypervigilance may be the fear of the patient dying. This constant vigilance may result in psychological distress and long-term emotional sequelae for caregivers of VAD patients, including post-traumatic stress disorders.^{32,33} Therefore, regular psychosocial assessments of the patient and caregiver are recommended to help identify and address evolving concerns.⁹ Findings from our study reiterate the importance of evaluating both patient and caregiver concerns across the trajectory of VAD therapy, as the source, nature, and duration of psychological distress may differ.^{8,31,34}

Participants and caregivers had a spectrum of responses to the topic of death, with the majority completely avoiding the topic, accepting lack of control over death, or talking around death in generalities. Although participants' responses reflected that they had potentially considered death before, no participants discussed the process of the patient's decline and death. In addition, no participants discussed the complexity in decision making as patients approach the end of life, such as decisions regarding deactivation of the VAD. One reason for this may have been that our sample included relatively stable VAD patients and caregivers, many of whom experienced improved symptoms and quality of life in comparison to their pre-VAD condition. However, end-of-life decisions are inevitable and particularly complex with a VAD.^{35,36}

Findings from this study reflect current evidence in other populations which suggest there is poor consensus about values and preferences between patients and caregivers.^{15,37,38} Similar to the themes identified in our study, a dyadic study among individuals with dementia and their caregivers by Reamy and colleagues found participants highly valued autonomy, control, and time with family. However, caregivers consistently underestimated the patient's perception of the importance of these values.³⁸ In addition, they found decreased caregiver quality of life over time was associated with placing less importance on the values of the person with dementia.³⁹ Therefore, targeted interventions to improve caregiver quality of life may help them more accurately judge the patient's perception of the importance of their values even as the disease worsens.³⁹

Overall, our findings and those from dementia studies illuminate the importance of regularly evaluating the values and preferences of both members of the dyad while the patient is able to participate. This is particularly pertinent for VAD patients due to the high proportion of VAD patients who die in intensive care (as compared to hospice or home settings).^{36,40} Coupled with providers' discomfort discussing the process of dying with a VAD with families,^{41,42} caregivers may be particularly vulnerable to adverse outcomes associated with end-of-life decision making (e.g. complicated grief,⁴³ post-traumatic stress disorder⁴⁴) especially in the event the patient is unable to communicate.⁸ Understanding the level of

dyadic congruence of values and preferences over time may assist the caregiver in decision making if the patient is no longer able to communicate.

By discussing common trajectories of end of life with a VAD earlier (e.g. before or early after implantation), patients and caregivers may be more prepared to recognize decline and make choices according to their preferences.^{4,7,8} In a qualitative study by McIlvennan and colleagues, bereaved caregivers of VAD patients were surprised, unprepared, and overwhelmed as their loved one approached end of life.⁸ Caregivers reported a lack of knowledge regarding how death would occur with the device in place and often hadn't discussed deactivation.⁸ Caregivers have also reported a sense of relief when a detailed plan for withdrawal of pump support was established.⁴⁵ As interventions to improve shared decision making prior to VAD are implemented, such as the DECIDE-LVAD trial,⁴⁶ additional focus is needed on end-of-life planning and shared decision making soon after VAD implant. Family conversations pre-VAD may provide an anchor for revisiting end of life discussions post-VAD to facilitate goal concordant care.

The importance of considering death and dying is increasingly being integrated across the heart failure trajectory using a palliative care approach,⁴⁷ but palliative care interventions in VAD patients primarily focus on pre-VAD consultation and have not been shown to adequately address important concerns that emerge after implant.^{7,48} Future interventions are needed to examine how ongoing palliative care support for patients and caregivers following VAD implant may improve preparedness planning for end of life.⁷ Many tools and resources are available to assist in having these crucial planning conversations.⁴⁹

Consistent with existing literature, many patients and caregivers did not discuss end of life because quality of life improved following VAD implant.¹⁰ Patients described the VAD becoming "part of you," adjusting to an adapted way of life while enjoying everyday moments and independence. In this study, patients emphasized the importance of autonomy in defining a good quality of life and not wanting to be a burden on their families. However, end-of-life decisions are often made by family members due to lack of decision-making capacity of the patient at the end of life.⁴¹ This makes assessing within-dyad congruence important, and suggests the need for future interventions to explore shared understanding of values and preferences. Both palliative care and VAD providers can use the patient, caregiver, and dyadic definitions of quality of life and meaning in life to guide goals of care and advance care planning conversations.⁹ Exploring patient and caregiver congruence regarding definitions of quality of life and meaning in life may present a valuable opportunity to discuss how these values translate into end-of-life preferences.⁹

Strengths and Limitations

This study has several limitations. First, the interview guide questions about end of life did not always elicit the richest data, despite changing our wording and order of questions. For many participants, this was first time they directly discussed end of life and it may have been challenging for them to articulate their thoughts. Second, we did not validate themes with participants although we engaged in reflexive processes within the study team. Finally, our sample had limited heterogeneity of caregiver types, ethnicity, and type of LVAD despite

purposive sampling. Future samples with more non-spousal/partnered caregivers, male caregivers, and representation of additional racial/ethnic groups is crucial.

By interviewing participants after the initial adjustment period following VAD implant had passed, this study provides unique evidence to push the science of comprehensive VAD care forward by examining dyadic end-of-life perspectives in later stages of adaptation to living with a VAD. Our deep exploration of uncertainty and meaning in care dyads living with a VAD may also provide foundational knowledge to develop psychosocial and communication interventions to enhance family centered care throughout the VAD process.

Conclusion

Findings from this study improve our understanding of dyadic perspectives of uncertainty surrounding end-of-life considerations with a VAD, as well as quality of life and meaning in life. Building from this work, further descriptive work and interventional approaches for managing uncertainty and discussing end of life with VAD care dyads in an accessible, individualized, and goal-oriented way are needed to improve long-term adjustment and end-of-life experiences for VAD patients and caregivers.

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References

1. Magid M, Jones J, Allen L a., et al. The Perceptions of Important Elements of Caregiving for a Left Ventricular Assist Device Patient. *J Cardiovasc Nurs.* 2015;00(0):1. doi:10.1097/JCN.0000000000000242
2. Abshire M, Prichard R, Cajita M, DiGiacomo M, Dennison Himmelfarb C. Adaptation and coping in patients living with an LVAD: A metasynthesis. *Hear Lung J Acute Crit Care.* 2016;45(5):397–405. doi:10.1016/j.hrtlng.2016.05.035
3. Rogers JG, Aaronson KD, Boyle AJ, et al. Continuous Flow Left Ventricular Assist Device Improves Functional Capacity and Quality of Life of Advanced Heart Failure Patients. *J Am Coll Cardiol.* 2010;55(17):1826–1834. doi:10.1016/J.JACC.2009.12.052 [PubMed: 20413033]
4. Wordingham SE, McIlvennan CK, Fendler TJ, et al. Palliative Care Clinicians Caring for Patients Before and After Continuous Flow-Left Ventricular Assist Device. *J Pain Symptom Manage.* 2017;54(4):601–608. doi:10.1016/J.JPAINSYMMAN.2017.07.007 [PubMed: 28711755]
5. Brouwers C, Denollet J, De Jonge N, Caliskan K, Kealy J, Pedersen SS. Patient-reported outcomes in left ventricular assist device therapy: A systematic review and recommendations for clinical research and practice. *Circ Hear Fail.* 2011;4(6):714–723. doi:10.1161/CIRCHEARTFAILURE.111.962472
6. Gustafsson F, Rogers JG. Left ventricular assist device therapy in advanced heart failure: patient selection and outcomes. *Eur J Heart Fail.* 2017;19(5):595–602. doi:10.1002/ejhf.779 [PubMed: 28198133]
7. Chuzi S, Hale S, Arnold J, et al. Pre-Ventricular Assist Device Palliative Care Consultation: A Qualitative Analysis. *J Pain Symptom Manage.* 2019;57:100–107. doi:10.1016/j.jpainsymman.2018.09.023 [PubMed: 30315917]

8. McIlvennan CK, Jones J, Allen LA, Swetz KM, Nowels C, Matlock DD. Bereaved caregiver perspectives on the end-of-life experience of patients with a left ventricular assist device. *JAMA Intern Med.* 2016;176(4):534–539. doi:10.1001/jamainternmed.2015.8528 [PubMed: 26998594]
9. Feldman D, Pamboukian SV, Teuteberg JJ, et al. The 2013 International Society for Heart and Lung Transplantation Guidelines for mechanical circulatory support: Executive summary. *J Hear Lung Transplant.* 2013;32(2):157–187. doi:10.1016/j.healun.2012.09.013
10. Sandau KE, Høglund BA, Weaver CE, Boisjolie C, Feldman D. A conceptual definition of quality of life with a left ventricular assist device: Results from a qualitative study. *Hear Lung J Acute Crit Care.* 2014;43(1):32–40. doi:10.1016/j.hrtlng.2013.09.004
11. Han PKJ, Klein WMP, Arora NK. Varieties of uncertainty in health care: a conceptual taxonomy. doi:10.1177/0272989X11393976
12. Steger MF, Mann JR, Michels P, Cooper TC. Meaning in life, anxiety, depression, and general health among smoking cessation patients. *J Psychosom Res.* 2009;67(4):353–358. doi:10.1016/j.jpsychores.2009.02.006 [PubMed: 19773029]
13. Martela F, Steger MF. The three meanings of meaning in life: Distinguishing coherence, purpose, and significance. *J Posit Psychol.* 2016;11(5):531–545. doi:10.1080/17439760.2015.1137623
14. Thompson NJ, Coker J, Krause JS, Henry E. Purpose in life as a mediator of adjustment after spinal cord injury. *Rehabil Psychol.* 2003;48(2):100–108. doi:10.1037/0090-5550.48.2.100
15. Kitko Lisa A., RN PhD Judith E. Hupcey, EdD CRNP, FAAN2, Casey Pinto, RN, MS, CRNP, FNP-BC2, and Maureen Palese, RN M. Patient and Caregiver Incongruence in Advanced Heart Failure. *Clin Nurse Res.* 2016;176(1):139–148. doi:10.1016/j.physbeh.2017.03.040
16. Creswell JW. *Qualitative Inquiry and Research Design: Five Traditions.* 3rd ed. Thousand Oaks, California: SAGE Publications; 2013.
17. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3(2):77–101. doi:10.1191/1478088706qp063oa
18. Ryan P, Sawin KJ. The Individual and Family Self-Management Theory: Background and perspectives on context, process, and outcomes. *Nurs Outlook.* 2009;57(4):217–225.e6. doi:10.1016/j.outlook.2008.10.004 [PubMed: 19631064]
19. Lyons KS, Lee CS. The Theory of Dyadic Illness Management. *J Fam Nurs.* 2018;24(1):8–28. doi:10.1177/1074840717745669 [PubMed: 29353528]
20. Adler ED, Goldfinger JZ, Kalman J, Park ME, Meier DE. Palliative Care in the Treatment of Advanced Heart Failure. *Circulation.* 2009;120(25):2597–2606. doi:10.1161/CIRCULATIONAHA.109.869123 [PubMed: 20026792]
21. Arnold SV, Jones PG, Allen LA, et al. Frequency of poor outcome (Death or Poor Quality of Life) after left ventricular assist device for destination therapy. *Circ Hear Fail.* 2016;9(8). doi:10.1161/CIRCHEARTFAILURE.115.002800
22. Kitko L, McIlvennan CK, Bidwell JT, et al. Family Caregiving for Individuals With Heart Failure: A Scientific Statement From the American Heart Association. *Circulation.* 4 2020.
23. Nicholas Dionne-Odom J, Hooker SA, Bekelman D, et al. Family caregiving for persons with heart failure at the intersection of heart failure and palliative care: a state-of-the-science review. *Heart Fail Rev.* 2017;22(5):543–557. doi:10.1007/s10741-017-9597-4 [PubMed: 28160116]
24. Nasreddine ZS, Phillips NA, Bédirian V, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc.* 2005;53(4):695–699. doi:10.1111/j.1532-5415.2005.53221.x [PubMed: 15817019]
25. Davis KK, Allen JK. Identifying cognitive impairment in heart failure: a review of screening measures. *Heart Lung.* 42(2):92–97. doi:10.1016/j.hrtlng.2012.11.003
26. Gallagher R, Sullivan A, Burke R, et al. Mild cognitive impairment, screening, and patient perceptions in heart failure patients. *J Card Fail.* 2013;19(9):641–646. doi:10.1016/j.cardfail.2013.08.001 [PubMed: 24054341]
27. Gure TR, Blaum CS, Giordani B, et al. Prevalence of cognitive impairment in older adults with heart failure. *J Am Geriatr Soc.* 2012;60(9):1724–1729. doi:10.1111/j.1532-5415.2012.04097.x [PubMed: 22882000]
28. Eisikovits Z, Koren C. Approaches to and Outcomes of Dyadic Interview Analysis. *Qual Health Res.* 2010;20(12):1642–1655. doi:10.1177/1049732310376520 [PubMed: 20663940]

29. Boeije H A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Qual Quant.* 2002;36(4):391–409. doi:10.1023/A:1020909529486
30. Retrum JH, Nowels CT, Bekelman DB. Patient and caregiver congruence: The importance of dyads in heart failure care. *J Cardiovasc Nurs.* 2013;28(2):129–136. doi:10.1097/JCN.0b013e3182435f27 [PubMed: 22343213]
31. Marcuccilli L, Casida JM. From Insiders' Perspectives: Adjusting to Caregiving for Patients with Left Ventricular Assist Devices. *Prog Transplant.* 2011;21(2):137–143. doi:10.1177/152692481102100209 [PubMed: 21736243]
32. Bunzel B, Laederach-Hofmann K, Wieselthaler GM, Roethy W, Drees G. Posttraumatic stress disorder after implantation of a mechanical assist device followed by heart transplantation: Evaluation of patients and partners. In: *Transplantation Proceedings. Vol 37.* Elsevier USA; 2005:1365–1368. doi:10.1016/j.transproceed.2004.12.248 [PubMed: 15848722]
33. Bunzel B, Laederach-Hofmann K, Wieselthaler G, Roethy W, Wolner E. Mechanical Circulatory Support as a Bridge to Heart Transplantation: What Remains? Long-term Emotional Sequelae in Patients and Spouses. *J Hear Lung Transplant.* 2007;26(4):384–389. doi:10.1016/j.healun.2007.01.025
34. Bidwell JT, Lyons KS, Mudd JO, et al. Quality of Life, Depression, and Anxiety in Ventricular Assist Device Therapy. *J Cardiovasc Nurs.* 2016;00(0):1. doi:10.1097/JCN.0000000000000378
35. Slavin SD, Allen LA, McIlvennan CK, Desai AS, Schaefer KG, Warraich HJ. Left Ventricular Assist Device Withdrawal: Ethical, Psychological, and Logistical Challenges. *J Palliat Med.* 2020;23(4):456–458. doi:10.1089/jpm.2019.0622 [PubMed: 31895635]
36. Dunlay SM, Strand JJ, Wordingham SE, Stulak JM, Luckhardt AJ, Swetz KM. Dying with a Left Ventricular Assist Device as Destination Therapy. *Circ Hear Fail.* 2016;9(10). doi:10.1161/CIRCHEARTFAILURE.116.003096
37. Gardner DS, Kramer BJ. End-of-Life Concerns and Care Preferences: Congruence among Terminally Ill Elders and Their Family Caregivers. *OMEGA - J Death Dying.* 2010;60(3):273–297. doi:10.2190/OM.60.3.e
38. Reamy AM, Kim K, Zarit SH, Whitlatch CJ. Understanding discrepancy in perceptions of values: Individuals with mild to moderate dementia and their family caregivers. *Gerontologist.* 2011;51(4):473–483. doi:10.1093/geront/gnr010 [PubMed: 21383111]
39. Reamy AM, Kim K, Zarit SH, Whitlatch CJ. Values and preferences of individuals with dementia: Perceptions of family caregivers over time. *Gerontologist.* 2013;53(2):293–302. doi:10.1093/geront/gns078 [PubMed: 22899426]
40. Nakagawa S, Ando M, Takayama H, et al. Withdrawal of Left Ventricular Assist Devices: A Retrospective Analysis from a Single Institution. *J Palliat Med.* 2020;23(3):368–374. doi:10.1089/jpm.2019.0322 [PubMed: 31599703]
41. Dunlay SM, Foxen JL, Cole T, et al. A survey of clinician attitudes and self-reported practices regarding end-of-life care in heart failure. *Palliat Med.* 2015;29(3):260–267. doi:10.1177/0269216314556565 [PubMed: 25488909]
42. McIlvennan CK, Wordingham SE, Allen LA, et al. Deactivation of Left Ventricular Assist Devices: Differing Perspectives of Cardiology and Hospice/Palliative Medicine Clinicians. *J Card Fail.* 2017;23(9):708–712. doi:10.1016/j.cardfail.2016.12.001 [PubMed: 27932271]
43. Mason TM, Toftagen CS, Buck HG. Complicated Grief: Risk Factors, Protective Factors, and Interventions. *J Soc Work End-of-Life Palliat Care.* 2020. doi:10.1080/15524256.2020.1745726
44. Gries CJ, Engelberg RA, Kross EK, et al. Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU. *Chest.* 2010;137(2):280–287. doi:10.1378/chest.09-1291 [PubMed: 19762549]
45. Brush S, Budge D, Alharethi R, et al. End-of-life decision making and implementation in recipients of a destination left ventricular assist device. *J Hear Lung Transplant.* 2010;29(12):1337–1341. doi:10.1016/j.healun.2010.07.001
46. Allen LA, McIlvennan CK, Thompson JS, et al. Effectiveness of an intervention supporting shared decision making for destination therapy left ventricular assist device the DECIDE-LVAD randomized clinical trial. *JAMA Intern Med.* 2018;178(4):520–529. doi:10.1001/jamainternmed.2017.8713 [PubMed: 29482225]

47. Rogers JG, Patel CB, Mentz RJ, et al. Palliative Care in Heart Failure. *J Am Coll Cardiol.* 2017;70(3):331–341. doi:10.1016/j.jacc.2017.05.030 [PubMed: 28705314]
48. O'Connor NR, Moyer ME, Kirkpatrick JN. Scripted Nurse Visits: A Resource-Efficient Palliative Care Model for Ventricular Assist Devices. *J Palliat Med.* 2016;19(12):1312–1315. doi:10.1089/jpm.2016.0065 [PubMed: 27400133]
49. Swetz KM, Ottenberg AL, Freeman MR, Mueller PS. Palliative Care and End-of-Life Issues in Patients Treated with Left Ventricular Assist Devices as Destination Therapy. doi:10.1007/s11897-011-0060-x

VAD Caregiver Interview Guide Questions

1. Sometimes caregivers struggle with this idea of uncertainty or worry about the future too. How do you manage worry about the future?
 - Do you think about end of (patient's) life and how you will handle it?
 - Have you talked about this with other family or friends?
2. From what experiences do you draw the most meaning or purpose?
3. How would you describe 'good quality of life'?

VAD Patient Interview Guide Questions

1. People with a VAD often talk about how difficult it is to know that you depend on a device for life. How are you managing the uncertainty of living with a VAD?
2. Do you think about the end of your life?
 - What do you think about?
 - How do you talk about this with others?
3. From what experiences do you draw the most meaning or purpose?
4. How would you describe 'good quality of life'?

Figure 1:
Qualitative Interview Guide

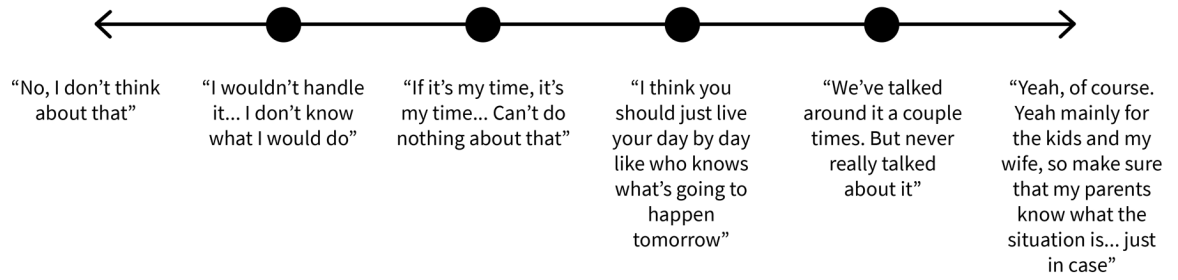


Figure 2:
Spectrum of End-of-Life Perspectives

Table 1

Sample Characteristics

	PATIENT (n=10) n (%)	CAREGIVER (n=10) n (%)
Age (mean \pm SD); median	55.8 \pm 12.8; 49	52.6 \pm 14; 55
Gender		
Male	6 (60)	2 (20)
Female	4 (40)	8 (80)
Race		
African American	4 (40)	4 (40)
White	5 (50)	5 (50)
Asian	1 (10)	1 (10)
Employment Status		
Working Now	1 (10)	2 (20)
Looking for work, unemployed	1 (10)	2 (20)
Retired	4 (40)	4 (40)
Disabled, permanently or temporarily	3 (30)	2 (20)
Homemaker	1 (10)	
Education Level		
<12 th grade	2 (20)	2 (20)
Graduated high school	1 (10)	3 (30)
Some college, no degree	4 (40)	2 (20)
Bachelor's degree	2 (20)	1 (10)
Graduate degree	1 (10)	2 (20)
Marital Status		
Never Married	2 (20)	1 (10)
Married	6 (60)	7 (70)
Widowed	1 (10)	1 (10)
Divorced	1 (10)	1 (10)
Type of Home		
Rented apartment		3 (30)
Single family		7 (70)
Number in Household (mean \pm SD); median		3.2 \pm 1.3; 3
Annual Household Income		
Less than \$14,000		1 (10)
\$14,000-\$21,999		1 (10)
\$22,000-\$35,999		2 (20)
\$49,000 or more		4 (40)
Prefer not to say		2 (20)
In general, how do your finances usually work out at the end of the month? Do you find that you usually end up with:		
Some money		4 (40)

	PATIENT (n=10) n (%)	CAREGIVER (n=10) n (%)
Just enough to make ends meet		4 (20)
Not enough to make ends meet		2 (20)

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