

A QUALITATIVE EXPLORATION OF THE IMPACT OF DESTINATION THERAPY ON
PATIENTS AND THEIR FAMILIES

Suellen Richardson RN MBA DNP

Laura Bourdeanu, DNP, Committee Chair

Cara Wallace, PhD, Committee Member

Christopher Kowal, DNP, Committee Member

Capstone Presented in Partial Fulfillment

of the Requirements of the Degree

Doctor of Nursing Practice Executive Leadership

American Sentinel University

June 2015

Abstract

The purpose of this research was to explore the lived experiences of destination therapy (DT) left ventricular assist device (LVAD) patients and their families using a narrative method of inquiry. Previous research documented that patients and families identified God/religiosity, family support, and the realization of a second chance for life. Interviews with patients and families provided extensive and personal insight into the dynamics faced by these participants. The needs of the patient and family vary based on the pathway traveled; thus, the education and support mechanisms must be guided by the needs of the participants, not a pre-determined timeline. The journey is unique but the outcome is consistent: DT is a lifesaving technology, giving patients and family members gratitude for today and hope for the future.

Keywords: Heart assist device, Heart failure, Qualitative research

BACKGROUND

Destination Therapy Left ventricular assist devices (DT VAD), are rapidly becoming the long-term treatment of choice for some advanced heart failure patients.¹ DT patients, their families, and caregivers require extensive pre-implant education along with psychosocial and financial counseling. The same resources are needed post-operatively to prepare them for life at home. The burden of the care of the patient rests on the primary caregiver; thus, the life change experienced by the primary caregiver is as drastic as that of the patient.

DT VADs are life-saving devices, but they are also life-changing. As access to this technology expands, much remains to be understood about its impact on the patient and family. This impact needs to be determined and heard from the patients and those intimately involved in the life of the DT patient. This will give us insight into what education they may require to make well-informed and appropriate decisions and deal with the burdens and blessings of this disruptive but welcome technology.

PURPOSE

The purpose of this research was to explore the lived experiences of DT patients and their families using a narrative method of inquiry. The information can be used to enhance assessment protocols leading to the decision point, better predict post-procedural outcomes, and provide individualized support for this fragile population of patients and families throughout the experience

METHODS

Design

A qualitative narrative methodology was chosen for this study. What patients say about their experience gives insight into the reality, much more than answers to simple questions, as the narratives articulate the emotions, thoughts, and interpretations, highlighting the uniqueness of each human action and event. Stories are enabled and constrained by social circumstances and resources.²⁻³

Procedure Recruitment

The study was posted on left ventricular assist device (LVAD) support group websites. Interested participants contacted the researcher by phone or email. If the patient and family agreed to participate and they met the eligibility criteria, then the consent form and demographic data tool were mailed to the participants with stamped return envelope. Once the researcher received the signed consent form, interviews were conducted by phone. Interviews of patient and family member occurred separately. Interviews were semi-structured while assuring aspects of Section V of the McGill Illness Narrative Interview (MINI), which deal with impact of an illness on life, were covered.⁴ Permission to use the tool was granted by Dr. Danielle Groleau, who developed the tool. Permission for research was granted by American Sentinel University Institutional Review Board.

Sample

Convenience sampling was the chosen methodology for this study. The individuals chosen for the narrative inquiry were a sample of DT patients and family members willing to share their story.

Inclusion criteria. Included in the study were all participants over the age of eighteen. The study included both male and female DT patients who were at least one-month post-

discharge. Family members interviewed were the primary caregiver living with the patient or other family members who have taken a supportive role with the patient and primary caregiver.

Exclusion criteria. Excluded were participants whose caregiver was unwilling to participate, participants who were unable to communicate or had decreased cognitive function, such as dementia or stroke, and non-English speaking participants.

Data Collection and Analysis

Twelve interviews were conducted: 6 were interviews with patients and 6 were interviews with the caregivers. The interviews lasted 45 to 90 minutes, depending on the participant's ability to express themselves. All interviews were recorded and transcribed verbatim, and the recordings were then compared with transcription to ensure accuracy. Two researchers independently evaluated the transcripts and compared their findings in order to accomplish member checking for validity of the findings. All interviews were conducted by same person to reduce bias.

HyperRESEARCH™ (2013) by Researchware is the software program that was utilized to analyze the qualitative data, due to its strengths for qualitative research and ability to easily organize coding for large amounts of data. Major themes were identified and recorded appropriately after each interview. When new themes emerged from new interviews, previous transcripts were reviewed to determine if the new theme was identified in previous interviews. Two researchers independently coded transcripts and compared their findings. Three other researchers were consulted at all stages of the study.

RESULTS

Of the twelve participants, six were DT patients, all of whom were at least one-month post-discharge from their device implantation. The remaining six participants were the primary caregivers for these patients. All participants were asked to complete a demographic collection

tool. Table 1 displays the information from the demographic collection tool. Three of the caregivers chose not to complete the demographic tool.

Table 1 - Demographics

		Patient	Caregiver
Gender	Male	3	3
	Female	3	3
Median Age		46	41
Ethnicity	Caucasian	2	0
	African American	4	3
Religion	Christianity	6	3
Education	< High School		1
	High School Graduate	4	1
	Some College	2	
	Bachelor's Degree		1
Work Status	Full-Time		2
	Retired	6	
	Unemployed		1
Annual Income	No Response	1	4
	< \$5000		1
	\$5000-\$11,999	1	
	\$12,000-\$15,999	1	
	\$25,000-\$34,999	1	
	\$50,000-\$74,999	1	
	> \$100,000	1	1

Themes discovered in the study included (1) enhanced positive outlook, (2) spirituality, (3) gratitude for a second chance at life, (4) altered lifestyle, (5) value of support network, (6) altered perception by others, and (7) altered self-image. These themes were present in both patient and caregiver interviews.

Enhanced Positive Outlook

An enriched life and positive outlook was a major theme among patients and caregivers. Despite the physical alterations and lifestyle changes associated with DT, patients and caregivers all professed a heightened relationship between each other, gratitude for life, and hope for the future. Patients identified a return to normalcy for their family. A patient and father of five noted: "I had time to reflect and know there is more to life than what I want". Another noted, "My wife and I are closer than we have ever been. We love each other more". A caregiver noted: "It allowed her to have some kind of normalcy".

Spirituality

A reliance on faith and an enhanced spiritual life was a common theme. Participants professed Christian beliefs and expounded that their current situation in life accomplished a purpose in their spiritual life. They articulated closeness to God that was not present prior to the illness and implantation. One patient noted "As far as spiritual things, I think it is the best thing that ever happened. Because now I stick close to God".

Some shared intensely personal spiritual experiences. One patient noted, "I know I got to a point when they were operating on me that to me I felt that I was right near heaven. I remember it was real bright and I felt this peace and I was so happy in this spot. I begged God not to wake me up from the operation . . . I felt so happy. I felt loved. It was like 'now is not your time' and I woke up".

Faith, to others, was explained as faith in oneself or faith in some higher power. Those who were markedly self-sufficient prior to DT continued to be self-sufficient after the implant. The participants repeatedly identified faith as that which helped them most through the DT process. One caregiver noted: “God has really been a very important part of this experience because he put a level of patience and understanding and compassion that you hope you can have”. Another expounded, “I don't know if I would have done it (without faith). I thought about killing myself”.

Gratitude for a Second Chance at Life

Participants expressed gratitude for technology that was life- saving. Regardless of the burdens associated with the device, participants saw those as minor inconveniences in exchange for a longer and more productive life. Through all of the financial barriers, the pain, the tears, and the life change experiences, participants would not change anything. Patients were alive; families had their loved ones.

The things they miss the most included, for the women, bubble baths and swimming and wearing dresses. One stated: “sometimes you are gonna cry and sometimes there are gonna be those days when you are gonna question. And don't feel guilty because of that. You have a life to live, so live it”. For the men, they missed the physical activity level they had prior to their illness and implant. One patient had been a marathon runner prior to his heart failure. One entrepreneur had traveled extensively but was now limited due to complications from the implant. A husband of a DT patient recalled the suddenness of the diagnosis: “We went from running on the beach in Virginia Beach to fourteen days later, her getting an LVAD . . . It was a total shock. When the doctor came in and told us, it was like dumping a 100 pounds on you at one time”.

Altered Lifestyle

Perceived lifestyle changes varied with the time from diagnosis of heart failure to the time of implant. In situations where families and patients dealt with prolonged chronic heart failure, lifestyle changes were more positively viewed. “It was a new day . . . congestive heart failure makes you so tired. I couldn’t do the little things. I couldn’t brush my hair or brush my teeth; it hurt too much. The LVAD has brought me so much more energy. I feel even better than I did when I was 28 years old”. Living with the chronicity of heart failure was viewed as much more difficult than living with an LVAD. Patients were more active and grateful for a new opportunity at life. Caregivers articulated that caring for the DT patient was easier than dealing with the physical restrictions brought on by heart failure.

Patients who had a rapid journey to DT LVAD therapy due to sudden onset congestive heart failure verbalized the shock of being healthy one day and in ICU the next. One noted “I was always a very healthy person . . . working out and eating right to keep (my) body right. With this happening to me, it made me angry at first because I was like ‘I don’t drink. I don’t smoke. I’ve never done any drugs. Why did this have to happen?’” The sudden change in lifestyle after implant was more problematic for patients and caregivers. Though they also had a feeling of gratitude and a positive outlook on life, there remained the memories of the normal healthy life for which they grieved.

Caregivers overwhelmingly noted lifestyle changes following the implantation of an LVAD in their family member. They spoke to the daily tasks necessary to assist their loved one. Another said “It was harder then [before the implant]”. One husband states that he was “able to do a few things but after a while she was off and on her own”.

All participants noted changes in financial status with the retirement of the patient and the constraints imposed on the caregiver. Only two of the caregivers continued full-time employment. The remainder of the caregivers were either retired or left their jobs to care for the patient. The repetitive theme flowing throughout the interviews was that they would not change a thing about the decision for DT. For this technology meant life.

Value of Support Network

The value of the support of family and friends was a frequently noted theme in the interviews. These supporters reached out to the participants in myriad ways: (a) raising money; (b) taking patients out to dinner, movies, and shopping thereby giving the patient an outing and giving the caregiver some free time; (c) transportation to and from the hospital when necessary; and (d) psychological support through being a shoulder to lean on or a compassionate ear to which they could vent. In families where there were children, friends volunteered to work with children in sporting activities when the patient could no longer participate. One patient noted: “I didn't realize how many friends I had until this happened. You find out that you have friends that would do things for you that you never would think”.

Caregivers focused on the psychological support provided by friends and family. They provided a support system by being available as a “sounding board”. The impact of DT on children was illustrated: “The kids – it was a little hard on them – you never expect to see your Mom go through anything like that. I think everybody had their moments but all we could do was make sure we had a strong foundation for them to fall back on”. A sense of gratitude for these supporters was common in all conversations with participants.

Altered Perception by Others

Living with an external device attached to their body results in others questioning the

patient and caregiver about the device. One shared the fact that it frightens some people who “come direct to you and (ask) what is that; they want to make sure it’s not a bomb strapped to your body”. Participants took this as an opportunity to educate others about DT. Patients felt that others saw them as more fragile or limited in their ability to be physically active, which is not how the patients feel about themselves.

Caregivers generally gained much more self-confidence in themselves due to their ability to manage the patient’s at-home clinical needs. This enhanced self-confidence was perceived by others and validated through comments to the caregivers. One commented that friends actually began to “look at life in a different light also; they enjoy life more; they take life more seriously because of what I’m going through”.

Altered Self-Image

The physical changes associated with patients wearing an external device impacted the self-image of the female patients more than the males. Females spoke of being self-conscious of the changes in their body secondary to the device. “At times, it makes you feel somewhat inadequate because you have this machine that you are carrying around and you can’t do certain things. . . I can’t swim. I can’t take baths and I love baths. But at the same time, my positive thinking would go to ‘I’m living. I am alive’. Additionally, the presence of the device did not allow them to dress in the same way they could pre-implant, contributing to their self-esteem issue. Women missed many of the “small things” in life, such as taking baths, swimming, and wearing a bikini.

Male patients seemed to take the physical appearance changes in stride with no verbalization of any self-esteem issues. They were more concerned about diminished physical ability. Though they could still participate in many physical activities, such a driving, cutting

grass, and working on the house, they mentioned the things they could no longer do such as play ball or run in marathons.

Two caregivers reported enhanced self-confidence. Prior to the DT implantation, these caregivers did not participate in highly skilled tasks as those they had to take on to care for their loved ones. One stated: "I'm more confident. I can do it now. I used to be very dependent. Now, whatever it is, I can do it". One caregiver remarked about the amount of energy she expends daily now to care for her husband as well as her five children.

CONCLUSIONS

Prior studies have reported some of the findings of this study.⁵⁻⁶ However, these studies targeted either the patient or the caregiver, not both in the same setting.⁶⁻⁸ Thus, this study offers insight into the dynamics of both the patient and caregiver. An enhanced outlook replicates findings describing the phenomenon of the lived experience of bridge to transplant patients (BTT). However, the future for BTT patients differ from that of DT patients: for DT patients, it is life forever with a device. The themes of spirituality and gratitude for a second chance at life was previously reported in other studies of families of DT patients.⁶⁻⁸

Views of altered lifestyle varied based on the pre-implant circumstances. Living with the chronicity of heart failure was viewed by participants in this study and previous ones as much more difficult than living with an LVAD.⁹⁻¹⁰ Participants in this study who experienced a rapid diagnosis to implant time had greater difficulty adjusting to the alterations in their lifestyle. In the end, they seemed to adapt as well as others; the process was just more complex and prolonged. This built on previous findings regarding the ability of the caregivers to adapt to the demands of caring for the DT patient.⁵ The study refuted the sense of social isolation and the limited freedom found in previous studies.^{8,11}

A strong social support system was identified in previous research as a necessary component for elderly BTT patients.¹² This was identified as a driving force for adaptation and survival for caregivers.¹³ This study also illustrates how the support network impacts the patient, caregiver, and extended family. All participants lauded the value of a strong support network.

Participants in this study did not express as much concern about their public appearance and the ability to return to normalcy in life as had been identified in previous studies.¹⁴ Rather, they shared times when they used the curiosity of others to serve as an opportunity to educate them on the device. Alteration of self-image did reflect previous findings of improved confidence of both the patient and family in their ability to gain competence in the technical skills required of them.^{7,15}

A comprehensive understanding of the impact of DT on patients as well as families signals a need for healthcare leaders to develop multi-faceted teams to deal with the myriad issues encountered. The LVAD Coordinator alone cannot adequately assess nor address all of the potential problems faced by this population. A well-developed team of healthcare professionals should include a variety of clinical specialists such as renal, gastrointestinal, endocrine, diabetes, and others as indicated by the patient's medical history. Additionally, insurance specialists, financial counselors, and home health professionals can help guide participants through the challenges faced in these areas. Psychiatrists or psychologists are another specialty necessary for both patients and family members to have available as needed during the process.

Recommendations for Use of the Findings

Each patient and caregiver travels a different road to DT; thus, there can be no standardized educational training and support system that fits each situation. The key is to realize the uniqueness of each individual's experience and have resources available to guide them

through a successful journey to living with DT. Those who have a long history of heart failure prior to implant indicated different needs from those who have a sudden onset of heart failure and a short pathway to implant. Although larger studies are needed to confirm these findings, nurse or coordinators of care can use these findings to evaluate the patient and the caregiver for the presence of factors or barriers that may interfere with the successful adaptation to their condition.

Rather than a checklist with established times for education and training, providers should be sensitive to the specific needs of a patient and of their family. Whereas certain skills must be taught prior to discharge of the patient from the hospital, follow-up visits should include a reiteration of the requisite skill set as well as the psychological and emotional state of the patient and the family. Since each individual circumstance differs, the patient and family adaptation to the implantation differs. The commitment to the patient and family does not end with discharge or at a certain point in time. Subsequently, guidelines developed for any part of the process must be very flexible to fit the needs of each patient and family member.

In addition to professional healthcare provider support, LVAD support groups offer many ways to assist new implant families and patients in navigating this journey. Effectively using the voice of those who have been there to reassure and assist those who are at the beginning of the journey can lead to less stress, heightened awareness of what the road looks like, and an assurance that this process is navigable.

A small sample size as well as the use of convenience sampling are limitations of this study. By recruiting patients from LVAD support websites, the population may be somewhat skewed as a more positive sample than the general DT population. Future research by implanting institutions could provide more in-depth data by developing the protocol to follow patients for a

five-year period of time, utilizing the approach of this study. The verbal responses could then be compared to the observed behavioral and clinical indicators for both the patient and the caregiver.

The needs of the patient and family vary based on the pathway traveled; thus, the education and support mechanisms must be guided by the needs of the participants, not a pre-determined timeline. Additionally, the psychological readiness of patients and families depends on the inherent nature of the individual as well as their prior dealings with chronicity of disease. The journey is unique but the outcome is consistent: DT is a lifesaving technology, giving patients and family members gratitude for today and hope for the future.

References

1. Holman W: Interagency registry for mechanically assisted circulatory support (INTERMACS): What have we learned and what will we learn? *Circulation*, 2012; 126(11), 1401-1406.
2. Gregory S. Narrative approaches to healthcare research. *International Journal of Therapy & Rehabilitation* 2010; 17(12): 630-636.
3. Chase S. Narrative Inquiry: Multiple lenses, approaches, voices. In N. K. Denzin, & Y. S. Lincoln (Eds.), *The Sage Handbook of Qualitative Research* 3 ed. 2005; 651-680.
4. Groleau D, Young A, Kirmayer L. The McGill Illness Narrative Interview (MINI): An interview schedule to elicit meanings and modes of reasoning related to illness experience. *Transcultural Psychiatry* 2006 December, 43(4), 671-91.
5. Casida J. The lived experience of spouses of patients with a left ventricular assist device before heart transplantation. *American Journal of Critical Care*, 2005; 14(2), 145-151.
6. Kitko LA, Hupcey JE, Gilchrist, JH, Boehmer, J P. Caring for a spouse with end-stage heart failure through implantation of a left ventricular assist device as destination therapy. *Heart & Lung*, 2013; 42(3), 195-201.
7. Marcuccilli L, Casida J, & Peters R. Modification of self-concept in patients with left ventricular assist device: An initial exploration. *Journal of Clinical Nursing*, 2013; 22(17/18), 2456-2464.
8. Akbarin M, Aarts C. Being a close relative of a patient with a left ventricular assist device. *European Journal of Cardiovascular Nursing*, 2013; 12(1), 64-68.

9. Hopp F, Thornton N, Martin L. (2010). The lived experience of heart failure at the end of life: A systematic literature review. *Health & Social Work*, 2010; 35(2), 109-117.
10. Sykes C, Simpson S. Managing the psychosocial aspects of heart failure: A case study. *British Journal of Nursing*, 2011; 20(5), 272-279.
11. Vitale C A, Chandekar R, Rodgers PE, Pagani FD, Malani P N. A call for guidance in the use of left ventricular assist devices in older adults. *Journal of the American Geriatrics Society*, 2012, January 1; 60(1), 145-150.
12. Marcus P. Left ventricular assist devices: Psychosocial challenges in the elderly. *Annals of Thoracic Surgery*, 2009; 88(5), e48-49.
13. Williams J, Woods S, Bridges E, Motzer S, Ledoux D. Adaptation in adults living at home with Left Ventricular Assist Devices (LVADs), 2007; 16(3), 303.
14. Marcuccilli L, Casida JM. From insiders' perspectives: Adjusting to caregiving for patients with left ventricular assist devices. *Progress in Transplantation*, 2011, June 1; 21(2), 137-143.
15. Chapman E, Parameshwar J, Jenkins D, Large S, Tsui S. Psychosocial issues for patients with ventricular assist devices: A qualitative pilot. *American Journal of Critical Care*, 2007; 16(1), 72-81.