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Caring for a spouse with end-stage heart failure through implantation of a left ventricular assist device as destination therapy

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ABSTRACT

Objectives: This qualitative study describes the experiences of spousal caregivers of a patient with end-stage heart failure (HF) from pre-LVAD to post-LVAD-DT implantation.
Background: LVAD-DTs are implanted as permanent devices for end-stage HF patients with the goal of improving the length and quality of life. LVADs create new demands for both patients and caregivers.
Methods: In-depth, semi-structured interviews of 10 spousal caregivers were thematically analyzed.
Results: Throughout the process of caregiving, pre-implant through post-implant, all caregivers discussed their ability to adapt within the role as a caregiver. Adaptation as a caregiver occurred through three distinct time frames following the progression of the patient's HF and subsequent LVAD implantation: caring for a spouse with HF, decision for LVAD implantation made, and caring for a spouse with the LVAD-DT.
Conclusions: Caregivers were able to adapt and develop effective strategies to incorporate the demands of caring for a spouse with an LVAD-DT, but the role remained challenging. The findings underscore the need for continued research that may be translated into effective interventions to support patient and caregivers as they live through this end-of-life trajectory.

Introduction

Heart failure (HF) is a chronic and progressive disorder impacting approximately 5.8 million Americans.[1] Despite advances in technology, as well as risk prevention, the prevalence of HF continues to increase with over 550,000 new cases diagnosed each year.[1] There are approximately 50,000–150,000 patients with stage D HF[2] who remain symptomatic despite maximal medical management. Patients with end-stage HF have a mortality rate approaching 80% at five years[2] and once they become dependent on inotropic support the one year mortality rate approaches 50%.[3] The standard of care for the management of HF refractory to medical treatment continues to be cardiac transplantation,[4] but with a small number of available donor organs, this option is not attainable for many who do not meet the stringent eligibility criteria.

A left ventricular assist device (LVAD) is a type of mechanical circulatory support that is implanted to restore the physiologic function of the damaged left ventricle in patients with stage D HF. Currently, there are two approved long-term indications: LVAD as a bridge to transplant (BTT) and LVAD as destination therapy (DT). LVAD-DT is a permanent alternative for stage D HF patients who are not transplant candidates. Once implanted, the majority of these patients will live with and die with this device in place. The main goals of destination therapy are to improve the daily function and health-related quality of life, and to improve survival compared to patients who receive optimal medical management.[5] Studies have shown a 68% survival rate with an LVAD at 1 year and a 58% increase in survival at 2 years compared to those who are managed medically.[6] Based on the current evidence, quality of life also improves post-implant.[7–9] Since FDA approval, there has been an exponential increase in the use of LVAD-DT with a ten-fold increase from 2006–2010.[6] The implantation of LVADs will continue to increase with improvements in technology, scarcity of donor hearts, and the aging population.

Background

LVAD implantation creates new demands for both the patient and caregiver. Based on the complex care required at home, it is the

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standard of practice in most mechanical circulatory support programs to designate a member of the patient's family as the caregiver. This requires an extensive commitment from the dedicated caregiver(s). The caregiver is typically a spouse, immediate family member, or friend who provides around the clock help and support. The responsibilities involved in caregiving vary from simple tasks such as monitoring of vital signs, daily weights, and sterile dressing changes to more complex procedures such as monitoring the LVAD function, troubleshooting alarms, and responding to emergency situations.[10] These tasks are complex for a layperson and can be very stressful for caregivers, potentially affecting their health and quality of life.[11,12] Compounding the complexity of this caregiving role is the permanency of this caregiving situation. When an LVAD is implanted as a BTT, it is a bridge until a heart for transplantation becomes available.[13] Conversely, when an LVAD is implanted as destination therapy, the patient will live with this device until death, increasing the demands placed on the caregiver as the patient lives and dies with this complex device. To date, few researchers have examined the experience of caregivers of patients requiring LVAD support, and even fewer studies have examined caregivers when LVADs are implanted as destination therapy. The primary goal of this study was to explore the caregiving experience, as the patient transitioned from stage D HF to the implantation of an LVAD-DT.

A phenomenological study by Casida[10] examined the lived experience of spouses and patients with LVADs. The sample was small ($n = 3$), but three major themes emerged: emotional distress, determination, and optimism. Marcucculli and Casida[14] described the lifestyle adjustments of caregivers for patients with an LVAD as a BTT or DT. The main themes were caregiving as a constant responsibility, coping strategies, and satisfaction. Caregivers described how the adjustments to their new roles became easier over time with the use of effective coping strategies. Baker et al[15] described the experiences of caregivers of patients who received an LVAD as a BTT. The main themes in this phenomenological study were sacrifice and moving beyond. Caregivers reported that sacrifices were necessary in terms of family, friends, employment, and their own health as they adjusted to this new role. Although, these studies show effective adaptation over time, the majority of the participants were providing care for patients with an LVAD as a BTT. These caregivers may have had different experiences because they were waiting for a transplant and may not have viewed their caregiving roles as permanent and continuing through death. Although the experience of caring for patients with LVAD-DT may share some of the same characteristics as BTT, there may also be experiences specific to the caregivers of an LVAD-DT that have not be explored. Specifically, patients living with the device long term with no expectation of a transplant and the reality that the patient will die with the device. As the number of LVADs implanted as DT continue to increase, understanding the caregiving experience from the perspective of the spousal caregiver is crucial for healthcare providers who are developing and evaluating care for both patients and their caregivers.

Purpose

The purpose of this qualitative study was to describe the experiences of spousal caregivers of patients with stage D HF from pre-LVAD to post-LVAD-DT implantation. Understanding the experiences of spousal caregivers will provide avenues for the development of caregiver-centered interventions to support these instrumental partners in care. The goal of interventions is to improve the experiences and outcomes for both the patient and the caregiver.

Methods

Design

Data collection and analysis were conducted using a qualitative approach to elucidate spousal experiences of providing care for patients with stage D HF from pre-LVAD to post-LVAD-DT implantation. Qualitative methodology is appropriate for the exploration of this phenomenon as the variables influencing this experience have not been clearly described in the existing literature.[16]

Sampling and recruitment

Following IRB approval, spousal caregivers of patients with an LVAD-DT were recruited from one large LVAD service in a tertiary medical center. The center was a referral center with an LVAD coordinator on call 24/7 who could answer questions and troubleshoot device issues for patients and their caregivers. This purposive sample was limited to spousal caregivers, because they are caregiving on a daily basis and would be able to provide rich descriptions of the experience. The inclusion criteria for participants included: the ability to speak and understand English; being the spouse/partner residing with the patient and the primary care provider for the spouse/partner following device placement; and without gross evidence of cognitive impairment that may preclude insightful reflection. Spousal caregivers who accompanied LVAD patients to the LVAD clinic over a 6-month period were asked to participate. Sampling continued until thematic saturation was achieved.

Data collection

At a follow-up LVAD clinic appointment, spousal caregivers were asked to participate in the study. If they agreed, informed written consent was obtained. During this visit, sociodemographic data were collected. Due to the length of the clinic visit, the distance most patients lived from the clinic, and limited access to private interview space, face-to-face interviews were not completed at the clinic visit. Following the visit, participants were contacted to set up a mutually convenient time for a phone interview.

A semi-structured interview guide with probes (Table 1) was designed to capture the experience of the spousal caregiver. The interview guide was developed by two qualitative researchers who are experts in qualitative methods and have conducted multiple research studies with HF patients and caregivers. Participants were asked to describe their experiences of caring for a spouse with HF prior to and post-implantation of the LVAD-DT. One interviewer (LK) conducted the in-depth, semi-structured, 45–90 min interviews. Field notes were maintained during the interview to capture data that were not obtained from the transcribed interviews, such as emotional reactions. Interviews were digitally recorded, transcribed verbatim, de-identified, and entered into HyperRESEARCH[17] for coding.

Data analysis

A team approach was utilized for analysis. The initial codebook was based on the topics in the interview guide and was developed by three primary coders who met to discuss the coding of data and reach consensus on code labels. An inductive methodology was used for the analysis of the transcribed data. Through the analysis process, raw data were converted into themes. The purpose of the analysis was to reduce large amounts of data into meaningful themes for both the pre-implantation caregiving and post-implantation caregiving, and then to relate the themes to each