Published in final edited form as:

J Cardiovasc Nurs. 2016 ; 31(3): 215–225. doi:10.1097/JCN.0000000000000242.

The Perceptions of Important Elements of Caregiving for an LVAD Patient: A qualitative meta-synthesis

Molly Magid¹, Jacqueline Jones, PhD, RN², Larry A. Allen, MD MS³, Colleen K. McIlvannan, DNP, ANP³, Katie Magid⁴, Jocelyn A. Sterling, MA⁵, and Dan D. Matlock, MD, MPH⁶

¹High School Student at Colorado Academy, Denver, CO

²University of Colorado School of Nursing, Aurora, CO

³Division of Cardiology, University of Colorado School of Medicine, Aurora, CO

⁴Brown University, Providence, RI

⁵Colorado Health Outcomes, University of Colorado School of Medicine, Aurora, CO

⁶Division of General Internal Medicine, University of Colorado School of Medicine, Aurora, CO

Abstract

Background—The use of a left ventricular assist device (LVAD) is becoming increasingly common in patients with end-stage heart failure. Many LVAD programs require patients to have a caregiver prior to receiving a device. There are few studies exploring the experience, burden, and impacts on caregivers of patients with LVADs.

Objectives—The aim of this study was to synthesize the qualitative literature regarding what caregiver’s perceptions about caring for an adult LVAD patient.

Methods—We searched Medline, CINAHL, PsychInfo and Web of Science to find English articles on the topic of LVAD caregiver’s perceptions. The articles were then synthesized using a formal process of qualitative meta-synthesis.

Results—Eight articles met criteria for inclusion. The meta-synthesis across the articles resulted in eight themes categorized under three domains. Many of the articles suggested a longitudinal process of caregiving with perceptions largely dependent upon the time of interview in relation to the LVAD. The first domain of caregiving is the “early” stage covering life before the LVAD through the procedure. This phase is characterized by the pre-LVAD “*emotional rollercoaster*,” the decision seen as “*no option*,” and the thought of “*leave it [the LVAD] at the hospital*.” The second domain is the “middle” stage covering the timeframe following discharge from the hospital. This phase is characterized by fragility of the patient, recognition of a need to adapt, and a transformed life. The final domain is “late LVAD” and describes how late in the LVAD process, the LVAD indication (bridge to transplant or destination therapy) brings in to focus what is important to caregivers.

Conclusions—Existing literature indicates that the LVAD caregiver experience is intense, burdensome, and the need to adapt to a new life. Given the burdens caregivers experience, clinicians and future research should explore strategies to support these important individuals.

Introduction

Heart failure affects 5.8 million Americans and is the primary cause of approximately 300,000 deaths annually nationwide.^{1, 2} Certain patients with end-stage heart failure are now presented with viable interventions that can partially or completely reverse their disease process. One such option, left ventricular assist device (LVAD), has been shown to prolong life and improve quality of life.³ LVADs were originally created for bridge to transplant (BTT) use in patients awaiting heart transplant. Now LVADs are also used as “destination therapy” (DT) for long-term support in patients who are ineligible for heart transplant. Use of DT is growing, with an estimated 150,000–250,000 patients annually who are potentially eligible for the device.⁴ Use of LVADs will continue to grow in the U.S. due to the aging population, an inadequate supply of donor hearts, and the increasing frequency of risk factors for heart failure.⁵

Most hospital-based programs that implant LVADs require patients to identify a designated caregiver. LVAD programs rely on informal, unpaid caregivers to take care of the patient after they have been discharged from the hospital. These informal caregivers are usually spouses, family members, or close friends. Significant variability regarding the requirements of caregivers across hospital programs exists. Caregivers help with the everyday management of the device and patient including performing driveline site dressing changes, monitoring the driveline site for infection, changing the batteries, ongoing equipment maintenance, responding to alarms, managing medication intake, taking patient vital signs, arranging patient follow-up, providing transportation to appointments, and providing care during post-operative recovery time.^{6, 7} In addition, caregivers psychologically support the patient. The primary caregiver generally must commit to daily caregiving for up to 3 months and attend training to learn how to manage care of the LVAD. The degree and length of caregiver involvement is highly variable, depending on the hospital program and the patient and his/her clinical course.^{7, 8} For most, caregiving extends beyond the post-operative period and continues for the life of the patient. For patients who have an uncomplicated recovery, caregiving can be minimal. For patients with complications or ongoing non-cardiac medical issues, caregiving can be intense.

Current quantitative literature on LVAD caregiving suggests that the job can be burdensome.^{9, 10} One study of 27 spouses of patients with BTT LVADs reported that 26% met clinical criteria for post-traumatic stress disorder including avoidance and hyper-arousal.⁹ Multiple qualitative studies have also been conducted to better understand LVAD caregiver experience. However, these studies are limited because they are all from single centers, have very small patient populations, primarily focus on patients receiving BTT LVADs, and include all generations of LVADS. Given the limitations of literature on this topic, a formal meta-synthesis provides a strategy to gain a broader and deeper understanding of an LVAD caregiver’s experience. The goal of our meta-synthesis was to synthesize existing data into a larger picture of caregiving for adult patients with LVADs.

Specifically, this meta-synthesis aims to answer the question: What are caregiver's perceptions in caring for an adult LVAD patient?

Methods

Overview

This project followed a formal process for a qualitative metasynthesis,^{13, 14} including a comprehensive search strategy to identify all relevant articles related to the research question, a quality appraisal of included articles, and a formal meta-synthesis of the findings. We chose to perform a meta-synthesis to explore the topic of caregiving across a variety of contexts from multiple articles, combine each member's interpretations, and create an understanding of features of importance in the caregiver experience beyond the original studies. As a rigorous systematic interpretive study, this method does not incorporate quantitative literature in a way that a meta-analysis or a systematic review might.

Search Strategy

We searched PubMed (MEDLINE), the Current Index to Nursing and Allied Health Literature (CINAHL), PsycInfo and Web of Science from 2000 through 2014 filtering for English-language and human subjects. We used the following search algorithm: (heart-assist devices OR left ventricular assist device OR lvad OR mechanical circulatory support) AND (caregiving OR caregivers OR family OR spouses OR relatives OR informal caregiver OR family caregiver). MeSH terms were used, along with other related words and phrases in order to be as broad and inclusive as possible with our search. Abstracts and titles were scanned to determine relevance. We included only qualitative articles related to caregiver's perceptions regarding caregiving of adult patients (> 18 years of age). (Figure 1)

Quality Appraisal

Each article meeting the inclusion criteria was subjected to independent quality appraisal by a multidisciplinary team composed of a research assistant (MM), registered nurse (JJ), and geriatrician (DM). Using this quality appraisal tool and its supporting guidelines, we evaluated each of the articles for them presence or absence of the 17 quality domains,¹¹ consistent with these guidelines and our prior work¹². This appraisal is not intended to exclude articles; rather it is designed to provide the analysts with a deeper understanding of each article. Consequently, each domain is only evaluated presence or absence. Additionally, the results were presented to a broader study team, which included a heart failure doctor of nursing practice (CM) and a heart failure cardiologist (LA). Using a 17 item formal qualitative appraisal instrument,¹¹ we evaluated articles. In a meta-synthesis, quality appraisal is an important first step in helping the study team determine the relevance and value of each study. (Table 2)

Meta-synthesis

We followed a meta-synthesis approach based on that of Noblit and Hare,¹³ which states that qualitative studies including similar findings can be amassed in order to draw larger and different interpretative meaning. We read the articles and extracted the following information: study aim, LVAD type, country of origin, study design, methods, time from

implantation, participants, and main findings. Three members of the study team (MM, JJ, and DM) reviewed all articles and determined a list of relevant themes that emerged from the body of literature. Upon identifying the themes individually, these three members met and discussed the findings as a group. After group discussion, the team members re-immersed in the articles to determine if the picture that emerged in the team process still resonated with the original data. This interactive process occurred over the course of several months in order to map an evidentiary matrix between newly defined themes and the original studies. The process of interpretive integration, adapted from Noblit & Hare is known as reciprocal translation.¹³ Finally, the team met for an extended meeting to construct the reciprocal translation table summarizing the themes that emerged across the included studies.

Results

Overview

The initial search produced 253 articles. On initial review of abstracts, 233 articles were excluded. On detailed review of the articles, studies were excluded based on the following: not full articles but only abstracts (n=5), about caregiving for children with LVADs (n=2), quantitative (n=4), and not centered on caregiver experience (n=1) (Figure 1). There were no additional studies identified from the references of the articles. Eight articles remained and were included for synthesis based on the inclusion criteria (Table 1).^{16,17,18,19, 20, 21, 22, 23}

The meta-synthesis across articles resulted in eight themes categorized under three domains. We noted that many of the articles suggested a longitudinal process of caregiving and that caregiver's perceptions were largely dependent on which stage in the caregiving course they were in. The first domain of caregiving is the "early" stage covering the timeframe from life before the LVAD, the LVAD decision, and the hospital course. The second domain is the "middle" stage, covering the timeframe from discharge home and going forward. The final stage is "late LVAD" and covers time near the end of the caregiver trajectory. It describes how the LVAD indication (bridge to transplant or destination therapy) brings in to focus what is important to caregivers and how they think about the patient's future. (Table 3)

Early Stage—This domain covers the timeframe from life before the LVAD, the LVAD decision, and the hospital course. The early stage is characterized by three specific themes: First, before the LVAD was implanted caregivers felt a wide range of emotion described as an "*emotional rollercoaster*." Second, caregivers were confronted with the LVAD decision and many felt that they had "*no option*." Third, after the LVAD surgery, caregivers felt that hospital was a safe place and they did not want the patient to be discharged.

Pre-LVAD: "*emotional rollercoaster*": For many, caregiving for their relative with heart failure had been going on for years before LVAD implantation.²¹ Caregivers experienced a myriad of emotions when they realized that their loved one was sick enough to warrant an LVAD. Caregivers often felt fear, anxiety, shock, disbelief, and ultimately felt as if they were riding on an "*emotional rollercoaster*." One caregiver explained:

"[loved one] was doing well, then...just the ups and downs. He would fill up with fluid and then the next option would be a pacemaker. He would do well and then the

fluid. Next it was the ICD. We were getting back to normal and he would fill up with fluid...; what a roller coaster. I just kept thinking, ‘what are they going to do next and what if nothing else could be done?’ (#7, p198)

Prior to the LVAD, caregivers also worried about losing their loved one during surgery or to a post-operative complication. Most caregivers felt that it was very important for loved one to survive but the uncertainty was sometimes difficult to bear:

“life just sort of stops and it’s difficult to focus on things, especially when you know that he’s lying here...” (#1, p166)

Decision: “no option”: Some caregivers felt that they played a key role in assisting their loved one in making the decision to implant an LVAD. Occasionally, the caregiver even had to decide on behalf of the patient. In either case, caregivers felt a great responsibility to choose the right option for their loved one. That said, most caregivers note that they did not feel as if they actually had a choice or that the choice was a Hobson’s choice: a choice where one has a choice of the one option offered, but no real alternative.

“LVAD or hospice – what would you pick?” (#7, p198)

One caregiver described the process through a metaphor relating to baseball:

“When a fast ball is thrown at you, you have to take it and do the best you can with it, you know, you either swing the bat or you keep the bat on your shoulder.” (#6, p145)

Hospital Course: “leave it [the LVAD] at the hospital” (#4, p148): After the implantation of the LVAD, hospitals provide caregivers with training and materials in order to prepare them for the caregiver role. After this process, caregivers felt more prepared to complete all the necessary tasks and felt confident in their abilities to care for their loved one. However, many were reluctant to take the patient home.

“I would rather leave it at the hospital for the duration of the LVAD because that is how much it scared me.” (#4, p148)

Caregivers often feel tensions during this experience: even though caregivers felt prepared for the role, once they were discharged home from the hospital, they became anxious with thoughts that they would not be able to help the patient, especially in an emergency situation.

“I felt prepared to go home when we were in the hospital, but the first time the alarm went off at home, I was in a complete panic.” (#7, p198)

Middle Stage—This domain covers the time period following discharge from the hospital and is defined by three themes. First, shortly after discharge from the hospital, caregivers felt that patients were fragile and this caused anxiety, fear, and hyper-vigilance. Second, caregivers recognized a need to adapt and developed strategies for adaptation. Third, caregivers felt their life had been transformed by the LVAD experience in numerous ways.

Fragility of the patient and the associated anxiety, fear, and hyper-vigilance:

A particularly strong theme that emerged from many of the articles was that caregivers felt that their patient was fragile and “*like a baby*.” (Table 4) Consequently, caregivers felt hyper-vigilant, experiencing a need to be around the patient at all times in case anything happened and being fearful to leave the patient alone. A caregiver explained that caring for the patient changed what activities she participated in:

“Neither do we dare take the boat out somewhere – imagine if the boat capsized or if we became stranded. I daren’t risk it.” (#1, p66)

Caregivers often felt they needed to give up certain parts of their previous life: a job, social events, or free time, in order to be with the patient:

“I don’t go any place unless he goes. I don’t do all the things I used to and don’t go all the places I used to.” (#2, p198)

Recognition of a need to adapt: After discharge from the hospital, caregivers realized that they needed to adapt to being a caregiver. Many used certain strategies in order to adjust including faith, downtime, acceptance, and empathy. Ultimately, caregivers found ways to add the caregiver role into their lives.

“You have to make a schedule, sit down and say this is what we’ve got to do and you have to follow through if you love them.” (#2, p198)

Caregivers found that receiving a break from caregiving could help them cope with the experience and more easily adapt. Another caregiver found that her faith helped her cope:

“Well, spiritually, I have a strong relationship with God, so I already know that he’s not going to put more on me than I can handle, and everything happens for a reason, and it’s just positive strength that strengthens us as a family.” (#8, p140)

Having support from other family members helped to lessen caregiver burden and allowed the caregiver more time to cope and adapt.

“what saved me was being with my son and daughter-in-law because they weren’t sick.” (#5, p383)

Conversely, a lack of support can be hard for caregivers:

“I remember I sat out in the court yard and I smoked a lot that night... When I came back they had made a bed for me, but I could have done with a nurse, who sat next to me and talked to me. That’s what I needed.” (#5, 383)

Transformed life: After caregivers adapted to the caregiving role, they recognized that their life had changed. Caregivers conveyed the idea of a transformed life by expressing gratitude and relief, acknowledging a new relationship with the patient, recognizing personal growth, and potentially feeling a twinge of guilt or regret. The caregiver experience includes both positive and negative aspects. Many caregivers were grateful for the device and, in a BTT situation, they were relieved that the patient survived until heart transplantation. One caregiver expressed:

“...by his receiving the pump I understood that life was never going to be the same again but that’s just how it is. I’m glad he’s alive...” (#1, p66)

Caregivers realized that the sacrifice of normalcy was necessary but accepted this fact and chose to focus on the idea that their loved one was alive. Caregivers also felt grateful that they had gone through the experience.

“all the participants expressed their gratitude for their ‘new lease on life.’” (#7, p199)

Reflecting on the caregiver experience, caregivers often recognized that their relationship with the patient had changed. A caregiver reported:

“[we] didn’t have much of a social life. We couldn’t travel and I wasn’t working. [patient] wasn’t working. I mean that was our life.” (#6, p144)

Caregivers are undoubtedly changed by the caregiver experience and many spoke about their personal growth.

“I have no reason to weep or crying or breaking down. If she’s not doing it... I can be just as strong. She has made me strong.” (#8, p141)

Occasionally, caregivers endorsed slight feelings of guilt or regret. One person regretted the lifestyle changes caused by being a caregiver:

“I see my friends coming and going places and I can’t leave. That’s the only thing that bothers me.” (#2, p198)

“Caregivers of patients who did not experience increased quality of life with the device, although thankful that their spouse was still alive, expressed regret over their decision to have the device implanted.” (#7, p199)

According to a study of caregivers for patients specifically with DT LVADs, some caregivers *“expressed regret over the decision to have the device implanted, but none talked about advance care planning.”* (#7, p199 – discussion section)

Late Stage—The “late” stage refers to the end of the LVAD. This is an important distinction as for some caregivers the end of the LVAD meant that the patient would receive a transplant (BTT), while for other caregivers, the end of the LVAD meant the end of the patient’s life. The meta-synthesis identified interesting differences between these two groups. Most of the literature (n=6) included only caregivers of BTT LVAD patients, only two articles including caregivers of DT LVAD patients. One article discussed the caregivers of patients who had died; however, it was limited to describing the events surrounding the death and deactivation.

BTT LVAD: For caregivers of BTT patients, the LVAD is not a permanent therapy. A BTT LVAD is a short-term solution; therefore, it appeared to be easier for caregivers to accept burden because there was an end in sight.

“We were glad to pack [the power base unit] up and bring it to the hospital.” (#6, p145)

“If needed, I would do it all again” (#2, p198)

“the narratives included a great sense of relief at receiving the call for a transplant.”
(#6, p147 – discussion section)

DT LVAD: Two articles described the experience of DT LVAD patient caregivers. One study did not include quotes from caregivers and described only the end-of-life process for DT LVAD patients. The study reported: “most DT patients and their families did not think about death very often when quality of life was acceptable.” (#3, p1339 –) However, when, due to new or worsening comorbidities, quality of life of the patients decreased, “most had been discussing death prior to the team broaching the subject.” (#3, p1339 – not pt. quote) One area in particular where the DT interviews seemed to diverge from the BTT interviews was in the uncertainty about the future.

“hopefully they can just keep replacing the device.” (#7, p199)

“when asked about the future, none of the caregivers talked about end-of-life decisions, planning, or thoughts about deactivation.” (#7, p200 discussion)

Discussion

This meta-synthesis created deeper understanding of what caregivers perceive in caring for people with LVADs. There is a clear trajectory of caregiving experience starting with a stage characterized by fear, emotion, disempowerment, and the feeling that there are no other options. Upon leaving the hospital and going home, there is a clear change in what caregivers perceive: they feel a profound sense of fragility about their loved ones. Caregivers must learn to cope with hyper-vigilance and other emotions. In contrast to anxiety and hyper-vigilance, caregivers also perceived an acute sense of gratitude because their loved one was still alive. Finally, the caregiver experience appears to be highly dependent on the context of the LVAD (DT vs. BTT). Caregivers in a BTT context see an end in sight, hope for the future and feel relief when the transplant occurs. However, caregivers in a DT context have no such relief, and their perspectives are highlighted by uncertainty about the future. The caregiving burden experienced by caregivers of LVAD patients seemed to be as significant as caregiving for people with long-term ventilators.²⁴

In addition to obtaining a greater sense of the caregiver experience, a qualitative meta-synthesis also had the ability to identify the gaps in our understanding about LVAD caregiving. First, none of the studies included perspectives of caregivers of patients who died either peri-operatively or after device implantation. One study did include caregivers whose loved ones had died and “themes related specifically to the death of their loved one that were identified during this session will be reported separately.” (#6, p144) Per personal communication with the author, this follow-up manuscript has not yet been published. Caregivers in a situation in which the patient does not recover are bound to have a different caregiver perspective, especially if the patient died peri-operatively and the caregiver was unable to follow the usual caregiver trajectory. Caregivers may feel a greater sense of guilt and regret because the patient did not survive. This is a significant gap in the literature.

Information about the experience of these particular caregivers is necessary to acknowledge the entire caregiver experience.

Caregiving can be extremely stressful. In other medical illnesses, caregiving has been linked to anxiety, depression, and loneliness; fatigue and sleep disturbance, increases in circulating cortisol, and the resultant decreases in immune function, increases in infections, higher rates of cardiovascular disease, and early mortality.^{15-21, 25} Caregivers tend to place the needs of their loved ones above their own, and poor health among caregivers has been linked to worse outcomes among patients.^{15, 22} In the case of LVADs, caregiving has been associated with increases in depression, anxiety, and post traumatic stress disorder.^{9, 10, 23} The findings of this meta-synthesis suggest that LVAD caregivers are at high risk for nearly all these negative outcomes.

The stress and the associated allostatic load, the continual physiological damage created by the stressful experience of caregiving, almost certainly have adverse effects on at least some of the caregivers. The uncertainty and lack of hope for a transplant for some DT LVAD caregivers may even create a more complicated caregiving situation than has been previously described. While there is a significant focus on the logistics involved with caregiving, there appears to be very little in terms of assessing emotional stability. Current support for LVAD caregivers may exist in the form of support groups, online forums like MyLVAD.com,²⁵ or other approaches, but support, both hospital-based and otherwise, may be minimal. Some hospitals do provide support, but not always, and often caregivers are responsible for finding support themselves. These data suggest that more could be done for these individuals specifically to address what they perceive to be important: caregivers should be given more support both at the time of implantation to help with the disempowerment and fear and after they go home to help with hyper-vigilance and coping strategies. Some strategies for helping caregivers cope before and during the caregiver experience are to set up support groups with other LVAD patient caregivers or recommend that caregivers go through some sort of therapy.

There are several potential limitations in this review. First, the qualitative literature we searched was already published; therefore, we did not have access to preliminary data including field notes or transcripts. In turn, we could not draw our own conclusions from the raw data. Second, a meta-synthesis may be viewed as limited due to the fact that the results are interpretations of others' interpretations. However, there is significant literature that shows that the summary of prior knowledge is new knowledge and that interpretation of interpretations is, in fact, the strength of a meta-synthesis.¹⁴ In our study, the multidisciplinary nature of the analytic team is an additional strength. Third, the study is limited by the available caregiver literature. The majority of the studies included only BTT LVAD caregivers with few focused on DT LVAD caregivers (n=2). Also, some articles were published during the pulsatile era, so not all caregivers had loved ones with continuous-flow devices. This difference in device types might have affected how some caregivers experienced the care of the device and patient. Additionally, caregiving surrounding adverse events and hospitalizations is a particularly challenging time for caregivers and was not specifically addressed by any of the articles. Finally, none of the studies included caregivers of patients who did not survive the LVAD implant. This gap in the literature significantly

limits our findings, as they are not representative of the experience of all caregivers of LVAD patients. This is an important avenue for future research.

Conclusions

This meta-synthesis has created a deeper understanding of the perceptions of caregivers while caring for patients with LVADs. In short, the experience is extremely challenging and taxing albeit rewarding for some. However, a significant gap still remains in our understanding of the caregiver experience. Future research should focus on gaining a better understanding of the caregivers of patients with DT LVADs with a particular focus on caregivers of patients who do not do well. Similar to many caregiver articles, this article highlights the need for ongoing improvement in support systems available for all caregivers in general and caregivers of people with LVADs in particular.

Acknowledgments

Source of Funding

Dr. Matlock was supported by a career development award from the National Institutes on aging (K23AG040696).

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Figure 1.
Search Flow Chart

Table 1
A Summary of the Included Articles in the Caregiver Qualitative Meta-Synthesis

Author, Date, Country	Type of Device	Aim of Study	Study Design	Methods	Time from implantation	Participants (BTT and DT)	Summary of Main Findings
Akbarin, 2012, Sweden	Unknown	To research how close relatives view responsibilities and role in the care of the LVAD patient	Exploratory	Tape-recorded, 4 in-person and 2 by telephone; in-depth, open-ended, individual interviews; lasted 1–3 hours; transcribed verbatim. Theme analysis	2 months–3 years	Six close relatives (spouses and children) of BTT LVAD patients who had lived with LVAD between 2 months–3years.	Caregivers described they experienced anxiety, shock, fear and uncertainty but could still “cope” and accept the caregiver role. At home caregivers felt limited freedom and a need for alone time and support of family and friends.
Baker, 2010, USA	Unknown	To research the experience of LVAD patient caregivers	Descriptive Phenomenological Qualitative	Tape-recorded, in-person individual semi-structured interviews; lasted 45–60 minutes; transcribed verbatim. Theme analysis	26–372 days	Six middle-aged caregivers of BTT LVAD patients waiting for a heart transplant.	Identified two themes. One was sacrifice relating to social relationships with friends and family, health, joy and livelhood, and peace of mind. The other was “moving beyond” that came with coping and acceptance of the caregiver role.
Brush, 2010, USA	Pulsatile	To research the role caregivers have in EOL decisions of LVAD patients	Descriptive Qualitative	Individual verbal survey; notes taken during interview; Content analysis	72–1,726 days	Twenty caregivers of DT LVAD patients who had made an EOL decision	Found that the caregivers were able to discuss end of life decisions with the patient and make an informed decision. Caregivers

Author, Date, Country	Type of Device	Aim of Study	Study Design	Methods	Time from implantation	Participants (BTT and DT)	Summary of Main Findings
Casida, 2005, USA	Pulsatile	To gain insight into the lives of LVAD patient caregiver spouses	Interpretative Phenomenology	Tape-recorded, in-person individual semi-structured interviews; lasted 40 minutes; field notes taken and recording transcribed verbatim. Data analysis	3–26 weeks	Three designated caregiver wives of BTT LVAD patients who had recently had a heart transplant within the last six months	Described 3 themes: (1) emotional distress related to fear and anxiety, (2) determination to continue caring for the patient, and (3) optimism: a new lease on life.
Egerod, 2012, Denmark	Unknown	To investigate the experience of close relatives of LVAD patients	Qualitative Descriptive	Audio-recorded, in person one group interview and one paired interview; lasted 84–90 min; transcribed verbatim. Grounded Theory Analysis & NVivo version 9 software.	1–39 months	Seven close relatives (parent, spouse, or sibling) of LVAD patients who had a heart transplant within the last three years	Found that support and self-preservation were vital for a positive caregiving experience. A support system for the caregiver was developed: medical professionals and relatives support the caregiver while they support the patient.
Kaan, 2010, Canada	Pulsatile	To investigate the experience of caregivers of LVAD outpatients	Phenomenological Framework	Focus groups; semi-structured interviews; grounded theory analysis of transcriptions.	101–519 days	13 caregivers of 9 patients with BTT LVADs who were discharged home	Identified 4 main themes: (1) anxiety and shock, (2) loss (of patient, life, and independence), (3) physical and mental burdens, and (4) finding coping strategies through faith, empathy, and support.

Author, Date, Country	Type of Device	Aim of Study	Study Design	Methods	Time from implantation	Participants (BTT and DT)	Summary of Main Findings
Kitko, 2013, USA	Continuous flow	To describe the experience of a caregiver of a heart failure patient from pre- to post-LVAD implantation	Qualitative Methodology	Tape-recorded; Semi-structured interview with probes; lasted 45–90 min; Field notes and transcribed verbatim. HyperRESEARCH coding.	5–38 months	10 spousal caregivers of patients with DT LVADs who accompanied the patient to the LVAD clinic for at least six months	Found that spouses adapted to the caregiver role in 3 stages: (1) Caring for a spouse with heart failure, (2) Decision made, (4) Caring for a spouse with an LVAD-D
Marcuccilli, 2011, USA	Continuous flow	To explore the lifestyle changes LVAD patient caregivers experience	Hermeneutic Phenomenology	Tape-recorded; Semi-structured and open-ended, in-depth individual interviews; lasted 24–62 min; transcribed verbatim. Qualitative data analysis software.	>3 months	Five 21+ caregivers that had cared for a BTT LVAD patient for at least 3 months	Determined 3 major themes: (1) caregiving is a 24/7 responsibility, (2) it is vital to find coping strategies, and (3) caregivers found satisfaction with their role in helping the patient.

BTT: Bridge to Transplant

DT: Destination Therapy

LVAD: Left Ventricular Assist Device

Table 2

Critical Review of Identified Studies

	Akbarin et al.	Baker et al.	Brush et al.	Casida et al.	Egerod et al.	Kaan et al.	Kitko et al.	Marcuccilli et al
Study purpose: Was the purpose and/or research question stated clearly?	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Literature: Was relevant background literature reviewed?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Study design: Was a theoretical perspective identified?	No	No	No	No	No	Yes	No	No
Sampling: Were the sampling methods appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was sampling done until redundancy in data was reached?	No	Yes	No	No	No	No	Yes	No
Data collection: Was procedural rigor used?	No	No	No	No	Yes	No	Yes	No
Descriptive clarity: Clear and complete description of participants	No	Yes	No	Yes	No	Yes	Yes	Yes
Role of researcher and relationship with participants	No	No	No	Yes	No	No	No	Yes
Analytical rigor: Were data analyses inductive?	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Were findings consistent with and reflective of data?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Auditability: Was a decision trail developed?	No	Yes	No	Yes	Yes	No	Yes	Yes
Was the process of analyzing the data described adequately?	No	Yes	No	Yes	Yes	No	Yes	Yes
Theoretical connections: Did a meaningful picture of the phenomenon under study emerge?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Overall rigor Credibility: Do the descriptions and interpretations of the participants appear to capture the phenomenon?	No	Yes	No	Yes	Yes	Yes	Yes	Yes
Transferability: Can the findings be transferred to other situations?	Yes	Yes	Yes	No	Yes	No	Yes	Yes
Dependability: Was there consistency between the data and findings	No	Yes	No	No	Yes	No	Yes	Yes
Confirmability: Were strategies employed to minimize bias?	No	Yes	No	Yes	Yes	No	Yes	Yes
Conclusions: Were conclusions appropriate given the study findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table 3

Reciprocal Translation Table

Derived Analytic Themes and Sub-Themes	In paper # (as listed with table 1)	Primary Study Themes
Early: This domain covers the timeframe from life before the LVAD, the LVAD Decision, and the Hospital Course		
<ul style="list-style-type: none"> Pre-LVAD: “Emotional Rollercoaster” 	#1, #4, #7	Being on an Emotional Rollercoaster ride, shock, anxiety and uncertainty (#1); Emotional distress, fear and anxiety, an overwhelming experience and a burden (#4); caring for a spouse with HF (#7)
<ul style="list-style-type: none"> Decision: “No option” 	#7	Decision for LVAD implantation made (#7)
<ul style="list-style-type: none"> Hospital Course: “leave it at the hospital” 	#1, #4	The staff as a resource (#1)
Middle: This domain covers the timeframe from discharge to going home.		
<ul style="list-style-type: none"> Fragility of the patient and the associated anxiety, fear, and hyper-vigilance 	#4, #6, #7, #8	Fear and anxiety, an overwhelming experience and a burden (#4); fear and anxiety, potential loss of their loved one (#6); overwhelmed fear (#7); overwhelming experience, hypervigilant (#8)
<ul style="list-style-type: none"> Recognition of a need to adapt <ul style="list-style-type: none"> Coping, need for support, new knowledge 	#1; #2; #4, #5, #6, #8	Coping with the new situation; the need for respite care (#1); Moving beyond (#2); Determination, coping (#4); Self-preservation in close relatives, close relatives made sacrifices, close relatives eventually needed to help themselves(#5); coping, faith, emotional support, cognitive support(#6); supportive role, coping strategies (positive thinking, good family support, developing a routine, acceptance, prayer, faith and hope, religiosity and fatalism) (#8)
<ul style="list-style-type: none"> Transformed life <ul style="list-style-type: none"> Expressed by gratitude and relief Acknowledgement of a new relationship Personal growth Twinge of guilt/regret 	#1; #2; #4, #5, #6, #7, #8	Gratitude and willpower (#1); Commitment; sacrifice (#2); Optimism: a new lease on life, realization of a loving relationship, adaptation to a “new life”, a joyful feeling (#4); Close relatives made sacrifices, supporting the patient was a means of self-preservation.(#5); loss of usual family roles, loss of independence, burden (#6); regret (#7); less personal time (#8)
Late Stages: The end of the LVAD appears to have significant contextual differences depending on why their loved one has the device (BTT vs DT) brings into focus what’s important to the caregivers.		
<ul style="list-style-type: none"> BTT: The device is on the way to a transplant. They can cope because there is an end in sight 	#2; #4; #6; #8	Moving beyond through hope (#2); Joyful Feeling (#4); Burden: “relief” (#6); Faith and Hope (#8)
<ul style="list-style-type: none"> DT: “Hopefully they can just keep getting the LVAD replaced” <ul style="list-style-type: none"> Uncertainty 	#3, #7	End of life decision making process (#3); declining functional ability (#3); uncertainty (#7)

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Table 4

Caregivers Expressions of the Neonate-like fragility of Caring for a Person with an LVAD.

<i>"They depend on you. It's like a baby needs you. If you're not willing to help them, they are not going to get up get up and walk...." (#2, p198)</i>
<i>"...she asked me to hold it [LVAD] because she needed to go to the bathroom, and I felt that I held her life in my hands, and I couldn't do it." (#5, p382)</i>
<i>[After purchasing a baby monitor] "It was like having a kid." (#6, p144)</i>
<i>"I felt like a new mom again caring for a newborn, I just hovered; I slept when he did and I was awake when he was." (#7, p198)</i>
<i>"and it just felt like when you bring your baby home from the hospital for the first time." (#8, p141)</i>

LVAD: Left Ventricular Assist Device