

Abstract

Background: Left Ventricular Assist Device (LVAD) patients have shown improvements in measures of quality of life and functional status compared to those who are medically managed. Qualitative research has not yet been meaningfully integrated.

Aim: To synthesize and convey information to inform components of LVAD education programs that support the coping and adaptation of patients living with an LVAD and to identify opportunities for future interventions.

Methods: Qualitative meta-synthesis using Lazarus and Folkman's Transactional Model of stress and coping

Results: Four distinct stages of adaptation were identified: Pre-LVAD, Implant Hospitalization, Early Home Adaptation and Late Home Adaptation. Each stage includes tasks related to physical, psychological and social domains. Further, two themes emerged: 1) Primary Appraisal: Every stage is a new challenge and 2) Secondary Appraisal: Routines are achievable, emotions are more difficult.

Conclusions: The emotional challenges LVAD patients face including fear and anxiety related to living with a life limiting illness and changed social roles need to be honestly addressed.

Individuals living with LVAD can achieve a sense of independence and enjoy social interactions and activities that are important to them through addressing practical and emotional problems to facilitate effective coping.

Keywords: Adaptation, Coping, Left Ventricular Assist Device, LVAD, heart failure

Coping and adaptation in LVAD patients: a meta-synthesis

Left Ventricular Assist Devices (LVADs) are pumps that assist the failing heart and are powered through a driveline that attaches externally to batteries or non-portable sources of power. They are used as a bridge to heart transplantation and increasingly, as destination therapy, meaning that the patient will use this therapy until death.¹ Seventy-eight percent of LVAD recipients live for at least one year and nearly 50% survive four or more years with the LVAD, extending life much longer than medical management alone.^{1,2} In addition to surviving longer, patients experience functional and quality of life (QOL) gains during the first year of therapy and these gains remain stable for the duration of therapy.³ However, in comparison to age-adjusted norms and heart transplant patients, LVAD patients have been found to have worse QOL and functional status.^{4,5}

Qualitative research has suggested unique aspects of life with an LVAD that may be stressful, including alteration in body image, managing the batteries and device, limitations of bathing and swimming, driving restrictions, and effects on intimacy.⁶⁻⁸ Emotional distress, adjustment disorders, and disability have been identified after device implant.^{9,10}

The complexity of care and changes in lifestyle for LVAD patients likely contributes to a unique adaptive process.¹¹ While functional status and patient reported outcomes, including quality of life, have been reviewed in the literature, no single study has provided a holistic account regarding the ways in which patients experience and adapt to living with an LVAD. The purpose of this review is to synthesize and convey information to inform components of LVAD education programs that support the coping and adaptation of patients living with an LVAD and identify opportunities for future interventions.

For the purposes of this synthesis, we used the Lazarus and Folkman Transactional Model of Stress and Coping to inform our analysis. This model asserts that coping processes mediate the relationships between stress and outcomes.¹²⁻¹⁴ Key components of this model

include primary and secondary appraisals which inform emotion and problem-focused coping strategies.

Search Methods

A meta-synthesis was conducted to enhance our understanding of individuals' experiences and processes involved in living with a LVAD for the purpose of designing and delivering services to support patient coping with LVADs. An electronic database search of Pubmed, Cinahl, Medline and PsycINFO was undertaken in May 2015. Ex. ((heart-assist device (MESH term) OR LVAD OR mechanical circulatory support) AND (qualitative OR adjustment OR adaptation OR coping)). The titles and abstracts of articles were independently reviewed by 2 researchers, both cardiac nurses (MA & MC). Studies were included if they involved adult LVAD patients and used qualitative data collection and analysis methods (see Figure 1). Studies were excluded if they focused on caregivers, used mixed methods without separate reporting of qualitative methods and results, or were published before 2007. The last criterion reflects the dramatic improvement in LVAD technology in recent years. A landmark study was conducted in 2007 that resulted in the transition from pulsatile to continuous-flow devices.^{15,16} Seven articles met inclusion and exclusion criteria.

Each paper was independently evaluated according to the Critical Appraisal Skills Program (CASP) (see Table 1).^{17,21} The articles were read multiple times by two independent reviewers who are both nurses with experience caring for LVAD patients in the intensive care unit (MA and RP). A thematic synthesis of qualitative literature was undertaken using the methods of Thomas and Harden.¹⁷ Two articles, with high qualitative rigor according to the CASP, were selected to create a codebook.^{7,8} After each reviewer coded the text from two articles, the reviewers met to discuss and create a combined spreadsheet organized into descriptive themes. Components of the Transactional Model of Stress and Coping were used to organize the coding framework.¹²⁻¹⁴ Coding continued on the remaining 5 articles. Discrepancies between coders were discussed and a consensus code was created. Themes

were drawn from the codes both within and across studies. A clear audit trail was maintained through the use of memos and notes. As a further measure of analytic rigor, a third researcher (MD) performed an independent analysis of the results of the seven articles. Analytical themes were then synthesized from the descriptive themes. Any discrepancies in the analysis were resolved through discussion.

Results

Of the seven articles included in the review, two articles reported results from a single sample, yet asked different research questions.^{7,18} All studies reported methods to maintain qualitative rigor as measured by the CASP, but the article by Sandau was most transparent, reporting attributes of the non-clinician interviewers and more details regarding the grounded theory approach (see Table 1).^{7,8,18-22} Sample sizes ranged from 5-12 patients with a total of 59 patients included in the 7 studies (see Table 2). The mean age of participants was 52.3 years and 25% (n=15) were women. Two of the studies were conducted in the United Kingdom^{20,19}, four in the United States^{7,18,21,22} and one in Denmark⁸. The two studies in the United Kingdom included participants' recall of living with an LVAD after they had been explanted, meaning that at the time of the interview, the LVAD had been removed because of recovery or transplantation.^{20,19} Each study sample was drawn from a single LVAD center. As yet, no qualitative studies have recruited patient participants from multiple LVAD centers.

Four studies described the implant strategy (bridge to transplant or destination therapy); however, none of the studies used implant strategy to compare findings.^{7,18,21} One study included only destination therapy participants, yet little is known about how adaptation may differ by implant strategy of patients living with an LVAD.²¹ Although these studies span a period of less than 10 years, recommendations for care of LVAD patients have evolved in that time. For instance, one study commented on the extensive involvement of the palliative care team in their program, which although called for in recent recommendations for care, is still an unmet

goal in many programs.^{21,23,24} No studies included sick or hospitalized LVAD patients who may have a very different perspective on aspects of life with an LVAD.

As we read the seven studies, it became clear that patients remember their journey in 4 distinct stages: Pre-LVAD, the time from first discussions for the device to surgery, Implant Hospitalization, Early Home Adaptation and Late Home Adaptation. These stages were identified through thematic analysis and were organized based on the Transactional Model of Stress and Coping (see Figure 2) including physical, psychological and social domains (see Table 3).¹⁴ Further, two themes emerged: 1) Primary Appraisal: Every stage is a new challenge and 2) Secondary Appraisal: Routines are achievable, emotions are more difficult.

Primary Appraisal: Every stage is a new challenge

Primary appraisal, as described by Lazarus and Folkman, involves the evaluation of harm, threat and challenge to determine if the stress has a significant impact on well-being.¹⁴ This appraisal is a constant process but is more pronounced at times of transition. The initial implant of an LVAD, the transition to home and then dealing with the device in the long term were stages in which LVAD patients appraised new challenges, threats to normalcy and independence.

For LVAD patients who participated in these studies, a repeated theme was that being dependent on another person is undesirable.^{7,8,18-22} Previous roles and the personal identity were threatened by dependence. However, LVAD patients recognized their need for a caregiver and that learning to live with the device would be nearly impossible without their support.^{7,8,21} The pursuit of independence was discussed particularly in the hospital, early home and late home stages. It is likely that preoccupation with symptom burden made this less relevant during the pre-LVAD stage.

Individuals living with LVAD consider 'normal life' to be their life before the LVAD was implanted and often their life before significant heart failure symptom limitations.^{7,8,18-22} They felt that learning to find normalcy while living with an LVAD was difficult, particularly if LVAD lifestyle

changes were dissonant with developmental stage.^{8,22} Finding a “new normal” was hampered by unexpected hospitalizations and poor outcomes (ie. gastro-intestinal bleeding, stroke or even vision loss).^{20,22} In addition, LVAD patients were plagued with concerns that the LVAD itself would have device problems or that infection might develop.^{8,19} They also had concerns about body image and difficulty with managing transplant expectations.^{7,18,19,22}

Pre-LVAD stage

As patients reflected on their experiences during the pre-LVAD stage, many talked about their heavy symptom burden (Table 3).^{21,19} Their strong need to be relieved of their symptoms affected the decision-making process as they learned about LVADs and went through the evaluation process. LVAD patients felt that although they were offered the choice of LVAD or medical treatment, many felt that there was only one choice – to live.^{21,22} Patients needed to take time to reflect on the experiences and decisions that led to the device placement. For some, who received the device emergently, and had no recollection of this period, it was necessary to cognitively and emotionally process events that were out of their control prior to implantation during later stages of recovery.^{8,20,19}

Implant Hospitalization stage

The hospital stage of the adaptation process includes a high level of dependence on the care team while recovering from surgery and learning basic LVAD skills.^{7,21} In the hospital many talked about the impact of seeing their bodies with scars and the driveline.

“I look at myself now in the mirror. Before I didn’t have any scars. Now I’m covered in scars. It doesn’t really bother me.”¹⁹

Learning basic LVAD skills during the hospitalization was a key activity and was overwhelming for many.^{7,8,18–22} Emphasis on mastery of skills was placed on the caregiver with the expectation that the patient would later master VAD-related skills.^{7,21} The basic skills include learning to manipulate the battery pack, using supportive gear to wear the device and methods for bathing, dressing and driveline dressing changes.^{7,8,21,22} Alarms and vibrations of the device

were frightening at first and those who had more frequent alarms struggled with fear and anxiety about device failure.¹⁹

“They give you a lot of information on that first [visit], and they put it into a folder, and they treat you like a scared hog in a packing plant but they do it right.”²¹

Early Home stage

Early Home Adaptation involves the early testing and development of routines for activities of daily living while slowly initiating steps of independence. However, in this stage the necessary dependence on the family caregiver (instead of the professional team) is a significant change from the hospital experience and even the pre-LVAD disease state. LVAD coordinators were available by phone and mentioned as good communicators through this transition.^{21,19} All of the skills acquired in the hospital must be adapted for the home environment.^{7,8,19,21,22} The home environment needed to be changed to support the patient. For example some homes required electrical work. The privacy of being back at home allowed some to re-explore sexual intimacy described as a significant benefit.¹⁸

However, the stress of the early home stage was also influenced by the frequency of clinic visits and related testing or travel.^{7,21} LVAD patients mentioned that they did not understand prior to surgery how much follow-up care would be necessary.²¹

Late Home Stage

Lastly, in the Late Home Adaptation phase, patients discussed a change in their sense of normalcy and an acceptance, even gratitude, for the LVAD. This stage was characterized by increasing confidence in device manipulation and increased independence in self-management. This new confidence allowed for increased sexual intimacy.^{18,22} However, it was difficult for LVAD patients to return to work and resume previous roles, which are considered to be priorities to achieve normalcy.⁸ For instance, only 4 LVAD patients across 6 studies were described as working at the time of data collection.^{7,8,18–20,22} (1 study did not describe any return to work, but

the average age of participants was over 70 and this may not have been a relevant consideration.²¹⁾

“Well I think I was fairly comfortable mentally, because I’m good at accepting things and working from there...it took about 6 months to adjust to daily life with the [LVAD].”⁸

“The whole thing about it is feeling better; going to bed with this equipment, getting up with this equipment, um, is living.”⁷

Secondary Appraisal: Routines are achievable, emotions are more difficult

Secondary appraisal is the cognitive process of evaluating what steps can be taken to decrease the challenges.¹⁴ Problem-focused, emotion-focused and spiritual coping strategies may be used to cope with threats. Coping with life with an LVAD was described as extremely challenging in all of the studies.

Problem focused coping

Problem focused coping included focusing on the skills required to be more independent.^{13,14} Routines for activities of daily living, such as bathing and dressing, helped establish a sense of control and independence for the individual living with an LVAD. Having control over life situations was seen as highly desirable for patients who had experienced many symptom burden-related losses of control. Routines serve as an important key to adapting to life with an LVAD.^{7,8,18–22}

“I prefer to [change my own bandages]. If I don’t, I feel sick, like I can’t do anything, then I feel disabled.”⁸

“I didn’t want to be alone just after I got the [LVAD], so I moved in with my aunt, who was home all day.”⁸

Patients stated that having a full-time caregiver and the support of family or social networks addressed the problem of loneliness and isolation for them.^{7,8,18–22} Involving friends and family in the adaptation process helped distract from fears and worry. Returning to social

activities also supported a sense of normalcy and LVAD patients reported feeling closer to their families and social networks. But some transitioned to having family gatherings at their own home to limit the need for exhausting travel. Patients also discussed the benefit of participating in professional counseling.¹⁹

Some patients reported having a deeper intimate connection with their sexual partner and described how they and their partners coped with the practical challenges of adapting their intimate routines to the encumbering device and cords.^{18,22} Men preferred the flexibility of battery use, while women felt they were more comfortable knowing they were attached to AC power.¹⁸

“We keep on changing positions a little bit, but (laugh) it’s good, I mean it’s a little slower, little more awkward but you adapt to it.”¹⁸

Emotion-focused Coping

Patients reported that over time, they were able to develop confidence by increasing their independence, developing safe routines, and coping with uncertainty.^{7,8,19–22} Managing expectations about timing for each stage began as soon as the decision to implant the device was made while patients awaited implant surgery and was especially difficult for patients with longer implant hospitalizations waiting to go home.²¹ Some of the coping mechanisms involved intentionally keeping a positive attitude, having a sense of humor, religious involvement and prayer.^{7,8,18–22} Several patients pointed out the value of meeting with other LVAD patients and families in a support group or one-on-one.^{8,21} One patient described finding value and meaning in being the LVAD mentor and reaching out to hospitalized patients with newly implanted devices.

“...it’s getting better, but you got to learn to lift your feet and you got to learn not to make a fast turn.”²¹

Sandau et al (2014) highlighted the way that participants used their spiritual beliefs to cope with existential distress and find peace with decisions that were made, events that had

transpired and to cope with the uncertainty of the future.²² Social support may be enhanced through religious affiliation.

*"I believe in a Higher Power and the strength from that...those around you where you can find your strength."*²²

Finally, prayer, meditation and even the quiet of a day spent fishing were ways that LVAD patients found to still their anxieties and establish a sense of peace.^{7,22}

Participants also identified several factors that made coping difficult. Living with the LVAD left some feeling exposed or vulnerable.^{7,8,18-22} This was reinforced when, despite best attempts to maintain a clean driveline site, they experienced driveline infections or a VAD malfunction.¹⁹ Some LVAD patients also reported that the over-protection of their caregiver and family prevented them from having any feeling of control.⁷ Focusing on the differences between life before significant illness and after the LVAD was distressing, but some were unable to avoid it.^{7,8,18-22} Noticing that although they were able to be social, they had less visitors than usual was a challenge.^{7,8} Similarly, it was difficult for some patients to accept that there are some activities that cannot be done with the LVAD in place, like taking a bath or swimming.⁸ Some chose to intentionally test limits of batteries or ignore advice of providers to avoid favorite activities such as boating.^{8,22} There was also a definite sense of physical restriction that was related to the need for battery power during outings.^{7,8,21} Although LVAD patients are taught to carry additional batteries and the charger for long trips, concern for battery life had an impact on patients' sense of return to normalcy and life satisfaction. Finally, some were embarrassed of the attention the LVAD and their scars attracted, expressing that when in a public area, people would often stare and ask questions.^{19,22}

*"I think I am emotionally scarred...I am not 100% right, but I think it is all in the mind"*¹⁹

Discussion

A gap exposed by this synthesis is that there is very little discussion of avoidant behaviors or non-compliant patients. No patients were hospitalized and the perspective of

those LVAD patients who are frequently hospitalized is relatively absent from the literature. All of the studies had a very positive, upbeat tone, but many LVAD patients have very adverse outcomes and the lifestyle changes for the most fragile VAD patients are poorly understood. A strength of the qualitative approach is that it is amenable to discussing outliers. In using non-clinician interviewers Sandau et al (2014) was more successful at eliciting the breadth of positive and negative experiences. Using clinician interviewers may leave studies vulnerable to social desirability bias. More qualitative work should be done to explore the coping of LVAD patients who experience poor outcomes including functional status and quality of life.

Casida et al. (2011) introduced the idea of early and late stage adjustment to living with an LVAD.⁷ Our expanded view of the temporal sequence of primary appraisal (Table 3) offers a more comprehensive understanding of patients' progression from pre-implantation to late adaptation living with the device. While it is not possible to directly compare these findings to outcomes literature, it is likely that continued improvement in perceptions of quality of life observed in the first 3-6 months of LVAD therapy are related to the transition from the early to late home adaptive stages.^{3,4,25,26} As physiologic improvements occur over time, each adaptive phase may coincide with functional improvements. Rather than a linear process, adaptation has been elsewhere characterized as an iterative process with mini-regressions which, in the case of LVAD patients, may be associated with unexpected hospitalizations or complications.¹⁴ A recent study of educational materials available to LVAD patients and their families found that while 100% of materials discussed benefits of the device only 38% discussed lifestyle considerations, 12% provided information for caregivers and 3% presented any information about palliative care.²⁴ Because of this, some patients may have high expectations that following LVAD implantation, they will return to pre-HF functioning. Managing such expectations is an important component of pre- and post-implant education for recipients and caregivers and helps normalize the experience since very few VAD patients improve to a pre-HF level of function. This synthesis has identified that it is common for LVAD patients to seek

reassurance of normal progress with recovery. Based on these findings, LVAD patients may need more education about expectations throughout surgical recovery and initial adjustment to living with the device. Helping patients and families to manage expectations may also help them manage emotions and improve coping.

Limitations

The studies included in this synthesis used convenience samples from single LVAD centers. Few of the studies mentioned a qualitative theory or conceptual framework, although all of them described methods to provide qualitative transparency. Additionally, the diversity of perspectives was narrow; samples across studies were primarily white, educated men. Some of the studies included patients who received pulsatile devices, which are no longer in use. In addition, across studies the samples varied by implant strategy. Patients were primarily bridge to transplant, but included some explanted LVAD patients and some destination therapy patients. Considering that destination therapy is now the most prevalent reason for implantation in the US, future studies should consider implant strategy to ensure that the perspective of destination therapy patients is better understood.¹ Finally, LVAD programs may vary significantly between countries, limiting comparability for synthesis and transferability to other LVAD populations. However, the involvement of an international, interdisciplinary team for this meta-synthesis is a strength.

Implications

This synthesis draws attention to the need to foster a sense of independence and normalcy for LVAD patients. It is clear that LVAD programs have been successful at helping patients establish routines related to LVAD care, which contributes to independence. However, developing and providing additional materials that explain the recovery and adaptation process may help promote emotional coping and help patients regain a sense of normalcy. Little is known about how different LVAD centers educate patients and the efforts of LVAD coordinators to provide education. Because stress is a commonly used term in the community, the stress

model may help LVAD patients and caregivers better interpret their own responses. An educational program that incorporates the concepts of stress and coping, while presenting typical tasks at each transitional stage would provide a theory-based format for delivering LVAD education. Studies should be conducted to support the development of best practices and guidelines. In addition, more research is needed for destination therapy patients and examining the perspective of LVAD patients who have had the device for greater than 1 year, particularly as more patients are surviving several years on the device.²⁷ This synthesis suggests that interventions to support emotional coping, spiritual coping and body image recovery may also be needed. Finally, as research moves forward to further understand adaptation and develop interventions to improve lifestyle adaptation for LVAD patients, it will be important to increase the focus on patients with mal-adaptive coping responses and poor outcomes.

The Authors declare that there are no conflicts of interest.

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Table 1: Analysis of Qualitative Rigor per CASP

*Same sample

Author/ Title/ Year	Sandau et al. Conceptual Definition of Quality of Life 2014 ²²	Ottenberg et al. Choices for Patients "Without a Choice" 2014	Overgaard et al. Illness and Vocational Adjustment 2012 ²⁴	Marcuccilli et al. Sex and Intimacy* 2011 ²⁶	Casida et al. Lifestyle Adjustments* 2011 ²⁵	Hallas et al. Psychological Experience 2008 ²³	Chapman et al. Psychosocial Issues 2007 ²¹
Was there a clear statement of the aims of the research?	Yes - To allow patients to share impressions and experiences about life after receiving and living with DT	Yes - To allow patients to share impressions and experiences about life after receiving and living with DT	Yes - Explore the lived experience of patients living with LVAD	Yes - explore the experience of adults living with LVAD including the effect on their intimate and sexual functioning	Yes - Explore and describe the lifestyle adjustments of adults living with LVAD through lived experience	Yes - Identify Psychological processes that patient use to make sense of adjustment to LVAD and consider adjustment construct	Yes - Determine the impact of LVAD on body image, psychological functioning and social support
Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims of the research?	Yes Grounded theory With in-depth interviews, individual or paired with an average of 6 weeks between interviews	Yes No qualitative approach discussed, although phenomenological approaches were used	Yes No qualitative approach discussed, although phenomenological approaches were used	Yes Hermeneutic phenomenology	Yes Hermeneutic phenomenology	Yes Grounded theory With in-depth interview with f/up phone call	Yes Interpretive Phenomenological Analysis
Was the recruitment strategy appropriate to the aims of the research?	Purposive, convenience sample: - 3/11 women - diverse implant strategies	Purposive, convenience sample: - inclusion based on availability and cognitive/physical appropriateness	Purposive, convenience sample: - sample included the most females - 4/10 females	Purposive, convenience sample: (may have enhanced study to purposively select more female perspective although most LVAD patients are men)	Purposive, convenience sample: - only two women - wide range of time with LVAD	Purposive, stratified sampling: - VAD in situ, explanted, transplanted	Purposive stratified sample: - VAD in situ and transplanted
Were the data collected in a way that addressed the research issue?	Yes - disclosed interview questions - interviews were audio taped and transcribed - described audit trail - saturation of data with 11 participants	Yes - disclosed interview questions - tape recorded interviews - many qualitative techniques discussed but did not use term 'saturation'	Yes	Yes - disclosed interview questions - tape recorded interviews - did not discuss transcription methods - saturation of data with 9 participants	Yes - disclosed interview questions - tape recorded interviews - transcribed verbatim - saturation of data with 9 participants	Topics of discussion were disclosed, but not interview questions	No disclosure of questions - interviews were audio taped and transcribed - described audit trail - no mention of saturation
Has the relationship between researcher and participants been adequately considered?	Yes Heart Center Staff did not conduct interviews	Yes Disclosed author experiences related to heart failure and LVAD care.	Not addressed	Yes Bracketing	Yes Bracketing	Not addressed	Not addressed

Have ethical issues been taken into consideration?	Yes Institutional Review Board	Yes Institutional Review Board	Yes Ethical Considerations thoroughly addressed	Yes Institutional Review Board	Yes Institutional Review Board	Yes Ethical approval	Yes Research Ethics Committee
Was the data analysis sufficiently rigorous?	Yes Thorough description audit trail, transcription and thematic analysis and non-clinicians conducted interviews to reduce bias	Yes Thorough description audit trail, inter-rater reliability, transcription and thematic analysis	Yes Thorough description of credibility, transferability, dependability and confirmability	Yes Thorough description of credibility, transferability, dependability and confirmability	Yes Thorough description of credibility, transferability, dependability and confirmability	Yes Audit trail, inter-rater reliability addressed	No Audit trail is mentioned - Coding methods are not addressed
Is there a clear statement of findings?	Yes 5 Themes organized by QOL domains: Physical, Emotional, Social, Cognitive and Spiritual	Yes 6 themes: preparedness planning, new lease on life, optimizing support networks, systemic limitations, reflections on time, and communication matters	Yes Table describing themes: transition to illness, transition to LVAD, Life with LVAD and Life with Transplant	Yes 3 themes: improved sexual relations with the LVAD, sexual adjustment and non-sexual intimacy	Yes 1 theme and 2 sub-themes: adjustment takes time -early adjustment: changes in everyday life -late adjustment: new way of living	Yes Theme of control with 6 sub-categories: normality, uncertainty, emotional state, identity of illness, impact of LVAD, Independence	Yes 2 major themes: body/self and trust
How valuable is the research?	First study to explore the unique attributes of QOL in the LVAD population	First qualitative study to consider only the Destination Therapy Patient perspective	Using the Lifestage Development Model is innovative and provides valuable insight	High level of importance to patients, first to report patient perspectives, implications discussed	Significant contribution to what was previously reported. Confirms prior studies and adds early/late stage adjustment themes	Highlights importance of perceived control and independence in advanced heart failure patient care.	Supportive care mentioned as part of discussion

Table 2: Study Characteristics

Author/ Title/ Year/ Country	Purpose	Sample	Design	Paradigm/ Framework
Sandau et al. Conceptual Definition of Quality of Life 2014 ²² United States	To develop a conceptual definition of quality of life (QoL)with LVAD.	N = 11 3/11 female 10/11 White 4/11 DT 6/11 BTT 1/11 BTR	Qualitative design with in-depth Interviews	Grounded Theory
Ottenberg et al. Choices for Patients "Without a Choice" 2014 ²¹ United States	To allow patients to share impressions and experiences about life after receiving and living with DT	N = 12 1/12 female 1/12 Asian 11/12 White DT only	Qualitative design with in-depth Interviews	None identified
Overgaard et al. Illness and Vocational Adjustment 2012 ⁸ Denmark	Explore the lived experience of patients living with LVAD	N = 10 4/10 female No race reported BTT only	Qualitative explorative design with in-depth interviews	Life Span Development model
Marcuccilli et al. Sex and Intimacy* 2011 ¹⁸ United States	Explore the experience of adults living with LVAD including the effect on their intimate and sexual functioning	N = 9 2/9 female 2/9 Black 6/9 White 1/9 other	Qualitative Design with in-depth interviews	Hermeneutic Phenomenology
Casida et al. Lifestyle Adjustments* 2011 ⁷ United States	Explore and describe the lifestyle adjustments of adults living with LVAD through lived experience	2/9 DT 7/9 BTT	Qualitative Design with in-depth interviews	Hermeneutic Phenomenology
Hallas et al. Psychological Experience 2008 ²⁰ United Kingdom	Identify Psychological processes that patient use to make sense of adjustment to LVAD and consider adjustment construct	N = 11 3/11 female No race reported 4 with LVAD in situ 4 LVAD explanted 3 s/p heart transplant	Prospective, cross- sectional qualitative design with in-depth interviews	Grounded Theory
Chapman et al. Psychosocial Issues 2007 ¹⁹ United Kingdom	Determine the impact of LVAD on body image, psychological functioning and social support	N= 6 2/6 female 4/6 s/p heart transplant 2/6 LVAD explanted	Qualitative Idiographic approach with in- depth interviews	Phenomenology

DT – Destination Therapy, BTT – Bridge to Transplant, BTR – Bridge to Recovery

Table 3: Temporal sequence of primary appraisal tasks: physical, psychological and social domains

	Pre-LVAD	Implant Hospitalization	Early Home	Late Home
Physical	<ul style="list-style-type: none"> • Very low functioning^{7,8,18,19} • Very severe lifestyle-limiting symptoms^{7,8,18,19,21,22} • Waiting for the device until “sick enough”^{7,8,18,19} 	<ul style="list-style-type: none"> • Pain and surgical recovery⁸ • Drastic changes in physical body including disfiguring scars^{8,18,20–22} • Learning basics of device and safety routines;^{7,8,19–22} <ul style="list-style-type: none"> ○ Frequent practice ○ Becoming used to vibration of device ○ Alarms – confidence effected by alarm frequency 	<ul style="list-style-type: none"> • HF symptom management, but symptoms improving^{21,19} • Surgical recovery continues^{7,21} • Frequent appointments require exhausting travel²¹ • Need to create and adapt safe routines to home environment;^{7,8,18–22} • ADLs <ul style="list-style-type: none"> ○ Medication ○ Batteries ○ Driveline care ○ Sleeping ○ Clothing comfort 	<ul style="list-style-type: none"> • Routines become normal^{7,8,21,22} • Learn to make time for necessary device care^{7,8,19} • Testing limits of device^{8,22} • Improving mobility and energy^{7,18}
Psychological (cognitive, emotional and spiritual)	<ul style="list-style-type: none"> • Trauma^{8,20,19} • Lack of memory^{8,20} • Facing mortality^{8,21,20,19} • Waiting for the device^{8,21,20} 	<ul style="list-style-type: none"> • Early body-image^{7,8,18,19,22} • Feeling different from others^{7,18,22} • Grappling with meaning of life – existence = device dependency^{7,8} • Fear and anxiety related to device (ie. alarms and disconnecting driveline)^{7,8,18} 	<ul style="list-style-type: none"> • Fear of complications^{7,8,19} • Confidence with basic device builds^{7,8,20,19} • Poor memory, unfocused thoughts²² 	<ul style="list-style-type: none"> • Reflection^{7,20,22} • Making peace with decisions and life with LVAD^{7,20,22} • Anger when others don’t understand²² • Fear diminishes as routines are normalized and time passes without complications^{7,18–22} • Feeling grateful^{7,8,18,21,22} • Increased intimacy^{7,18,19,22}
Social	<ul style="list-style-type: none"> • Patient role changes with increased illness^{21,20} • Family providing support at home and has large role in decision making^{8,21,20} 	<ul style="list-style-type: none"> • Dependence on care team^{8,19} • Early discussions with family can be supportive or stressful^{8,21,20} 	<ul style="list-style-type: none"> • Dependence transitions from hospital team to caregiver^{7,8,21,20} • Importance of LVAD coordinator^{7,21} • Change in home roles^{7,8,18,21,22} 	<ul style="list-style-type: none"> • Outings are valuable but require;^{7,8,21,20,19} <ul style="list-style-type: none"> ○ need to come to terms with body image and embarrassment ○ anxiety regarding new environments • Return to work^{8,20,22}

Figure 1: Literature Review and Inclusion

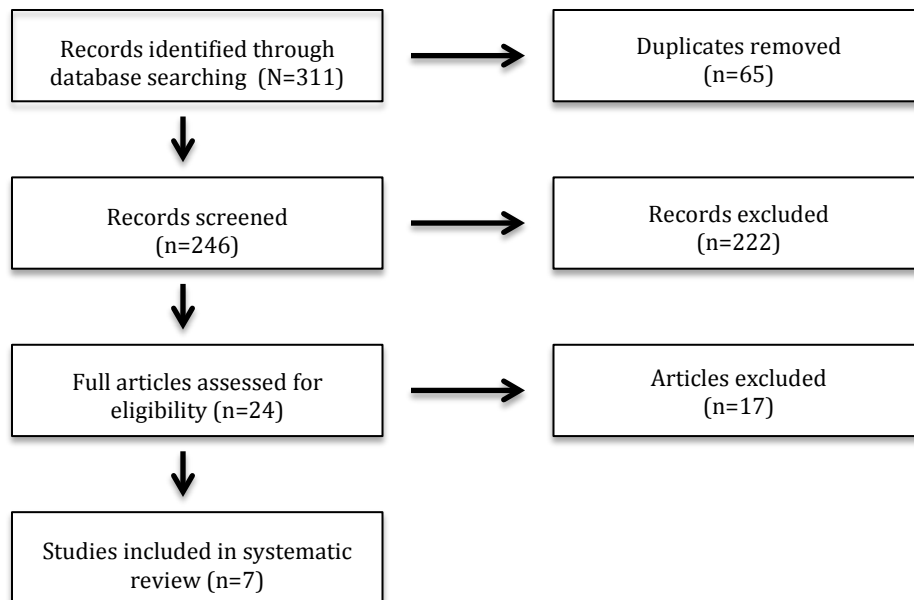


Figure 2: LVAD Transactional Model of Stress and Coping

