

AMERICAN UNIVERSITY OF BEIRUT

EXPLORING THE LIVED EXPERIENCES OF LEFT
VENTRICULAR ASSIST DEVICE PATIENTS AND THEIR
CAREGIVERS

by
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ABSTRACT OF THE THESIS OF

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Title: Exploring the Lived Experiences of Left Ventricular Assist Device Patients and their Caregivers

Background: An advanced therapy for Heart Failure patients with left ventricular dysfunction consists of the Left ventricular assist device (LVAD). The LVAD procedure is complex and results in prominent lifestyle changes. In Lebanon, the lived experiences of patients living with an LVAD and their caregivers have not been explored. The *purpose* of the study was to explore the lived experiences of patients with an LVAD and their family caregivers. The study is the first inquiry to address the paucity of research on the Lebanese LVAD population and their direct caregivers. The study *aimed* to understand in depth how LVAD patients and their direct caregiver experience transition to a new life with the LVAD.

Using a qualitative phenomenological *design*, unstructured *interviews* were conducted with a convenience sample of 5 patients and 5 caregivers recruited from a medical center in Lebanon. Colaizzi's descriptive phenomenological method guided the *analysis*. Six themes emerged capturing the in-depth description of the participants' lived experiences.

Results: Participants described the lived LVAD journey from being doomed to a new life (Theme I). They portrayed their life journey from living with HF to the LVAD. Though the LVAD decision was the only choice to sustain patients' lives, they then perceived it as a life saver. Participants started to appreciate the LVAD given the positive health changes leading to a new life and the establishment of new routines.

Theme II consisted of embodiment and attachment to the LVAD. Contrary to their first impressions, participants perceived the LVAD with positive descriptors. As a trust bond was established, they personified and embodied the LVAD. Being reliant on the LVAD to sustain living, participants felt attached and fully dependent on it.

Participants shared their personal experiences on how they coped and adjusted with the lifestyle changes introduced with the LVAD. Theme III denoted how participants lived through: self-determination, coping and adjustment. They explained how they empowered themselves to reach self-determination. Coping through the stages of grief, participants progress with time until they reach acceptance. With acceptance, participants were able to

integrate the LVAD into their lives. Adjustment was identified to be time dependent with the first two weeks being the hardest.

Patients and their caregivers identified facilitators and challenges of the LVAD experience (Theme IV). Among the facilitators, faith, mental wellbeing, high spirits, caregiver, familial and social support eased adjustment with the new life after the LVAD implantation. Valid only to the single patient, lack of commitments and responsibilities allowed him to accept his destiny with the LVAD. Several challenges to the LVAD experience were identified, the economic crisis in Lebanon being one of them. Participants reported financial difficulties with employment restrictions. Another challenge consisted of the body image alterations acting as a barrier for participants' intimacy. Spousal caregiver role was problematic. With the first impression on the LVAD, participants had to deal with their anticipated concerns. Complaints on the LVAD weight was perceived as a challenge. Last but not least, dyads had to deal with the electrical supply shortage.

Despite the subsequent lifestyle changes, the LVAD brought hope and expectations (Theme V). Participants dwelled on the lifestyle changes introduced with the LVAD. Living with an LVAD was a shared experience between patients and their caregivers. The LVAD brought hope and expectations with their second chance in life. They still aspired to be free from the LVAD's external components, the driveline and the batteries.

Finally, patients and their caregivers were provoked by others' perception of the LVAD machine (Theme VI). Participants felt they were being singled out. Their privacy was disrupted by frequent stares and inquiries on the LVAD. Their physical appearance labeled them as either businessmen or terrorists. Patients feared people's misperceptions of the LVAD as a valuable item and potential theft attempts. Given the public's unfamiliarity with the LVAD, participants emphasized the need to raise awareness as this directly impacts their lived experiences.

Implications: This study is among the first research queries to address the Lebanese LVAD population and their direct caregivers. Participants had the chance to voice their personal experiences on how they lived through and adapted to a new life with the LVAD. These findings will inform healthcare providers on how to facilitate the coping of patients and their caregivers with the LVAD. The Clinical Nurse Specialist's role is essential to coordinate and optimize the care aligning with their competencies. This study sets the grounds for future research addressing the coping and adjustment processes along with the quality of life of Lebanese patients and their caregivers.

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ABBREVIATIONS

Terminology	Abbreviation
Heart Failure	HF
Left Ventricular Assist Device	LVAD
American University of Beirut Medical Center	AUBMC
Clinical Nurse Specialist	CNS
Quality of life	QOL
Bridge to Transplantation	BTT
Destination Therapy	DT
New York Heart Association classification	NYHA
International Registry for Mechanically Assisted Circulatory Support	IMACS
National Social Security Fund	NSSF

CHAPTER I

INTRODUCTION

Heart failure (HF) denotes a complex syndrome characterized by specific signs and symptoms secondary to structural or functional cardiac alterations (Ponikowski et al., 2016). Patients living with HF experience symptoms varying between decreased functional capacity, chronic fatigue, palpitations, insomnia, and shortness of breath. Common signs present on physical examination include crackles, peripheral edema and elevated venous pressures. These signs and symptoms impose prominent limitations to the HF patient extending from limited activity tolerance, decreased appetite to impaired sleeping capacity (Ponikowski et al., 2016). To adequately manage symptoms and decrease symptom load, strict compliance to disease modifying interventions is required. This entails a multidisciplinary approach to HF management and interventions that include lifestyle changes, dietary modifications, and medication compliance. From the moment HF is diagnosed, patients would have already experienced to some extent the concomitant hardships of an acute presentation, symptom burden, and medical treatment (Morton et al., 2018).

Patients living with HF experience a vicious cycle with their health status fluctuating between periods of clinical stability and exacerbations. The chronicity of HF taxes both members of the dyad, the patient and his/her caregiver (Metra & Teerlink, 2017). Caregivers of HF patients experience stress, anxiety, and burden of care that affect their quality of life (Pressler et al., 2013). The impact of HF extends beyond the dyad to affect

healthcare expenditures (Mozaffarian et al., 2016). It is estimated that HF is prevalent in around 5.7 million cases in the United States necessitating a 30.7-billion-dollar healthcare expenses (Heidenreich et al., 2011; Mozaffarian et al., 2016). In Lebanon, HF prevalence is estimated to be around 72,000 cases yielding a 104-million-dollar annual expenses (Tatari et al., 2015). These healthcare expenses comprise inpatient admissions and outpatient visits including medication costs. On a wider scope, HF affects individuals, caregivers, families, communities, and healthcare systems (Heidenreich et al., 2011; Metra & Teerlink, 2017).

The HF's load results from both the magnitudes of HF symptoms and its medical management. International guidelines recommend optimizing medical and device therapy for patients living with HF. Patients are maintained on pharmacological therapy to prevent re-hospitalization, decrease mortality, and improve quality of life (Yancy et al., 2017). For some patients, optimal medical therapy preserves clinical stability. The response to therapy is different for others where their HF rapidly progresses into a vicious cycle of deterioration entailing frequent re-hospitalizations and advanced interventional therapies (Ponikowski et al., 2016). These advanced interventions vary between implanted pacemakers and defibrillators, mechanical circulatory support and heart transplantation (Gustafsson & Rogers, 2017). The aim of these therapies is to assist or eliminate the circulatory compromise occurring with HF. Heart transplantation remains a challenging intervention due to the scarcity of organ donation and its suitability if made available (Gustafsson & Rogers, 2017). As such, the need for mechanical circulatory support arises to manage HF progression. One of these advanced interventions for acute HF decompensation consists of the Left Ventricular Assist Device (LVAD) implantation. The indication for LVAD

implantation include short term LVAD placement as a bridge to transplantation or recovery, and long-term placement as destination therapy.

The LVAD is a surgically implanted pump positioned in the left ventricle responsible to drain the blood through an outflow graft to the aorta. This circulatory conduit mimics the physiological function of the left ventricle; hence, assisting the poorly functioning left ventricle. An LVAD necessitates continuous electrical support through a percutaneous driveline that exits in the abdominal area. The driveline then connects to the LVAD controller that enables the supply of electrical support either through batteries or direct AC power (Gustafsson & Rogers, 2017).

Moreover, the LVAD aims to prolong survival and improve quality of life of patients living with HF (Udelson & Stevenson, 2016). Its effects on HF symptomatology and improved organ perfusion is clinically noted (Schroder & Milano, 2017).

A. LVAD background

1. Past and Present

In 1963, the first external LVAD was implanted for a comatose patient a couple of days prior to her death (American Heart Association News, 2018). The first human heart transplantation was performed in 1967; whilst the program faced discouraging outcomes and failure (Helman & Rose, 2000). Efforts persisted with the use of LVAD as an external

device for short term recovery from 1966 until 1984 which marked the implantation of the first permanent LVAD and total artificial heart (Kurian et al., 2018).

The path of LVAD therapy and heart transplantation intertwined when LVAD started to be implanted as bridge to transplantation. An upsurge in the need for LVADs emerged due to the scarcity of heart donation and increased mortality of HF patients on the transplant waiting list (Helman & Rose, 2000). Subsequently, this challenge resulted in more research funding to acquire the first permanent FDA approved LVAD in 1994 (Kurian et al., 2018). Portable LVADs were then developed and implanted globally. LVAD devices that are currently implanted consist of HeartMate II and III, and HeartWare Ventricular Assist Device (HVAD). The INTERMACS registry outlines a linear surge in LVAD implantation cases with more than 2500 pumps implanted yearly in the United States (Gustafsson & Rogers, 2017). Moreover, the utilization of LVAD shifted from it being used exclusively on a short-term basis as a bridge to transplantation or recovery to long-term placement as destination therapy. Destination therapy targets advanced HF patients who cannot benefit from heart transplantation due to the therapy's unavailability or contraindications (Gustafsson & Rogers, 2017).

Aligning with medical advancement, the LVAD evolved from a temporary external device to an internally implanted one. Its indication also advanced to cover short and long term circulatory support. For an in-depth deliberation, the LVAD therapy will be examined in the Lebanese context.

2. Lebanese context

In Lebanon, LVAD placement is mainly performed as destination therapy as heart organ donation is uncommon (National Organization for Organ & Tissue Donation & Transplantation, 2011). The first heart transplantation in Lebanon took place in 1999 (Tedy, n.d.). The first pediatric heart transplantation was performed at the American University of Beirut (AUBMC) in June 2017. The low heart transplantation rate results from poor organ donation due to cultural and religious misconceptions (National Organization for Organ & Tissue Donation & Transplantation, 2011). To overcome the complexity of heart transplantation, medical management adopted a mechanical circulatory support therapy (the LVAD) to optimize clinical stability and improve the quality of life of eligible HF patients (Gustafsson & Rogers, 2017). As for patients eligible for heart transplantation, LVADs are placed as a bridge to transplantation for stabilization until a heart becomes available.

Five main hospital institutions offer LVAD implantation as an advanced HF therapy; one of these institutions consists of the American University of Beirut Medical Center (AUBMC). The implanted LVAD devices varied between HeartMate II, HeartMate III and HVADs. A national repository headed by the Ministry of Public Health to track the Lebanese LVAD population is lacking. The resort to institutional repositories remains a challenge despite its availability. The limited access to institutional repositories results from competition among these various institutions and potential conflict of interest. As a result, the number of LVAD patients and their geographical distribution across Lebanon are not identified. The Beirut Cardiac Institute (BCI) is the only institution that has recently published the characteristics of their LVAD patients. BCI reports to have the largest LVAD

population with a total of 82 pumps implanted for 78 patients from 2010 until 2019 (Hamdan et al., 2020). The indication for LVAD implantation was mainly as a bridge to transplantation, followed by destination therapy and bridge to recovery with a distribution of 53%, 42% and 5% respectively (Hamdan et al., 2020). There was no mention of the medical and nursing care delivery applied to cater for the needs of these patients. To date, other institutional repositories did not share their private data related to their respective quota of patients living with an LVAD.

The care of patients living with an LVAD will be reviewed in depth at AUBMC as patients and their identified caregivers will be recruited from the outpatient cardiology clinics.

B. Background of the Study setting: American University of Beirut Medical Center

AUBMC, an academic and referral tertiary care center, is a leading medical center which housed Lebanon's first LVAD. The first HeartMate II was implanted in August of 2009 with a total of 23 patients by October 2020. AUBMC has established a multidisciplinary LVAD team for the comprehensive care of LVAD patients. This team comprises of a Heart Failure Specialist, a Heart Failure Clinical Nurse Specialist, a cardiothoracic surgeon, a licensed dietician and a physical therapist. All these specialists team up to provide a comprehensive evidenced-based patient care. A distinctive feature that the LVAD team holds is the merging of both medical and surgical specialties to provide coordinated quality of care. Extensive education starts at an early stage along with the preparatory phase for LVAD implantation.

It is essential to highlight the role of the HF Clinical Nurse Specialist (CNS) as it embeds the clinical expertise and collaborative practice of an Advanced Practice Nurse. The HF CNS is responsible to provide education, clarification and support to the patient and his/her caregiver. The encounter starts with a thorough comprehensive needs assessment to collect baseline information in order to tailor the patient's plan of care. Follow up meetings are then planned regularly on outpatient and inpatient basis. Patients and their caregivers are accompanied through their LVAD journey; patient care extends from the preparation for the LVAD implantation to post implantation clinic follow ups. During these follow ups, patients and their caregivers are seen by both the HF Specialist and the HF Clinical Nurse Specialist. All through, the HF CNS coordinates patient care among the team members serving as the main liaison between the LVAD team and the dyad. Additionally, the multidisciplinary LVAD team resorts to the expertise of companies' clinical specialists to provide additional education and support for technical challenges.

The care provided is the culmination of numerous efforts with a major role attributed to the HF CNS. This specialized multidisciplinary LVAD care remains a unique feature to the AUBMC LVAD care delivery. Despite this advanced care delivery model, we are still lacking the life perspectives and experiences of the patients living with an LVAD and their caregivers.

C. Significance

The complexity of LVAD implantation is challenging not only for the LVAD multidisciplinary team but to the patient and caregiver dyad as well. The struggle extends

beyond the acute intraoperative phase as it results in major lifestyle changes. Similar to the concept of subjectivity with pain, living with an LVAD cannot be assimilated unless truly experienced. Despite being educated on LVAD components and lifestyle changes prior to the surgical operation, a patient would only appraise the life with an LVAD right after its implantation.

From a direct clinical nursing practice viewpoint, LVAD patients are seen through the acute phase where nurses witness them struggling to accept the device. This stems from major physical and psychosocial drastic lifestyle changes. The driveline exiting from the abdominal area results in body image alterations affecting dress routine (Marcuccilli & Casida, 2012). With this limitation, females are no longer able to wear dresses or one-piece outfits. We might consider these restrictions/changes as manageable, but this is an underestimation of the lived experiences of LVAD patients on daily basis, even with extremes of age. The body image alteration was experienced with two female patients, a young 12-year-old girl and a 77-year-old woman. Both patients shared similar grieving/coping processes about their physical look changes and dressing restrictions. The thoughts of having an LVAD was coupled with anxiety that further developed to panic attacks when their thoughts and apprehension merged with the reality of the device. These personal and indescribable moments were only for them to feel and for us to appraise the hardships that they endure. It is overwhelming for a patient to depend on an electrical device stemming out of their own bodies while being accustomed with a new imposed lifestyle.

This dependency on the LVAD comes with new uncertainties vis-à-vis pump malfunction in case of electrical dysfunction (Casida et al., 2011). These ambiguous thoughts extend to perplex the patient-caregiver dyad. Doubts emerge to question their ability to handle device connections. Indeed, device handling is not a simple task and it requires in-depth knowledge and hands-on experience to attain confidence and control. Additionally, the ability to identify the LVAD related alarms, to recognize them per priority level and to manage them accordingly is laborious and stressful. The manipulation of the LVAD is entrusted to the patient and its identified caregiver; thus, it possibly adds additional anxiety and burden to their emotional underpinnings (Casida et al., 2011).

Living with an LVAD is a new life experience imposed on the recipients with staggering demands for a new daily lifestyle. This comes with required modifications to their daily routine; major limitations to perform basic activities of daily living such as bathing and dressing with a hold on contact sports and swimming as well. Patients and their caregivers endure challenges associated with the new LVAD lifestyle (Casida et al., 2011). The needs and challenges of LVAD patients and their caregivers differ across the globe. This difference depends on the services provided to assist the dyad; these services may include financial and psychological support, health insurance, home healthcare, environmental appraisal among others. The perfected amenities can be found in developed countries capable to provide the needed services. Lebanon, a developing country, has limited resources when it comes to the services provided to meet the needs of LVAD patients and their caregiver. This may amplify and modify the needs and challenges the dyad experience as they are context bound.

In Lebanon, the lived experiences of patients living with an LVAD and their caregivers have not been explored. We currently lack knowledge about how patients and their caregivers experience life with an LVAD, what does an LVAD mean to them and how they perceive it. We question if they accept having an LVAD willingly or they are somehow forced to accept it leading to anxiety and regret. We currently lack an understanding of the dyad's perceptions and feelings coupled with the LVAD. We are unfamiliar with the challenges they face on a daily basis beginning from the LVAD implantation phase. We have insufficient understanding of their needs and what services they desire accessible to fulfill them. We do not know how they cope with the challenges and adjust to the new lifestyle.

As such, we need to explore what an LVAD means to the dyad's life acknowledging all the concomitant challenges. The balance between the caregiving requirements and burden of care is unidentified. That is why there is a need to explore the lived experiences of patients living with an LVAD and their caregivers.

D. Purpose

The purpose of this study is to explore the lived experiences of dyads living with an LVAD in a sample of Lebanese patients. To date, research on patients living with an LVAD in Lebanon and the Middle East region is scarce. This results in a lack of initial assessment of this population's characteristics and healthcare demands. Patients and their caregivers endure privately the lifestyle changes associated with the LVAD therapy. Their needs, challenges and coping processes remain unidentified. Findings will guide the

multidisciplinary team to assist the dyad in attaining their specific needs and facing the challenges. The program will be tailored to adapt to unforeseen difficulties and challenges that HF patients and caregivers experience.

In this chapter, an outline of the LVAD's historical trajectory was presented to conceptualize how this surgical treatment evolved to existence. This was followed by a discussion of the Lebanese context highlighting the common use of the LVAD therapy as destination therapy. Institutional LVAD repositories are limited to access while a national LVAD registry is non-existing. The significance and purpose of this study were examined. As a new life experience, LVAD imposes drastic lifestyle changes and challenges to both patients and caregivers. The purpose of this study is to explore the lived experiences of LVAD patients and their caregivers.

Furthermore, appraisal of the existing literature on the HF self-care from a quantitative and qualitative perspective will be conducted in Chapter II along with empirical literature on the LVAD population and their caregivers. Although findings will not portray specific challenges, needs and lifestyle changes of the Lebanese LVAD population, it will depict what has been studied to date. Chapter III will provide a detailed methodological overview of this study. Chapter IV will entail an exhaustive presentation of the study's results. Chapter VI will include a discussion of the study's results, implications for practice and future recommendations.

CHAPTER II

REVIEW OF LITERATURE

In this chapter, pertinent studies will be reviewed from the literature addressing patients living with HF and LVAD. These studies integrate diverse quantitative and qualitative methodologies to provide insight on particularities of life of patients living with HF or an LVAD. Literature will be synthesized from global research and compared to and contextualized with the Lebanese context. Research addressing HF self-care in Lebanon will be appraised as studies on patients living with an LVAD remain unavailable.

A. Empirical Literature of patients living with HF and LVAD

Given the demanding nature of the syndrome of HF, the literature is rich in quantitative studies that have addressed HF's impact on both patients and their caregivers.

1. Quantitative Investigations

a. Quantitative Inquiry on Patients Living with HF and their Caregivers

Interdisciplinary research on HF is abundant given the chronicity and complexity of its disease process. HF has been associated with palpable symptom burden and poorer quality of life (McMurray et al., 2012). Studies included in this review will address issues known to directly affect lived experience such as studies investigating HF self-care and its determinants from the individual (patient or caregiver) to dyadic contextual factors.

HF self-care is commonly measured with the Self-care of Heart Failure Index (SCHFI) (Bidwell et al., 2015). It conceptualizes a series of activities actively performed to cater for the HF lifestyle restrictions and medical management behaviors. This assessment tool delineates three major self-care processes consisting of the self-care maintenance, management, and confidence (Riegel et al., 2009). In self-care maintenance, patients implement the necessary activities by adhering to treatment regimen in order to maintain and improve his/her health stability. By identifying symptom changes, patients apply self-care management with a decision-making process guiding treatment changes and its subsequent evaluation (Riegel et al., 2009). These two processes are bridged together by the self-care confidence which consists of active engagement in monitoring behaviors. These behaviors reinforce the monitoring of HF symptoms resulting in the successful detection of minor changes necessitating an immediate action plan (Lee et al., 2009). The significance of HF self-care lies in its complementary contribution to the HF medical management in terms of health outcomes (Jurgens et al., 2009; Lee et al., 2009). Literature has identified factors and determinants that could impact HF self-care; these are characteristics pertaining to both patients and their caregivers. Patient related factors that were studied are not limited to age, gender, depression, cognitive function, lifestyle impairments (sleep), HF symptom burden, HF duration, and hospital re-admissions (Jurgens et al., 2009; Lee et al., 2009; Riegel et al., 2011; Sedlar et al., 2017; Seto et al., 2011). As for caregiver related determinants, social support and good relationship quality enhanced self-care in HF patients (Riegel et al., 2009; Buck et al., 2018). After revision, Riegel and colleagues brought forward a new intermediate concept to the HF self-care involving of the symptom perception (Riegel et al., 2016). From its name, symptom perception delineates

identification of HF symptoms and precedes self-care management. Another term was added among HF literature consisting of self-care efficacy which can be used interchangeably with self-care confidence. Self-care confidence influences both self-care maintenance and management (Cené et al., 2014; Riegel et al., 2016). Self-efficacy is defined mainly by how patients monitor and manage their HF symptoms by complying to the HF management (Riegel et al., 2016).

Buck and colleagues conducted a mixed methods study to examine the dyadic experience with HF self-care. Twenty-seven dyads were recruited with these sample characteristics (patients: mean age 76.6, 66 % males, 52 % LVEF <50 %; caregivers: mean age 64.1, 74 % females, 52 % spousal relationship, remaining types: child, friend and unknown) (Buck et al., 2018). The majority of the dyads were found to have inadequate self-care. The majority of the recruited dyads were congruent in their HF self-care categorization (78 %). With respect to the congruent dyads, collaborative HF self-care was the most common approach (85.7 %), followed by the caregiver (9.5 %) and patient oriented (4.8 %) care types. In what concerns the self-care appraisal, HF patients scored better in self-care maintenance (56 %) than in self-care management (19 %) and self-efficacy (22 %). The higher score in self-care maintenance indicated that patients were capable of performing their daily HF care. Conversely, caregivers scored higher than their paired HF patients in the self-care management (33 %) reflecting superiority in symptom management. As discussed, HF self-care is determined by the patients and caregivers' specific determinants, in addition to their interdependence. Hence, HF self-care was found to be complex and experienced within a dyadic context (Buck et al., 2018).

Scoping on the dyadic interdependency, Bidwell and colleagues explored the dyadic determinants directing HF self-care maintenance and management. This secondary data analysis re-examined three-hundred-sixty-four dyads with these sample characteristics (patients: mean age 76.26, 57 % males, 54 % married, 52 %, mean HF duration 59.65 months \pm 48.99, 43 % NYHA III/IV; caregivers: mean age 57.44, 52 % females, 33 % spousal relationship, remaining types: adult child (48 %), others (19 %), 49% employed) (Bidwell et al., 2015). Findings outlined that both patients and caregivers' contribution to HF self-care maintenance were inadequate ($p < 0.001$ for both) with dyadic variabilities. Looking first at the individual characteristics, some factors were linked to either enhancement or decline in HF self-care. For patients, male gender and high caregiver physical quality of life predicted worse self-care management ($p < 0.05$ for both). Better cognition and patient-reported mutuality was linked to better self-care management ($p < 0.05$ for both). Emotional quality of life (QOL) was significantly correlated with better self-care management and enhanced caregivers' contribution. Significant determinants for caregivers' contribution to patients' self-care management consisted of perceived social support and positive mutuality, non-spousal caregiver role, frequent hospital admissions and superior patients' physical QOL. Caregiver strain did not present as a significant determinant for the caregivers' input in HF self-care; this could be related to the positive perceived relationship quality among patients and their caregivers. Enhanced HF self-care management practices was determined by the perceived relationship quality for both patients and caregivers. This study has highlighted the dynamic nature of HF self-care influenced by individual (patient or caregiver) determinants along with the dyadic determinants' interdependency (Bidwell et al., 2015).

Along the same line, Lum and co-investigators explored caregiving in 19 caregivers of patients living with HF (mean age 59, 95 % females, 58 % married, 47 % employed full-time, 58 % spousal relationship) (Lum et al., 2014). Findings showed a positive association between dyadic relationship quality and caregiver benefit ($p= 0.05$). Whereas a significant negative correlation was found with the relationship quality and both caregiver burden ($p < 0.0001$) and depression ($p= 0.0001$).

In another study, also conducted by Bidwell with other co-investigators, a meta-analysis reviewed fifteen articles with the aim of examining the impact of caregiver well-being on patient outcomes (Bidwell et al., 2017). It was found that higher caregiver strain was significantly correlated with patient's symptom overload ($p < 0.001$) and lower patient quality of life ($p < 0.001$). The interdependency between caregiver determinants (strain) and patients' outcomes (symptom load, QOL) was also observed (Bidwell et al., 2017; Hooker et al., 2015).

Studies addressing HF self-care were reviewed. There was a strong emphasis on the shared aspect of self-care. Indeed, HF self-care is affected by within-individual (dyad) determinants along with their interdependence in a dyadic context (Bidwell et al., 2015, Buck et al., 2018; Riegel et al., 2009). Moreover, patients living with an LVAD have already experienced HF at large until the LVAD therapy presented as an advanced surgical intervention. Literature will be examined to address what has been studied on the LVAD recipients and their caregivers to date.

b. Quantitative Inquiry on Patients Living with an LVAD and their Caregivers

Quantitative studies addressing LVAD recipients focused on prominent assessments ranging from functionality, control of HF symptoms including the emotional and psychological components, to the quality of life (Okam et al., 2020).

Lee and colleagues studied the correlation between LVAD implantation and change in HF symptoms. A total of 86 patients were recruited with 64 recipients of LVAD therapy as BTT and 22 as DT (mean age of 53 ± 14.4 , 79.1% males, 15% diagnosed with depression/anxiety, majority in NYHA Class III-IV). Assessments were conducted for four times: pre-LVAD and post LVAD implantation at 1, 3 and 6 months (Lee et al., 2018). After six months of LVAD implantation, significant improvement in health related QOL was noted for both BTT and DT patients at 6 months ($p = 0.031$ and $p = 0.028$ respectively). Also, improvement in symptoms such as sleep-wake disturbances, depression, and anxiety was noted in both patient groups. For implanted patients on DT, significant improvement was assessed in symptoms such as dyspnea and sleep difficulties when compared to baseline pre-LVAD implantation and BTT patients ($p < 0.05$ for dyspnea and sleep disturbances). Interestingly for the pre-LVAD depression's assessment, patients eligible for DT showed greater depression score through PHQ9 as those planned for BTT with moderate depression. It was followed by a small reduction in depression score initially ($p = 0.025$) and a prominent improvement six months later ($p = 0.003$). Anxiety scores were elevated at pre-LVAD assessment for both categories. Post LVAD implantation, BTT patients were less anxious at 1 month ($p < 0.001$) with a plateauing score six months later ($p = 0.256$). This could be explained as patients on BTT considered

the LVAD as a temporary process awaiting heart transplantation. Mild Initial reduction was noted for patients on DT at one and three months ($p = 0.064$) with a notably improved anxiety score at 6 months ($p = 0.006$) (Lee et al., 2018). In congruence with other studies, this study associated the LVAD implementation to the marked improvements of the patients' quality of life, HF symptoms, and psychological health (Udelson & Stevenson, 2016; Schroder & Milano, 2017). It also outlined the indication for LVAD implantation as a factor to consider given the inter-variabilities of the procedure related impact (Lee et al., 2018).

In a mixed-method design, Modica and colleagues studied twenty-eight patients implanted with an LVAD to explore the impact of the LVAD on their quality of life (QOL), psychological symptoms and coping (96% males, mean age 54 ± 11 , mean duration of mechanical support 16 ± 12 months, majority in INTERMACS level 2-3) (Modica et al., 2014). Pre-and post LVAD implantation scores reflected statistically significant improvement in the mental component (SF36, $p = 0.002$) and the physical component (MLHFQ, $p = 0.02$). Psychological symptoms reflected unchanged scores pre-and post LVAD implantation. Though this study showed varying improvements in the LVAD recipients' quality of life, emotional distress remained. Coping seemed to play an important role in the acceptance process. Indeed, avoidant coping was correlated significantly with anxiety ($r = 0.732$, $p < 0.001$) and depression ($r = 0.764$, $p < 0.001$). In this study, the qualitative component assisted to fully cover the emotional dimension for LVAD recipients (Modica et al., 2014).

In examining the correlation between patients' psychological Symptoms and VAD Implantation, eighty-seven patients pre-and post VAD implantation were studied (mean age

of 58, 77% males, 75.8% married, 45% destination therapy, 95.4% LVAD type) (Weerahandi et al., 2017). By psychological symptoms, depression and anxiety consisted of the symptoms investigated using their related modules pertaining to the Patient-Reported Outcomes Measurement Information System (PROMIS) Short Form 8a (SF8a). For the depression domain, a reduction in depression scores was noted post implantation ($p = 0.03$). As for the anxiety component, the mean anxiety score decreased over time ($p < 0.001$). When controlling for the indication for LVAD implementation (DT or BTT), the reduction in anxiety scores remained ($p < 0.001$ and $p = 0.03$ for BTT and DT respectively).

Another study's findings also supported patients' improvements with the LVAD implantation. However, worse health related QOL pre-and post-implantation were obtained when compared to the normative US adult population (Grady et al., 2014). Building on that, another study addressed how post implant complications affect patients' health related QOL (Rizzieri et al., 2008).

Furthermore, the LVAD implantation did not affect the implanted patient alone; it also results in caregivers' life changes (Cicolini et al., 2016; Marcucilli et al., 2014). Bidwell and colleagues studied the changes in quality of life, depression and anxiety among patients implanted with an LVAD and their informal caregivers prospectively (Bidwell et al., 2017). For this purpose, they recruited forty-one dyads with these sample characteristics (patients: mean age 53.8 ± 14.2 , 85.4 % males, 51.2 % NYHA class III, 62.5 % BTT; caregivers: mean age 54.7 ± 11.4 , 80.5 % females, 73.2% spousal relationship, with the remaining parental relationship to the patients). Data collection occurred at three time intervals: pre-implantation, at one and three months post LVAD implantation. In congruence to literature findings, implanted patients experienced statistically significant

improvements in their QOL post implantation, in addition to their depressive symptoms and anxiety scores ($p < 0.001$ for all). Contrarily, caregivers experienced worsening QOL from pre-to post implantation ($p = 0.03$). Caregivers' PHQ-8 scores and BSI scores were stable ($p = 0.22$ for depression, $p = 0.45$ for anxiety). Depression and anxiety were not significantly correlated among patients and caregivers at pre-implantation ($r = 0.06$). Also, high depression and anxiety scores for patients were correlated to higher scores for their caregivers at three months post implantation ($r = 0.31$ for depression, $r = 0.55$ for anxiety). This study highlighted how the person reported outcomes (QOL, depression and anxiety) vary inversely among dyad members with the LVAD implantation. The caregivers' specific outcomes seem to worsen and remain affected all throughout the implantation trajectory (Bidwell et al., 2017).

Within the same spirit, another study conducted by Bidwell and other investigators aimed to examine the dyadic determinants of patient QOL and caregiver strain post LVAD implantation. Fifty dyads were recruited (patients: mean age 54.6 ± 13.9 , 84 % males, 40 % NYHA class III, 28 % DT; caregivers: mean age 54.7 ± 12.5 , 82% females, 76% spousal relationship, with the remaining parental relationship to the patients) (Bidwell et al., 2018). Data collection occurred at four point intervals: pre-implantation, at one, three and six months post LVAD implantation. Regarding the patients' QOL, similar findings were obtained; hence, supporting the literature consensus on the improvement in QOL post LVAD implantation (Bidwell et al., 2017; Weerhandi et al., 2017). Positive quality relationships reported by caregivers at baseline were significantly related to an improved patients' QOL from one to 6 months post implantation ($p = 0.01$). Thus, caregivers' support and positive dyadic relationship were considered as a determinant for patients' QOL. When

controlling for the caregiving relationship, having non-spousal caregivers was significantly related to the worsening of patients' QOL from one to six months post-implantation ($p = 0.02$). HF symptoms affected patients and their caregivers likewise as HF symptoms were related to worsened patients' QOL at baseline ($p < 0.001$) in addition to greater significant caregiver burden ($p = 0.04$). Adding to the shared care concept, dyads shared the HF symptoms as well. Concerning caregiver strain, a moderate upsurge occurred during the period following implantation until one month ($p < 0.05$) then normalized progressively back to baseline caregiving burden at 6 months ($p < 0.05$). This upsurge can be explained with the stressful immediate changes associated with the early LVAD implantation phase. Caregiver strain resulted mainly from time, social, and physical constraints. In short, this study supported the LVAD experience's bidirectional impact on both patient and caregiver entities. Person specific outcomes related to either patients or caregivers exerted a two-way influence on the other dyad members in return (Bidwell et al., 2018).

Quantitative studies examined the positive and negative effects subsequent to the LVAD implantation experience. Numerous studies elucidated the positive changes in patients' QOL and control of HF symptoms post implantation (Bidwell et al., 2017; Bidwell et al., 2018; Modica et al., 2014; Weerahandi et al., 2017). Implanted patients did not experience the LVAD process alone. Prominent life changes were incurred on the caregivers as well. Caregiver strain or burden, used interchangeably, had been quantitatively studied. Quantitative appraisal of the LVAD experience is challenging as questionnaires are prone not to capture all related experiences pertaining to both dyad members (Modica et al., 2014). To enrich the findings and move beyond numbers,

qualitative overview addressing patients and caregivers of HF patients and LVAD recipients will be conducted.

2. Qualitative Studies

In line with quantitative studies addressing patients living with HF and LVAD, qualitative studies complement findings by providing a detailed and in-depth overview of the patients' needs (Buck et al., 2013; Paturzo et al., 2016; Roston et al., 2020; Taylor et al., 2017). As such, qualitative literature on patients living with HF and LVAD along with the caregivers' perspectives will be addressed.

a. The Qualitative Inquiry on Patients Living with HF and their Caregivers

Given the complexity and chronicity of HF, patients experienced cyclic and progressive worsening of symptoms with concomitant lifestyle changes and challenges (Taylor et al., 2017).

In a phenomenological study conducted by Paturzo and co-authors, thirty patients with HF were interviewed to gain an in depth understanding of their lived experiences (76% males, age range between 48 and 86 years, 70% in NYHA class I or II). Thematic analysis yielded seven themes that will be reviewed. Participants informed that HF instigated *major life changes* affecting their employment status, functional abilities, and their family and social lives. With enhanced dependency on their family caregivers, a doubting perception of their autonomy and capabilities dominated. HF symptomatology, mainly dyspnea, impaired their functional abilities for social engagement resulting in *HF*

related social isolation. While some participants beheld the limitations imposed by HF with *anger*, others maintained their *willingness to live*. The determination to sustain life was primarily instilled from familial support and encouragement. The resort for *spirituality relieved* and assisted some patients to cope with their HF. Given the complexity of HF, participants endured thoughts of *uncertainties related to their future*. *Death* seemed *inescapable* for patients with advanced HF in NYHA III-IV (Paturzo et al., 2016).

With all these lifestyle restrictions, changes and challenges, patients with HF are compelled to adapt and cope. Li and colleagues completed a qualitative descriptive study examining the self-care coping processes among patients living with HF (27 participants, 63% males, mean age of 63 years, 93% married, majority in NYHA class II-III). Once the patients started to experience HF symptoms and changes in their abilities to carry regular activities of daily living, the coping process started by *responding to the HF self-care*. First things first, they dealt with their fears, worries and uncertainties among other negative feelings generated by their HF condition. This enabled them to accept their HF diagnosis, lifestyle modifications and self-care regimen. They struggled maintaining their personal preferences with the HF needed self-care. To overcome these struggles, they decided to *find ways to live with their HF*. Faith, social support, and information literacy were possible means to adapt to a life with HF. Analogous to the acceptance in the grieving process, patients with HF finally accept their condition and restructure their life perspectives and meanings (Li et al., 2018).

Similarly, Nordfonn and colleagues explored the experiences of patients living with HF in what concerns the burden coupled with the HF treatment and self-care. Seventeen patients were interviewed (Male to Female ratio 11:6, mean age of 61.5 years, NYHA class

II-III). Two themes were generated to reflect on these experiences: emotional challenges and troublesome self-care (Nordfonn et al., 2019). With a new HF diagnosis, a new life emerged loaded with functional limitations and symptom burden. Patient perceived the dependency on caregivers as an emotionally pressure with feelings of guilt at times. These emotional challenges were concomitant with the bothersome self-care. Self-care activities were difficult to complete; yet, considered as essential foundation of treatment (Durante et al., 2019). Overwhelmed by the additional self-care tasks, patients reported lack of information and education on HF treatment and self-care. Medication regimen was considered the hardest of all tasks (Nordfonn et al., 2019).

Caregivers also contributed to the patients' self-care maintenance and management (Durante et al., 2019; Vellone et al., 2015). The caregivers were responsible to ensure compliance with the prescribed medication regimen and dietary restrictions. They have also contributed to patients' knowledge development in efforts to enhance symptom monitoring and management (Buck et al., 2015). They were the primary collaborators linking patients with HF and the healthcare professionals (Bangerter et al., 2019). These tasks were easily mentioned and talked about when compared to when they are lived nonstop. Caregivers were often the first to identify symptoms of HF and worsening of the patient's condition. This was followed by a decision on whether they need to seek emergency care or contact the healthcare professionals (Wingham et al., 2015).

Despite the HF being a specific diagnosis for a patient, living with HF was a shared experience with lifestyle changes also incurred on their caregivers (Joo et al., 2015). The needs of HF patients were complex, variable, and unstable as they fluctuate through periods of clinical stability to periods of health. This taxes back on their caregivers as they have to

deal with uncertainty, fears and doubts (Wingham et al., 2015). Transitioning to their role as caregivers occurred continuously in congruence with the progressive feature of HF progression (Wingham et al., 2015). They needed to emotionally support their loved ones living with the HF; but at the same time, they had to preserve their well-being and emotional health (Vellone et al., 2015; Wingham et al., 2015). This balance was not only limited to the emotional domain. Indeed, caregiving for patients with HF challenged the caregivers' status quo. It interfered with their career stability, financial needs, life goals, and personal well-being (Bangerter et al., 2019; Hamilton, 2016; Wingham et al., 2015). Caregiver burden would result when these personal particularities were unmet or affected (Bangerter et al., 2019).

The impact of HF on patients and their caregivers was examined from the effect of HF on these two entities distinctly. Moreover, literature has addressed another facet of the HF's impact affecting the patient-caregiver relation. The HF self-care activities took place in a dyadic context where both dyad members share their lives along with their HF (Buck et al., 2013). Both dyad members shared life decisions, health related decisions, HF management interventions, and lifestyle modifications (Bangerter et al., 2019). This shared process was directed primarily by the patient-caregiver relationship. The interaction between patients and their caregivers had been studied and classified into four types of dyadic care: patient oriented, caregiver oriented, collaboratively oriented, and complementary oriented (Buck et al., 2013). While the first two approaches clearly indicated how either the patient or his/her caregiver act independently to meet the HF's care needs. For the collaborative oriented type, dyads collaborated and shared HF decisions and actions together. While, complementary oriented dyads divided HF care in a non-

overlapping approach. When this dyadic relation displayed disagreement, HF care got compromised (Bangerter et al., 2019). Certainly, HF care was complex and contextual as it was bound to diverse antecedents and determinants (Buck et al., 2018).

Likewise, patients living with an LVAD experienced one of the HF disease management trajectories. They have already experienced HF symptomatology and imposed lifestyle changes. The improvements in symptom burden were nevertheless accompanied by new imposed needs, lifestyle adaptations and challenges (Casida et al., 2011; Ottenberg et al., 2014).

A meta-synthesis of seven studies, conducted by Abshire and colleagues unveiled four-time specific phases that impact the LVAD experience along with coping strategies. These studies were conducted in the United States (4), United Kingdom (2) and Denmark (1) with a mean participant age of 52.3 years. These outlined phases consisted of the pre-LVAD phase, hospitalization phase, early adaptation phase and late adaptation phase (Abshire et al., 2016).

b. The LVAD Experience's Four Specific Phases

i. Pre-LVAD phase

The *pre-LVAD phase* was recognized as an emotionally distressing period dominated by symptom overload and fear of death (Abshire et al., 2016). This phase did not include some constant timeframe as unstable and sicker HF patients were implanted quickly. This resulted in a rather short period of time for patients and their caregivers to adapt with the concept of the new device. During the pre-LVAD phase, the focus was

shifted to the acute postoperative period while dismissing thoughts on the future lifestyle despite the educational activities (Abshire et al., 2016).

ii. Hospitalization Phase

The recovery post operatively was then considered challenging as it is not restricted to the acute post-operative phase but extends to a new lifestyle adjustment (Casida et al., 2011). This lifestyle adjustment imposes drastic changes altering previously established routines. The patient and its main caregiver were left to acquire a combination of basic and complex tasks ranging from simple activities of daily living to handling device connections and alarms (Casida et al., 2011). The *hospitalization phase* consisted of basic learning on how to manipulate the LVAD with a major dependency noted on the healthcare team (Abshire et al., 2016).

iii. Early Adaptation Phase

The activities of daily living have undergone major modifications with hygiene, sleeping and clothing being affected. Marcuccilli & Casida (2012) reported on the body image alteration with LVAD placement and its significant impact on the patient's quality of life. With the altered body image, clothing has been reported as a challenge while healthcare professionals tend to disregard its influence and take adaptive processes for granted (Marcuccilli & Casida, 2012). As for sleeping activity, the sleep position was considered challenging until a comfortable position was found. Dependency on caregivers occur for hygiene related activities specifically bathing and dressing changes (Casida et al., 2011). Moreover, it was recommended for a qualified electrician to check the home environment for safety and needed modification to meet the needs of the new device prior

to the hospital discharge. Throughout this early adaptation phase, patients' feelings fluctuated between an appreciation of remaining alive to an apprehension of their capacity to handle such device (Casida et al, 2011). Coping with LVAD did not only consist of physical and technical changes but it also imposed psychological and social adjustments (Brouwers et al., 2014). Stress complaint remained even with appropriate and strong social support. It was only during the mid to late adaptation phase when a daily living routine is established that the stress starts to fade away. As for social dynamics, interpersonal and social rapports evolved both positively and negatively with themes of dependency (Casida et al., 2011). In the early adaptation phase, all these adjustments are perceived as sources of distress and anxiety.

iv. Late Adaptation Phase

Up until the late adaptation phase, patients would have then considered the LVAD as a new body component (Casida et al., 2011). It marked the acceptance phase where proficiency with device handling is reached, a gratitude for a new life was felt lessening dependency. Patients with established strong social support reached often times this acceptance successfully (Abshire et al., 2016; Okam et al., 2020).

Throughout these four phases, lifestyle changes occur filled with challenges and difficulties (Casida et al., 2011). For that, patients resorted to different coping strategies to overcome these difficulties and adapt. This meta-synthesis delineated three main coping approaches that guided patients living with an LVAD. A *problem focused coping* strategy consisted of acquiring the necessary skills to complete their activities of daily living with some degrees of independency. It was noted that the strong social support extending from

caregivers to family members and friends facilitated the modifications of the patients' lifestyles. For some patients, the return to their old pre-LVAD routine with the LVAD related modifications fostered the revival of normalcy. The *emotion focused coping* strategy consisted of managing their expectations in order to regain confidence, strengthen independency, and maintain a positive life outlook. Independency was viewed as a prominent challenge these patients endured with their desire to regain their independency. This desire was limited by the LVAD restrictions imposing the need for assistance, in addition to their caregiver's fear and control. For some, getting in contact with newly implanted patients assisted in regaining confidence, value and meaning. Faith, prayers, and *spirituality* supported the patients in their adaptation to a new life post LVAD implantation (Abshire et al., 2016).

Positive coping mechanisms would flourish into the end outcome of a new "normal life" (Casida et al., 2011). Patients and their caregivers experienced these LVAD phases with time inter-variability due to their coping processes and support systems (Abshire et al., 2016; Okam et al., 2020). Although delineated by phases and timeframes, the LVAD experience was complex and diverse. This results in challenges amongst qualitative literature to explore the true essence of the LVAD experience.

c. Challenges with the Qualitative Literature Analysis of the LVAD Experience

Despite the standard surgical procedure, nursing and medical management, the LVAD implantation process yielded diverse life related experiences (Overgaard et al., 2012). The dyadic perception and experience of the LVAD will be reviewed based on the

LVAD's indication as destination therapy (DT) or bridge to transplantation (BTT). It is important to address the similarities and differences of the dyad's experiences with the LVAD to obtain the true essence of what they endure and live through. There is a need to examine if the quality of life improves and balances with the challenges and subsequent lifestyle changes for both members of the dyad. All these in mind, there is a challenge for qualitative literature to investigate their experiences given all these inter-differences and variabilities. An overview will illuminate on what is known in the literature and what it is still needed to be identified.

i. Coping with LVAD implantation as DT versus BTT

The indication for LVAD implantation as BTT or DT resulted in different life experiences for its implanted patients. The end outcome encompasses the main difference as patients will either undergo heart transplantation or sustain life with an LVAD. Although these patients shared the same experience with LVAD implantation, different perspectives on life with an LVAD were documented in the literature.

In a study conducted by Overgaard and colleagues, ten patients with their LVADs implanted as a BTT were interviewed in Denmark (60% Males, age range between 19 and 63 years) (Overgaard et al., 2012). Participants considered the LVAD implantation phase as part of the preparatory period preceding heart transplantation. Their feelings fluctuated between relief, anger and impatience. Having an LVAD stabilized their health status and provided a source of relief. Yet, the LVAD brought on additional lifestyle changes and complex device maneuvers to be handled. The driveline was perceived as an LVAD related

burden (Modica et al., 2015). These changes were met with anger as they waited for a heart donation and transplantation. Impatience resulted from the uncertain waiting time, unguaranteed transplantation outcome and desire to reach a normal life (Modica et al., 2015). Participants considered life with an LVAD implanted as BTT as a period when their real life was placed on hold as they waited for the heart transplantation process to be completed (Overgaard et al., 2012). Placing their lives on standby mode were explained by the temporary LVAD experience impeding adaptation and coping with the LVAD phase (Modica et al., 2015).

Given the transient aspect of the LVAD experience, patients on BTT perceived adaptation to the LVAD as a surplus to their preferred outcome with heart transplantation (Overgaard et al., 2012). Conversely, patients on DT foresaw the LVAD as the only advanced surgical intervention to limit the symptom burden and preserve their clinical stability (Ottenberg et al., 2014). In the meta-synthesis conducted by Abshire and colleagues, the indication for LVAD implantation was not specified with an exception of one study. The latter focused on patients with an LVAD implanted as DT; an option Ottenberg and colleagues considered as an imposed choice. Twelve patients were interviewed in the United States to explore their perspectives with DT (92% Males, median age of 71.5 years, median LVAD support of 1.37 years) (Ottenberg et al., 2014). These patients acknowledged a new life chapter with the LVAD implantation. For them to take advantage of this new opportunity in life, they had to balance the pros and cons with the implanted LVAD. Patients balanced the positive outlook in health status' improvement with the burdened lifestyle changes. The burden consisted of device handling and the modification of activities of daily living, mainly with bathing and clothing (Ottenberg et al.,

2014). Their life goals and expectations shifted to meet those that remained applicable after LVAD implantation. This balanced perspective facilitated coping, acceptance and adjustment with the new LVAD lifestyle (Abshire et al., 2016; Ottenberg et al., 2014).

It is imperative to acknowledge both different perceptions when exploring the experiences of patients living with the LVAD. Despite the LVAD implantation being an unvarying life addition with its subsequent lifestyle changes, patients for DT or BTT perceived and adapted to it differently. This adaptation required lifestyle adjustment to meet with the added demands of the LVAD therapy. Regardless of the implantation's indication, the LVAD aims to control symptom burden and improve quality of life (Udelson & Stevenson, 2016; Schroder & Milano, 2017). Literature on how the LVAD affects the quality of life of patients and their caregivers will be presented.

ii. Quality of Life with LVAD Implantation

In assessing the quality of life of patients living with an LVAD, Sandau and colleagues completed a grounded theory study to conceptually define the quality of life of patients living with an LVAD. For that, eleven patients were recruited (73% Males, average age of 60 years, 54.5% BTT). Participants linked having a good quality of life with their abilities to perform some of the activities of daily living perceived important (Sandau et al., 2014). The conceptual definition of quality of life for patients living with an LVAD aligned with the five domains; being physical, emotional, social, cognitive and spiritual. On the physical level, patients had to adapt to a new routine post LVAD implantation with difficulty faced at first. The adaptation phase was motivated by their willingness to regain

their independency vis-à-vis their activities of daily living with lessened dependency on their caregivers. Interestingly, female patients complained of discomfort resulting from the heavy weight load of the LVAD related components. On an emotional level, patients experienced a myriad of feelings. Anxiety was associated with their hospital discharge and transition back to their homes. Depressive symptoms persisted for around two weeks marking the early period directly post LVAD implantation. Some encountered frustration while others enjoyed being symptom free depending on their coping strategies. Socially, patients were dependent on caregivers at varying magnitudes. Efforts were undertaken to preserve productivity, positive self-esteem, and self-image as they go through familial role changes. Concerning intimacy, patients reported improvements in sexual activity with control of HF symptoms. It was essential to note that the majority of recruited patients were married with their spouses being their primary caregivers. Nonetheless, they reported annoyance from the driveline and the external LVAD components; a challenging variation they adapted to. Regarding the cognitive domain, some patients reported concentration difficulties, memory losses and troubled thought processes. These complaints were resolved with time. Spiritually, patients credited their faith and support with the LVAD need for life sustainment (Sandau et al., 2014).

It is fundamental to note that these findings were obtained from a non-diverse sample: mostly males, majority married with spouses as main caregivers, and varied LVAD indication. Patients perceive their quality of life from a personal viewpoint. The outlined domains are fluidly experienced. The advantage of qualitative literature consists of its ability to capture the detailed patients' experiences (Sandau et al., 2014). Similar findings were observed in a systematic review of nineteen studies exploring the concept of quality of

life for both patients living with an LVAD and their caregivers (Adams & Wrightson, 2018).

Additionally, the indication for LVAD implantation also played a factor with the patients' quality of life. Patients with their LVAD implanted as BTT considered the LVAD as only bearable for the transition until heart transplantation (Standing et al., 2017).

Conversely, patients on DT were forced to accept the LVAD as the only therapy available for them to remain alive and symptom free (Ottenberg et al., 2014; Adams & Wrightson, 2018). With the LVAD implantation, patients often reported improved quality of life secondary to the control of HF symptomatology (Adams & Wrightson, 2018; Casida et al., 2011; Ottenberg et al., 2014; Park et al., 2012). This literature consensus did not mark a linear relation between LVAD implantation and improved quality of life (Adams & Wrightson, 2018). Patients might experience enhanced psychological distress due to the LVAD related complications and dependency on caregivers' assistance (Rizzieri et al., 2008). Naturally, the LVAD implantation decision presented as the only alternative besides death (Kitko et al., 2016). For some patients, the LVAD implantation did not fulfill patients' expectations in terms of improved quality of life (Kitko et al., 2016).

Concisely, the LVAD experience is complex, challenging and laborious to both members of the dyad. The aim of the LVAD as a therapy is to improve symptom burden, stabilize and sustain lives of implanted patients; hence, optimizing their quality of life (Udelson & Stevenson, 2016; Schroder & Milano, 2017). But these life changes do not impact the patients as one distinct entity. These changes indeed affect their caregivers as well.

d. LVAD Implantation's Impact on Caregivers

Although the LVAD implantation process involved the patients primarily, it did impact their caregivers' lives alike (Adams & Wrightson, 2018; Baker et al., 2010; Cicolini et al., 2016; Majid et al., 2016). As previously discussed, quantitative studies have described caregivers' psychological determinants, quality of life and caregiver burden (Bidwell et al., 2018; Kirkpatrick et al., 2015). Consistently, qualitative studies have also addressed the life changes and experiences of caregivers of patients living with an LVAD. Some qualitative studies have addressed caregivers of patients with their LVAD implanted as BTT; while others included those responsible for DT only. Different qualitative methodologies were utilized from descriptive qualitative to grounded theory but mainly phenomenology.

Cicolini and colleagues performed an integrative literature review addressing family caregivers of patients living with an LVAD. Fifteen studies were reviewed with diverse qualitative methodologies (10 qualitative studies, 6 studies conducted in Europe, remaining 9 in the United States). Ten of these studies focused on caregivers of patients living with an LVAD primarily (Cicolini et al., 2016). Three main themes reflecting the caregivers' experience with the LVAD were obtained; themes comprising of *emotional distress*, *responsibility* and *coping strategies*. Caregivers experienced emotional fluctuations throughout the LVAD experience (Akbarin & Arts, 2013; Cicolini et al., 2016; Majid et al., 2016). All through the pre-LVAD implantation phase, caregivers felt overwhelmed, stressed and anxious (Akbarin & Arts, 2013). This *emotional distress* remained even after hospital discharge where caregivers reported added *responsibility* and lifestyle changes

(Marcuccilli & Casida, 2012; Marcuccilli et al., 2014). To cater for the patients' needs, caregivers were responsible for the dressing changes, care and technical handling of the LVAD (Casida et al., 2011; Egerold et al., 2012). This responsibility was coupled with self-doubt (Akbarin & Arts, 2013), burden (Kaan et al., 2010), regret (Baker et al., 2010), sacrifice (Baker et al., 2010), and endurance (Egerold et al., 2012). All these in picture, caregivers adjusted their lifestyle to accept the LVAD while resorting to *coping strategies*. This acceptance was often reached with time and determination in addition to faith, prayers and social support (Kaan et al., 2010; Kitko et al., 2013; Marcuccilli & Casida, 2012).

Adding to the findings of the literature review previously discussed, Streur and colleagues conducted a systematic review of quantitative and qualitative studies synthesizing caregivers' life experiences with the LVAD (Streur et al., 2020). For the qualitative synthesis, eight studies were reviewed (qualitative descriptive (4), phenomenology (2), mix methods with descriptive/ grounded theory (2)) with five studies examined in common. This review yielded three themes being caregiver role, coping strategies and LVAD decisions. There is a caregiving role shift post LVAD implantation necessitating adaptation; new routines are established (Kirkpatrick et al., 2015; Kitko et al., 2013; Marcucilli et al., 2014). The same concept of heightened responsibility re-emerged to meet the patients' needs and demands (Kirkpatrick et al., 2015; Kitko et al., 2013; Adams & Wrightson, 2018). Though satisfied with their caregiving activities, caregivers were persistently worried, overwhelmed, and burdened on a physical and psychological level (Kirkpatrick et al., 2015; Marcucilli et al., 2011). To endure these challenges, caregivers resorted to numerous coping strategies, as previously discussed, based on personal preferences and choices. Some caregivers would seek a break time from the round-the-

clock caregiving's responsibility; others would emotionally energize when meeting the patient's needs (Egerold et al., 2012). An additional finding examined interestingly the patient-caregiver dyadic perception of the LVAD implantation's decision. Feelings of uncertainties, bewilderments and healthcare team dependency were coupled with the LVAD decision. Caregivers struggled in balancing their desire for the LVAD as a life-saving therapy with the perceived subsequent burden post implantation (Blumenthal-Barby et al., 2015; McIlvennan et al., 2015).

In harmony, a meta-synthesis conducted by Majid and colleagues reviewed eight studies in the qualitative literature addressing the caregivers of patients who underwent LVAD implantation (Majid et al., 2016). The caregiver's experience was divided into three major time related phases. The first stage delineated the implantation decision and the period until the LVAD implantation. During this phase, caregivers experienced emotional instability with the LVAD viewed as an imposed decision. Immediately post LVAD implantation, caregivers would perceive the LVAD and its components with anxiety and tension. Moving to the middle stage, the period following hospital discharge and early home recovery where the caregivers' lives were transformed. The newly added caregiving responsibilities embraced the patients' fragility and recognized the need to adapt to new lifestyle changes. The late stage marked the late adaptation period for caregivers, albeit variabilities with the LVAD indication as DT or BTT (Majid et al., 2016).

Similar to the disparate perspectives of patients with DT and BTT, caregivers experience the LVAD differently. For the caregivers of patients on BTT, the LVAD experience was contemplated as a temporary intermediate until heart transplantation. As it is short-lived, guaranteed the heart availability, caregivers tend to disregard the LVAD

related burden and complexities (Majid et al., 2016). Indeed, caregivers were committed to deliver the needed patient care, adjust their lifestyles, sacrifice their priorities and adapt to their new roles (Baker et al., 2010). Caregivers comprehended that the LVAD implantation stabilized patients' clinical status until a heart became available for their loved ones (Baker et al., 2010; Majid et al., 2016). The full focus and expectations were linked to the heart transplantation process. Parallel to the LVAD as BTT, caregivers of patients living with an LVAD experienced the same early and middle stages as depicted by Majid and colleagues. The main difference relies in the permanent need and dependency on the LVAD. They recognized the worrisome and burdensome nature of the LVAD right from its implantation time. Their life perspective had shifted to a life dominated by stress, anxiety and worry (Marcucilli et al., 2014). However, they were aware of their new responsibilities and caregiving tasks and determined to meet their patients' needs (Cicolini et al., 2016; Marcucilli et al., 2014). In the late adaptation, caregivers accepted the LVAD as part of their new lives; it being a given rather than a burden (Majid et al., 2016).

As discussed, caregivers of patients living with an LVAD experienced prominent life changes varying from added responsibilities, emotional instabilities, uncertainties, self-doubt, gratitude, regret, worry, and more. Each caregiver responded differently depending on the coping strategies one resorted to; possible assistive determinants were not limited to faith, social support, strong morale (Cicolini et al., 2016; Majid et al., 2016; Marcucilli et al., 2014; Streur et al., 2020). A handful of qualitative studies have addressed the caregivers' experiences with the LVAD process acknowledging their essential roles (Casida et al., 2011). It is imperative to note that the term "caregivers" encompasses a wide array of familial relationships: mother/father, wife/husband, sister/brother. Each caregiver

experienced the LVAD first from his primary role as a member to the patient's family. Literature has synthesized what caregivers go through and how they react and adapt. The synthesis did not address the inter-variability of the caregivers' experiences given their primary roles. A comprehensive inquiry is needed to answer the numerous questions, concerns and clarifications needed to get the full picture of the caregivers' experiences when living with a patient dependent on an LVAD temporarily or permanently. This literature gap needs to be answered to proficiently uncover the caregivers' needs, thoughts and challenges.

Global Literature on patients living with HF and LVAD along with the caregivers' experiences was reviewed from a dual quantitative and qualitative lens. The LVAD implantation process was found to be complex, demanding and life-changing for both members of the dyad, patients and caregivers (Abshire et al., 2016; Brouwers et al., 2014; Casida et al., 2011; Cicolini et al., 2016). After a thorough review of published studies, the dyad's experiences with HF were first portrayed and followed by the LVAD related experiences. Moving from a global literature synthesis, studies exploring HF and LVAD with both patients and caregivers' experiences will be addressed in the Lebanese context.

B. Empirical Literature of patients living with HF and LVAD in the Lebanese context

Studies reviewing HF self-care in Lebanon will be presented. As the research on the Lebanese LVAD population is scarce, the only descriptive study examining the characteristics of an institution's LVAD population will be reviewed.

1. Quantitative Studies

HF self-care has been adequately researched in the Lebanese context. Deek and colleagues snapshotted the national HF population from the outlook of acute HF hospital admissions. The study included eight sites geographically distributed in an aim to represent the Lebanese HF population (Deek et al., 2020). Data collection was completed over a month period and covered 137 admissions with the following characteristics (52 % females, mean age 72 ± 13 years, 52 % illiterate, mean CCI score of 4 ± 2 , mean EF 41 ± 11 , HF ischemic etiology 52 %, mean length of hospital stay of 8 ± 7 days). The majority of participants were found to be frail (87 %) with moderate depression (mean PHQ9 score of 14 ± 6). Younger patients reported worse depression than older ones ($p = 0.006$). Self-care scores depicted inadequate HF self-care. Higher literacy level was significantly associated with higher self-care score ($p = 0.002$) and lower likelihood for frailty ($p = 0.013$) (Deek et al., 2020).

Similarly, Massouh and colleagues conducted a correlational study exploring whether self-care confidence mediated the relation between social support and HF knowledge with self-care (Massouh et al., 2019). Hundred patients with HF were recruited (mean age 67.59 ± 12.09 , 76 % males, 35 % employed, 78 % married, majority in NYHA II- III (39 % and 48% respectively), mean HF duration of 8.42 ± 7.11 years). Findings addressed HF self-care and various correlations among HF self-care processes. Patients with HF had high level of social support (ESSI scores with a mean of 24.72 ± 6.07). With respect to HF self-care, the sample exhibited adequate self-care maintenance (43 %), self-care management (55 %), and self-care confidence (47 %). Inadequate self-care among HF

patients was assessed (mean SCHFI scores < 70 %) with an overall adequate HF knowledge. Despite knowledge on HF behaviors, the majority of patients did not consistently apply these behaviors explaining the inadequacy in HF self-care. In terms of correlational analysis, self-care confidence positively predicted adequate self-care maintenance by mediating both social support and HF knowledge. Similarly, self-care confidence positively predicted self-care management by means of moderating HF knowledge (Massouh et al., 2019).

Moving from the literature scoping HF in the Lebanese context, studies published on the Lebanese LVAD population are limited to one descriptive retrospective study presenting the characteristics of one institution's LVAD population implanted between 2010 and 2020 (Hamdan et al., 2020). As reported, this institution covered the largest LVAD population in Lebanon; seventy-eight patients were implanted with a total of 82 LVAD pumps. Their LVAD population consisted of 68 % males with a mean age of 49.8 ± 12.7 years, a mean LVEF average of 18 ± 2.8 % and a mean INTERMACS of 2. The HF etiology consisted mainly of ischemic cardiomyopathy (49 %) followed by dilated cardiomyopathy. The LVAD implantation's indication varied between BTT (53 %), DT (42 %) with the remaining 5 % as bridge to recovery. Implanted devices were dominantly HeartWare VADs (71 %) followed by Heartmate II and III (8 and 17 % respectively). The procedure's costs were covered by only two insurance bodies those of the National Social Security Fund and the Lebanese Army. The LVAD related complications varied between driveline infection (28 %), pump thrombosis (12 %), and cerebrovascular events (20 %). Concerning pump thrombosis, interventions included thrombolysis therapy and two pump exchanges with one associated death from recurrent pump thrombosis post exchange.

Cerebrovascular events were ischemic (6 %) and hemorrhagic (14 %) in nature with 31 % mortality contribution. Hamdan and colleagues noted similar survival outcomes as documented in the International Registry for Mechanically Assisted Circulatory Support (IMACS). In congruence, survival rates consisted of 80 %, 68 % and 65 % for 12 months, five and ten years respectively (Hamdan et al., 2020). Out of 53 % of implanted LVADs as a BTT, seven patients had heart transplantation with a mean support period of 1303 ± 213 days. This is largely due to the absent awareness and organ donation culture. Procedure costs, delayed advanced HF care and deficient organ donation were acknowledged as three challenges hindering the Lebanese LVAD experience (Hamdan et al., 2020). This study described the characteristics of LVAD recipients from one medical center. Determinants such as social support, financial status, and quality of life were not examined. It did not address pertinent characteristics of their primary caregivers in addition to the patient-caregiver dyadic relationship. As the LVAD experience is not merely experienced by patients alone, caregivers' lives are also changed with difficult early adaptation and possible burden (Blumenthal-Barby et al., 2015; McIlvennan et al., 2015). Additionally, there is a literature consensus emphasizing the caregiver's prominent role in supporting LVAD recipients (Abshire et al., 2016; Casida et al., 2011; Kaan et al., 2010; Kitko et al., 2013; Marcuccilli & Casida, 2012).

In line with the deficient organ donation discussed earlier in Lebanon, Degheili and colleagues confirmed the suboptimal cadaveric organ donation (Degheili et al., 2020). Consistently, the National data organ donation rate was estimated at 0.825 donor per million Lebanese citizens yearly (National health statistics report in Lebanon, 2012). In examining the causes behind the paucity in organ donation, Ghorbani and co-authors

explored the causes of family members' refusal for organ donation in Iran (Ghorbani et al., 2011). Iran has a family oriented culture guiding major decisions such as organ donation; it mirrors the Lebanese family oriented culture. The study, retrospective in nature, consisted of a telephone assessment of potential causes. Eighty-one family members (55.5 % of population) of potential donors who refused organ donation at one time were contacted (72 % males). Prominent findings encompassed mainly denial and refusal of brain death diagnosis (44.4 %), belief in miracle (13.6 %), and religious beliefs (8.6 %). Similarly, family members' decisions were fundamental for organ donation and procurement in Lebanon. Religious misconceptions and lack of organ donation knowledge and culture remained as key obstacles in cadaveric organ donation and transplantation (Degheili et al., 2020).

Subsequent to the deficient organ donation process, the LVAD brought forth an advanced HF management intervention to ensure clinical stability and control of HF symptomatology (Schroder & Milano, 2017; Udelson & Stevenson, 2016). Patients implanted on BTT experienced long mechanical circulatory support with an undetermined heart transplantation timeframe if performed. For patients on DT, the LVAD interposed as a new variable in the lives of implanted patients and their caregivers. This variable turns into constant as the LVAD accompanied the dyad throughout their lifetime together. The challenges associated with the LVAD implantation and lifestyle changes for both members of the dyad were discussed previously. Literature has delineated the complexity of the LVAD experience (Abshire et al., 2016; Casida et al., 2011). It is indeed not simple to live with the LVAD from the patient and his/her caregiver's perspectives. However, knowledge on the challenges and needs of the dyad post LVAD implantation is lacking in the Lebanese

context. We need to address whether their experiences conform to the discussed global literature. We need to understand what the LVAD means to them and how they cope with it on day-to-day basis. For that, phenomenological methodology presents as a convenient approach to explore their lived experiences.

2. Qualitative Inquiries

Qualitative studies addressing both HF and LVAD patients along with their caregivers are scarce. To overcome this constraint, qualitative literature specific to the Lebanese population will be reviewed. Phenomenological research was conducted on Lebanese oncology patients. One of the studies completed by Doumit and colleagues explored the lived experiences of Lebanese oncology patients on palliative care (Doumit et al., 2007). Ten participants were interviewed (Male to Female ratio 4:6, age range of 21 and 71 years, 90 % married). Eight main themes were derived from the interviews. Participants conveyed *distress from their dependency, dislike for pity and hospital stay*. Their disease uncertainty generated a lot of *worry* experienced by all family members. *Reliance on God and divinity* was a common finding across all participants. They developed *fear of non-productivity, pain and suffering*. Emphasis was placed on *the need for communication* (Doumit et al., 2007).

A year later and within the oncology population, Doumit and other co-authors published another phenomenological study addressing the caregivers' lived experiences. Nine primary caregivers were interviewed (Male to Female ratio 7:2, age range from 41 to 70 years) (Doumit et al., 2008). These caregivers had different familial roles: two mothers,

two daughters, two sisters, one brother, a husband and a wife. Similarly, eight core themes were derived. Caregivers reported *living with uncertainty and fears* and *in a state of emergency*. A *loss of happiness* was coupled with them *sharing the pain* of their patients. They acknowledge their *feelings of added responsibility*. Specific to the oncology population, some lived with the *dilemma of truth telling* as the patient was not told the actual diagnosis. In similarity to the patients' perspectives, caregivers also reported *distress from being pitied*, and *reliance on God*. Caregivers were fully committed and lived through their own worries and fears (Dumit et al., 2008).

Shifting to a similar population, qualitative research has also explored cardiac patients and their caregivers. Dumit and co-investigators conducted a qualitative descriptive study informed by ethnography (Dumit et al., 2008). Fifteen cardiac patients with coronary artery disease and thirteen caregivers were interviewed with the aim to explore their perceptions of cardiac self-care (patients: Male to Female ratio 8:7, age range between 40 and 80 years, 80 % married; caregivers: age range from 33 to 82 years, relationship role: spouse (6 wives and 2 husbands), four daughters and one son. The overarching theme explained the unfamiliarity of the concept of self-care. Five themes also summarized their perceptions. Despite the unfamiliarity, dyads *engaged in self-care practices*. *Barriers* (socioeconomic status, political situation, and familial responsibilities) and *facilitators* (support from spouses and children) were identified in alignment with the Lebanese Culture. Causes of cardiac disease were linked to *stress and lifestyle determinants*. Despite their illnesses, patients *thanked God* while *accepting their fate*. They perceived the *cardiac event as a life and death warning* (Dumit et al., 2008).

In another analysis also conducted by Dumit and others, the role of the Lebanese caregivers in cardiac self-care was qualitatively reviewed (Dumit et al., 2015). Thirteen family caregivers were recruited (age range between 33 and 82 years, 77 % females [6 wives and 4 daughters], 33% Males [2 husbands and 1 son]). Data analysis identified one overarching theme (unfamiliarity with the term self-care) in addition to three themes. First, caregivers were committed into the patients' care from a moral and emotion duty out of obligation and responsibility. Second, both patients and caregivers labeled the self-care performed by the term "interdependent care". Last but not least, caregivers supported through multiple caregiving roles being the emotional, informational, and instrumental roles. From its name, the emotional role entailed emotional support and distraction from stress and worry. The caregivers' informational role oversighted the implementation of daily self-care behaviors. As for the instrumental role, caregivers ensured the availability of medications, healthy meals and medical follow-ups to optimize self-care practices. Interestingly, the caregivers' gender seems to influence behaviors and compliance to cardiac self-care with females outperforming male caregivers. Also, familial support played a prominent role with cardiac self-care. This study derived the perspectives of caregivers when caring for a cardiac patient in alignment with the familial oriented Lebanese culture (Dumit et al., 2015).

In this chapter, the literature addressing patients living with HF and LVAD along with their caregivers was examined from the dual quantitative and qualitative approaches. Sharing the same HF experience, LVAD recipients live through an additional advanced therapy. The LVAD procedure is complex as it elicits major lifestyle changes to the dyad. All this in mind, we aim to explore the lived experiences of LVAD patients and their

caregivers with the purpose of gaining an in-depth understanding of the needs and challenges of living with an LVAD. The significance of the study lies mainly on it being the first study to explore qualitatively the experiences of Lebanese patients living with an LVAD along with their caregivers. It is an initial assessment of the needs, challenges and difficulties the dyad face with LVAD implantation. These characteristics are pertinent to the Lebanese context. The inquiry on the caregivers' thoughts and perspectives is of utmost importance as the Lebanese culture follows a family oriented approach (Dumit et al., 2015). Findings will depict the specific Lebanese experience to compare and contrast with established literature scoping patients living with an LVAD and their caregivers. To achieve the study's purpose, chapter III will present the methodological approach guiding the study's procedure, data collection and analysis. Chapter IV will depict the study's sample demographics and participant profiles. It will be followed by chapter V elaborating on the study findings. Lastly, chapter VI will discuss those results and synthesize them to recommendations for further research and clinical practice.

CHAPTER III

METHODOLOGY

The purpose of this study is to explore the lived experiences of patients living with an LVAD and their family caregivers in Lebanon. This is to gain an in-depth understanding of their LVAD related life experiences. It is imperative to note that family caregivers will be referred to as caregivers all through the study. Also, both dyad members are familiar with the LVAD terminology as they usually receive extensive education before and after the operation. In this chapter, the study's methodology and procedures will be discussed. It will be followed by measures implemented for human subject protection and the approach used for data analysis.

A. Research Design

This study followed a qualitative phenomenological approach to explore the dyad's lived experiences with the LVAD. According to Creswell & Creswell (2018), phenomenology is a research method that explores the lived experiences of individuals sharing common characteristics of a certain phenomenon. As participants' experiences are unique to each individual, the aim of phenomenology is to depict the essence of the lived experiences through a merged description of the phenomenon at stake (Creswell & Poth, 2018).

Historically, the phenomenological research started with its Godfather Husserl back in the twentieth century and evolved with extended views by other philosophers including Moustakas, and van Manen among others (Creswell & Poth, 2018). For Husserl, the definition of phenomenology was broad to include the essence of the consciousness (Smith, 2013). This philosophical stance was later modified and expanded to different theories while preserving the lived experiences as the main realm of phenomenology (Creswell & Poth, 2018). Moustakas (1994) added on Husserl's definition that experiences are considered conscious processes. His theory consists of transcendental phenomenology where the researcher brackets his judgement in the exploration of any phenomenon (Moustakas, 1994, as cited in Creswell & Poth, 2018). For van Manen, phenomenology is considered as the study that captures the true essence of the participants' experiences (van Manen, 2014, as cited in Creswell & Poth, 2018). Van Manen's theory consists of hermeneutical phenomenology where the researcher interprets collected findings to form an understanding of the participants' lived experiences (Creswell & Poth, 2018).

There are several defining features in phenomenological research that will be presented. First, the aim of this type of research is to explore and study a certain phenomenon or experience. This phenomenon is experienced by a diverse sample of individuals with a small sample size ranging from three to fifteen participants. These participants then share their experiences on this specific phenomenon. The focus lies around those experiences where the researcher maintains an external position in a process termed bracketing and reduction. Data collection occurs mainly through participant interviewing. After the completion of data collection, a data analysis plan is followed that

starts with statements' selection and moves to the extraction of meanings. This is followed by a detailed description of the essence of the participants' lived experiences (Creswell & Poth, 2018). The strength of phenomenological research comprises mainly with the richness and depth of findings to capture the full description of the explored phenomenon.

The scope of this study is to explore the lived experiences of Lebanese patients living with an LVAD and their caregivers. As these life experiences remain unacknowledged, this phenomenological approach is relevant and convenient to explore the participants' related life experiences with the LVAD. Using a qualitative phenomenological approach, we aimed to explore the lived experiences of patients living with an LVAD and their caregivers with the purpose of gaining in-depth understanding of their perspectives on living with an LVAD. These findings will first inform healthcare professionals on the lifestyle related challenges that accompany the dyad in their new LVAD lifestyle. It will then optimize the educational program catered to fulfill the needs of patients undergoing LVAD implantation. This program will effectively prepare the dyad to cope with the related difficulties and challenges that patients living with an LVAD and their caregivers might experience.

B. Participants and Study Setting

We recruited a convenience sample of five patients living with an LVAD along with their identified caregivers; a combined total sample of ten participants. Patients living with an LVAD were recruited if they:

1. Aged 20 years and above

2. Had an identified caregiver
3. Had their LVAD implanted for more than six months
4. Followed up their medical care at American University of Beirut Medical Center (AUBMC)

Patients whom are younger than twenty years old, diagnosed mental health illness and had their LVAD implanted for less than six months were excluded. The six months timeframe is congruent with literature findings necessitating a three months period for adaptation following hospital discharge post LVAD implantation (Casida et al., 2011).

Patients along with their caregivers were recruited during their outpatient visits to the cardiology clinics at AUBMC from September 2020 to October 2020. The recruitment process applied will be discussed thoroughly.

C. Procedures

Recruitment started after obtaining IRB approval. The attending physician of LVAD patients and the HF Clinical Nurse Specialist were briefed on this study's purpose to facilitate participants' recruitments. They conveyed the latter to their patients by handing them the invitation letters to participate in this study. The invitation letter was made available in both Arabic and English languages and entailed the contact address of the Principal Investigator (PI). The PI had no prior relationship with the dyad, patients living with an LVAD and their caregivers. Willing participants contacted the PI who then informed the Co-Investigator of the participants' interest in joining this study. Next, the Co-Investigator contacted the dyad via telephone call to provide a detailed description of the

study' purpose and procedures. An agreement to meet on their clinic appointment date was arranged upon showing interest. The PI or Co-Investigator then approached willing participants at AUBMC outpatient clinics and introduced the study's purpose and significance to the participants. Participant rights, voluntary participation and data privacy were all explained and emphasized. Once the participant agreed to enroll, the PI or Co-Investigator asked him/her to sign the consent form shown in Appendix A, available in both Arabic and English languages. Data collectors consisted of either the PI or Co-Investigator. After signing the informed consents, data collectors proceeded to collect data on sociodemographic and health determinants of patients living with an LVAD and their caregivers. This was followed by a face to face interview with the patient and his/her caregiver; each interview was performed independently and consecutively. Independent interviews optimized their ability to express their thoughts freely while avoiding possible influence and interference among them. The data collection's two main processes will be reviewed in depth to reflect on the essence of the participants' encounters.

Sociodemographic data and health determinants of patients living with an LVAD and their caregivers were collected using the participants' form presented in Appendix B. Regarding medical related data, the HF Clinical Nurse Specialist or HF attending physician shared these de-identified data with the Co-Investigator. This step promoted data privacy and confidentiality as data collectors did not access patient's private medical files. Data anonymity was preserved by assigning codes to every dyad recruited. The Co-Investigator assigned a study code for every patient and caregiver recruited. For instances, the first dyad to be recruited was assigned patient 1/caregiver 1 as an identifier. The data collected

through the form safeguarded data privacy by following the de-identified study codes. Once the form was completed, a face to face interview was scheduled to conduct the phenomenological interviewing.

D. Interview Setting

An audio-taped face to face interview were accordingly set at the participant convenience. The interview was scheduled and conducted in a place and time convenient to each participant. All participants preferred to be interviewed at the cardiology outpatient clinics either before or after their scheduled appointments. Also, all participants consented for interviews' audiotaping. The interviews were conducted individually and separately with the patient living with an LVAD and their identified caregiver in order to eliminate any undue influence. A spacious private room was reserved at the cardiology clinics for each participant recruitment. It consists of a clinic room with a desk and three chairs with an examination bed that can be hidden by a curtain. This clinic room had a door that was locked when the interviews started to ensure privacy without any disruption. As data collection was completed during the Covid-19 pandemic, strict measures were performed in compliance to the IRB recommendations. As such, the participant was seated on a chair distanced from the data collector with at least one-and-a-half-meter gap. Also, the data collectors and participants wore their face masks at all times.

E. Data Collection

An unstructured interview approach was followed in congruence with the phenomenology's methodology requirements. The interview started with an open-ended question asking participants to describe their lived experiences with the LVAD. A topic guide presented in Appendix C was used for probing on life experiences. The guide was constructed initially in the English language. Since the interviews will be conducted in the Lebanese Arabic language, the question script was translated to colloquial Lebanese and back translated by an independent person fluent in both English and Arabic. The dyad's interview started in the same order by interviewing the patient living with an LVAD first then followed by the identified caregiver. The interviews for patients living with an LVAD were longer than the caregiver's ones. The patient's interviews time varied between thirty and fifty-five minutes long. The caregivers' interviews lasted between fifteen and fifty minutes long. This was expected as the main study's purpose was to gain the in-depth life experiences of patients living with an LVAD. None of the participants were restricted to share their lived experiences. Most of the participants considered the interviews as ventilation experience; this explains the length variability of the phenomenological interviews. Field notes were recorded and document right after each dyad's interview. These notes focused on participants' gestures, facial expressions, requests and emotions. Debriefing sessions were planned after each dyad's interview. The co-PI who conducted the interviews reflected on the whole interview experience while sharing perceptions on participants' engagement.

Each interview's transcript was given the same study code as the sociodemographic and medical data. For instances, the study code "Interview Patient 1/ Interview Caregiver 1" was used to identify the first dyad's interview. We recruited five patients living with an LVAD along with their caregivers resulting in a total sample size of ten total participants. In a qualitative study, the study's sample size is not simply driven by a limited number of recruited participants. Although for phenomenology, Creswell (1998) recommended around five to twenty-five participants while Morse (1994) suggested a minimal sample size of six participants. But these numbers are not enforced as limitations guiding the study's sample size. On the contrary, the focus is allocated to the comprehensive, rich and high quality of data obtained to meet the study's purpose (Braun & Clarke, 2013). As this study followed the phenomenological approach, the sample size was eventually determined by the complete generation of themes capturing the true essence of the lived experiences of patients living with an LVAD and their caregivers.

To ensure data quality, the member checking process was embedded early on during the informed consent process. Participants were asked if they accept to be contacted through a telephone call with the study's preliminary results for member checking. Out of five dyads, two dyads consented to be contacted for member checking. They insisted to be contacted for member checking and verbalized excitement for the study's findings. The member checking process consisted of a telephone follow up where the derived meanings and themes were shared and reflected upon. Two telephone calls were completed with dyad 1 and 5, each call took around thirty minutes. Member checking entailed sharing the study's analysis plan and generated lived experiences with the recruited participants (Braun &

Clarke, 2013). This process ensured that the analyzed data reflect the true essence of the lived experiences of patients living with an LVAD along with their caregivers. As a process, member checking is congruent with the phenomenological purpose as the overall goal is to explore the lived experiences of patients and their caregivers. These lived experiences are subjective and privately endured by the participants. Data analysis is completed by the research team's members; all of whom are external to these private life experiences. Therefore, member checking comes as a vital step to enhance the study's credibility by optimizing the quality of the generated thematic analysis (Braun & Clarke, 2013).

After reviewing the study's procedures comprehensively, the measures implemented to preserve human subject protection will be examined.

F. Human Subject Protection

Before the study's initiation, approval from the American University of Beirut Institutional Review Board (IRB) was obtained, shown in Appendix D. The study procedures followed was based on IRB recommendations. The PI had no prior relationship with recruited participants; the Co-Investigator had no direct relationship as well. Therefore, there was no conflict of interest between the PI, Co-Investigator and the participants. The informed consent included the participants' approval on audio-taping the interviews. Consent forms were made available in both English and Arabic languages (Appendix A). Written consents were obtained and copies of the signed consent were given

to the participants. The researcher copies of the signed consent forms were stored separately in a folder located in a locked drawer at the Principal Investigator's office.

As interviews were audio-recorded, the records were safely stored in a password protected computer at the Principal Investigator's office. The content of the consent form described the study in lay language using clear and simple terms. Voluntary participation was emphasized as participants can end their participation at any time without any consequences. The consent form also included contact addresses for the principal investigator as well as the IRB office to address questions and concerns. Data were reported in aggregate form; thus, ensuring anonymity of data and privacy of participants. Medical related data were collected by the HF CNS and shared with the PI and Co-Investigator in a de-identified format; this was needed to avoid access private medical charts. This study's procedures were adequately implemented as described. Moreover, IRB's guidelines on the resumption of face to face interviews amidst the Covid-19 pandemic were strictly followed. Maintaining physical distancing and the use of face masks were respected all through the face to face encounters to minimize risks of health-related harms.

After presenting the measures implemented to safeguard participants' rights, the process of data transcription and analysis will be described. Colaizzi's phenomenological method guided this study's data analysis plan.

G. Data analysis plan

As interviews were audio-taped, electronic transcription through word processing was done verbatim in Arabic. Colaizzi's phenomenological method was used to analyze the

generated data. Data analysis was conducted by the PI and co-investigator who completed the process independently. Following this approach, the interviews' transcripts are read several times for familiarization (Morrow et al., 2015). After the record's transcription, the Co-Investigator read the written Arabic transcripts and then re-read the transcripts twice while listening to the audio records. After capturing the interviews' spirit and essence, pertinent sentences and statements related to the participants' lived experiences were highlighted and extracted from each transcript. For example, one significant statement was highlighted and extracted. This statement was then translated into English and back translated to Arabic by another research team member. The translated statement consists of the following excerpt:

“First phase [LVAD] gave me hope and the second phase [LVAD] made me realize that I was alive anew. I will follow what the doctor or his team order me. It is essential to note that the doctor's role is over with the success of the operation, thank God. The responsibility is now handed to the patient after the operation where each patient needs to self-care and act as his own doctor”. (Patient 1)

Similarly, all selected statements representative of the lived experiences of the participants were translated into English and back translated into Arabic by a professional fluent in the two languages to be used in presenting study findings. The selected statements were then used to construct understanding of the dyad's lived experiences. Data are then grouped to describe related lived experiences of patients and caregivers. These statements are then analyzed to generate in depth meanings. The meanings are clustered into categories and major themes. Right after, the PI and co-investigator met to discuss analyzed data as they settle on common ground. The translation was also reviewed by the study's research team members to ensure data credibility. This step was performed for all transcribed

interviews and their selected statements. All generated themes were grouped together to describe the lived experiences of patients living with an LVAD and their caregivers. A summarized description of the dyad's lived experiences was also provided. Once the data analysis was finalized, member checking was pursued. Generated themes along with the major statements were shared with willing participants for verification. In case of disagreement, analysis was modified to reflect the true essence of the lived experiences. Any relevant emerging theme was added to the analysis plan (Morrow et al., 2015).

H. Rigor

Qualitative research has different criteria within its different methodologies to ensure data quality or rigor (Braun & Clarke, 2013; Cypress, 2017). These criteria remain a substance of debate and controversy among researchers with an agreement on strengthening the quality of qualitative data (Cypress, 2017). The purpose of these criteria is not to limit qualitative researchers but to ensure data quality. The rigor of a qualitative study consists of the quality of the data generated and how they relay the purpose of the study. The concept of rigor is sometimes substituted by another concept which consists of Trustworthiness (Cypress, 2017). From its name, the concept of Trustworthiness highlights the truthful and authentic data generated by qualitative studies. Trustworthiness can also be considered as a building block of rigor (Cypress, 2017). The concept of rigor can combine two notions supporting data quality, reliability and validity (Creswell & Poth, 2018).

Validity can be exchanged with the concept of Trustworthiness as both aim to reflect data truthfulness and authenticity in the production of qualitative inquiry. The lived

experiences of patients living with an LVAD and their caregivers were subjectively lived and endured. For that, verbatim transcription and independent back-translation processes ensured the trustworthiness of the study's results.

As for reliability in qualitative research, it delineates the consistency in the implementation of research strategies (Cypress, 2017). To enhance the concept of reliability, a series of methodological strategies were integrated in the data collection process. Indeed, field notes were detailed to depict non-verbal movements, emotions and interview actions. For instances, when the interview with Patient 1 was completed and the audiotaping stopped, the participant requested to restart audio-recording as he wanted to add an important life experience. This action was documented and also recorded through the transcript as it attached more significance and value to the shared life experience. Audio-records preserved high quality recordings to maintain the essence of the interviews. The transcription process captured the interviews' spirits by highlighting short pauses with the use of “..” in the records, hesitation demonstrated by “...”, and non-verbal actions encircled by the brackets. Another reliability criterion consists of the Intercoder agreement, which entails the stability of the coding process among different transcripts when performed by different trained researchers (Creswell & Poth, 2018). This step was implemented during the data analysis process. With every transcription finalized and after familiarization with its contents, the co-Investigator highlighted selected statements and derived study related codes. This process was also reviewed by the expert PI to settle on a common ground for the data coding process. This process ensured that the data related codes reflected the true essence of the participants' lived experiences while preserving the

integrity of the same coding spirit through the different transcripts. All these methodological steps aimed to strengthen the rigor of this phenomenological study to capture the true essence of the lived experiences of patients living with an LVAD and their caregivers.

This chapter presented the study's methodology and procedures followed for this phenomenological inquiry. Using a qualitative phenomenological approach, the study aimed to explore the lived experiences of patients living with an LVAD and their caregivers. A total sample of ten participants were recruited at the AUBMC's cardiology outpatient clinics after obtaining AUB IRB approval. Measures were implemented to safeguard human protection. Face to face Interviews were conducted and sociodemographic data were collected. Colaizzi's phenomenological method guided the data analysis plan. In the next two chapters, participants' profiles and derived study findings will be presented thoroughly. Chapter IV depicts the participants' profiles and characteristics. And, Chapter V is an amalgamation of the derived study themes, meanings and summarized descriptions of the participants' lived experiences.

CHAPTER IV

PARTICIPANTS PROFILES

The purpose of this study is to explore the lived experiences of patients living with an LVAD and their caregivers. Using a phenomenological methodology, data collection consisted of face to face interviews completed with the patients and caregivers separately. Patients and their caregivers will be referred to as participants hereafter. Recruitment was completed at the Cardiology Outpatient clinics at AUBMC. A total sample of ten participants were recruited as five dyads volunteered to participate. The study findings mainly consisting of the generated themes, meanings and descriptions will be presented next in chapter V. To reflect on the true essence of these lived experiences, the participants' profiles will be presented in depth throughout this chapter.

As these lived experiences are private and personal, participants' characteristics will inform the study's findings. For that, the socio-demographic and health determinants of both members of the dyad will be described first. It will be followed by a presentation of the participant profiles based on what they reported. It will also take into account their living context in illuminating the true essence of their lived experiences.

A. Demographic Data of the Participants

Participants were recruited from the Cardiology clinics at AUBMC during their medical follow ups. Patients living with an LVAD routinely follow up on outpatient basis

accompanied by their primary caregivers. The research team had direct access to the patients implanted with an LVAD and following up at AUBMC. The research team was also familiar with the multi-disciplinary LVAD care delivery model provided. Based on that, the recruited sample followed a convenience sampling approach. The data collection process was completed over a two months period between September and October 2020. To start with the recruitment process, the HF Clinical Nurse Specialist informed the dyad about the study and its purpose by handing them the study's invitation letters (Appendix A). Willing participants were then approached by the Co-Investigator via a telephone call to provide a detailed description of the study's purpose and procedures. An agreement to meet on their clinic appointment date was arranged upon showing interest. Two dyad interviews were conducted right before the patient's appointment. While the remaining three dyad interviews took place after finalization of their health appointments.

The AUBMC LVAD program encompasses twenty-four patients since its establishment in 2009 until October 2020. Sampling was completed from the AUBMC LVAD population. Out of these twenty-four patients, one patient had successful heart transplantation and five patients have passed away. In line with the study's inclusion and exclusion criteria, the sample size was reduced. The following ten patients were excluded:

1. One patient who does not hold the Lebanese nationality.
2. One patient younger than twenty years of age.
3. Three patients with an LVAD implantation time of less than six months.
4. Three patients diagnosed with mental health illnesses, specifically depression.
5. Two independent patients following up without their caregivers.

Out of the total AUBMC LVAD population, eight patients living with an LVAD could have been recruited. From these eight patients, successful recruitment of five patients along with their identified caregivers was completed. The total study sample size consists of ten participants. A better visualization of the sampling strategy is depicted in the Figure 1.

The characteristics of the participants will be examined in terms of demographic and health related determinants. The characteristics of the volunteered patients living with an LVAD will be presented first; followed by a description of their recruited caregivers.

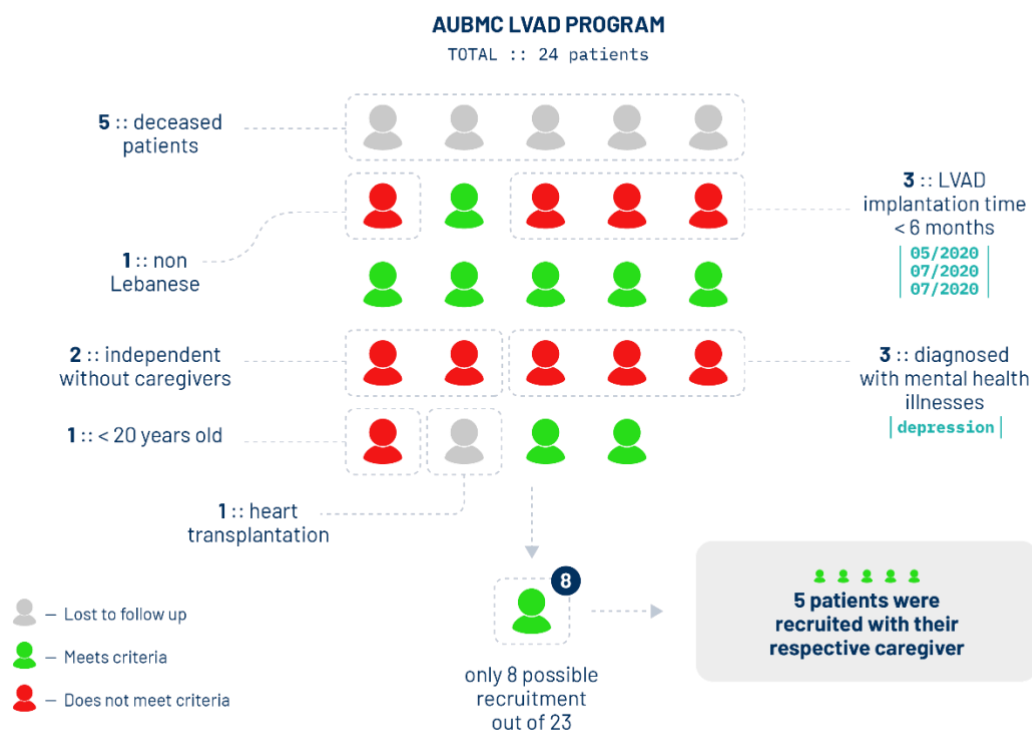


Figure 1 Convenience Sampling Approach

In terms of demographics, a gender-balanced sample of patients living with an LVAD was obtained. Three male patients and two female patients were recruited. Patients

had age variations from 48 years to 75 years with a mean of 58. One was single, one windowed and three were married. Educational preparation varied between elementary education for one, intermediate for three and one university education. Four out of five dyads had a yearly income ranging between 6000 US dollars and 12000 US dollars. The remaining fifth dyad had its yearly income between 12000 US dollars and 15000 dollars. It is essential to note that the recruitment process and data collection occurred when Lebanon was going through a major economic crisis. This crisis was outlined with inflation of prices and depreciation of the Lebanese Pound to the US dollar. The black-market US dollar rate is five to seven times its official rate. This can explain the limited yearly income and reported financial difficulties. All recruited patients were unemployed, benefited from the National Social Security Fund (NSSF), and lived with their caregivers. These five dyads had geographical residence variations with two dyads living in Beirut, one dyad in Mount Lebanon, and the other two in North Lebanon. It is imperative to note that Beirut, capital of Lebanon, incorporates the major and central sectors including the main healthcare services. These variations allowed to obtain diverse context related living perspectives.

In terms of health-related determinants, the Charlson Comorbidity Index (CCI) was used to assess for the disease burden, one year mortality risk and expected ten-year survival. The total CCI score ranged between 2 and 5 with a mean of 3.6. This indicates that one year mortality risk rises with the increase in CCI score from 26% to 85% for scores ranging from 2 to 5 respectively (Charlson et al., 1987). The mortality risk is consistent with the HF advanced stage, need for mechanical circulatory support and emergent LVAD implantation. The duration since HF diagnosis varied between three years and twenty years

with a mean of 11. Their HF etiology consisted of ischemic heart disease (40%), dilated cardiomyopathy (40%) and valvular disease, specifically aortic and mitral valves (20). All recruited patients had the HeartMate III implanted. The months since LVAD implantation extended from 11 months to 24 months with a mean of 17. Emergent LVAD implantation was predominant (60%). The New York Heart Association classification determined the HF functional limitation. The pre-LVAD NYHA score consisted of NYHA Class III (40%) and IV (60%). These findings are congruent with advanced Heart Failure necessitating mechanical circulatory support. Functional limitations improved post LVAD with NYHA classification changing to class I (60%) and II (40%). Health status improvement was clinically noted with the number of hospitalizations in the past year ranging from 0 admissions to 4 admissions (mean 1.8).

Patients reported a good relationship with their paired caregiver at sometimes (20%), often (20%) and always (60%). The care needed for the LVAD was primarily complementary (80%). A complementary approach depicted how both patients and caregivers were taking care of different aspects of the needed care; yet, balancing both efforts. The remaining care approach (20%) was caregiver oriented with the caregiver taking responsibility of the full patient's needed care.

For recruited caregivers, there was one male and four female participants aged between 42 years and 57 years of age with a mean of 49. Two of the caregivers were single merging the caregiver role with their duty as sister and daughter. The remaining three caregivers were married being the spouses of the volunteered patients. Four of them were

working and considered as the breadwinners for their families. Educational preparation varied between intermediate (40%), secondary (20%) and university (40%).

The demographic and health related determinants of both dyad participants will be presented in Tables 1 and 2.

Table 1: Demographic Characteristics of the Recruited Patients Living with an LVAD

Demographic characteristics of the recruited patients living with an LVAD			
PATIENTS :: N = 5			
// CATEGORICAL DATA			
:: Gender	Frequency	%	
♂ Male	3	60%	
♀ Female	2	40%	
:: Marital status			
Single	1	20%	
Married	3	60%	
Widowed	1	20%	
:: Living alone			
Yes	0	0%	
No	5	100%	
:: Number of people in household			
♂	1	20%	
♂♂	2	40%	
♂♂♂	3	20%	
♂♂♂♂♂	5	20%	
:: Yearly income			
6000 - 12000\$	4	80%	
12000 - 15000\$	1	20%	
:: Occupational status	Frequency	%	
Retired // Unemployed	3	60%	
:: Educational status			
Elementary	1	20%	
Intermediate	3	60%	
University	1	20%	
:: Good Relationship with caregiver			
Sometimes	1	20%	
Often	1	20%	
Always	3	60%	
:: Relationship category			
Caregiver oriented	1	20%	
Complementary	4	80%	
Health coverage			
NSSF	5	100%	
:: Heart Failure etiology	Frequency	%	
Ischemic heart disease	2	40%	
Valvular disease	1	20%	
Dilated cardiomyopathy	2	40%	
:: NYHA score			
Pre-LVAD			
NYHA III	2	40%	
NYHA IV	3	60%	
Post-LVAD			
NYHA I	3	60%	
NYHA II	2	40%	
:: LVAD device type			
HeartMate II	5	100%	
:: LVAD implantation			
Emergent	3	60%	
Non-emergent	2	40%	
// NUMERICAL DATA			
	Minimum	Maximum	Mean (± SD) *
:: Age in years	48	75	58 (± 11.212)
:: Heart Failure duration in years	3	20	11.2 (± 8.228)
:: Total CCI score	2	5	3.6 (± 1.140)
:: Duration of the LVAD hospitalization in days	17	27	22 (± 4.301)
:: Months since LVAD implantation	11	24	16.8 (± 6.181)
:: Number of hospitalization in the last year	0	4	1.8 (± 1.789)
:: Interview length in minutes	30	55	47 (± 9.747)
			:: SD Standard Deviation

Table 2: Demographic Characteristics of the Recruited Caregivers

Demographic characteristics of the recruited caregivers
CAREGIVERS :: N = 5

// CATEGORICAL DATA

	Frequency	%
:: Gender		
♂ Male	1	20%
♀ Female	4	80%
:: Marital status		
Single	2	40%
Married	3	60%
:: Living alone		
Yes	0	0%
No	5	100%
:: Yearly income		
6000 - 12000\$	4	80%
12000 - 15000\$	1	20%

	Frequency	%
:: Occupational status		
Currently working	4	80%
Retired/Unemployed	1	20%
:: Educational status		
Intermediate	2	40%
Secondary school	3	20%
University	2	40%
:: Relationship to the patient		
Spouse	3	60%
Sister/Brother	1	20%
Daughter/Son	1	20%

	Frequency	%
:: Living distance		
In same household	5	100%
:: Good relationship with patient		
Often	2	40%
Always	3	60%
:: Relationship category		
Caregiver oriented	1	20%
Complementary	4	80%

// NUMERICAL DATA

	Minimum	Maximum	Mean (± SD) *
:: Age in years	42	57	49 (± 6.272)
:: Number of people in household	1	5	2.60 (± 1.517)
:: Interview length in minutes	15	50	28 (± 16.047)

* :: SD
Standard
Deviation

B. Participant's Profiles

After presenting the characteristics of both recruited dyad members, the general impressions about every patient and his/her caregiver will be discussed. As the purpose of this study is to explore the lived experiences of patients living with an LVAD and their caregivers. The profile of every dyad will be depicted based on what they reported and the

interviewer's impressions. Safety measures implemented for Covid-19 were followed. Both participants and interviewer were wearing face masks while maintaining physical distancing. The study codes, discussed previously, will assist in presenting each dyad's profile. This is to maintain anonymity, privacy and de-identification. The profile presentation will be reported per dyad.

1. Dyad 1: Patient 1/ Caregiver 1

Patient 1 is a 65 years old male patient living with an LVAD since 2018. He is married to Caregiver 1 aged 57 years old with a 25 years old son. When the co-PI contacted this dyad to brief them in depth on the study's purpose and methods, they showed excitement to volunteer. They agreed and stressed on the need to conduct the lived experiences' exploration. As both reported, they did an exercise where they reviewed their whole experiences and planned how they want to go about sharing it. Their interest was clearly showing as they both shared their experiences freely and holistically. Patient 1 was smiling all through the interview, sitting comfortably while holding and caressing the LVAD bag. Experiences portraying hope, faith and social support were described. After around forty minutes of the interview, the audio-recording was stopped as the PI concluded the interview. The patient remembered that he wanted to share an important experience and asked to re-start audio-recording. The interview continued for another ten minutes where the patient shared a valuable life experience with the LVAD. He reported that the LVAD was a source of fear, worry and confusion as "perceived by others". He stressed on the "need to raise awareness" that patients living with an LVAD are not "terrorists" or "loaded

with bombs”. These safety related concerns may be linked to the geographical area given that this dyad reside in North of Lebanon.

Caregiver 1 highlighted the financial difficulties they are facing with the prices’ inflation by sharing examples. As she reported, her husband, son and herself are all unemployed. She shared her “financial worry”. Also, she explained that her son is unemployed as his university education was placed on hold during his father’s sickness and for financial reasons. They self-sustain through financial assistance from abroad with the help of the patient’s brother. She informed on the need for “financial sustainability” as an important necessity for a life with an LVAD.

Patient 1 and Caregiver 1 shared their experiences freely with interviews taking place for fifty and forty minutes respectively. They were all engaged through the interviews and did not even check the clock as they kept sharing unreservedly.

2. Dyad 2: Patient 2/ Caregiver 2

Patient 2 is a 56 years old male patient accompanied by his 42 years old sister, his caregiver. Both patient and sister live in the same household. Since his HF diagnosis five years ago, he was medically guided to have the LVAD implanted. But, he “disliked the idea” and eventually ran away after procedural explanation. He was “a few steps and moments away from death” until he had the LVAD implanted almost a year ago. He is single and attributed his “lack of responsibilities and commitments” as a facilitator for him to “deal with his disease”. He used to work as a private driver prior to the LVAD

implantation. He shared how the LVAD impacted his working status as his employers asked him “to stay home” when they saw the LVAD. Despite that, he reported that he is relieved from financial burden as they kept providing him with a reduced salary. His house is an owned property in Beirut which he recognized as a “cherished blessing”. At first, he seemed to be obstructed in sharing life experiences. But with probing questions, he was able to share his perspective. He even addressed limitations with intimacy and sexuality resultant from the LVAD and his single status. He also shared how his social engagement changed after LVAD implantation when he reported that “friends have been distant” due to health-related fears. But, he accepted the LVAD as part of his “destiny” meeting his desire to be “free of symptoms”. He focused on his independency with his sister being “responsible for dressing change on daily basis” only. He also reported that he felt “walking with the LVAD bag as strange”. He had concerns over his LVAD bag being considered as a valuable property; and for it to be “pulled away from” him. The Patient 2’s interview lasted for thirty minutes. During which, he illustrated the life perspective of a single patient without any commitments and how his single status facilitated his coping.

The caregiver consisted of his sister; her interview took around fifteen minutes. She reported that the LVAD came as an “imposed reality” necessitating forced adaptation; for the LVAD being its “only alternative”. Her daily routine was not affected as the patient was “independent”. Her only responsibility consisted of “his dressing change on daily basis” and the “adjustment of [her] working schedule for his medical follow ups”. Her interview was fast paced as her responsibility resolved around these two tasks. She reported relief with the LVAD “as he required to be admitted to the hospital every ten to fifteen days

because of congestion”. This routine cycle of hospital admissions occurred over a period of five years since HF diagnosis. She was then able to perceive it as “beneficial as it supported and assisted the heart”.

3. Dyad 3: Patient 3/ Caregiver 3

The third dyad volunteered to participate in this study. Once the study’s purpose and method were explained, they started automatically sharing some thoughts and perspectives. They had two clinic appointments with the HF CNS and HF attending physician that took around an hour each. They came all the way from Mount Lebanon. They still showed interest in participating after two hours of clinic appointments. It is important to note that the patient had three hospitalizations excluding his LVAD implantation during the past year. Four months ago, he was critically admitted to the hospital for Intraparenchymal hemorrhage. His condition has improved since his hospital discharge.

Patient 3 is the youngest recruited patient; he is married with two children, a 6-year-old boy and a 11-year-old girl. He was diagnosed with HF around three years ago and has his LVAD implanted a year ago. He was talkative and shared his experiences without any reserves. His interview took place over fifty minutes. At times, he needed re-direction to talk about the essence of his living experiences using probing questions. At first, he portrayed the LVAD to be “bulky” in size but he accepted it as it is “what God has planned for him”. He considered the LVAD as his “new life”. Not only for him, the LVAD brought a new life to “his family, his wife, his siblings and his brother living abroad”. He showed determination to live and the LVAD allowed his life continuity. He discussed the

challenges and changes associated with the LVAD. He stressed on the major role his wife has been doing. He verbalized that he has a “flaw in making her feel down” whether intentionally or not. His wife assisted him to complete his activities of daily living while “taking care of everything”.

The spouse of Patient 3, a 57 years old, accompanied him and reported her “moral duty to take care of her husband”. The interview completed was an emotional one, full of ventilation. She explained that she “did not accept the LVAD once it was presented as the only alternative”. She was forced to accept it as the “only therapy to save his life”. She explained that the “LVAD was implanted not only for the patient but eventually to both of them”. When asked about what makes her cope, she answered by “her children”. With this answer, she turned all flushed and started to cry. She then washed her face and took a deep breath as she insisted to resume with the interview. She reported that the LVAD “restrained him from living a normal life”. He “can no longer return to his working activity” with the LVAD making her the only breadwinner. She works as a school teacher; her salary covers the children’s school tuition fees. They receive a small financial assistance from his brother living abroad to cover living expenses. Still, the financial difficulties remain a source of “worry and anxiety” for her. She shared how she feels “stressed” with the dependency of her husband on her assistance. She is responsible for her children and husband. She explained that she ensures that all his needs are met, his activities of daily living completed and the LVAD dressing changed. A caregiver oriented approach was verbalized and depicted.

4. Dyad 4: Patient 4/ Caregiver 4

The fourth dyad consisted of a mother and her daughter. Patient 4 is a 75 years old female patient, widowed with three children. She happens to be the eldest of the recruited patients; living with HF for eight years after diagnosis. Her youngest girl, in her late thirties, accompanied her. They both reside in the same household. The eldest of her siblings reside nearby within a 10 minutes' drive. Both interviews occurred consecutively after two clinic appointments with the HF CNS and the HF attending physician; taking around an hour and thirty minutes.

Patient 4 was freely sharing her experiences in a positive outlook. She was holding her LVAD bag tightly over her lap all through the interview. She considered the LVAD as a “new chance in life”. After LVAD implantation two years ago, she explained how she “forced herself to strengthen and regain independency”. She focused on her independency in her activities of daily living “without any difficulty”. She mentioned that she is “changing her dressing on daily basis by herself”. She attributed significance to “bravery, willingness, and spirits” for coping.

The daughter of patient 4 shared her lived experience with the LVAD from the moment she heard of it until her late adaptation. She explained how she “did not accept” the LVAD as she “could not relate that her mother is dependent to a machine”. This idea “shocked her”. She reported how the device alarms “frightened her” and “changed her as a person”. Her sisters “took on the responsibility to take care of her” until she started to accept and adapt. But, “seeing her mother improve with acceptance eased the adaptation process”. Then, the LVAD became “part of their daily lives”. She presented her mother as

an “independent” person living a “normal life”. Her caregiving role consisted of handling device alarms, adjusting anticoagulation regimen and planning medical follow ups. She mentioned the need for “familial support” so the “patient can adapt and cope” with the LVAD. Her mother’s friends supported them as they accompanied her while the daughter was away at work. In case of any problems, they would directly report to her.

5. Dyad 5: Patient 5/ Caregiver 5

The fifth recruited dyad consisted of a female patient and her husband caregiver in their fifties of age. They have four girls: a twenty-three-year old, a twenty-two-year old, an eighteen-year old and a twelve-year-old. They live in the North of Lebanon, a place the husband described as “the area of the poor”. The husband is a taxi driver who benefit from the National Social Security Fund. Both participants shared their experiences directly and freely. The patient’s interview took around fifty-five minutes to complete. Similarly, the husband’s interview was completed in fifty minutes. These interviews occurred after two hours of clinic appointments each with the HF CNS and HF attending physician.

Participants had a lot of thoughts, perspectives and experiences to share and express. Time was not a barrier. They were both comfortable in sharing intimate and private details.

Patient 5 started by portraying her lived experience with HF and how she was “progressively losing her life”. She shared her traumatic experiences with the frequent pacemaker shocks. For her, the LVAD “changed her life”. She viewed the LVAD as a “lifeline” for “a new chance in life”. A chance she decided to hold on to for her “love of life”. She described how her lifestyle changed after the LVAD. She explained how she “got

rid of her dresses” and the need “for two-pieces outfits”. Showering was one of the difficulties experienced as it turned into a complicated process. The “weight of the LVAD” and body image alterations were additional difficulties. Faith helped her cope with the difficulties experienced from the LVAD. She was also supported by her husband and children. Her husband’s support was seen as most valuable. She reported that she was “intimated because there is a cable coming out of [her] abdomen” modifying her “feminine body”. This intimidation “inhibited her from removing her clothes in front of” her husband and “locking her bedroom’s door for dressing change”. She “used to ran away and sleep in her daughter’s bedroom or living room” to avoid him. But her husband was supportive and stressed that he “appreciates her body with or without a cable”. She had concerns over her husband leaving her. Again, her husband’s actions eliminated these thoughts. She regained her “self-perception as a queen”. She provided numerous examples of his care and attention. She explained the importance of “psychological support” in the recovery process and adaptation. This psychological support should be provided by the patient’s family. Without it, patients “would be left with depression”. She specified that for a married female patient, the husband matters most.

Once patient 5’s interview was completed, caregiver 5, the husband, verbalized content and satisfaction as his wife took ample time to ventilate and share her life experiences. Caregiver 5’s interview provided new insights on his caregiving role and lived experience with the LVAD. He started by sharing their struggle with the “progressive” worsening HF. He shared that his mother similarly went through the same disease trajectory before her death. Knowing the signs and symptoms, “this raised his suspicion” that his wife

has heart disease. Her HF was “progressively worsening” over a period of eight years necessitating emergent LVAD implantation a year ago. He laughed while sharing emotional thoughts and experiences. His laughs were not congruent with his non-verbal as his eyes were tearful and engorged. He stopped laughing when he reached their first transition from the hospital to their home. He described how he held her hand as they headed to the stairs leading to the third floor, the location of their apartment. This is when he started crying and sobbing. This was followed by silence and his attempt to stop and control his tears. He insisted then to resume the interview. He portrayed this experience with “victory” as his wife returned back home. He addressed all the patient’s concerns while providing his own perspectives and actions. One of the patient’s concerns consisted of her husband leaving her or resorting to polygamy. He elaborated on her concern by explaining that their religion allows polygamy. He was firm in responding that he considers himself “fully committed to his wife” without any second thoughts. He deliberately expressed “his willingness to leave his masculinity” granted she remains alive completing his family. He valued his wife as his life goal consisted of building his loving family. The interview was data rich as the husband ensured reporting of all related life experiences. With husband-patient caregiving relationship, he reported “heightened sensitivity” necessitating full attention and carefulness. He reported the need for vigilance as any comment can be perceived as devastating for the patient. He stressed on the importance and significance of husband/spouse support in caring for a married LVAD patient.

The patient was discharged home following LVAD implantation on the first day of the Lebanese uprising. A challenging period comprised of roads' closure, political instability, financial difficulties and economic challenges.

This chapter provided an insight on the demographics and health determinants of the recruited participants. An overview of the participants' key demographics is presented in Table 3 for a clearer visualization. Each dyad's profile was presented in terms of their living related context, report and interview reflections. These sample characteristics will help in capturing the essence of their lived experiences. Next, chapter IV will present the study's findings following Colaizzi's phenomenological method. Findings will mold the lived experiences of patients living with an LVAD and their caregivers in Lebanon.

Table 3: Overview of the Study Participants' Demographics and LVAD Support

Overview of study participants' demographics and LVAD support

<u>Patient</u>	<u>Age</u> (in years)	<u>Gender</u>	<u>Education Level</u>	<u>Marital Status</u>	<u>Primary Caregiver</u> (Age in years)	<u>Months since LVAD support</u>
1 ::	65	♂ Male	Intermediate	Married	Wife (57)	23
2 ::	56	♂ Male	Elementary	Single	Sister (42)	13
3 ::	48	♂ Male	Intermediate	Married	Wife (47)	11
4 ::	75	♀ Female	Intermediate	Widowed	Daughter (39)	24
5 ::	50	♀ Female	University	Married	Husband (50)	13

CHAPTER V

STUDY RESULTS

The purpose of this study is to explore the lived experiences of LVAD patients and their caregivers. Five dyads were interviewed at the Cardiology clinics at AUBMC. Following a semi-structured approach, audio-recorded interviews were completed with patients and their caregivers separately. The interview script mainly addressed what life with an LVAD means to the participants. Transcription was done verbatim in Arabic capturing the full essence of the interviews. Transcribed records were back translated to English by the investigators independently; an example on the back-translation process is presented in Appendix E. They were then compared to preserve the authenticity of the conducted interviews.

As discussed in chapter III, Colaizzi's phenomenological methodology guided the thematic analysis. After extensive immersion and deliberations, three hundred significant statements pertaining to the participants' lived experiences were extracted from ten transcripts. As it is a phenomenological study, simple descriptive statements were omitted as the purpose is to obtain an understanding of participants' lived experiences. An example on the extraction process of significant statements is included in Appendix F. Meanings were emanated from these statements and grouped into themes summarizing the participants' lived experiences (Appendix G). This thematic analysis was discussed by the PI and co-Investigator extensively. An expert faculty member on qualitative research in Lebanon also shared her input when finalizing the thematic analysis. After a rigorous analysis process, the research team merged the thematic analysis plan. Through telephone

calls, this plan was shared with three participants who consented for member checking. Their output was fully congruent with the study's results as it captured their lived experiences. No new experiences were added resulting in an enhanced study's rigor. The research team then agreed on the final thematic plan presented in table 4.

This chapter will first present the themes, categories and meanings supported by the participants' interview quotes. Each theme and its related meanings will be discussed thoroughly and separately. A summarized description will follow to portray the participants' lived experiences. This is to ensure an authentic description of the rich experiences shared by patients living with an LVAD and their caregivers.

Table 4: Final Thematic Plan

Themes	Meanings
<p>:: Theme I The lived LVAD journey from being doomed to a new life</p>	<p>1. LVAD decision 2. Health improvement 3. A new life to patients and their caregivers</p>
<p>:: Theme II Embodiment and attachment to the LVAD</p>	<p>1. Perceptions of the LVAD 2. Dependency on the LVAD and attachment</p>
<p>:: Theme III Living through: self-determination, coping and adjustment</p>	<p>1. Self-determination 2. Coping/Stages of grief 3. Adjustment is time dependent</p>
<p>:: Theme IV Patients and their caregivers shared facilitators and challenges of the LVAD experience</p>	<p>1. Facilitators to LVAD experience 2. LVAD related challenges</p>
<p>:: Theme V Despite the subsequent lifestyle changes, the LVAD brought hope and expectations</p>	<p>1. Lifestyle changes 2. Shared LVAD experience 3. Hope and expectations</p>
<p>:: Theme VI Patients and their caregivers were provoked by the perception of others about the LVAD machine</p>	<p>1. Being singled out 2. Unfamiliarity to the LVAD</p>

A. Theme I: The lived LVAD journey from being doomed to a new life

Theme I emerged from participants' description of their life journey from HF to the LVAD. Living with HF was viewed as gloomy, demanding and exhausting. Participants shared a transition of their lived experiences into a new life after the LVAD implantation. Three meanings were formulated illuminating this theme: 1. though the LVAD decision was not a choice, they then perceived it as a life saver; 2. health improvement noted with life comparison before and after the LVAD; 3. a new life to patients and their caregivers. To elucidate on these categories, significant statements and meanings will depict the participants' lived journey.

1. Though the LVAD decision was not a choice, they then perceived it as a life saver

The LVAD therapy was recommended as the “only option” for the management of HF (Patient 1). Building on a question addressed to another HF patient planned for LVAD implantation, Patient 3 asked, “I told him [patient] “*There is this ((pointing to the LVAD bag)) and [there is] death, which one do you prefer?*” [pause] I told him: “*you only have two choices, this*”.” The Patient 3’s statement highlighted that patients reach a point when they are left with two choices guiding their life trajectory. These two choices entail life with the LVAD against death. Patient 2 shared the necessity of the LVAD:

“Of course, I wanted to avoid [having the LVAD operation] and even the doctor tried all therapies but eventually he told me “you cannot live without it”. Another doctor I have consulted also told me “You cannot live [without it], it is not possible.”

All participants chose life over death as they agreed to have the LVAD implantation. Despite potential complications associated with the LVAD, dyads were determined that “*in between death and life, we choose infections*” (Caregiver 5). In this statement, infections were considered as the LVAD related complications.

The medical recommendation for the LVAD was coupled with the dyad’s desire to control HF symptoms and functionality limitations. Patients were responsible to suspend their health deterioration. Some patients were determined to live, “*not to end your life with your own hands*” (Patient 3). Their LVAD decision was also informed by their family commitments. They wondered what their children and significant others would have to go through if something bad ever happens to them. Though the LVAD was imposed as an advanced therapy, participants valued its significance. The LVAD was considered a life saver, “*a blissful addition in our lives*” (Patient 5).

2. Health Improvement noted when comparing their lives before and after the LVAD

The HF lived experience was recalled being a physically and emotionally demanding life phase. Dyads were living through “*cycles of pain, fear and sickness, going in and out of the hospitals*” (Caregiver 3). Participants experienced the progressive nature of heart failure, “*every day was worse than the previous, tiring all of us*” (Caregiver 5). They expressed how they felt “*threatened by death every moment of your life*” (Patient 5). Experiencing symptom overload and frequent hospital admissions were overwhelming and exhausting. Following the LVAD implantation, participants noted major health improvements. Patient 2 shared the control of HF symptoms with the LVAD implantation,

“[my breathing] changed, I used to be very short of breath, I couldn’t sleep when I wanted to [pause] the LVAD changed my life.”

As this statement indicated, the LVAD fulfilled its implantation goals as it was “essential for health improvement”, while pushing “life forward” (Caregiver 4). Patient 1 shared the difficult and challenging early recovery extending over a period of two to three months. Fatigue, physical weakness and poor appetite were predominately endured. However, the recovery process improved on daily basis with noticeable changes until complete recovery.

3. A new life to patients and their caregivers

Participants highlighted the transition of their experiences from living with HF to a life with an LVAD. Patient 5 conveyed the following:

“[The LVAD] made me love life even more [pause] when you are losing your life progressively [pause] Then, there is this thing [LVAD] that stops [death] halfway and redirects you back [to life] [pause] I believe that I regained five years of my life [pause] let’s make it seven years [pause] Regardless of the [device’s] weight, my [physical] capacities are those of a forty years old. So, I gained ten years.”

This statement demonstrated how the LVAD diminished the patient’s feelings of helplessness. For Patient 5, the LVAD allowed her to regain her life and physical health. Patient 4 added, the “LVAD gave me a second chance to live”. For other participants, the LVAD introduced a new life at large. An example on that would consist of a quote from Patient 4:

“It’s a loss if one gets scared [from the LVAD], don’t be scared as the LVAD provides you with a new life [pause]. If it weren’t for the LVAD, I would be gone [pause] gone [pause] or I would be bound to my bed asking them [my family] to take care of me and so on.”

Patients and their caregivers identified the beginning of a new life with the LVAD placement. The LVAD eventually fulfilled their desire to “*begin a new life [pause], to live a new life*” without the HF burden (Patient 3). This new life was not lived by patients only, but by their family members as well. Patient 3 stated, “*I told you that the LVAD is a [new life] to me [pause], a life to myself, my family, my wife and [pause] my brothers, even my brother who lives abroad.*”

In summary, the LVAD implantation emerged as the only life-saving therapy recommended by the healthcare team. The LVAD implantation decision was coupled with their desire to control their HF symptoms and lifestyle limitations. Having experienced HF at large, participants recalled their life experiences to be gloomy and exhausting. Post LVAD implantation, health improvement was reported in respect to the symptoms and functional limitations. The recovery was time dependent and progressive in nature. Participants started to appreciate the LVAD given the positive health changes leading to a new life.

B. Theme II: Embodiment and attachment to the LVAD

Theme II denotes the participants’ embodiment and trustful attachment to the LVAD. Following its implantation, not only did the LVAD get integrated into their bodies, but also to their lived experiences as a whole. Though the LVAD was implanted to the patients, it impacted the lives of patients and their caregivers alike. As Caregiver 3 deliberated, “*it is as if the LVAD [is placed] for the two*”. Two meanings depicted this theme: 1. The ways the dyads perceived the LVAD; 2. Dependency on the LVAD and

attachment. Participants' statements will be added to capture the essence of their personal interactions with the LVAD.

1. The ways the dyads perceived the LVAD

In answering the question on what the LVAD means to them, participants selected descriptors to portray their personal perceptions of the LVAD. For his first reaction, patient 3 shared how he found the LVAD to be “*bulky*” in size. Patient 4 addressed how they might “*get scared from the look of the devices [LVAD and connections]*”. With time, this first interpretation shifted to include significant and valuable descriptors as follows: a. companion/second soul; b. second heart; c. safeguard; d. lifeline.

a. Companion/ Second Soul

The LVAD gets implanted internally with external device components consisting of the driveline, controller and batteries. Patients incorporated the LVAD to their own bodies and lives. Patient 1 personified the LVAD to be his companion in life. More to that, he considered it his second soul, “*[The LVAD is] my companion my life [pause], it is my soul [pause] it is my hope [pause]. Logically, it needs care and attention ((holding the LVAD bag and then closing it)).*”

b. Second Heart

The embodiment of the LVAD went beyond the personification to include the acknowledgment of the physiological function of the LVAD. Patient 5 considered the

LVAD as a second heart she possesses. A second heart found effective physiologically and emotionally, she stated:

“I joke with them [my girls] and tell them “Look I have two hearts and I love you with my two hearts when they ask ((both patient and interviewer laugh)). Yes, the [LVAD] is for sure my heart, I improved around 100 %, let me say 90 % as I can’t completely deny my [real heart]’s work.”

Similarly, Patient 2 agreed on the description of the LVAD as a second heart.

c. Safeguard

With another description, the LVAD was perceived as a safeguard. This description relayed the trusting relationship patients experience with the LVAD. Patient 1 shared:

“In principle, [the LVAD] is the individual’s companion [pause] if the individual feels something is wrong, [the LVAD] should alert him by beeping, flashing lights or any alarm, or any written alarm. At least, [the LVAD] should alert him promptly in some way by a beeping sound: “tout tout”. The individual then shall have his eyes wide open [to respond for the alarms]. So, [the LVAD] becomes his safeguard. And in return, the individual acts as a safety guard by protecting it [LVAD].”

d. Lifeline

Participants set expectations when agreeing to the LVAD placement. These expectations mainly consisted of life sustainment. Patient 5 valued the LVAD to be a lifeline stating:

“[I consider the LVAD to be a] lifeline [pause] Yes, it is like a life-saving rope, a lifeline for me [pause] when you are threatened by death every moment of your life. Okay, one’s age is predetermined ((laugh while talking)).”

Patient 5 expressed this concept through a metaphor that compared the LVAD to a life-saving rope. This rope or lifeline emerged to save patients’ lives that were endangered with death from HF. The lifeline description was also shared by Caregiver 4 in this quote:

“Oof at first, if it weren’t for the LVAD, my mom maybe wouldn’t be here with us now [pause], so the [LVAD] was our lifeline if I can say [pause] for sure [pause] we did not have another option.”

2. Dependency on the LVAD and attachment

Following the acceptance and embodiment of the LVAD, participants shared their attachment to the LVAD. As without it, patients would no longer be alive enjoying the company of their families. Patient 4 stated:

“[The LVAD] is very good [pause] it gave me one more chance in life [pause] If it wasn’t for it, I would be dead [pause] Yes, it allowed me to live [pause] No [the LVAD] is very good but one has to adapt with the [LVAD] bag. One has to know how to hold it, shower with it, how [pause] to take care of the wound on daily basis for it to stay clean [pause] like that, no no it doesn’t annoy me.”

This dependency was translated into an equation. Indeed, the LVAD assists as much as it receives care and attention. This dual dependency was highlighted by Patient 1, *“I plan my essential arrangements selectively. The [LVAD] becomes your companion. You need to cherish its necessities so it assists you in sustaining your life.”*

For the LVAD to keep working, participants have to ensure that all its electrical essentials and dressing changes were met. These adjustments were integrated into participants’ lifestyles as an acknowledgment of the dependency and attachment to the LVAD.

Concisely, participants perceived the LVAD to be their companion, their full lives, their souls, their hope, their second heart, their safeguard, and their lifeline. Despite the complexity of the LVAD, these descriptors indicated that participants recognized the LVAD to be their life savers. They personified and embodied the LVAD as a trust bond

was established. Being reliant on the LVAD to sustain living, they feel attached and fully dependent on it.

C. Theme III: Living through: self-determination, coping and adjustment

Theme III highlights how participants navigate their new lived experiences after the LVAD implantation. Participants shared their personal experiences on how they coped and adjusted with the lifestyle changes introduced with the LVAD. Three meanings illustrated this theme: 1. self-determination to move on; 2. participants expressed their coping through the stages of grief; 3. adjustment to the new ways of life. Significant statements supporting the meanings associated to the participants' lived experiences will be presented.

1. Self-determination to move on

When transitioning home after the LVAD implantation, patients and their caregivers started integrating the LVAD into their new lifestyles. Patient 1 expressed this new responsibility in the following quote:

“It is essential to note that the doctor’s role is over with the success of the operation, thank God. The responsibility is now handed to the patient after the operation where each patient needs to self-care and act as his own doctor.”

During the early adaptation phase, participants were faced with added responsibilities and new lifestyle changes. Caregivers stepped in to support and assist the patients in performing their activities of daily living. Patients felt the urge to take matter into their own hands to cope and adapt to the LVAD. Patient 4 added:

“The first time I saw [the LVAD] I got really concerned [pause] there is a bag [pause] how will I be able to manage with it – because the first time I did not shower alone, my daughter helped me. Then I thought why not [to shower alone] ((higher

voice pitch)) I should empower myself ((hand in fists – gesture)) and adapt with it and adjust myself. And I really adapted and now I don't get help with anything.”

The majority of the patients communicated their need to regain independency after the LVAD implantation. Patient 4 emphasized the need for self-dependency and empowerment through this statement:

“Yes [pause] I can wash, change my clothes, [I can do] everything everything [pause] I no longer find any difficulty. There is no difficulty, it is up to the person to be self-dependent. He will find strength once he is self-dependent and everything will work out.”

Self-determination and self-empowerment allowed them to seek independency and navigate through the coping process. Caregivers then considered the patients to be their main helpers in adjusting to this new lived experience.

2. Participants expressed their coping through the stages of grief

To cope with the LVAD, dyads experienced the stages of grief to varying extents. Patients shared how they went through the phases from denial to acceptance. As for caregivers, their experience with the denial, depression and acceptance phases were only reported. The stages of the grieving process will be discussed covering the participants' shared experiences.

a. Denial

One patient and three caregivers reported experiencing denial. Patient 2 had his LVAD implanted after four years of purposeful delay. He was medically recommended to have the LVAD placed as he was a guarded condition. He shared that he felt frightened

once he heard about the LVAD. He disliked the thought of having a pump, batteries and a cable coming out of the abdomen. After he actively decided to avoid the LVAD, his health status stabilized for four years. Then, he started to experience the symptom load of HF, mainly breathlessness necessitating frequent hospital admissions. He reported that he was “*a few steps and moments away from death*”. This forced him to surpass the denial phase and hold on to his last chance in life, the LVAD.

Caregivers reported experiencing denial during the early adaptation phase.

Caregiver 4, being the daughter, expressed her denial state as she could not accept the thought of her mother living with the LVAD. She stated:

“When she first had the LVAD placed, I couldn’t accept the concept of [the LVAD], I had a kind of reflux when I thought about it [pause], we live together and this made me not accept [the LVAD] given the added responsibility delegated to me.”

The daughter is the main caregiver living with her mother under the same roof. She could not conceptualize the LVAD and accept the emerging responsibilities associated with it. This impacted her caregiving abilities as she did not want to be involved in any related tasks with the LVAD. Her sisters stepped in to support their mother’s recovery and resume her activities of daily living. Similarly, Caregiver 3, being the wife, shared that she could not process the idea of the LVAD and its external components. It took her time to overcome this denial.

Denial was also experienced differently. Families and caregivers could not believe that the patients were responding to the LVAD therapy and adapting. Caregivers assumed full responsibility in taking care of their patients. With that, they could not let go of this full responsibility easily and this challenged patients to seek their independency back. Patient 4 mentioned:

“[My family] are very pleased [with the LVAD], [pause] they did not believe that I am relying on myself [pause], They couldn’t believe that [pause] for instance, my daughter steps in to help me with something but I do it alone [pause], Even I cook at times, I cook any meal they want.”

b. Anger

The second stage of the grieving process denotes participants experiencing anger after the LVAD implantation. Patients felt frustrated that they were forced to have the LVAD. They wondered why they are the ones who have to live with the LVAD. Patient 5 reflected on her frustration:

“But now, I can no longer shower right away as I need to shift [the LVAD bag] to another one and then I need to do the dressing change after bathing. Sometimes, I say “Oh God, why did this happen to me dear God?” I get angry but now I got used to [the bathing difficulties].”

Anger was demonstrated through this feeling of frustration making them question their destiny. Patient 1 questioned why he ended up with the LVAD. He reviewed his behaviors and added, *“Sometimes I look back trying to understand why this has happened to me, although I did not cause harm to anyone.”*

As discussed previously, caregivers were supportive in stepping in and assisting their loved ones. Caregiver 3 juggled multiple roles: the wife, mother of two young children, caregiver and breadwinner. She reported her frustration with the imposed caregiving, *“yes [caring was imposed], what can I do? I cannot do anything and at the same time I cannot let go of this responsibility.”*

c. Bargaining

Commonly, participants voiced their experiences with bargaining. They wish they could go back in time and do anything to avoid their current life experience. Patient 2 indicated that his inadequate health behaviors resulted in his need for the LVAD. He stated:

“Maybe it is my fault that I did not take care of my health or it is my [destiny]. [I believe] that every person has a disease during his life. This is what I reason when I think and reflect by myself.”

To move beyond his feeling of guilt, he then added that it could have been his destiny call as well. In this grieving stage, participants conversed with God about their destiny and their life endurance. Patient 5 conveyed, *“for instance, when I complain: “Oh God, till when do I have to deal with this cable [driveline]? Or when I am in pain or something [pause]”*. In this quote, Patient 5 addressed how she communicated with God when facing a difficulty.

Caregivers did not share bargaining experiences; knowing they have already experienced HF at large.

d. Depression

During their early adaptation phase, participants experienced gloomy periods of helplessness. Patient 3 expressed how he felt down as early as he transitioned home after the LVAD implantation. This feeling even prompted him to ask God for relief with death.

He said:

“I am telling you [pause] this thing ((pointing to the LVAD)) really affected my life [pause]. I did not reach a phase of deep depression but I started with it [pause]. I then asked God “why dear God I am reaching this phase [depression]?” [pause] I got to a point [praying God] to relief me and take me away. That’s it.”

Interestingly, Patient 5 experienced a honeymoon phase post LVAD implantation.

This was reported by her spouse, sharing the below (Caregiver 5):

“Yes [pause] even she was mentally tired initially after [the LVAD] [pause] - at first, she enjoyed it, but then [pause], it is not easy for a person to be connected to batteries and electricity. And when she sleeps at night, she disconnects from the batteries to that [electricity device].”

As reported, Her HF experience was a terrible one with abundant pacemaker shocks. She was satisfied with her health status improving with the LVAD during the first two weeks.

But then, she realized her lifestyle changes. She voiced her experience via this quote:

“I lived through a down period, when I first got home from the hospital [pause], I struggled with bathing [pause] I used to shower instead of the ablution to pray [pause] , I used to shower directly but I can no longer do that as I need to change to another [LVAD] bag [pause] I need to clean the wound. This really restricted me especially that I am an [active] person always moving fast.”

e. Acceptance

Acceptance of the new life with the LVAD marked successful and efficient coping.

Abundant statements reflected acceptance of the LVAD and the life thereafter. Patient 5 expressed how she valued the significance of the LVAD:

“I was a dead person [pause], I couldn't live my life so I ignore [all these negative thoughts. I talk to myself that I am now annoyed changing [LVAD] bags but I could not even shower by myself before.”

Acceptance of the need and purpose of the LVAD allowed its integration into the participants' lives. Caregiver 4 deliberated on the normalcy of life with the LVAD. She added:

“For me, I couldn't picture my mom [dependent] on a machine. I couldn't accept this thought initially. But then, I saw her improving and adapting [to the LVAD]. This made me adapt to the [LVAD] with it being a part of our normal daily life.”

3. Adjustment to the new ways of life

Adjustment to the new life with the LVAD started early on. During the hospitalization phase, patient and caregivers were instructed on LVAD specific skills. Education extended from handling connections to the change of driveline dressings. The majority of participants delegated these skills to their caregivers at first. This was until they took their time to learn and handle the LVAD connections. Skill confidence was acquired in two weeks following discharge home. Patient 4 mentioned, *“It took me around two weeks [to adapt to the connections] [pause] I started managing [the connections] by myself.”*

As for dressing changes, caregivers were mainly responsible to perform it. An exception to this occurred with Patient 4. With her seventy-five years of age, she wears her eyeglasses and changes her driveline dressing in front of the mirror. It took a lot of patience and time to acquire this skill. Moreover, Patient 3 was fully dependent on his wife as caregiver to complete all these tasks.

In describing the progressive recovery, Patient 1 summarized his experience as he shared the following:

“[After the LVAD directly] your health status changes. You feel your body is in a different shape. You will feel down; you will experience body weakness, poor appetite and fatigue. All these improve with time. As your food intake increases and you comply with the healthcare instructions including medications’ intake, you will notice health improvements. Day by day, your activity level convalesces and your spirits rise. The first few months while recovering are hard.”

As they adapted to the LVAD, participants congruently described the first two weeks to be the hardest. Adaptation took place over a period of two to three months. Similar to the

imposed LVAD implantation decision, participants also referred to an imposed adaptation.

Patient 2 depicted this process through this quote:

“[I recovered in] around two months, the doctor told me “you need two months [to recover]”. The first two weeks were the hardest, very hard [period]. It is difficult as it is a new [device] implanted [pause], [It is difficult] to handle the connections, holding the [LVAD] bag. Then I was having left shoulder pain for around two months but it stopped on its own, thank God.”

In summary, participants experienced the five stages of grief to cope and adapt to the changes introduced with the LVAD. To initiate this process, participants were self-determined to surpass all these changes. They took matter into their own hands to live through this new journey. The coping was not a linear and steady process given the individual inter-variabilities. The majority of participants went through all the stages until they reached acceptance of their new lived experience. With acceptance, participants were able to integrate the LVAD into their lives. Similar to the imposed LVAD decision, participants had no other choices but to accept the LVAD. Along the same line, adaptation was identified to be time dependent with the first two weeks being the hardest. Recovery was progressive with improvement noted with time. Facilitators and challenges pertaining to the LVAD experience were identified and will be thoroughly examined in the next theme.

D. Theme IV: Patients and their caregivers shared facilitators and challenges of the LVAD experience

Participants deliberated comprehensively on their lived experiences after the LVAD implantation. Theme IV amalgamated the identified facilitators and LVAD related challenges. Facilitators that prompted adaptation and acceptance consisted of: a. faith/

God's will; b. mental wellbeing and high spirits; c. family and caregiver support; d. social support and e. scope of responsibilities. In what concerns the LVAD related challenges, the following were reported: a. financial difficulties (LVAD cost, unemployment and economic crisis); b. body image alterations as barrier for intimacy; c. anticipated concern with the LVAD; d. spousal role of caregivers; e. LVAD weight and f. shortage of electrical supply. These determinants will be reviewed thoroughly as they directly relate to the participants' lived experiences.

1. Participants identified facilitators of the LVAD experience

a. Faith/ God's will

Despite having different religious backgrounds, the majority of the participants expressed their faith to be guiding them along their new journey. As Patient 1 clearly stated, *“without faith, you cannot move a single step with your life”*. Patient 3 conceptualized the LVAD to be the mirror of his faith. Patient 5 explained how faith helped her to handle the negative feelings and thoughts instigated by the LVAD. She reported:

“Yes, I try to soothe myself with [my thinking]. Eventually, this is God's will and his wisdom [pause]. Maybe, his wisdom is for me to have the LVAD [pause]. Maybe God's will made me lose my consciousness in front of the doctor so he urgently operated.”

Also, she added that God offered a second chance with the LVAD. This chance should not be missed as she stated:

“Okay, one's age is predetermined ((laugh while talking)). Maybe, I could have died while having the operation then my life is simply over by then [pause.] It is fate and destiny that we don't have a say in [pause]. But, once God gives you a chance to have the LVAD, that means you have a chance in life, you need to take advantage of [pause], take advantage [of the LVAD], love life and do everything the right way.”

All through the interviews, participants did not miss a chance to thank God for the LVAD, the healthcare team, and their new lives.

b. Mental wellbeing and High Spirits

Participants highlighted the importance of mental well-being and high spirits in coping and adapting with the LVAD. Patient 1 stressed on the need to prepare patients psychologically prior to LVAD implantation. Caregiver 5 quantified the impact of mental wellbeing; he declared, *“first thing, because half the therapy consists of the mental wellbeing and the second half is the therapy itself.”*

To preserve their mental wellbeing, participants reported the need to have high spirits. Patient 4 deliberated on this:

“One has to be courageous [pause] he needs to – If he wants to [always self-excuse] with: I have a disease and I am sick and I can’t do that [pause], he gets lazy and his sickness worsens [pause]. But no, one has to raise the spirits and self-empower [pause] and everything will work out.”

Being the wife, Caregiver 1 acknowledged her husband’s strong spirits. She even hypothesized what could have went wrong without these high spirits. She explains, *“If it was a different patient, he would have been devastated and he might have died from delusions and worry [pause]. Another older patient did the operation and passed away [from fear and depression].”*

c. Family and Caregiver Support

Patients valued the support they received from their family members. Their care and attention facilitated the coping and adaptation process. Indeed, they cover up their fears,

worry and exhaustion. They sacrifice their personal lives to raise the patient spirits.

Caregiver 1 meticulously summarized what caregivers go through; she said:

“Honestly, I was feeling extremely down but I always hold it together in front of him. [The patient] survived difficult times including multiple surgical operations and even a pacemaker insertion. I cannot surpass how I felt that day, when [the doctor] told me he only has three weeks left [to live]. I couldn’t stand from the chair. I was really scared but I made sure to remain positive and encouraging. [Regardless of his condition], he always had strong and high spirits, even superior than ours [family].”

As Patient 5 clearly denoted, *“the familial support varied between physical, financial and psychological”* means of support. The majority of patients were unemployed.

Caregivers were then the main breadwinners supporting their families financially. Familial financial support was also reported to cover living expenses. For the physical form of support, caregivers mostly assisted patients to shower and were responsible of the wound dressing changes. Patient 5 explained how her family assisted her in holding the LVAD bag when walking up the stairs. Last but not least, the psychological support was crucial throughout the recovery and adjustment phase. Caregiver 5 highlighted its significance; he stated:

“The psychological support a patient receive from people surrounding him really helps him [pause]. In Lebanon on top of that, you need to add the financial factor. But, the psychological support helps the [patient] around 50 % if I can say ((laugh)) [pause] a big [percentage]. It is extremely important [pause] and we were all at home ((laugh)) healing ourselves psychologically. There is no issue with that.”

d. Social support

In addition to the familial support, the participants’ social entourage raised the patients’ spirits. Patient 1 deliberated on the care and attention he received from his friends.

He added:

“[My relationship with my friend after the LVAD did not change] of course not. When we are together, if they notice that the cable [driveline] is kinked ((showing how)), they would alert me that it is kinked [pause]. I comfort them by saying that nothing will go wrong and the cable is responsible to deliver the electricity without visibility to the naked eye.”

Patients’ social circle also assisted caregivers to optimize their care delivery.

Caregiver 4 explained how her mothers’ friends accompanied her all day long while she was at work. They would also contact her to report on any concern or problem experienced by her mother. Thus, their support assisted her to balance between caregiving and work commitments.

Having a supportive social circle was an advantage to the majority of the participants. However, this was not the case with Patient 3 who experienced social exclusion by his close friends after the LVAD implantation. They distanced themselves from him due to the fear of bearing responsibility in his company.

e. Scope of responsibilities

Patient 2, a single male patient, considered his lack of commitments and responsibilities as a facilitator to his life adjustment with the LVAD. He expressed:

“What really helped me to accept [my condition] and adapt is that I don’t have any responsibilities [pause]. I don’t have children, education [commitments], a wife or anything [pause]. This has helped me with [my medical condition] – God Almighty maybe knew [my health status was deteriorating] so that I didn’t commit myself to any form of responsibilities [pause]. This is what really made me accept [my condition and fate]. If I had commitments and responsibilities, it would have been different to me to deal with this situation.”

The situation would have been different if he was married and bound to familial responsibilities. This was a personal experience related to the marital status of the patient.

To summarize, participants identified several determinants that facilitated their adjustment with the new life after the LVAD implantation. Participants considered their health deterioration and the need for LVAD placement to be determined by God's will. Faith assisted them to cope and adapt to all the changes they experienced. Mental wellbeing promoted high spirits and motivated their recovery. Familial support was fundamental to the patients so that they can withstand the lifestyle changes. Caregivers were considered as building blocks of the LVAD experience. The patients' social circle raised patients' spirits and assisted the caregivers to fulfill their responsibilities. Applicable only to the single patient, lack of commitments and responsibilities allowed him to accept his destiny with the LVAD.

2. However, they identified challenges to the LVAD experience

a. Financial difficulties

Participants reported how it was financially demanding to cover for the LVAD operation costs. The majority of the participants had health coverage by the National Social Security Fund (NSSF). NSSF does not completely cover the expenses of procedures and hospitalization. To meet the full expenses, participants depended on external donations by humanitarian donations. Even with the donations, an amount was left for them to cover.

Caregiver 5 informed on this issue; he said:

“A problem with the LVAD in Lebanon is its cost [pause]. Those who do not have NSSF – I really thought at that time about those who don't [have NSSF]. But I had NSSF. Doctor _ {name} also extremely helped me. I am not sure if you know [laugh] Despite [all these assistance], me, my brothers and sisters, we still fought every minute ((laugh)) for [the LVAD operation] to work. [it worked] thank God.”

All the patients were unemployed post LVAD implantation due to physical restrictions. Caregivers were then assigned the breadwinning role on top of other responsibilities. Caregiver 1 was the only exception as she was unemployed. Living expenses for dyads 1 and 3 were covered through financial assistance from their families living abroad. Caregiver 3 shared the lived financial difficulties despite her full-time employment and external financial assistance. She stated:

“From the economical perspective, yes there are difficulties, honestly because he is not working. And all my income from the school goes [directly] to pay my children’s tuitions [pause]. We still have the living [expenses], my in-law lives abroad and he regularly send us [an amount] as much as he can, around 200 \$ not more. It is true that the value of [this amount] has increased but at the same time, the material [expenses] are rising as if nothing has changed.”

On a larger scale, Lebanon is going through a major economic crisis with the depreciation of the Lebanese Pound. Prices subsequently skyrocketed. As the supply necessities are needed on a long-term basis, the need for financial sustainability was raised. Caregiver 1 shared her anxiety with the augmented living expenses. She reported:

“The box of gauzes [now costs] twenty-five thousand LBP. The disinfectant costs thirty thousand LBP [pause]. These are daily items you use. If it was a monthly expense, [the financial impact] was non-significant. As they are daily items, don’t you think they are heavy expenses? Right, [the LVAD] requires [financial] sustainability as the [LVAD] is not a matter of a day or two. It might stay possibly a year, two, three or four I don’t know [pause]. Consider God Forbids that we no longer have financial assistance from abroad, what can we do for that? [pause]. Even the national social security fund does not cover our [medical expenses] hundred percent. You pay hefty amount and you get refunded reduced ones as they cancel [expenses] they don’t cover.”

Caregiver 1 emphasized this dedication by expressing that, *“despite [all the financial challenge], what really matters is his health, presence and well-being. [All other expenses] can be arranged.”*

b. Body image alterations

The LVAD implantation introduced body image alterations with the driveline exiting from the abdomen and connecting to the device's controller. Two patients reported on the body image alterations and how it hindered their intimacy. Patient 2 deliberated on his fears and concerns from permanent scars. This was the reason he avoided the LVAD procedure for four years. He expressed his satisfaction as the LVAD was implanted in a minimally invasive approach leaving no major scars. Still, the driveline affected his ability to engage in sexual relationships. Although he was hesitant to share, he reported:

“You know I am a single man. I get intimated if you know [pause] as they say [pause] How can I explain that? ((Saying it hesitantly)). No [sexual] relationship, I don't dare to do [sexual] relationships [pause]. This is the only thing [that I cannot do] [pause]. I had previous [sexual relationships] longtime ago before the LVAD – I don't dare to be [involved in sexual relationships] with something coming out of my abdomen and a bag [pause]. This is a life norm, sorry for that [pause]. You know [pause] so this is the only thing that annoys me [with the LVAD] but I adapted at last, I adapted thank God the Almighty.”

The same applied for a married female patient. The body image alteration impacted her intimacy with her significant other. She explained her difficulty with intimacy and how she overcame this with her spousal support:

“Even during the first phase, after my body recovered back to normal, I was shy with our intimate life [pause]. I was shy and I would escape to sleep at my daughters' room, at the living room or I would justify that I am tired. He then told me “why are you doing that [escaping from me]? I am accepting of you as you are, I like how your body looks with or without the cable [driveline] ((laugh)) why are you doing this to yourself? Why are you upsetting yourself? Why are you depriving us to be happy together? “He started assisting me with [getting back to our sexual life] [pause] we did not talk a lot about it [pause] you know [pause] he [communicated] this in his own way pampering me [pause] extra flirting ((laugh)) yes making me feel that he accepted me [pause]. Although we did not talk directly about it like why are you doing this? But in his own way with his pampering, I understood that “why are you doing this? I accept you as you are” [pause], you know.”

c. Anticipated concern with the LVAD

As a first impression, participants had anticipated concern and self-doubt early through their journey. They questioned their capacities to adapt to the new LVAD lifestyle.

Patient 4 said:

“The first time, I got really concerned [when I first saw the LVAD] [pause] because I was recently out of the hospital so I found some difficulties about how I will be [pause] when I want to shower, how will I be able to get dressed, how will I be able to do that? My daughter started to help me at first then I thought that no, I need to be self-dependent. Everything worked out when I became self-dependent.”

This anticipated concern resulted from the perceived complexity of the LVAD.

Patient 4 continued by adding:

“They might get scared from the look of the devices [LVAD and connections]. When they see the [LVAD] elements, they might get scared and wonder how they will [adjust] to the tube [driveline] coming out of their abdomen [pause]. But nothing is impossible when you simplify [things], [adaptation] gets easier.”

Caregivers had self-doubt on their caregiving competencies. For instance, Caregiver 5 reported her fears when handling the LVAD alarms.

d. Spousal role of caregivers

Caregivers reported that patients were more sensitive after having the LVAD implanted. The familial role assigned to the caregiver impacted patient-caregiver relationship. Caregiver 5 explained the sensitivity in regard to the spousal role of the caregivers; he stated:

“But I [thought to myself] that is it fair to make my wife feel that she is something abnormal? .. No and that’s when – I am telling you that the father or son [caregiving] might be simpler [pause]. [Patients] would not be super sensitive. But

the husband or wife or son, these are more complex [to patients]. [It is extremely sensitive] specifically when the spouse is the husband [pause]. Because the wife naturally could associate her illness to her husband possibly punishing her, betraying her or marrying over her. In our religion, we can marry multiple spouses [pause]. I don't know your religion, don't mind that ((laugh)). The husband should make her feel that he values his wife as a wife [pause] ill or not [pause]. Because if he made her feel that she became nothing for him, just a commitment, he would kill her."

Spousal caregiver role resulted in heightened patient sensitivity. The husband had to carefully monitor every word, comment, action, or gesture. All this to ensure that the patient will not be hurt accidentally.

e. Complaints on the LVAD weight

The majority of the patients reported and complained on the weight of the LVAD bag they constantly hold. Patient 3 said, *"you know, I feel something [LVAD] heavy [when I move] [pause]. But I am happy with my health condition [pause]. Yes, I adapted to it [LVAD] [pause]. [It took me] around a month [to adapt]."*

The LVAD weight was a source of bother restricting the patients' physical activities.

Patient 5 shared her experience while doing housekeeping chores; she reported:

"But now, [there are certain] activities [that requires] lifting [I can no longer do]. For example, I no longer remove curtains. Why? Because it [LVAD] has some weight [pause]. It [LVAD] is annoying when I lean forward to the ground. For example, I enjoy rinsing [the floor tiles], cleaning the house. But when I lean under the couches or something I get exhausted doing that. Okay, I fasten it well using the belt ((held LVAD bag to waist level)) [pause] I fasten it but I get exhausted from its weight [pause]. Its weight while walking the stairs is annoying as well."

f. Electricity supply shortage

Aside from the economic crisis, there is also a shortage in the electricity supply in Lebanon. The LVAD depends on continuous electrical support through direct current

electricity or charged batteries. Caregiver 3 shared their experience when the LVAD batteries were running out of power, while the electrical current was off. She shared her experience:

“Yes, we have an issue when the electricity goes off [pause] and the [electricity] generator in our village is not working – we went once to another place at our friends’ house to visit them so we can charge the batteries. This is another problem we face [pause]. Okay, we have a UPS but it does not last for a long [time] just for 5 minutes. It only lasts from when you change from the batteries to the monitor. Sometimes, it works and other times, it does not. This is why we use the batteries more.”

To recapitulate, participants reported on some challenges with their new lived experiences with the LVAD. With the economic crisis Lebanon is going through, participants were directly impacted. They were facing supply cutoffs and inflated prices for daily materials. They reported financial difficulties with employment restrictions. Another challenge consisted of the body image alterations acting as a barrier for participants’ intimacy. It was significant to note that the spousal caregiver role was problematic. With patients’ heightened sensitivity, spouses needed to be extremely vigilant with every comment and action. Moreover, the majority of the participants had anticipated concern with their first impression on the LVAD. These concerns were mainly spinning around self-doubt in adaptation and caregiving abilities. Complaints on the LVAD weight and its impact on their physical activities was noted. A context related difficulty was with the electrical supply shortage. As such, theme IV incorporated the recognized facilitators and challenges affecting the participants’ lived experiences.

E. Theme V: Despite the subsequent lifestyle changes, the LVAD brought hope and expectations

With the LVAD implantation, life as they know it had changed. New lifestyles and new living experiences surfaced. Theme V highlighted the derived changes and hopeful viewpoints participants reflected upon. Three meanings formulated this theme, as follows:

1. the lifestyle changes experienced by patients and their caregivers; 2. patients and caregivers share the LVAD experience and 3. the LVAD brought hope and expectations.

These meanings will be supported by significant statements and shared meanings pertaining to the participants.

1. The lifestyle changes experienced by patients and their caregivers

As their lifestyle changed, patients reported difficulties in showering and bathing. The majority of participants required assistance from caregivers during the early months post LVAD implantation. Later, some of the patients developed a safe showering routine.

Addressing the showering struggle, Patient 2 reported:

“I get really annoyed with the shower [pause]. I told her that “I really get annoyed while showering [because of the LVAD]”. I feel annoyed and afraid [for the LVAD] to get in contact with the water [pause]. I hold the shower head [diagonally to avoid water contact with the LVAD].”

In addition to this change, they had to change their clothing routine. Male patients shared the difficulty wearing formal clothing. Patient 5 uttered her frustration that she had to change all her wardrobe. She addressed this matter:

“One of the things that really annoy me [with the LVAD] is the physical look of the [LVAD] bag with the clothing [pause]. Yes, I can no longer wear everything that I want to. My clothing [consists] mostly of shirts and pants, and I am picky with my choices [pause]. I let go of a lot of items in my wardrobe like dresses and so on

[pause]. Yes, they no longer work with me [pause]. You cannot have the cable [driveline] coming out without a two-piece clothing.”

Patients also conveyed on the limitations with their physical activities. Patient 1 enjoyed swimming prior to the LVAD placement. He reminisced on his swimming days; he added:

“[my social routine changed] for sure [pause]. When we go by the beach, I wish I am able to swim, I wish these [pointing at the LVAD bag and the driveline] can turn internally so I could return to swimming. I long for the day these [the LVAD bag and the driveline] can turn compact and internal.”

In comparing the HF experience to the LVAD one, caregivers reported decreased burden and relief. Caregiver 2 stated:

“At first, we were worried and sad [seeing him unable to walk] but he slowly recovered and improved [pause], he started to sleep, started to – Before [the LVAD], he couldn't sleep and anything. [there is a huge difference] in his condition before and after [the LVAD].”

During the early adaptation phase, caregivers reported stress and burden from the care and attention. With time, they coped and adapted as the LVAD was integrated in their daily lives. Caregiver stress remained for one caregiver, Caregiver 3. A wife, a mother of two and a teacher, juggled many roles and obligations. She was responsible to care for her husband and two children, perform the LVAD daily needs and complete her teaching duties. This load of responsibilities was coupled with the absence of the patients' input and assistance. She even cried during the interview as she shared her stress and concerns. She reported that it was her first time venting about her feelings and experiences.

Regarding dressing changes and handling connections, caregivers did not complain of these tasks as they were not time consuming. With time and adaptation, they acquired confidence in performing them. On top of caregiving, Caregivers were assigned with the

patients' social duties. Patient 1 delegated his social responsibilities to his wife. He said, *"Visits [after the LVAD] of course not [pause]. For sure, I keep my visits [and social activities] limiting them to just the necessary. I delegate all social duties to my wife."*

2. Patients and their caregivers share the LVAD experience

Though the LVAD was personally implanted to the patient, the subsequent changes impacted both members of the dyads. Caregiver 3 expressed that the *"LVAD is placed for the two"*. Caregiver 5 highlighted that living through this experience is different than hearing or observing it. He repeatedly mentioned about the personal aspect of these experiences. He stated, *"I'm [living everything], seeing everything with my bare eyes [as they say], the one hearing about [something] is different than the one seeing it. Yes, I am seeing with my own eyes [her condition]."*

He also emphasized the concept of shared lived experiences. He reported, *"[I can say] from my personal experience, that the [LVAD] has changed my life [pause]. Yes, the patient is not the only one with the illness as his surroundings share his illness [pause]"*.

Beyond the lifestyle changes, this shared experience applied to caregiving as well. The majority of participants followed a complementary caregiving relationship. They divided their care with each being responsible for different tasks. Caregivers were mostly responsible for driveline dressing changes. An exception was noted with dyad 3 having a caregiver oriented relationship. As was presented earlier, the wife was responsible for all the care delivery and breadwinning. This resulted in a compromised lived experience, loaded with stress and burden. Caregiver 3 conveyed:

“((sigh)) [I manage everything] with difficulty ((laugh)). I got stressed as well. It affected my blood pressure – I also got ill ((lowered voice)). But I need to stay strong [in control]. You can't have both [parents] ill within the same family.”

3. The LVAD brought hope and expectations

a. Dyads reported contentment with the LVAD

Caregiver 5 expressed that it was “*not easy to be connected to batteries and the electricity*”. Despite the complexity and the lifestyle changes introduced with the LVAD, participants reported contentment and satisfaction with the LVAD. Most importantly, they were still alive, thus meeting the aims of the LVAD. Patient 3 confirmed that:

“If it was this [LVAD] or even bigger [in size], even if I am mostly staying at home, the important thing is that I can still walk [pause]. I am no longer working but I can walk, go out, go to the bathroom, and go to the beach only to walk as I am not allowed to swim.”

The majority of the dyads reported some normalcy in life with the LVAD. Patient 4 explained that with time and acceptance, the LVAD became part of the new normal. She stated:

“I empowered myself [pause] I empowered myself [pause] in everything even at home. I do the dishes, if I had a small thing to iron, I would do it ((with a pride tone)) I arrange my house [pause]/ I start the washer and then hang the laundry to dry out. [I do] everything everything, life is normal [pause]. Yes ((excited tone)) I get dressed if I want to go out. I close the door and I go out. So, nothing nothing annoys me anymore.”

b. They Hoped and desired for future LVAD development

Hope was a common feeling shared by all the participants. The LVAD brought forth a streak of hope despite all the challenges and complexities. Patient 1 reported, “*First thing, the [LVAD] gave me hope and the second thing, it [LVAD] made me realize that I was alive anew.*”

Participants shared their aspiration on having a fully internal pump without the need for a driveline and external batteries. Caregiver 4 enlightened on these aspirations; she said:

“Concerning the machine [LVAD], let me start by saying that it would be best if they develop it [LVAD] to avoid external components so everything would be internal. This eases the patient’s [life]. If they develop an internal [device] inside the body [pause], the operation would consist of an internal one with nothing to hold and no tubes [driveline coming out [of the abdomen]].”

In summary, living with an LVAD introduced additional lifestyle changes. These changes were not experienced by patients alone. Caregivers were significantly affected as well, hence the shared aspect of these lived experiences. Despite the subsequent lifestyle changes, the LVAD brought hope and expectations. Participants were hopeful as they benefited from a second chance in life. As the LVAD had its pros and cons, participants aspired for some technical modifications. They shared their desire to be free from the driveline and the batteries. Still, the majority of the dyads reported some normalcy in life after the LVAD implantation.

F. Theme VI: Patients and their caregivers were provoked by others’ perception of the LVAD machine

Participants dwelled on the external perception of the LVAD. Theme VI stemmed from two meanings: 1. Being singled out (disruption of privacy, wonder whether businessman or terrorist, fear of people’s misperceptions) and 2. Public unfamiliarity to the LVAD. Participants’ statements will be added to explore these concepts.

1. Being singled out

a. Patients experienced disruption of privacy

The majority of the patients shared the frequent questions people asked about the LVAD. Other than the questions, patients dealt with stares of wonder and curiosity. Patient 5 explained that she disliked sharing her cardiac illness with her neighbors. Her dislike turned into frustration as she described being looked at with “*stares of stupidity*”. People stared with wonder looking at the driveline and the LVAD bag. These looks were noticed by both patients and caregivers. Moreover, the privacy disruption extended to stalking; Patient 2 reported:

“I get followed by a lot of people frequently asking me if I am a doctor or a realtor [as I am] holding a bag. I usually reply by “I am sorry [this is not true] this is a heart device”.

b. Wonder whether businessman or terrorist

Adding to these stares, people wondered if the patients were businessmen. Patient 2 stated, “*I get frequently asked “what is your job? And they also monitor my side [where the LVAD bag is placed]. I later found out that realtor hold bags [similar than the LVAD one], where they place their [contact] cards.”*

Others were suspicious if the patient was a terrorist loaded with bombs. Patient 1 detailed this terrorist perception; he stated:

“I was placing it [LVAD bag] next to me. Someone comes and says, “Why the hell is a big guy holding a bag on his shoulder?” [Pause]. I even told my doctor that I was placed in common situations when people ran away from me and got scared from me. This behavior can be explained as it is scary to see a cable coming out of a person. This perception has even increased nowadays. People seriously wonder that the person might be holding an explosive cable [referring to the driveline].”

c. Fear of people’s misperceptions

Patients feared that people might misperceive the LVAD bag to be a valuable item. This misperception may result in potential thefts. Patient 2 stated, *“If they consider [the LVAD] as [a valuable property] like money or anything ((laugh)) and they try to pull it from me.”* To avoid such circumstances, patients held the LVAD bag tightly closer to their bodies. Patient 5 added, *“when I walk on the street, you will find me walking while I [hold the LVAD and tighten the driveline closer to my body] like that.”*

2. Public unfamiliarity with the LVAD

The majority of participants reported that people were unfamiliar with the concept of the LVAD. Patient 5 stated:

“By the way, you will rarely find someone who knows what an [LVAD is about] in North Lebanon [pause]. They look at you, wondering how you hold an artificial heart [pause]. I usually just explain that it is an artificial heart to ease their understanding [pause]. If you say LVAD or pump, they won’t [understand][pause]. I get [people] staring [with wonder] at me like that thinking “what is she holding?” [Pause] This lady asked me: “are you leaving?” but we are coming to visit you and you are leaving”.”

Patient 1 emphasized on the need to raise awareness on the LVAD. His request aimed to clarify misconceptions and reduce wondering. He stated:

“What I want to convey is that the doctors should inform the Ministry of Health to post educational material on Television. So, they can know that patients with an LVAD are not terrorists. They should raise awareness on this topic.”

In summary, participants’ personal experiences were also affected by the people’s perception of the LVAD. Participants felt they were being singled out. Their privacy was disrupted by the frequent stares and inquiries on the LVAD. Their physical appearance categorized them as either businessmen or terrorists. Patients feared people’s misperceptions of the LVAD as a valuable item and potential theft attempts. These

experiences were linked to the general public's unfamiliarity to the LVAD. Participants emphasized on the need to raise awareness as this directly impacts their lived experiences.

In conclusion, this study aimed to explore in depth the lived experiences of patients living with an LVAD and their caregivers. The thematic analysis generated six themes covering the participants' lived experiences. Appendix H summarized the themes, categories and meanings derived from the participants' interviews. This chapter has presented the study's results with the thematic analysis.

Next, Chapter VI will entail a discussion of the study's results with their cultural interpretation. Additionally, strengths and limitations along with the implications for future research and clinical practice will be presented.

CHAPTER VI

DISCUSSION

This phenomenological study explored the lived experiences of Lebanese patients living with an LVAD and their caregivers. It is one of the first studies addressing the essence of the participants' perceptions, feelings and experiences. The interviews were data rich as participants freely shared on their personal experiences. The aim of this study was to illuminate on the life with an LVAD in the context of Lebanon. Participants have already experienced living with HF until the LVAD implantation. After transitioning to a life with an LVAD, participants explained how they coped and adjusted with the lifestyle changes. They identified facilitators and challenges to their experiences. Some of the challenges were attributed to the country's economic instability and subsequent financial difficulties. As discussed in chapter V, the participants' interviews were analyzed yielding six themes that were examined thoroughly.

This chapter will present a discussion of the study's thematic analysis, one theme at a time. Due to the limited literature, the discussion will relate to the studies conducted in Lebanon addressing the context and cultural interpretation. It will be followed by implications for research and nursing practice. Additionally, the limitations and strengths of the study will be addressed along with a summary concluding this study.

A. Discussion of the emerged themes

1. Theme I: The lived LVAD journey from being doomed to a new life

In the decision-making process of the LVAD implantation, participants were not approached with multiple alternatives. Heart transplantation is a low volume intervention due to the deficient organ donation culture (Degheili et al., 2020; Hamdan et al., 2020). This resulted in HF dyads being restricted to “two choices, the LVAD or death” (Patient 3). Participants would not actively choose death over life. Subsequently, the LVAD presented as the “only option” imposed to sustain life and preserve functionality. The aim of the LVAD procedure merged with the participants’ desire for relief from HF symptoms and lifestyle limitations. Despite its perplexity, participants valued the LVAD’s significance as it saved the patients’ lives. The complex nature of the decision-making process prompts for adequate patient and caregiver support. This can be accomplished through exhaustive education on the life with an LVAD from a holistic perspective. An educational role that is best accomplished by the CNS.

Not only it sustained living, the LVAD also introduced health improvements. All the participants compared their lives before and after the LVAD. The lived HF experience was perceived to be exhausting and demanding. The majority of participants were congruent in reporting feeling helpless and doomed when living with HF. Patients and their caregivers were troubled from the HF symptom load and frequent hospitalizations. These “cycles of pain, fear and sickness” were controlled with the LVAD implantation (Caregiver 3). The recovery process following the LVAD procedure overlooked progressive health

improvements with daily changes. Upon establishment of complete recovery, participants valued their new lives with the LVAD.

After experiencing HF at large, patients felt they were given a second chance in life. Through personally experienced, the LVAD did not impact the lives of patients alone. The caregivers also deliberated on a new life with the LVAD. This goes in line with the established literature addressing the impact of the LVAD on caregivers (Adams & Wrightson, 2018; Baker et al., 2010; Cicolini et al., 2016). With that in mind, nurses should prioritize the needs of patients and caregivers alike as they are both affected by the changes introduced by the LVAD.

2. Theme II: Embodiment and attachment to the LVAD

The LVAD is a foreign entity with both internal and external components. As first impressions, participants considered the LVAD to be “bulky” in size (Patient 3) and a source of intimidation (Caregiver 4). This can be explained by the physical features of the external component of the device. It includes the driveline, device controller and the electrical charging modules. Participants were overwhelmed from the device they have to constantly deal with. To address this conveyed difficulty, guidance and support is needed early on. Nurses could assist the patients and their caregivers in assimilating the different components of the LVAD.

With time, patients shifted their perceptions on the LVAD as they adapted. When asked what the LVAD means to them, participants used an array of personal descriptors. As

they have to hold the LVAD bag constantly, patients considered the LVAD to be their *companion* in life. This description does not solely involve the concrete delineation of a companion. It also extends to the expressive personification of the LVAD as a *second soul*. Participants appreciated the LVAD's capacities to assist their hearts physiologically. Hence, they considered the LVAD to be their *second heart*. Entrusting the LVAD's function and purpose, they contemplated the LVAD to be their *safeguard*. They relied on the LVAD to notify them when something goes wrong through the device's alarms. When living with HF, participants felt threatened by death with every minute passing. Feeling helpless and doomed dominated. The LVAD brought forth a mean to escape the HF lived experiences. Thus, they depicted the LVAD to be a *lifeline*. These descriptors delineated a positive outlook of the LVAD perceptions. They cherished having the LVAD as they could not sustain living without it.

The LVAD completes her constant physiological function. While, the individual is responsible to ensure adequate battery charging and driveline hygiene. This dual dependency enabled the integration of the LVAD related lifestyle changes. The protective nature of the LVAD facilitated its acceptance and embodiment. The acceptance process is not an immediate and passive one. It marks the successful adaptation following the LVAD implantation. The coping process will be addressed next to examine how participants navigate through their new lived experiences with the LVAD.

3. Theme III: Living through: self-determination, coping and adjustment

Participants shared how they transitioned to a new life with the LVAD. This transition was depicted as complex and time dependent. It occurred during the early adaptation phase following LVAD implantation. Upon discharge home, participants understood that their daily routines were changed. They were physically recovering with weakness, fatigue and poor appetite. They were dependent on their caregivers to complete their activities of daily living. During that phase, patients had mixed feelings. On one hand, they were thankful that they are still alive. On the other hand, they were anxious and doubting of their capacities to adapt. For them to regain independency, they figured out that they need to take matters into their own hands. They should be determined to empower themselves to overcome the changes they are experiencing. These findings align with those of the early adaptation phase derived by the meta-synthesis previously discussed (Abshire et al., 2016). Building on that, nurses at the outpatient cardiology clinics can play an important role in guiding patients navigate this phase. Being contacted by a healthcare professional routinely at this sensitive period propagate a sense of security and reassurance. Psychological support and guidance alleviate stress and worry; thus, facilitating patients' self-determination. Also, determined patients eased the caregiving process as patients assumed responsibility with the LVAD.

Right from the LVAD implantation decision, patients and their caregivers navigate through the stages of grief. These stages are fluidly experienced depending on personal characteristics and support systems. First, the denial stage was not commonly reported by the patients. This can be explained by the symptom load of HF and its direct impact on

patients. As a result of HF, patients could not deny having HF. Their health status was deteriorating rapidly. It was followed by the imposed decision of the LVAD as the only lifesaving therapy. The majority of the participants had the LVAD implanted urgently due to their clinical instability. Given the imposed addition of the LVAD into their daily lives, patients did not have ample time to experience this phase. For a clinically stable patient, the medical recommendation of the LVAD was not assimilated. Denial then resulted in a four years delay until clinical deterioration and urgent need for LVAD implantation. As for caregivers, they experienced denial in the decision-making process for the LVAD. They couldn't picture their loved ones depending on the LVAD. As the LVAD was the only option available, they were forced to accept it and directly managed the load of responsibilities. During the early to mid-adaptation phase, caregivers were full in control and impeded patients to regain their independency. A second form of denial consisted of the caregivers' dubiousness about patients' call for independency.

Second, Patients transitioned to anger as they realized they are trapped with the LVAD. Frustration accumulated as they wondered why they are the ones who have to endure living with an LVAD. As for caregivers, anger was not commonly experienced. Caregivers poured in all their efforts in the hopes that their loved ones will improve. Patient-caregiver relationships were primary collaborative and this could result in them not experiencing anger and frustration. An exception to that occurred with dyad 3 as the patient-caregiver relationship was caregiver oriented. Caregiver 3, the wife, was overloaded with the patient care in addition to her other responsibilities. As such, she reported stress and frustration with caregiving.

As coping took place, participants transitioned to the third grieving stage, bargaining. During this stage, patients reviewed their past experiences while wishing they rewind time. Maybe if they adjust their health behaviors, they might have escaped the need for the LVAD. Bargaining, as a process, generates a sense of control as patients have the opportunity to consider the LVAD as a temporary process. Additionally, patients conversed with God in an attempt to deal with their difficulty and question their destiny. As for caregivers, they did not convey experiencing bargaining. This can be explained with their direct engagement in caregiving with the LVAD necessities.

Then, they realized the LVAD is not a short-lived experience. The feeling of gratitude for remaining alive dissipated; the honeymoon period is over. Feelings of helplessness emerged to the extent of death contemplation. This phase highlighted the experience of depression. Patients reached this phase as early as two weeks following LVAD implantation. This is a prominent finding necessitating nursing interventions starting with depression assessment to psychological support.

When successful, coping through the new life with the LVAD culminates with acceptance. This phase marks the integration of the LVAD into the participants' daily routines and living experiences (Casida et al., 2011).

Adjustment to the new life occurred from the hospitalization phase and onward. Similar to the imposed nature of the LVAD implantation decision, participants had to cope and adapt with the LVAD. During the early adaptation phase, patients moved from complete dependency on their caregivers to the progressive re-establishment of their capacities (Abshire et al., 2016). They estimated that lifestyle adjustment occurs over a

period of three months with the first two weeks being the hardest. This is congruent with the findings addressed in the review of qualitative research (Majid et al., 2016). Skill confidence to manage and handle connections were acquired during the first two weeks. Caregivers were mainly responsible for dressing changes as patients were able to perform their activities of daily living. The adjustment's timeframe can guide the multidisciplinary LVAD team in monitoring the coping process of the participants. Patients are usually discharged home and advised to follow up at the cardiology clinics after two weeks. Yet, participants portrayed the difficulty they face during these two weeks. The CNS and cardiology clinic nurses can address this interval gap by follow up telephone calls and home visits when needed.

4. Theme IV: Patients and their caregivers shared facilitators and challenges of the LVAD experience

The adjustment process, discussed at length, is influenced by certain variables that either enable or hinder its progress. Participants identified facilitators and challenges following the LVAD implantation.

a. Dyads identified facilitators of the LVAD experience

Among the facilitators of the LVAD experience, participants recognized faith, mental wellbeing and high spirits, family and caregiver support, social support and scope of responsibilities. There was a strong emphasis on faith as a catalyst enabling them to cope. Mental wellbeing and high spirits were valued as fundamental determinants guiding the

recovery process. Support stemming from family members and social entourage played a positive role for both patients and caregivers.

To cope, participants considered the LVAD to be part of their destiny and God's predetermined will. Participants verbalized their gratitude as they thanked God constantly throughout the interviews. Considering the LVAD as an extension of God's will, this facilitated the acceptance of the LVAD. Patients conceptualized the LVAD to be a mirror of their faith as they were offered a second chance in life. For caregivers, they were thankful for the life extension the LVAD provided to their loved ones. Additionally, participants resorted to faith when coping with the depression phase and negative thoughts instigated by the LVAD. Though they have different religious profiles, participants entrusted and depended on God with their lives. Faith and reliance on God is a common finding in the Lebanese population. Qualitative literature conducted with the cardiac and oncology Lebanese patients examined the significance of faith and its contribution to the coping process (Doumit et al., 2007; Doumit et al., 2008; Dumit et al., 2015). Given the impact of faith in the participants' lives, further studies are needed to explore its use as an intervention tailored for coping and adjustment.

Participants emphasized the importance of mental wellbeing and high spirits in the recovery process following the LVAD implantation. Participants highlighted the eminent role that high spirits contribute to patients' self-determination. Patients will then be determined to navigate through the recovery process and their new lifestyle. Also, participants attributed key significance on the mental wellbeing in the recovery process post LVAD implantation. In the coping process, mental wellbeing was contemplated as a major

contributor to overcome depression and reach acceptance. It is imperative to note that the LVAD implantation procedure is complex and results in major lifestyle changes. As such, mental wellbeing should be assessed and monitored during the follow up telephone calls and outpatient visits. Participants also identified the need to include psychological preparation among the education HF patients receive pre-LVAD.

Another facilitator to the LVAD lived experiences consists of family and caregiver support. Being members of the patients' families, caregivers played different roles and responsibilities. They could relate to the patient as spouses, children or siblings. Caregivers were considered the building blocks of the LVAD experience. They were ready to sacrifice their daily routines and step up to take care of their loved ones. Caregivers typically assisted the patients in meeting their ADLs requirements and performing wound care. Their support is not based on the physical form solely. But, it also extends to the financial and psychological types of support. Caregivers became instantly the primary breadwinners of the family as patients could not resume their occupations. As for the psychological form, they were active listeners in venting sessions. They assisted patients to overcome negative thoughts on the LVAD by reminding them of their HF experience. The Lebanese culture is family oriented with members empowering each other (Dumit et al., 2015). Patients and caregivers also received the whole family's support. All this in mind, caregivers and family members should be included in the development of the patient's plan of care. Literature has not addressed in specific the difference of the caregiver role in terms of patient outcomes and experiences. This needs to be examined in depth as findings will assist healthcare professionals to develop patient specific plan of care.

Similar to the familial support, the direct social entourage also contributed positively in the coping process. Their presence generated a sense of security and gratitude. The patients' social circle assisted in raising the patients' spirits and assisted the caregivers to fulfill their responsibilities. But, this was not always the case. Patient 2 experienced distancing of his friends following LVAD implantation due to fear and worry. The relationship with the social circle evolved either positively and negatively (Casida et al., 2011). Thus, the clinical and research focus shall be maintained on family members given their constant support.

Familial and caregiver support contributed significantly to the adjustment of the new LVAD related lifestyle. For single patients, the lack of direct familial responsibilities facilitated the acceptance of the LVAD. Things would have been different to them if they were bound to marital and parental responsibilities. As such, the patients' family characteristics need to be assessed prior to the LVAD implantation. This will allow for an in-depth appraisal of potential facilitators of the patients' experiences.

b. However, they reported the challenges to the LVAD experience

Several challenges were experienced with the life transition following LVAD implantation comprising of the financial difficulties, body image alterations, anticipated concern, spousal role of caregivers, LVAD weight and electricity supply shortage. Some of these challenges are bound to the Lebanese context; while others are specific to the LVAD characteristics.

One of the challenges participants experienced consists of the financial difficulties. The financial struggles were a source of anxiety and worry. All the patients were covered by the NSSF. Though, NSSF does not cover the full medical expenses. As discussed earlier, the breadwinners were mainly the caregivers with an income barely covering their living expenses. Some participants had external financial support from their families abroad. These difficulties were paired with the economic and political crisis Lebanon is going through. Although these findings were documented in the qualitative study of Lebanese cardiac patients, they remain valid to date (Dumit et al., 2008). Adding to that, the economic crisis even intensified with the depreciation of the Lebanese pound to the US dollars. As a result, Lebanese are dealing with inflation of prices and availability shortage. This impacts the patients and their caregivers on multiple levels. On top of the medical bill's increase, the supply needed for the wound care augmented by ten times its baseline cost. It is essential to note that these supplies are needed on daily basis. As such, participants raised their concerns on their fears of financial sustainability. On top of the financial difficulties, shortage in material supply and cutoffs were reported as alarming circumstances. Despite all these difficulties, families and caregivers were determined and committed to do their best to support the patients financially. The impact of the economic conditions on the lived experiences of participants needs to be acknowledged and attended to.

Body image alterations constitute also a challenge to the LVAD experience. With the external component of the LVAD, patients have to deal with the driveline coming out of their abdominal area. This driveline connects to the controller, which in turn connects to the

charging components. The body image alterations have constituted a major barrier for intimacy among married and single patients. Being single, that patient was intimated to meet someone new and decided to let go of his sexuality. Being married, the intimacy was also challenging. A female patient reported on her experience with body image alterations and intimacy. She was intimated by how her body looked and wondered how her husband will respond to that. She even feared her husband would leave her. On the contrary, her husband was extremely supportive making her overcome this barrier. Communication among spouses and spousal support were crucial to overcome this barrier. As such, educational activities in preparation for LVAD implantation should include information on sexual activity with the LVAD. Additionally, healthcare professionals should inquire on the sexual activity and the need for counseling during follow up clinic visits.

Given the complexity of the LVAD, participants had anticipated concerns with first encounters with the LVAD. Patients experience self-doubt on how they will adapt with the LVAD and integrate the latter to their daily routines. Similarly, caregivers encounter uncertainties of their caregiving competencies. Caregiver stress may result secondary to the load of responsibilities assigned. With adequate family support and coping mechanisms, caregivers overcome the stress. If these facilitators are inadequate, caregiver burden will result. These concerns shall be addressed early on with emphasis on facilitators to overcome these challenges. Early assessment and interventions aim to ensure adequate coping and limit caregiver stress or burden.

Caregivers compared and contrasted their familial role and its impact on caregiving. After the LVAD implantation, patients were more sensitive. This can be explained with the

complexity of the LVAD coupled with the subsequent lifestyle changes. The husband caregiver role was found to be extremely delicate and complex. The patient-wife became super fragile with heightened sensitivity. As such, the husband monitored every word, opinion and gesture. Resulting damage can be quite destructive and critical to the patient's adaptation and adjustment.

The majority of patients complained from the LVAD weight and the resulting discomfort. They quantified this weight to be around "three and a half kilograms" (Patient 3). This number was the result of the patient's perception and experience with the sustained weight of the LVAD external components. When comparing it to the actual weight reported by the manufacturer, the perceived weight was beyond doubled. This can be explained by the need to constantly hold the LVAD with every movement. Patients had some concerns on how they will be able to deal with the weight complaint as they grow older. Despite the load, they still managed to cope and adapt with it.

Moreover, the LVAD depends on the continuous electrical support for it to function. Another problem faced in the Lebanese context includes the electrical supply shortage. Participants shared this difficulty as they face frequent power shortages. Among the different experiences participants shared, dyad 3 portrayed this problem. They were forced to visit their friends' house in a distant village to charge the LVAD batteries. This was reported as a stressful addition to the LVAD experience. As part of the preparatory education for the LVAD, this problem is addressed by asking patients to ensure continuous electrical supply. So, they resort to private power generators in addition to the UPS charger.

5. Theme V: Despite the subsequent lifestyle changes, the LVAD brought hope and expectations

During the early adaptation phase, participants adapted to the lifestyle changes introduced with the LVAD (Casida et al., 2011). Patients reported struggling with showering. They feared water contact with the device and depended on the caregivers' assistance for bathing. Their clothing routine had changed as well. Marcuccilli & Casida addressed the impact of body image alteration and clothing adjustment after the LVAD implantation (2012). Both male and female patients conveyed their limitations with clothing. Male patients encountered difficulties with formal dressing. They preferred wearing loose outfits. Female patients had to change their wardrobe to accommodate for the driveline and external LVAD components. They were forced to get rid of the dresses they have as they can only wear two-pieces clothing. For female patients, the clothing restrictions were limiting. On top of these changes, patients who enjoyed swimming can no longer do that. In regard to employment, patients could not get back to their occupation. This was secondary to physical constraints or employer's decisions following LVAD implantation. The lifestyle changes are fundamental to assess and follow during the outpatient clinic visits. This is to monitor the progress of the adjustment process and intervene to avoid inadequate coping. It is essential to ensure that their quality of life is improved aligning with the aim of the LVAD implantation.

Transitioning to a life with the LVAD, caregivers also encountered lifestyle changes. During the early adaptation phase, they reported stress and burden from the care and attention. They were anxious and self-doubting at first (Casida et al., 2011). With time,

they coped and adapted as the LVAD was integrated in their daily lives. Caregivers did not consider the dressing changes and handling connections to be as troublesome. Seeing the patients improve and having support from other family members facilitated coping and adjustment. When patients fully depended on their caregivers without any input, the load of responsibilities intensified. This resulted in caregiver burden and disturbed quality of life. Based on these findings, health care professionals shall include checking on caregivers' adjustment and quality of life during the outpatient clinic visits.

Together, patients and caregivers lived through the new life with the LVAD. Although the LVAD is implanted to patients alone, caregivers share the experience with them. They lived through the prominent lifestyle changes and imposed restrictions. Despite all these difficulties, the LVAD journey engendered hope and expectations. Participants shared their contentment and satisfaction with the LVAD. During the late adaptation phase, participants recognized the LVAD as part of their new normal (Abshire et al, 2016; Casida et al, 2011). All the participants shared their feelings of hope and desire for future LVAD development. They desire to have the LVAD completely internal without the driveline and the batteries protruding. They even thought about wireless charging as an option.

6. Theme VI: Patients and their caregivers were provoked by others' perceptions of the LVAD machine

The majority of the participants expressed the way they were perceived by others. These looks were interpreted in the context of being singled out. Due to their external appearance with the LVAD, patients experienced disruption in their privacy. Disruption

ranged from the frequent inquiry questions to the wondering stares. People gazed and wondered about the LVAD bag and the driveline. These looks were detected by both patients and their caregivers, leading to frustration. On interpretation of their looks, people considered patients as either businessmen or terrorists.

These two considerations are quite dissimilar. Some interpreted the external components of the LVAD as business bags used by realtors or doctors. While others were more suspicious in their interpretation. They misjudged the patients as terrorists loaded with bombs. Two dyads informed on the terrorist perception. Being perceived as terrorists resulted in internalized distress and frustration. They happened to reside in the North of Lebanon, an area with political instabilities and safety concerns. Patients who resided in Beirut and Mount Lebanon did not report on being misperceived as terrorists. However, they shared being asked about their occupation as they held the LVAD bags. The terrorist suspicion could be related to the geographical context. This is an alarming finding as there are safety concerns for the patients when they head to unfamiliar places. Additionally, this might impact the patients' mental wellbeing.

Sharp and colleagues published a case study illuminating on the terrorist perception while living with the LVAD. They shared the experience of a young Pakistani male patient living with an LVAD and residing in the United Kingdom. As a result of this misperception, the patient struggled with anxiety and depression until his heart transplantation. Sharp and co-investigators linked it this experience to two main causes. First, there is minimal public awareness on the LVAD. As for the other, there was an upsurge of crime rates along with intensified media coverage (Sharp et al., 2018).

Similarly, the majority of participants reported on the public unfamiliarity with the LVAD. This unfamiliarity also extended to the healthcare team working at peripheral hospitals. Participants emphasized on the need to raise awareness on the LVAD. They expect the Ministry of Public Health to intervene through educational brochures or publicities made available for the public. Healthcare professionals should implement awareness strategies in the aim to optimize the patients' mental wellbeing and safety.

Patients feared people's misperceptions of the LVAD as a valuable item and potential theft attempts. Given the economic instability in Lebanon, these safety concerns are of utmost importance. Nurses should raise the safety concerns to prospect patients planned for the LVAD implantation.

B. Implications for future research

This study addressed the paucity of knowledge about the living experiences patients with LVAD go through along with their caregivers. As it followed a qualitative phenomenological approach, findings consisted of a primary assessment on a sample of the Lebanese LVAD patients and their caregivers. As data were collected from one medical center, the sample does not represent the whole population. Future studies are recommended to include a larger representation of the LVAD population and main caregivers. Thus, a collaboration among different medical centers providing LVAD implantation services is advised.

The study's thematic analysis portrayed the coping and adjustment process the participants lived through following the LVAD implantation. Participants experienced a

transitional phase until they accepted the LVAD and integrated the latter into a newest version of their daily routines. To address coping and adjustment, mixed methods studies coupled with a longitudinal approach can illuminate on the different adjustment phases experienced. Hence, these studies would provide detailed and rich knowledge about the transition of their lived experiences.

Quality of life is another domain that is important to address. Future research can include an investigation on the quality of life of LVAD patients using established questionnaires such as Sandau and colleagues' QOLVAD questionnaire (Sandau et al., 2020). The questionnaire has not been used in Arabic among the Lebanese or Middle Eastern population. Future studies can comprise of translating the tool to Arabic and subsequent validation for such interest.

As it was discussed, participants considered the first three months to comprise the early adaptation period. They highlighted that the first two weeks are the hardest. After discharge home, they are scheduled for an outpatient check-up visit in two weeks. Experimental studies can assess the effectiveness of telephone call interventions during these two weeks. More research is necessary to optimize the healthcare delivery model provided to the LVAD patients.

Concisely, more research addressing the Lebanese LVAD population is needed. Further knowledge should be attained on the adjustment process, healthcare delivery model, and quality of life among Lebanese patients living with an LVAD and their caregivers.

C. Implications for nursing practice

The LVAD procedure is complex and imposes lifestyle changes to both patients and their caregivers. During the pre-LVAD phase, psychosocial assessment needs to be incorporated and documented to have a baseline assessment. This assessment can be compared to and monitored on follow up visits after the LVAD implantation. Additionally, the CNS exercises ethical decision making in the pre-operative assessment to inform on procedural contra-indications and limitations.

Participants receive education on the LVAD during the pre-LVAD and hospitalization phases. The technical education on the implantation procedure is usually delivered by the cardiothoracic surgeon. The CNS and cardiology nurses are responsible to provide education on the handling of the device connections and lifestyle changes. Education should be tailored according to the personal characteristics of the patients and caregiver dynamics. During the hospitalization phase, nurses need to identify potential challenges in collaboration with the patients and their caregivers. These challenges should be attended to by proactive planning and the use of personal facilitators. The CNS also develops treatment guidelines to optimize the quality of care as per the latest evidence.

The education should take into account the adjustment and coping processes occurring over time. Nurses need to prepare the patients and their caregivers on the difficulty they will face during the first two weeks, extending up to three months. Upon discharge, dyads are given clinic appointments for follow up at one week and two weeks. The first two weeks period marks the period when patients transition home. To assist them adjusting with the LVAD, outpatient cardiology nurses can conduct telephone follow ups

addressing their needs, difficulties and challenges. Based on the identified difficulties, nurses can refer them to the specialized personnel.

Multidisciplinary care planning is extremely crucial and allows the delivery of a holistic quality care. Aligning with her leadership competencies, the CNS can act as a liaison between the dyads and the rest of the multidisciplinary team. The team can also comprise of a psychologist or a psychiatry-mental health nurse to cater for disturbances in the mental wellbeing. Caregivers' psychological health should be included in the optimization of the plan of care delivered during the LVAD follow-up visits.

In terms of public awareness, participants identified the need to address the public's unfamiliarity with the LVAD. From stares to suspicions, patients feel being singled out. This results in stress, anxiety and worry when heading to unfamiliar places along with safety concerns. Additionally, this can impair the adjustment process and results in delayed acceptance of the LVAD. The lack of awareness is coupled with the small population of patients living with an LVAD as compared to the whole Lebanese population. To overcome this problem, educational activities should be planned along with the Ministry of Public Health to reach the wider Lebanese population. Educational activities can range from educational brochures to short filmed videos; relaying in simple terms what an LVAD is.

D. Limitations and strengths of the study

This study explored the lived experiences of patients living with an LVAD and their caregivers. Findings enlightened on what patients and their caregivers live through as they

adapt with the LVAD. This study has limitations and strengths that should be acknowledged and discussed.

Among the limitations, it should be noted that the recruited sampling does not reflect and represent the whole Lebanese population. The sampling occurred from one medical center with a limited LVAD population. However, the study's sample was diverse in terms of demographics, socio-economic status, geographical residence and caregiver roles. This is in aim of obtaining a primary assessment of the everyday experiences the patients and caregivers go through. As for the sample size, ten participants were recruited and interviewed, five patients and five caregivers. The small sample size concurs with phenomenology (Creswell & Poth, 2018). Given the personal and private nature of the lived experiences, there are limitations with transferability of the findings to the general population. However, this also aligns with phenomenology as the aim does not incorporate the transferability of the data (Braun & Clarke, 2013).

A second limitation results from the translation process of the significant statements from Arabic to English. As with that, contextual meanings might get lost in the process. To prevent such occurrences, the translation was completed by the Co-investigator, fluent in both Arabic and English. The back-translation process was completed by two independent individuals, a cardiac nurse and the PI. The assistance of the cardiac nurse improved the study's credibility given her cardiac knowledge, cultural awareness and unfamiliarity with the study details. The records were then reviewed; a consensus was achieved on the English translations. The procedure to overcome this limitation is considered as one of the study's strengths.

Regarding the strengths of the study, the PI is an expert in qualitative interviewing. The Co-investigator completed extensive training and attended workshops on qualitative research. Participants freely shared their experiences and considered the interviews as venting sessions. Debriefing sessions among the research team members followed every dyad's interview. This is to enhance the capturing of the interviews' essence. Transcription was completed verbatim to ensure the integrity of the data records. Patients and their caregivers were congruent in sharing their living experiences. The interview transcripts were data rich as three hundred significant statements were extracted. These records were complemented with field notes referencing any non-verbal reactions, gestures, events. These data management procedures aimed to safeguard the credibility of the qualitative data.

The thematic analysis aligned with Colaizzi's phenomenological method. With the generation of meanings, discussion occurred among the research team members to ensure intercoder agreement. Upon completion of the thematic analysis, the member checking process was completed through telephone calls for consenting participants. The phone calls lasted for thirty minutes with participants' full engagement. It consisted of presenting the themes and the meanings and discussing the findings. Participants agreed with the generated themes without adding any new experiences. This demonstrated an enhanced study's rigor.

E. Summary

The LVAD implantation procedure results in prominent lifestyle changes. In Lebanon, the lived experiences of patients living with an LVAD and their caregivers have not been explored. The *purpose* of the study was to explore the lived experiences of patients living with an LVAD and their caregivers. The study aims to understand the needs, facilitators, and challenges experienced as patients and their caregivers transition to a new lifestyle with the LVAD. The study addressed the paucity of research on the Lebanese LVAD population and their direct caregivers. This study followed a qualitative phenomenological *design* with the intent of obtaining in-depth findings to capture the full description of the participants' lived experiences. The study was *approved* by the Institutional Review Board of the American University of Beirut.

Recruitment occurred at the outpatient cardiology clinics at the American University of Beirut Medical Center from September 2020 to October 2020. The *sample* comprised of ten participants interviewed using an unstructured interview approach, five patients along with their identified caregivers. Inclusion criteria for patients consisted of age greater than 20 years, had the LVAD implanted for more than six months, had an identified caregiver and followed up their medical care at American University of Beirut Medical Center (AUBMC). Patients were excluded if they were younger than twenty years old, diagnosed with mental health issues and had their LVAD implanted for less than six months. Caregivers were included if they were the ones designated by patients.

Audio-recorded *interviews* with patients and their caregivers were conducted separately and consecutively to avoid any undue influence. A topic guide composed of open-ended questions was constructed in English to assist with probing. It was then

translated to Arabic and back translated to English by the members of research team. Participants preferred to conduct the interviews before or after their scheduled appointments at the outpatient clinics. Interviews followed an unstructured approach; data collection completed in between September 2020 and October 2020. The PI or Co-Investigator conducted the data collection. Procedures were implemented to safeguard **human subject protection**. These interventions included the signature of informed consents and emphasis on voluntary participation and autonomy. Signed copies of the informed consents, audio-records, and transcripts were stored in the office of the PI, in a locked drawer and password protected computer.

Data transcription was completed verbatim in Arabic. Colaizzi's phenomenological method guided the **thematic analysis**. After immersion, data analysis started with the extraction of significant statements related to the participants' lived experiences. Statements were then translated to English by the research investigator and back translated to Arabic. This process was independently performed by two members of the research team. Several meetings were completed to ensure achieving a consensus on the translation process. This safeguarded the integrity of the derived meanings and enhanced the credibility of the findings. These statements were then analyzed to generate in depth meanings. The meanings were clustered into major themes. Right after, the PI and co-investigator met to discuss analyzed data as they settle on common ground. All generated themes were grouped together to describe the lived experiences of patients living with an LVAD and their caregivers. A summarized description of the dyad's lived experiences was also provided. Once the data analysis was finalized, **member checking** was pursued with

two dyads. Generated themes along with the major statements were shared with willing participants for verification.

Upon completion of the member checking process, the study's *results* were finalized. The final thematic plan incorporated six themes reflective of the participants' lived experiences.

Theme I: The lived LVAD journey from being doomed to a new life. Participants portrayed their life journey from HF to the LVAD. Though the LVAD decision was the only therapy choice, they then perceived it as a life saver. Health improvement was reported when they compared their lives before and after the LVAD. Participants started to appreciate the LVAD given the positive health changes leading to a new life and the establishment of new routines.

Theme II: Embodiment and attachment to the LVAD. Despite the complexity of the LVAD, participants described the LVAD with positive descriptors. As a trust bond was established, they personified and embodied the LVAD. Being reliant on the LVAD to sustain living, participants felt attached and fully dependent on it.

Theme III: Living through: self-determination, coping and adjustment. Participants shared their personal experiences on how they coped and adjusted with the lifestyle changes introduced with the LVAD. They explained how they empowered themselves to reach self-determination. Coping through the stages of grief, participants progress with time until they reach acceptance. With acceptance, participants were able to integrate the LVAD into their lives. Adjustment was identified to be time dependent with the first two weeks being the hardest.

Theme IV: Patients and their caregivers shared facilitators and challenges of the LVAD experience. Participants recognized several determinants that facilitated their adjustment with the new life after the LVAD implantation. Faith assisted them to cope and adapt to all the changes they experienced. Mental wellbeing promoted high spirits and motivated their recovery. Caregiver and familial support were fundamental to the patients. The patients' social circle raised patients' spirits and assisted the caregivers to fulfill their responsibilities. Valid only to the single patient, lack of commitments and responsibilities allowed him to accept his destiny with the LVAD. Several challenges to the LVAD experience were identified, the economic crisis in Lebanon being one of them. Participants reported financial difficulties with employment restrictions. Another challenge consisted of the body image alterations acting as a barrier for participants' intimacy. Spousal caregiver role was problematic. With the first impression on the LVAD, participants had to deal with their anticipated concerns. Complaints on the LVAD weight was perceived as a challenge. Last but not least, dyads had to deal with the electrical supply shortage.

Theme V: Despite the subsequent lifestyle changes, the LVAD brought hope and expectations. Participants dwelled on the lifestyle changes introduced with the LVAD. Living with an LVAD was a shared experience between patients and their caregivers. The LVAD brought hope and expectations with their second chance in life. They still aspired to be free from the LVAD's external components, the driveline and the batteries.

Theme VI: Patients and their caregivers were provoked by others' perception of the LVAD machine. Participants commented on the external perception of the LVAD. Participants felt they were being singled out. Their privacy was disrupted by frequent stares and inquiries on the LVAD. Their physical appearance labeled them as either businessmen

or terrorists. Patients feared people's misperceptions of the LVAD as a valuable item and potential theft attempts. Given the public's unfamiliarity with the LVAD, participants emphasized on the need to raise awareness as this directly impacts their lived experiences.

The study has *limitations and strengths* that were presented and discussed. This study is among the first research queries to address the Lebanese LVAD population and their direct caregivers. Participants were able to voice their experiences as they coped and adjusted to a life with an LVAD. *Recommendations for future research* should target the adjustment process, healthcare delivery model, and quality of life among Lebanese patients living with an LVAD and their caregivers. Findings also generated *some recommendations for clinical practice* in what concerns the optimization of the care delivery according to contextual and personal determinants.

APPENDICES

APPENDIX A

Patient consent form to participate in a study

American University of Beirut, Hariri School of Nursing

Title: Exploring the lived Experiences of LVAD patients and their caregivers

Principle Investigator: Dr. Nuhad Yazbik Dumit

You are being asked to participate in a research study conducted at the American University of Beirut. This study has been approved by the Institutional Review Board at the American University of Beirut for compliance with ethical standards.

You are invited to participate in this study because we are exploring the lived experiences of Lebanese patients having an LVAD and their caregivers. We will include LVAD patients aged 20 years and above who have undergone LVAD implantation for at least 6 months. We will exclude LVAD patients whom are younger, have an LVAD implanted within a shorter period of time and diagnosed with a mental illness.

Please read the following information carefully before you decide whether you want to take part in this research study or not. Feel free to ask your doctor if you need more information or any clarification about what is stated in this form or the study as a whole.

What is this research study about?

The primary purpose of this research study is to explore the lived experiences of Lebanese patients living with an LVAD and their caregivers. We want to understand what does it

mean living with an LVAD and taking care of an LVAD patient. Knowledge from this study will help in giving educational activities to address the needs and challenges LVAD patients and their caregivers live with.

This research is being conducted by a team of researchers that include: Dr. Nuhad Yazbick Dumit, Dr. Angela Massouh, Mrs. Mireille Chehade, and Dr. Ekaterini Lambrinou.

You will be provided with an invitation letter by your cardiologist or the cardiology clinical nurse specialist. If you agree to participate, you will be asked to answer a set of questions about you. The interview will be done at your convenience; you get to decide where to meet at a place and time suitable for you. An empty office in the clinic will be available as well in case you decide to do the interview at the outpatient clinic. Each interview is expected to last between 30 to 45 minutes. 4 to 6 participants will be recruited for this study.

What are the risks and benefits of participating in the study?

Your participation in this study does not involve any physical or emotional risk to you beyond the risks of daily life. You have the right to refuse to participate, withdraw your consent, or discontinue participation at any time during or after the interview and for any reason. Your decision to withdraw will not involve any penalty or loss of benefits to which you are entitled. Discontinuing participation in no way affects your relationship with the American University of Beirut Medical Center.

You receive no direct benefits from participating in this research study; however, your participation might help researchers better understand the perceived needs, experiences and challenges of LVAD patients and their caregivers in Lebanon.

Confidentiality

Confidentiality will be strictly maintained at all times. For that reason, your name and other identifying information will never be attached to your answers and interviews. All codes and data are kept in a locked drawer in a locker room or in a password protected computer that is kept secure.

Data access is limited to the Principal Investigator and researchers working directly on this project. Records may be audited by the Institutional Review Board at the American University of Beirut maintaining confidentiality at all times.

All data will be destroyed responsibly after three years. Your privacy will be maintained in all published and written data resulting from this study. Your name or other identifying information will not be used in our reports or published papers.

Contact Information

If you have any questions or concerns about the research, you may contact Dr. Nuhad Dumit at the below information:

Telephone Number: 0135000 Extension: 5955

Office: American University of Beirut, Hariri School of Nursing, Room 411F

Email: ny00@aub.edu.lb

If you have any questions, concerns or complains about your rights as a participant in this research, you can contact the Social & Behavioral Sciences Institutional Review Board office at AUB:

Telephone Number: 0135000 Extension 5445

Office: Halim and Aida Daniel Academic and Clinical Center; 3rd Floor Email:

irb@aub.edu.lb

Participant Rights

Participation in this study is voluntary. You are free to leave the study at any time without penalty. Your decision not to participate will not influence your relationship with AUB.

Your participation might be terminated by the investigator if deemed necessary. A copy of this consent form will be left with you.

Patient's Participation:

I have read and understand the above information. I agree to participate in the research study.

.....
Participant Name	Participant Signature	Date and Time

.....
Investigator Name	Investigator Signature	Date and Time

Caregiver consent Form to participate in a study

American University of Beirut, Hariri School of Nursing

Title: Exploring the lived Experiences of LVAD patients and their caregivers

Principle Investigator: Dr. Nuhad Yazbik Dumit

You are being asked to participate in a research study conducted at the American University of Beirut. This study has been approved by the Institutional Review Board at the American University of Beirut for compliance with ethical standards.

Please read the following information carefully before you decide whether you want to take part in this research study or not. Feel free to ask your doctor if you need more information or any clarification about what is stated in this form or the study as a whole.

You are invited to participate because we are exploring the lived experiences of Lebanese patients having an LVAD and their caregivers. We are targeting caregivers of LVAD patients who are aged 20 years and above and who have undergone LVAD implantation for at least 6 months.

What is this research study about?

The primary purpose of this research study is to explore the lived experiences of Lebanese patients with LVAD and their caregivers. We want to understand what does it mean living with an LVAD and taking care of an LVAD patient. Knowledge from this study will help

in giving educational activities to address the needs and challenges LVAD patients and their caregivers live with.

This research is being conducted by a team of researchers that include: Dr. Nuhad Yazbick Dumit, Dr. Angela Massouh, Mrs. Mireille Chehade, and Dr. Ekaterini Lambrinou.

You will be recruited to this study if you are the primary caregiver of an LVAD patient.

Recruitment will be done by your patient's cardiologist or the cardiology clinical nurse specialist. If you agree to participate, you will be asked to answer a set of questions about you. The interview will be done at your convenience; you get to decide where to meet at a place and time suitable for you. An empty office in the clinic will be available as well in case you decide to do the interview at the outpatient clinic. Each interview is expected to last between 30 to 45 minutes. 4 to 6 caregivers will be recruited for this study.

What are the risks and benefits of participating in the study?

Your participation in this study does not involve any physical or emotional risk to you beyond the risks of daily life. You have the right to refuse to participate, withdraw your consent, or discontinue participation at any time during or after the interview and for any reason. Your decision to withdraw will not involve any penalty or loss of benefits to which you or your patient are entitled. Discontinuing participation in no way affects your relationship with the American University of Beirut.

You receive no direct benefits from participating in this research study; however, your participation might help researchers better understand the perceived needs, experiences and challenges of LVAD patients in Lebanon.

Confidentiality

Confidentiality will be strictly maintained at all times. For that reason, your name and other identifying information will never be attached to your answers and interviews. All codes and data are kept in a locked drawer in a locker room or in a password protected computer that is kept secure.

Data access is limited to the Principal Investigator and researchers working directly on this project. Records may be audited by the Institutional Review Board at the American University of Beirut maintaining confidentiality at all times.

All data will be destroyed responsibly after three years. Your privacy will be maintained in all published and written data resulting from this study. Your name or other identifying information will not be used in our reports or published papers.

Contact Information

If you have any questions or concerns about the research, you may contact Dr. Nuhad Dumit at the below information:

Telephone Number: 0135000 Extension: 5955

Office: American University of Beirut, Hariri School of Nursing, Room 411F

Email: ny00@aub.edu.lb

If you have any questions, concerns or complains about your rights as a participant in this research, you can contact the Social & Behavioral Sciences Institutional Review Board office at AUB:

Telephone Number: 0135000 Extension 5445

Office: Halim and Aida Daniel Academic and Clinical Center; 3rd Floor Email:
irb@aub.edu.lb

Participant Rights

Participation in this study is voluntary. You are free to leave the study at any time without penalty. Your decision not to participate will not influence your relationship with AUB. Your participation might be terminated by the investigator if deemed necessary. A copy of this consent form will be left with you.

Caregiver's Participation:

I have read and understand the above information. I agree to participate in the research study.

.....
Participant Name	Participant Signature	Date and Time
.....
Investigator Name	Investigator Signature	Date and Time

APPENDIX B

Socio-demographic Factors and Health Determinants of LVAD patients

Study Code			Interview Date		
Gender	<input type="checkbox"/> Male	<input type="checkbox"/> Female	Age	----- years or Year Born 19-----	
Marital Status	<input type="checkbox"/> Single	<input type="checkbox"/> Married	Living Alone	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	<input type="checkbox"/> Divorced	<input type="checkbox"/> Widowed	# of People in the Household	[Exclude Patient]: ----- --	
Income per Year (Household)	<input type="checkbox"/> Between \$6 and \$12,000		<input type="checkbox"/> Between \$12 and \$15,000	<input type="checkbox"/> Above \$15,000	
Occupational Status	<input type="checkbox"/> Currently working		<input type="checkbox"/> Retired/ Unemployed	<input type="checkbox"/> On Medical Leave	
Education	<input type="checkbox"/> Illiterate		<input type="checkbox"/> Can read and write/elementary	<input type="checkbox"/> Intermediate	
	<input type="checkbox"/> Secondary or Technical school		<input type="checkbox"/> University	<input type="checkbox"/> Others	
Do you have a good relationship with the person you care for?	<input type="checkbox"/> Never		<input type="checkbox"/> Sometimes	<input type="checkbox"/> Often	<input type="checkbox"/> Always
How do you and your patient take care of his/her VAD?	<input type="checkbox"/> Patient Oriented Category where your patient takes care of his/her HF without input from you.	<input type="checkbox"/> Caregiver Oriented Category where you take care of the HF patient without any input from him/her.	<input type="checkbox"/> Collaborative Category where both of you take care together.	<input type="checkbox"/> Complementary Category where both of you take care of different aspects of the HF.	

Health Coverage	<input type="checkbox"/> Medical Insurance	<input type="checkbox"/> NSSF	<input type="checkbox"/> None	
Duration of HF	Years since the patient first knew:		Actual Duration of HF:	
# of Hospitalizations in past year	----- times; State Reason:			
HF Etiology	<input type="checkbox"/> Ischemic Heart Disease	<input type="checkbox"/> Hypertension	<input type="checkbox"/> Chemotherapy Induced	
	<input type="checkbox"/> Valve Disease: -----	<input type="checkbox"/> Dilated Cardiomyopathy	<input type="checkbox"/> Others:	
Left Ventricular Ejection Fraction		NYHA score	Prior to VAD -----	Post VAD -----
Year of LVAD implantation		Type of LVAD device		
LVAD implantation	<input type="checkbox"/> Emergent	<input type="checkbox"/> Non-Emergent	Duration of hospitalization	

Charlson Comorbidity Index [CCI]

Disease	Yes	No	Disease	Yes	No	Disease	Yes	No
Myocardial Infarction	1	0	Peripheral Vascular Disease	1	0	Leukemia (acute or chronic)	2	0
Heart Failure	1	0	Peptic Ulcer Disease	1	0	Lymphoma	2	0
COPD	1	0	Diabetes – End-Organ Damage	1	0	Metastatic Solid Tumor	6	0
Cerebrovascular Disease	1	0	Diabetes + End-Organ Damage	2	0	Tumor without metastasis (exclude if > years from dx)	2	0
Hemiplegia	2	0	Mild Liver Disease	1	0			
Dementia	1	0	Moderate/Severe liver disease	3	0	AIDS (not just HIV+)	6	0
Connective Tissue Disease	1	0	Moderate/Severe renal disease	2	0	For each decade above 40: +1		

Sociodemographic Factors and Health Determinants of LVAD Caregivers

Study Code			Interview Date		
Gender	<input type="checkbox"/> Male	<input type="checkbox"/> Female	Age	----- years or Year Born 19-----	
Marital Status	<input type="checkbox"/> Single	<input type="checkbox"/> Married	Living Alone	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	<input type="checkbox"/> Divorced	<input type="checkbox"/> Widowed	# of People in the Household	[Exclude Patient]: ----- ---	
Income per Year (Household)	<input type="checkbox"/> Between \$6 and \$12,000		<input type="checkbox"/> Between \$12 and \$15,000	<input type="checkbox"/> Above \$15,000	
Occupational Status	<input type="checkbox"/> Currently working		<input type="checkbox"/> Retired/ Unemployed	<input type="checkbox"/> On Medical Leave	
Education	<input type="checkbox"/> Illiterate		<input type="checkbox"/> Can read and write/elementary	<input type="checkbox"/> Intermediate	
	<input type="checkbox"/> Secondary or Technical school		<input type="checkbox"/> University	<input type="checkbox"/> Others	
Relationship to Patient					
Where do you and the person you care for live?	<input type="checkbox"/> In the same household		<input type="checkbox"/> In different households but same building		
	<input type="checkbox"/> Within walking distance		<input type="checkbox"/> Within a 10-minute drive	<input type="checkbox"/> Within a 30-minute drive	
	<input type="checkbox"/> Within a 1-hour drive		<input type="checkbox"/> More than an hour drive		
Do you have a good relationship with the person you care for?	<input type="checkbox"/> Never	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Often		<input type="checkbox"/> Always
How do you and your patient take care of his/her VAD?	<input type="checkbox"/> Patient Oriented Category where your patient takes care of his/her HF without input from you.	<input type="checkbox"/> Caregiver Oriented Category where you take care of the HF patient without any input from him/her.	<input type="checkbox"/> Collaborative Category where both of you take care together.	<input type="checkbox"/> Complementary Category where both of you take care of different aspects of the HF.	

APPENDIX C

Interview Guide for patients and their caregivers

Main questions addressed to the LVAD patients enrolled:

- What does it mean to you living with an LVAD?
- Can you describe a typical day after you had LVAD?

Additional probing questions used for assistance:

- How would you describe your life before your LVAD operation?
 - How do you portray the hospitalization period after your LVAD placement?
 - After three months from your LVAD placement, how did you feel?
 - How would you describe living with an LVAD now?
 - What do you think has changed in your life between the hospitalization phase and now?
 - Is there anything you want to share on what's living with an LVAD feels like?
-

Main questions addressed to the caregivers of LVAD patients:

- What is it like having to care for an LVAD patient?
- Can you describe a lived day with your patient?
- What are your thoughts on how caregiving for an LVAD patient affect your life?

Additional probing questions used for assistance:

- How do you describe your experience as a caregiver for a heart failure patient?
- How did you feel when your patient was undergoing an LVAD operation?
- What was your role as a caregiver after the LVAD placement?
- Can you compare your experience as a caregiver before and after LVAD placement?

APPENDIX D

AUB IRB APPROVAL



Institutional Review Board | لجنة الأخلاقيات

www.aub.edu.lb

APPROVAL OF RESEARCH

November 27, 2019

Nuhad Dumit, PhD
 American University of Beirut
 01-350000 ext: 5955
ny00@aub.edu.lb

Dear Dr. Dumit,

On November 27, 2019, the IRB reviewed the following protocol:

Type of Review:	Initial, Expedited
Project Title:	Exploring the Lived Experiences of Left Ventricular Assist Device Patients and their Caregivers
Investigator:	Nuhad Dumit
IRB ID:	SBS-2019-0358
Funding Agency:	None
Documents reviewed:	<p>Received November 27, 2019:</p> <ul style="list-style-type: none"> • Appendix B: Patient Consent Form (English and Arabic) • Appendix B: Caregiver Consent Form (English and Arabic) <p>Received November 15, 2019:</p> <ul style="list-style-type: none"> • IRB Application • Proposal • Appendix A: Invitation Letter for LVAD Patients (English and Arabic versions) • Appendix A: Invitation Letter for Caregivers of LVAD Patients (English and Arabic versions) <p>Received September 16, 2019:</p> <ul style="list-style-type: none"> • Appendix C: Sociodemographic Factors and Health Determinants of LVAD Patients • Appendix D: Interview Guide for patients and their caregivers (English and Arabic versions)

The IRB approved the protocol from November 27, 2019 to November 26, 2020 inclusive. Before September 26, 2020 or within 30 days of study close, whichever is earlier, you are to submit a completed "FORM: Continuing Review Progress Report" and required attachments to request continuing approval or study closure. If continuing review approval is not granted before the expiration date of November 27, 2020 approval of this research expires on that date.

Please find attached the stamped approved documents:

- Proposal (received November 15, 2019)
- Appendix A: Invitation Letter for LVAD Patients (English and Arabic versions) (received November 15, 2019)
- Appendix A: Invitation Letter for Caregivers of LVAD Patients (English and Arabic versions) (received November 15, 2019)
- Appendix B: Patient Consent Form (English and Arabic) (received November 27, 2019)
- Appendix B: Caregiver Consent Form (English and Arabic) (received November 27, 2019)
- Appendix C: Sociodemographic Factors and Health Determinants of LVAD Patients (received September 16, 2019)
- Appendix D: Interview Guide for patients and their caregivers (English and Arabic versions) (received September 16, 2019)

Only these IRB approved consent forms and documents can be used for this research study.

Thank you.

The American University of Beirut and its Institutional Review Board, under the Institution's Federal Wide Assurance with OHRP, comply with the Department of Health and Human Services (DHHS) Code of Federal Regulations for the Protection of Human Subjects ("The Common Rule") 45CFR46, subparts A, B, C, and D, with 21CFR56; and operate in a manner consistent with the Belmont report, FDA guidance, Good Clinical Practices under the ICH guidelines, and applicable national/local regulations.

Sincerely,



Ljma El-Onsi Daouk, MSc
Senior Regulatory Analyst/ IRB Co-administrator
Social & Behavioral Sciences

Cc: Michael Clinton, PhD
Co-Chairperson IRB Social & Behavioral Sciences

Fuad Ziyadeh, MD, FACP, FRCP
Professor of Medicine and Biochemistry
Chairperson of the IRB

Ali K. Abu-Alfa, MD, FASN, FAHA
Professor of Medicine
Director, Human Research Protection Program
Director for Research Affairs (AUBMC)

APPENDIX E

Example on the back-translation process

①
المرحلة الأولى أعطيتي التحليل وعند وصولي
إلى المرحلة الثانية أدركت أنني لم أزال على
قيد الحياة. سوف أتبع ما يطلبه مني الطبيب
و الطاقم الطبي. إنه من الضروري أن نلاحظ
أن دور الطبيب قد انتهى منذ نجاح العملية،
الحمد لله، إن المسؤولية تقع الآن على عاتق
الريضة بحيث أنه يجب على الريضة أن يهتم
بنفسه ورأته أصبح طبيبه نفسه.
مباشرة بعد انتهاء العملية الجراحية
وضعتني المستشفى يتغير، تشعر بأن هناك تغير
سوف تشعر ببعض من اليأس، سوف تشعر
بضعف جسدي، بضعف للتربية وبالتعب
(البرهان) كل تلك التغيرات تتحسن مع الوقت
مع تحسين مشيتك على الأكل، ومع الترامك
بالتعليقات الصحية (بما فيها الدواء)، سوف
تشر تتحسن حتى. مع مرور الأيام،
مستوى نشاطك و وضعك النفسي سيتحسنان
إن أول بضعة أشهر من فترة النقاهة صعبة
مغناطيس القوية ساهمت في الإمراع في
مضائي وسريع من العتشف بعد يوم
من تاريخ العملية الجراحية. بعد مرور 3 يوم

APPENDIX F

Example on the Extraction of Significant Statements

Transcript Patient 1

Annotation Key

- .. Short pause
- ... Hesitation
- Stopped
- _ Names
- { } What is intended

ملاحظة: كان المريض متبسماً طوال المقابلة

محاور: بالنسبة لإلك من بعد ما خضت هل تجربته ونحطلك ال-LVAD شو بيغنيك تعيش مع هيدي الآلة؟ شو يتغنيك الحياة؟

مريض 1: أول شي عطيتني أمل وتاني شي ثاني مرحله يعني أول مرحله عطيتني أمل وتاني مرحله خلثني فكر إنا أنا إنسان عايش عن جديد. شو لازم ينعمل أنا لازم أعمل شو بينطلب مني من group الحكيم أو من group تبع أيلي بتابع مع الحكيم أنا مفروض تابع وبالأساس الحكيم خولص دوره مفروض والعملية نجحت ونشكر الله وكلو تمام. الحكيم خلص دوره هلق المفروض هو الإنسان يلي عامل العملية يعني المريض هو يهتم بأمره وهو يكون حكيم نفسه.

محاور: فإذا إنت لما عملت هل عملية وقلت نجحت وحضرت حالك لتروح علييت ووصلت إنت عالييت نمط حياتك اليومية شو تغير فيها؟

مريض 1: هلق بالأساس بتعرفي بي هالجسم بيتغير بكون بوضع بتسير بوضع جسمك ضعف ايه.. بكون ما عندك - نفسيتك شوي تعبانة إيه.. قلة أكل قلة حيل مع الوقت كل ما تاكلي كل ما تتغذي وتعملي واجباتك وتخدي أدويتك مذبوط وكل شي مذبوط وعالوقت وكلو طبيعي، كل يوم بتزدي نشاط شوي بتزدي معنويات شوي إلا ما تمرقي بكم شهر بكم شهر - أنا ما أخذت معي كثير لأن أساساً معنوياتي قوية أنا بعشرين يوم كنت طالع وكنت زايد سبعة كيلو بعشرين يوم

محاور: كنت زايد سبعة كيلو لأن كنت عم تغذي حالك؟

APPENDIX G

Final Thematic Plan

Themes	Categories	Meanings
<p><u>Theme I:</u></p> <p>The lived LVAD journey from being doomed to a new life</p>	<p>A. Though the LVAD decision was not a choice, they then perceived it as a life saver</p> <p>B. Health Improvement noted when comparing their lives before and after the LVAD</p> <p>C. A new life to patients and their caregivers</p>	<p>A. The LVAD decision was the only therapy available to sustain life.</p> <p>B. During the pre-LVAD phase, patients were living through “cycles of pain, fear and sickness going in and out of the hospitals” (C.3).</p> <p>C. Despite the complexity of the LVAD experience, patients and their caregivers identified the beginning of a new life with the LVAD placement.</p>
<p><u>Theme II:</u></p> <p>Embodiment and attachment to the LVAD</p>	<p>A. The ways the dyads perceived the LVAD</p> <ul style="list-style-type: none"> a. Companion/ Second Soul b. Second Heart c. Safeguard d. Lifeline 	<p>A. “The LVAD is my companion, my life, my soul, my hope, my second heart”, my safeguard, my lifeline. Patients and their caregivers recognized the LVAD as their savers.</p>

	<p>B. Dependency and attachment to the LVAD</p>	<p>B. The patient and the LVAD are both each other's companion. The LVAD assists as much as it receives care and attention. This dual dependency was highlighted.</p>
<p><u>Theme III:</u> Living through: self-determination, coping and adjustment</p>	<p>A. Self-determination to move on</p> <p>B. Participants expressed their coping through the stages of grief</p> <ul style="list-style-type: none"> a. Denial b. Bargaining c. Anger d. Depression e. Acceptance <p>C. Adjustment is time dependent</p>	<p>A. Self-determination allowed patients to adapt and assume responsibility with the LVAD. Caregivers perceived the patients as their main helpers.</p> <p>B. Dyads have experienced the stages of grief in their coping post LVAD implantation. Patients explained how they went through the phases from denial reaching acceptance. As for caregivers, their experience with the denial, depression and acceptance phases were only reported.</p> <p>C. Both members of the dyad accepted the LVAD as a part of their new normal life. Reducing complexity and comparing their experiences before and after the LVAD placement facilitated their adjustment.</p>

<p><u>Theme IV:</u></p> <p>Patients and their caregivers shared facilitators and challenges of the LVAD experience</p>	<p>A. Participants identified facilitators of the LVAD experience</p> <ul style="list-style-type: none"> a. Faith/ God’s will b. Mental wellbeing and High Spirits c. Family and Caregiver Support d. Social support e. Scope of responsibilities <p>B. However, they identified challenges to the LVAD experience</p> <ul style="list-style-type: none"> a. Financial difficulties 	<p>A. Facilitators:</p> <ul style="list-style-type: none"> a. Patients considered their journey through their illness to the LVAD determined by God’s will. b. Patients and caregivers highlighted the importance of mental well-being and high spirits in the coping and adaptation to the LVAD. c. Patients valued the support they received from their family members. Their care and attention facilitated the coping and adaptation process. Caregivers were considered as building blocks for the LVAD experience. d. Patients’ social circle also assisted caregivers to optimize their care delivery. They also raised the patients’ spirits knowing they are present by their sides. e. One patient reported that his single status facilitated his acceptance given his lack of responsibilities. <p>B. Challenges:</p> <ul style="list-style-type: none"> a. Financial Difficulties
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	<ul style="list-style-type: none"> i. LVAD cost ii. Unemployment iii. Economic crisis b. Body image alterations as barrier for intimacy c. Anticipated concern with the LVAD d. Spousal role of caregivers 	<ul style="list-style-type: none"> i. Dyads reported how it was financially demanding to cover for the LVAD operation costs. Health coverage by NSSF and sometimes external donations were not enough to cover all related expenses. ii. All patients were unemployed post LVAD implantation due to physical restrictions. Caregivers are then the main breadwinners on top of their responsibilities. iii. Lebanon is going through a major economic crisis with the depreciation of the Lebanese Pound. b. For a single male patient, having the driveline and the LVAD affected his ability to engage in sexual relationships. The same applies for a married female patient. The body image alteration impacted her intimacy with her significant other. c. Patients have projected concern over their abilities to adapt to the new LVAD lifestyle. d. The familial role of the caregivers impacted the dyadic relationship. Spousal caregiver role resulted in heightened patient sensitivity.
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	<p>e. Complaints on LVAD weight</p> <p>f. Electricity supply shortage</p>	<p>e. Patients complained from the LVAD weight as a source of annoyance restricting their physical activities.</p> <p>f. Lebanon has shortage in electricity supply. This is a stressful reality imposed on the dyad. One dyad shared how they visited their friends in a distant village to charge the batteries.</p>
<p><u>Theme V:</u></p> <p>Despite the subsequent lifestyle changes, the LVAD brought hope and expectations</p>	<p>A. The lifestyle changes experienced by patients and their caregivers</p> <p>B. Patients and their caregivers share the LVAD experience</p>	<p>A. Lifestyle changes Patients reported difficulties in showering and clothing. In addition, they had restrictions in swimming and physical activity. Caregivers were delegated with the patients' social responsibilities. In comparing the HF experience to the LVAD one, caregivers reported a decreased burden and relief. Only one caregiver reported increase in stress and burden from the care and attention (C.3).</p> <p>B. The "LVAD is placed for the two" (C.3). This shared experience applies to caregiving as well. Patient and caregivers divided their care with both of them responsible for different tasks</p>

	<p>C. The LVAD brought hope and expectations</p> <ul style="list-style-type: none"> a. Contentment with the LVAD b. Hope and desire for future LVAD development 	<p>(complementary caregiving relationship). One dyad had a caregiver oriented relationship with the wife being responsible for all care delivery and breadwinning. The wife also reported caregiver stress and burden.</p> <p>C. Hope and expectations</p> <ul style="list-style-type: none"> a. Patients and caregivers reported contentment and satisfaction with the LVAD fulfilling its aims. The majority of the dyads reported some normalcy in life with the LVAD integration. b. The LVAD brought forth hope to both members of the dyad. They shared their aspiration on having a fully internal pump without any driveline, could be with wireless charging.
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<p><u>Theme VI:</u></p> <p>Patients and their caregivers were provoked by others' perception of the LVAD machine</p>	<p>A. Being singled out</p> <ul style="list-style-type: none"> a. Disruption of privacy b. Wonder whether businessman or terrorist c. Fear of people's misperceptions <p>B. Unfamiliarity to the LVAD</p>	<p>A. Being single out</p> <ul style="list-style-type: none"> a. Patients shared the frequent questions they get when people know they have an LVAD or an artificial heart. b. People stared with wonder on the driveline and the LVAD bag. These looks were noticed by both patients and caregivers. c. Patients feared that people might misperceive the LVAD bag to be a valuable item. This misperception may result in threats of thievery. Hence, patients tend to hold the LVAD bag tightly closer to their bodies to avoid such threats. <p>B. Patients reported that people were not familiar with what an LVAD is. The need to raise awareness on the LVAD was identified.</p>
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APPENDIX H
Translated Statements of Chapter V

Theme I: The lived LVAD journey from being doomed to a new life
1. Though the LVAD decision was imposed on them, they then perceived it as a life saver
<p>Patient 3: "I told him [patient] <i>"There is this ((pointing to the LVAD bag)) and [there is] death, which one do you prefer?"</i> [pause] I told him: "you only have two choices, this"."</p> <p style="text-align: center;">"قلته "في هيك ((pointing to the LVAD bag)) وفي موت أبي بتحب"؟ ... قلته "عندك خيارين يا هاي"."</p>
<p>Patient 2: <i>Of course, I wanted to avoid [having the LVAD operation] and even the doctor tried all therapies but eventually he told me "you cannot live without it". Another doctor I have consulted also told me "You cannot live [without it], it is not possible."</i></p> <p style="text-align: center;">"أكيد بدي إتجنبها وحتى دكتور _ حاول يجبني اياها دكتور _ قال لي " ما فيك بلاها " .. دكتور لعنده كمان قال لي " ما فيك مستحيل " دكتور _ قال لي " كمان مستحيل عضلتك كثير ضعيفة عضلتك "</p>
<p>Caregiver 5: <i>"in between death and life, we choose infections".</i></p> <p style="text-align: center;">" قلته لأختي "طيب بين الموت والحيا وإلتهاب ماشي من نقيه" مثلاً يعني إذا"</p>
<p>Patient 3: <i>"not to end your life with your own hands".</i></p> <p style="text-align: center;">" حبت لعيش لكفي حياتي مش لأقعد خلص حياتي بإيدي ... "</p>
2. Health Improvement noted when comparing their lives before and after the LVAD
<p>Caregiver 3: <i>"cycles of pain, fear and sickness, going in and out of the hospitals".</i></p>

"لما كنا عايشين بدوامة الوجع ونقزة وسخونة وروحا وجايي عالمستشفيات. {emotional tone}"

Caregiver 5: "every day was worse than the previous, tiring all of us".

"يعني كان كل يوم نحس في فرق عم نتعب أكثر. "

Patient 5: "threatened by death every moment of your life".

"انتي مهددة بالموت كنت كل لحظة حياتك مهددة. "

Patient 2: "[my breathing] changed, I used to be very short of breath, I couldn't sleep when I wanted to [pause] the LVAD changed my life."

"تغيرت كنت حس كثير بضيقه نفس كثير اتضايق بس نام ما اقدر نام LVAD .. غيرتلي حياتي."

3. A new life to patients and their caregivers

Patient 5: "[The LVAD] made me love life even more [pause] when you are losing your life progressively [pause] Then, there is this thing [LVAD] that stops [death] halfway and redirects you back [to life] [pause] I believe that I regained five years of my life [pause] let's make it seven years [pause] Regardless of the [device's] weight, my [physical] capacities are those of a forty years old. So, I gained ten years."

"إنو هوي حبيبي بالحياة أكثر .. يعني انتي لما بتكوني عم تفقدي حياتك بالتدريج .. وشي يوقف لنصف الطريق وبرجعك هيك ... مثلاً أنا بعنبر حالي رجعت خمسة سنين لورا .. يا إختي خلي سبعة سنين .. إنو همتي صح إنو في وزن معي .. بس أنا همتي مثل ما كان عمري أربعين سنة .. في عشر سنين. "

Patient 4: "LVAD gave me a second chance to live".

[LVAD] عطيتني حياة جديدة ..

Patient 4: "It's a loss if one gets scared [from the LVAD], don't be scared as the LVAD provides you with a new life [pause]. If it weren't for the LVAD, I would be gone [pause] gone [pause] or I would be bound to my bed asking them [my family] to take care of me and so on."

"يعني إذا بده يخاف ... حرام ما يخاف ما يخاف .. يعني ال-LVAD بتعطي حياة جديدة .. أنا لو ما من ال-LVAD وهيدا يمكن كنت رحت .. كنت رحت .. لأنو - أو كنت قاعدي بالفرشة جيبوا خدولي وعملولي وهيك. "

Patient 3: "I told you that the LVAD is a [new life] to me [pause], a life to myself, my family, my wife and [pause] my brothers, even my brother who lives abroad."

"ايه طبعاً.. أنا قتلتك أنا .. ال-LVAD هي حياة لإيلي ...
حياة لإيلي لعيلتي ولمرتتي ولي... ولخياتي ولخيي يلي مسافر. "

Theme II: Embodiment and attachment to the LVAD

1. The ways the dyads perceived the LVAD

Patient 1: "[The LVAD is] my companion my life [pause], it is my soul [pause] it is my hope [pause]. Logically, it needs care and attention ((holding the LVAD bag and then closing it))."

"رفيقتي حياتي ... شو هيدي روحي شو .. أملي هاي شو.. بدها عاطفي .. ((صوت تسكير شنطة ال-LVAD)) المنطق هيك بيقول. "

Patient 5: "I joke with them [my girls] and tell them "Look I have two hearts and I love you with my two hearts when they ask ((both patient and interviewer laugh)). Yes, the [LVAD] is for sure my heart, I improved around 100 %, let me say 90 % as I can't completely deny my [real heart]'s work."

"أنا بمزح أنا وياهن بقولهن ليكه أنا بقلبين ((both patient and interviewer laugh)) بحبكن بقلبين بيسألوني إيه أكيد هوي {LVAD} قلبي إنو ريحني تقريباً مية بالمية فيني قول تسعين ما فيني انكره ((laugh)) إله فضل عليي. "

Patient 1: “*In principle, [the LVAD] is the individual’s companion [pause] if the individual feels something is wrong, [the LVAD] should alert him by beeping, flashing lights or any alarm, or any written alarm. At least, [the LVAD] should alert him promptly in some way by a beeping sound: “tout tout”. The individual then shall have his eyes wide open [to respond for the alarms]. So, [the LVAD] becomes his safeguard. And in return, the individual acts as a safety guard by protecting it [LVAD].*”

"بالمبدأ مثل ما قلناك هي رفيقة الإنسان و.. هي حقه إذا حس عنده شي منو مطبوظ هي لازم- هي بتزمرله ولا بتعطي ضو أو شي ولا بتكتبله شي بس بالقليلة بطعني توت توت مفروض تبادر مفروض هوي يفتح عينيه يعني هي حارس الأمان تبعه وهوي حارس الأمان تبعها مثل ما هي بتطلع عليه بيطلع عليها. "

Patient 5: “*[I consider the LVAD to be a] lifeline [pause] Yes, it is like a life-saving rope, a lifeline for me [pause] when you are threatened by death every moment of your life. Okay, one’s age is predetermined ((laugh while talking)).*”

"حبل نجاة .. إيه حبل نجاة كان بالنسبة أيلي .. انتي مهددة بالموت كنت كل لحظة حياتك مهددة بقول الأعمار بإيد الله.

Caregiver 4: “*Oof at first, if it weren’t for the LVAD, my mom maybe wouldn’t be here with us now [pause], so the [LVAD] was our lifeline if I can say [pause] for sure [pause] we did not have another option.*”

"أوف أول شي يعني لو ما من ال-LVAD يمكن ماما ما كانت موجودة معنا هلق .. يعني ... هي كانت المسعفة إذا بدك ... إيه أكيد ... ما كان في عنا حل إلا هي. "

2. Dependency on the LVAD and attachment

Patient 4: “*[The LVAD] is very good [pause] it gave me one more chance in life [pause] If it wasn’t for it, I would be dead [pause] Yes, it allowed me to live [pause] No [the LVAD] is very good but one has to adapt with the [LVAD] bag. One has to know how to hold it, shower with it, how [pause] to take care of the wound on daily basis for it to stay clean [pause] like that, no no it doesn’t annoy me.*”

"كثير منيحة يعني ... عطيتني chance بالحياة أكثر ... لو ما منا أنا كنت متت ... إيه خلتنني عيش .. لا كثير منيحة بس الواحد مش أكثر بده يتأقلم مع الشنطة إنو يضل كيف حاملها بده يعرف حاله كيف يتحمم كيف بده ... يربط الجرح إنو يتغير كل يوم تا يضله نضيف ... هيك شي يعني ما ما مضايقتني أبداً. "

Patient 1: “I plan my essential arrangements selectively. The [LVAD] becomes your companion. You need to cherish its necessities so it assists you in sustaining your life.”

"مشوار ضروري بتروحي مشوار منو ضروري بتعتذري منو .. (مشيراً ولامساً حقيبة ال-LVAD)) هلق هي رفيقتي بدك انت تريحها تا حتى هي تريحك. "

Theme III: Living through: self-determination, coping and adjustment

1. Self-determination to move on

Patient 1: “It is essential to note that the doctor’s role is over with the success of the operation, thank God. The responsibility is now handed to the patient after the operation where each patient needs to self-care and act as his own doctor.”

"وبالأساس الحكيم خولص دوره مفروض والعملية نجحت ونشكر الله وكلو تمام. الحكيم خلص دوره هلق المفروض هو الإنسان يلي عامل العملية يعني المريض هو يهتم بأمره وهو يكون حكيم نفسه. "

Patient 4: “The first time I saw [the LVAD] I got really concerned [pause] there is a bag [pause] how will I be able to manage with it – because the first time I did not shower alone, my daughter helped me. Then I thought why not [to shower alone] ((higher voice pitch)) I should empower myself ((hand in fists – gesture)) and adapt with it and adjust myself. And I really adapted and now I don’t get help with anything.”

"أول ما شفتها بصراحة عطلت هم .. إنو شنطة ... كيف بدى اتدبر أمري كيف بدى هيدا - لأنو أول مرة حتى ما فتت عالحمام اتحممت أنا وحدي فانت بنتي ساعدتني بعدين قلت أنا لأ ليش؟ ((higher voice pitch)) أنا لازم قوي ((hand gestures: fists)) حالي وانا اتأقلم معها وظبطت وضعي وفعلاً أنا ظبطت وضعي وهلق ما حدا بساعدني بشي. "

Patient 4: “Yes [pause] I can wash, change my clothes, [I can do] everything everything [pause] I no longer find any difficulty. There is no difficulty, it is up to the person to be self-dependent. He will find strength once he is self-dependent and everything will work out.”

"ايه ... بدى غسل بدى إلبس تيابي كل شي كل شي أنا .. ما بلاقي صعوبة بقى ما فى صعوبة الإنسان هوي بده يتكل على حاله بلاقي حاله قوي هوي عم يتكل على حاله بيمشي الحال. "

2. Participants expressed their coping through the stages of grief

Caregiver 4: *“When she first had the LVAD placed, I couldn’t accept the concept of [the LVAD], I had a kind of reflux when I thought about it [pause], we live together and this made me not accept [the LVAD] given the added responsibility delegated to me.”*

"أول ما نحطت {LVAD} أنا كى concept ما اتقبلها عملت هيكي reflux عالموضوع .. ولأنو أنا لحالي بالبيت so أنا ما تقبلت الفكرة لأنو أنا هالقد مسؤولية أنا بدى اعملها يعني. "

Patient 4: *“[My family] are very pleased [with the LVAD], [pause] they did not believe that I am relying on myself [pause], They couldn’t believe that [pause] for instance, my daughter steps in to help me with something but I do it alone [pause], Even I cook at times, I cook any meal they want.”*

"لأ كتير مبسوطين .. هيني كتير مبسوطين هني ما صدقوا إنو أنا عم بعمل كل شي لحالي .. ما صدقوا .. بتجي بنتي مثلاً بدى ساعدك لأ أنا بعملها .. بدى أعمل شغلة لأ أنا بعملها .. حتى أوقات بطبخ .. بطبخ مثلاً في شي أكلت بدهن اياها أنا بعملهن اياها. "

Patient 5: *“But now, I can no longer shower right away as I need to shift [the LVAD bag] to another one and then I need to do the dressing change after bathing. Sometimes, I say “Oh God, why did this happen to me dear God?” I get angry but now I got used to [the bathing difficulties].”*

"وهلق بدى فوت اتحمم دغري لأ بدك لتتقلي على شنطة تانية لبدك تعقمي الجرح بعد ما الحمام فأوقات يعني "يا الله يا ربي ليه هيك صاير فيني؟" إنو بعصب هلق تعودت. "

Patient 1: *“Sometimes I look back trying to understand why this has happened to me, although I did not cause harm to anyone.”*

"براجع أوقات بتعرفي براجع الواحد أوقات بسأل حالي أنا لي عم يصير فيبي هيك مع إنى أنا منى أذى حدا. "

Caregiver 3: *“yes [caring was imposed], what can I do? I cannot do anything and at the same time I cannot let go of this responsibility.”*

"ايه شو بدى أعمل؟ ما فينى أعمل شي ما فينى شي وبنفس الوقت ما فينى اتخلى عن هالمسؤولية. "

Patient 2: “*Maybe it is my fault that I did not take care of my health or it is my [destiny]. [I believe] that every person has a disease during his life. This is what I reason when I think and reflect by myself.*”

"يمكن أنا غلطي ما درت بالي عصحتي يا أنا هيكي يعني كل إنسان عنده مرض بهالذنيا هيك بقعد بفكر أنا بس هيك بقعد بفكر. "

Patient 5: “*for instance, when I complain: “Oh God, till when do I have to deal with this cable [driveline]? Or when I am in pain or something [pause]”.*”

"مثلاً لما بعصب إنو يا ربي هيدا لامتن هالشريط؟ أو وجعت أو شي..."

Patient 3: “*I am telling you [pause] this thing ((pointing to the LVAD)) really affected my life [pause]. I did not reach a phase of deep depression but I started with it [pause]. I then asked God “why dear God I am reaching this phase [depression]?” [pause] I got to a point [praying God] to relief me and take me away. That’s it.*”

"عم فلك شو .. هيدي الشغلة {مؤشراً على ال-LVAD} هيدي كثير أثرت معي كثير بحياتي ... مش وصلت لمرحلة اليانس كثير كثير بلشت فيها أنا .. إرجع قول لربي أنا "دخلك يا ربي ليش عم بوصل لهالشغلة هاي؟" ... وصلت لمرحلة إنو خلص خلصني .. ربحني يا هيك يا هيك خلص. "

Patient 5: “*Yes [pause] even she was mentally tired initially after [the LVAD] [pause] - at first, she enjoyed it, but then [pause], it is not easy for a person to be connected to batteries and electricity. And when she sleeps at night, she disconnects from the batteries to that [electricity device].*”

"ايه .. وحتى يعني ... هي تعبت نفسياً أول شي من ال... - أول شي أمبسطت بس بعدين .. منها هينة هي الإنسان ينوصل عالبطارية كهربيا ولما بتنام من شيل البطارية ومن حظ هيدا. "

Patient 5: “*I lived through a down period, when I first got home from the hospital [pause], I struggled with bathing [pause] I used to shower instead of the ablution to pray [pause] , I used to shower directly but I can no longer do that as I need to change to another [LVAD] bag [pause] I need to clean the wound. This really restricted me especially that I am an [active] person always moving fast.*”

"فلك فتت بمرحلة الإكتئاب أول ما طلعت من المستشفى بيضيقني خلقي فترة الحمام .. لأنو أنا كنت اتحمم مثلاً ما اتوضى .. أنا دغري إفتح ال-douche اتحمم بعدين صرت حس إنو لأبدي إنقل عالشنطة .. بدنا نعقم الجرح إنو هيدا عرقلني يعتبر إنو خاصة انتي إنسانة بتشتغل بسرعة .. أنا إنسانة عندي حركة زيادة. "

Patient 5: *“I was a dead person [pause], I couldn’t live my life so I ignore [all these negative thoughts]. I talk to myself that I am now annoyed changing [LVAD] bags but I could not even shower by myself before.”*

"إنو أنا إنساني كنت ميتة .. ما عم بقدر عيش حياتي فبطنش يقول لأ انتي كنت عم تنزعجي انك عم تنقلي على شنة بس إنت ما كان فيكي تتحممي لحالك . "

Caregiver 4: *“For me, I couldn’t picture my mom [dependent] on a machine. I couldn’t accept this thought initially. But then, I saw her improving and adapting [to the LVAD]. This made me adapt to the [LVAD] with it being a part of our normal daily life.”*

"إنو لأ أنا ما كنت عم تفوت براسي إنو أنا ماما عال-machine ما كنت تفوت براسي أول شي donc .. بعدينا صرت شوفها إنو لأ عم تتحسن وكذا وهيكي متجاوبة هي صارت القصص أحسن تقطع .. وصرنا نتعود عليها يعني وهلق خلص صارت من حياتنا العادية يعني."

3. Adjustment to the new ways of life

Patient 4: *“It took me around two weeks [to adapt to the connections] [pause] I started managing [the connections] by myself.”*

"لأ مش كتير شي جمعتين .. صرت أنا أعملهن لوحدي. "

Patient 1: *“[After the LVAD directly] your health status changes. You feel your body is in a different shape. You will feel down; you will experience body weakness, poor appetite and fatigue. All these improve with time. As your food intake increases and you comply with the healthcare instructions including medications’ intake, you will notice health improvements. Day by day, your activity level convalesces and your spirits rise. The first few months while recovering are hard.”*

"هلق بالأساس بتعرفي بي هالجسم بيتغير بتكون بوضع بتسير بوضع جسمك ضعف ايه.. بكون ما عندك - نفسيتك شوي تعبانه ايه.. قلة أكل قلة حيل مع الوقت كل ما تاكلي كل ما تتغذي وتعملي واجباتك وتخدي أدويتك مطبوط وكل شي مطبوط وعالوقت وكلو طبيعي، كل يوم بتزيدي نشاط شوي بتزيدي معنويات شوي إلا ما تمرقي بكم شهر بكم شهر. "

Patient 2: *“[I recovered in] around two months, the doctor told me “you need two months [to recover]”. The first two weeks were the hardest, very hard [period]. It is difficult as it is a new [device] implanted [pause], [It is difficult] to handle the*

connections, holding the [LVAD] bag. Then I was having left shoulder pain for around two months but it stopped on its own, thank God.”

"شي شهرين اجا الدكتور وقال لي إنه " بذك تاخذ شهرين " .. أول جمعيتين كتير صعبة كانت كتير صعبة ...
صعبة كانت شي جديد عم ركبه .. شيل و حط و هيدا شنة تمشي وحسيت بوجع هون {الكتف الشمال} شي شهرين
بعدين الحمد لله راح وحده .. شي داخل عجمي جديد .. حطينا {LVAD} هوني {الكتف الشمال} صار حس بوجع
عكتفي هوني شي شهرين بعدين راحت الحمد لله. "

Theme IV: Patients and their caregivers shared facilitators and challenges of the LVAD experience

1. Participants identified facilitators of the LVAD experience

Patient 5: “Yes, I try to soothe myself with [my thinking]. Eventually, this is God’s will and his wisdom [pause]. Maybe, his wisdom is for me to have the LVAD [pause]. Maybe God’s will, made me lose my consciousness in front of the doctor so he urgently operated.”

"إيه براضي حالي من حالي إنو خلص ربنا شايك هيك وهي يمكن إله حكمته .. يمكن حكمة ربنا إنو وصلك لل
LVAD.. يمكن ربنا خليكي توقعي قدام الدكتور لحتى يعجل بالعملية . "

Patient 5: “Okay, one’s age is predetermined ((laugh while talking)). Maybe, I could have died while having the operation then my life is simply over by then [pause.] It is fate and destiny that we don’t have a say in [pause]. But, once God gives you a chance to have the LVAD, that means you have a chance in life, you need to take advantage of [pause], take advantage [of the LVAD], love life and do everything the right way.”

"الأعمار بإيد الله ((laugh while talking)) يمكن كنت عملت العملية ومنت بقول إنو عمري خلص لهون.. بكون
شي قضاء وقدر ما فينا نلعب في .. بس انتي لما ربنا عطاكي فرصة انك تحطي هالجهاز معناتها هوي عم يعطيك
فرصة للحياة إستغليها .. إستغليها وحي الحياة و عملي كل شي الصح. "

Caregiver 5: “first thing, because half the therapy consists of the mental wellbeing and the second half is the therapy itself.”

"أول شي ... لأنو نص العلاج هوي عامل النفسي نص العلاج ثاني شي . "

Patient 4: “One has to be courageous [pause] he needs to – If he wants to [always self-excuse] with: I have a disease and I am sick and I can’t do that [pause], he gets lazy and his sickness worsens [pause]. But no, one has to raise the spirits and self-empower [pause] and everything will work out.”

"الواحد بده يكون عنده جراءة .. بده هوي - إذا بده yih دخيلكن أنا مريضة وأنا ساخنة وأنا ما فيي .. بيتكسلن الواحد وبيمرض بزيادة .. بس لأ بده الواحد هوي يعطي معنويات لحاله ويقوى .. وكل شي بيزبط. "

Caregiver 1: “If it was a different patient, he would have been devastated and he might have died from delusions and worry [pause]. Another older patient did the operation and passed away [from fear and depression].”

"شفتي لو مريض غيره يمكن كان نهار يمكن مات من الوهم .. من الفزع عن جد .. مريض غيره ما بعرف إذا الاختيار يلي عمل بعد منه وتوفى. "

Caregiver 1: “Honestly, I was feeling extremely down but I always hold it together in front of him. [The patient] survived difficult times including multiple surgical operations and even a pacemaker insertion. I cannot surpass how I felt that day, when [the doctor] told me he only has three weeks left [to live]. I couldn’t stand from the chair. I was really scared but I made sure to remain positive and encouraging. [Regardless of his condition], he always had strong and high spirits, even superior than ours [family].”

"أنا صراحة يعني كنت يعني أعصابي كثير تعباني بس أنا قدامه دائماً - قدي مرق بمراحل عمليات وحط بطارية يعني كان هيدا الوضع يومتها وقتنا قال له ثلاث جمع صدقي إنوا أنا ما عدت اقدر قوم عن الكرسي بس أنا قدامه ما بظهر إنوا أنا خايفة يعني بضل أعطي معنويات مع إنوا هوي معنوياته أحسن مننا معنوياته كثير قوية. "

Caregiver 5: “The psychological support a patient receive from people surrounding him really helps him [pause]. In Lebanon on top of that, you need to add the financial factor. But, the psychological support helps the [patient] around 50 % if I can say ((laugh)) [pause] a big [percentage]. It is extremely important [pause] and we were all at home ((laugh)) healing ourselves psychologically. There is no issue with that.”

"العامل النفسي يلي حول المريض بساعده يعني ... شي بدي فلك هلق نحنا عنا بلبنان زائد العامل المادي .. إيه بس العامل النفسي بساعده للإنسان إذا بدك لحد الخمسين بالمية معلية شي خمسين بالمية ((laugh)) كثير ... إله أهمية كثير .. كثير كثير ونحنا بالبيت حسينا حالنا ((laugh)) عم نعالج بعضنا نفسياً معليش ما مشكلة. "

Patient 1: “[My relationship with my friend after the LVAD did not change] of course not. When we are together, if they notice that the cable [driveline] is kinked ((showing

how)), they would alert me that it is kinked [pause]. I comfort them by saying that nothing will go wrong and the cable is responsible to deliver the electricity without visibility to the naked eye.”

"أبداً لا أبداً، حتى هني حرام رفقاتي مثلاً إذا قاعدين وطعج الشريط ((مقلداً تطعيج الشريط)) بقولوا ليك _ طعج الشريط عرفتي كيف ... إيه بصيروا ينبهوني بقلن لأ هيدا ما بصير شي يعني وإنو هيدا بوصل الكهربا شي ما بتشوفي بعين المجردة. "

Patient 2: “What really helped me to accept [my condition] and adapt is that I don’t have any responsibilities [pause]. I don’t have children, education [commitments], a wife or anything [pause]. This has helped me with [my medical condition] – God Almighty maybe knew [my health status was deteriorating] so that I didn’t commit myself to any form of responsibilities [pause]. This is what really made me accept [my condition and fate]. If I had commitments and responsibilities, it would have been different to me to deal with this situation.”

"كوني ما عندي مسؤوليات .. هيدا يلي بخليني أتقبل الأمور .. ما عندي ولاد مدارس ما عندي مرا أو شي .. ما وصلت لهون يمكن - رب العالمين عارفين حى أوصل لهون ما فنتت بمسؤوليات يعني .. هيدا يلي أتقبلت هل شي لو عندي مسؤوليات كان غير وضع عرفتي كيف كان غير وضع. "

2. However, they identified challenges to the LVAD experience

Caregiver 5: “A problem with the LVAD in Lebanon is its cost [pause]. Those who do not have NSSF – I really thought at that time about those who don’t [have NSSF]. But I had NSSF. Doctor _ {name} also extremely helped me. I am not sure if you know [laugh] Despite [all these assistance], me, my brothers and sisters, we still fought every minute ((laugh)) for [the LVAD operation] to work. [it worked] thank God.”

"مشكلة بهيدا ال-LVAD بلبنان السعر .. يلي ما عنده ضمان يمشي يعني - أنا فكرت بهيك وقتها بيلى ما عنده ضمان يعني أنا عندي ضمان وأنا دكتور _ ساعدني مساعدة رهيبة مع بعرف إذا بتعرفيها ... إيه ورغم هيك كان بتحسبها بدك تقايلي كل الوقت ((laugh)) لمشي الحال يعني أنا اخواتي وإخواتها والحمدلله يعني.. "

Caregiver 3: “From the economical perspective, yes there are difficulties, honestly because he is not working. And all my income from the school goes [directly] to pay my children’s tuitions [pause]. We still have the living [expenses], my in-law lives abroad and he regularly send us [an amount] as much as he can, around 200 \$ not more. It is true that the value of [this amount] has increased but at the same time, the material [expenses] are rising as if nothing has changed.”

"من الناحية الإقتصادية إيه في صعوبة صراحة لأنو ما عم يشتغل وانا بالمدرسة يعني بيروح كل معاشي بدفع ق قسط ولادي في .. يعني بضل عنا المعيشة سلفي مسافر بضل بيعطلنا بالشهر يلي بيقدّر عليه مية ميتان دولار مش أكثر صحيح هلق شوي عم تشقّع بس إنو نفس الوقت الغراض عم تغلى يعني ما كأنو الواحد عمل شي. "

Caregiver 1: *"The box of gauzes [now costs] twenty-five thousand LBP. The disinfectant costs thirty thousand LBP [pause]. These are daily items you use. If it was a monthly expense, [the financial impact] was non-significant. As they are daily items, don't you think they are heavy expenses? Right, [the LVAD] requires [financial] sustainability as the [LVAD] is not a matter of a day or two. It might stay possibly a year, two, three or four I don't know [pause]. Consider God Forbids that we no longer have financial assistance from abroad, what can we do for that? [pause]. Even the national social security fund does not cover our [medical expenses] hundred percent. You pay hefty amount and you get refunded reduced ones as they cancel [expenses] they don't cover."*

"علبة الشاش خمسة وعشرين ألف تطهير ثلاثين ألف .. يعني هودي يومي مش إنو بالشهر مرة بتمرقها .. بس إنو هودي اشيا يومك بدك تعملين إنو كمان هيدا ما بده مصاري؟
مضبوط في إستمرارية يعني مش إنو يوم وتنين يمكن سنة تنين ثلاثة أربعة ما بعرف .. اعتبري لا سمح الله ما عاد حدا ودلنا ولا قدروا يودوا كيف الواحد بيعمل؟ بتروحي بتشحدي؟ .. حتى الضمان ما بردلك مية بالمية بتدفعي بلاوي بتروحي ترديهن بتالاقيهن يلا مخطشين ها مخطشين ها ما بيعترف في. "

Caregiver 1: *"Despite [all the financial challenge], what really matters is his health, presence and well-being. [All other expenses] can be arranged."*

"يلا ماشي بس يضل بصحته ويضل قدامنا قتلته كلو بيتدبر [مصروف تاني]. "

Patient 2: *"You know I am a single man. I get intimated if you know [pause] as they say [pause] How can I explain that? ((Saying it hesitantly)). No [sexual] relationship, I don't dare to do [sexual] relationships [pause]. This is the only thing [that I cannot do] [pause]. I had previous [sexual relationships] longtime ago before the LVAD – I don't dare to be [involved in sexual relationships] with something coming out of my abdomen and a bag [pause]. This is a life norm, sorry for that [pause]. You know [pause] so this is the only thing that annoys me [with the LVAD] but I adapted at last, I adapted thank God the Almighty."*

"بتعرفي أنا زلمه عزابي باستحي بتعرفي ما في ... مثل ما يقوله ... كيف بدّي فسرّها ((متردد)) ...
ما في علاقة ما بعملا ما بسترجي أعمل علاقات .. هيدي الشغلة الوحيدة بس .. إنه كان عندي علاقات من زمان قبل ما ركب - هلق ما بسترجي هلق شي طالع من بطني وكذا وشنطة .. هيدي سنة الحياة عفواً ... عرفتي كيف .. بقي هيدي الشغلة الوحيدة يلي زاعجتني بس تعودت تعودت خلص تعودت الحمد لله رب العالمين ..."

Patient 2: “Even during the first phase, after my body recovered back to normal, I was shy with our intimate life [pause]. I was shy and I would escape to sleep at my daughters’ room, at the living room or I would justify that I am tired. He then told me “why are you doing that [escaping from me]? I am accepting of you as you are, I like how your body looks with or without the cable [driveline] ((laugh)) why are you doing this to yourself? Why are you upsetting yourself? Why are you depriving us to be happy together? “He started assisting me with [getting back to our sexual life] [pause] we did not talk a lot about it [pause] you know [pause] he [communicated] this in his own way pampering me [pause] extra flirting ((laugh)) yes making me feel that he accepted me [pause]. Although we did not talk directly about it like why are you doing this? But in his own way with his pampering, I understood that “why are you doing this? I accept you as you are” [pause], you know.”

.. بعد ما صرت صار جسمي كله طبيعي إنو كحياتنا إنو مع بعضنا .. استحي .. استحي وحاول إهرب نام بأوضة البنات نام بأوضة القعدة اتحجج تعبانة إيه بعدين قال لي "ليه عم تعملي هيك؟ أنا متقبلك كيف ما انتي، انتي شكل جسمك عاجيني بشريط { driveline } ولا بلا شريط ((laugh)) إنو ليش عم تعملي بحالك هيك؟ لش عم تنقهرني؟ ليه عم تحرمينا إنو نحن نكون مبسوطين مع بعضنا" .. صار هوي يتعاون معي بهالموضوع .. إنو بس ما حكينا في كثير .. عرفتي كيف .. إنو هوي بطريقته يغنجني يدللني .. إيه يتغزل فيني زيادة ((laugh)) إيه يحسني إنو لا إنو أنا متقبلك .. يعني ما حكينا إنو بطريقة مباشرة إنو ليش عم تعملي هيك بس بطريقة اسلوبه هوي وغنجه ودلاله فهمت إنو "انتني ليه عم تعملي هيك؟ أنا متقبلك كيف ما انتي" .. عرفتي كيف."

Patient 4: “The first time, I got really concerned [when I first saw the LVAD] [pause] because I was recently out of the hospital so I found some difficulties about how I will be [pause] when I want to shower, how will I be able to get dressed, how will I be able to do that? My daughter started to help me at first then I thought that no, I need to be self-dependent. Everything worked out when I became self-dependent.”

"أول نهار عطلت هم .. لأنو كنت بعدني جديدة ضاهرة من المستشفى يعني لقيت صعوبة إنو كيف أنا بدي هلق ... بدي فوت أعمل douche كيف بدي البس تيايبي كيف هيدا صارت تساعدني بنتي أول شي بعدن لا ليش أنا بدي اتكل عحالي اتكلت عحالي ومشي الحال."

Patient 4: “They might get scared from the look of the devices [LVAD and connections]. When they see the [LVAD] elements, they might get scared and wonder how they will [adjust] to the tube [driveline] coming out of their abdomen [pause]. But nothing is impossible when you simplify [things], [adaptation] gets easier.”

"ليه معقول يخافوا يمكن بدهن يشوفوا المكناات بدهن يشوفوا هالاشيا كلها يمكن يخافوا أنا كيف بدي خلي النبريش ببطني كيف بدي أعمل .. لا ما في شي صعب هونها بتهون."

Caregiver 5: “But I [thought to myself] that is it fair to make my wife feel that she is something abnormal? .. No and that’s when – I am telling you that the father or son [caregiving] might be simpler [pause]. [Patients] wound not be super sensitive. But the husband or wife or son, these are more complex [to patients]. [It is extremely sensitive] specifically when the spouse is the husband [pause]. Because the wife naturally could associate her illness to her husband possibly punishing her, betraying her or marrying over her. In our religion, we can marry multiple spouses [pause]. I don’t know your religion, don’t mind that ((laugh)). The husband should make her feel that he values his wife as a wife [pause] ill or not [pause]. Because if he made her feel that she became nothing for him, just a commitment, he would kill her.”

"بس إنو صرت اصفن إنو أنا معقولة حسس مرتي إنو هي شي غلط؟ .. إيه لأ هون - عم قلك يمكن الأب أو الإبن يمكن حتى الأب والإبن بضله ... الأب والإبن بضلهن أهون .. ما بيتحسس منهن بس الزوج أو الزوجة والولد هني أهم شي هول الزوج أو الزوجة إذا كان زوجها أو زوجة خصوصاً إذا زوج .. إيه لأن المرة بطبيعة الحال بمرضاها يعني بطبيعة البشرية هي بتعتبر الزوج ممكن يعقابها يخونها أو يتزوج عليها نحنا عنا بيتزوجوا - في تعداد الزوجات sorry ما يعرف شو الديانة معك ما تواخذيني .. ((laugh)) إيه بس بده يحسها بده يحسها إذا زوج ... ومرته بتعنيله بده يحسها انها مرتته .. مريضة أو مش مريضة هي حالة مريضة أو مش مريضة .. لأن إذا حسسها إنو هي صارت .. ما بقى شي بالنسبة إله بس مجرد إلتزام بيقتلها. "

Patient 3: “you know, I feel something [LVAD] heavy [when I move] [pause]. But I am happy with my health condition [pause]. Yes, I adapted to it [LVAD] [pause]. [It took me] around a month [to adapt].”

"إيه حاسس شي ثقيل عرفتي كيف شي ثقيل .. بس سعيد يمكن وضعي الصحي هيكي عال .. تعودت ... إيه تعودت عليها ... شي شهر تقريباً ... "

Patient 5: “But now, [there are certain] activities [that requires] lifting [I can no longer do]. For example, I no longer remove curtains. Why? Because it [LVAD] has some weight [pause]. It [LVAD] is annoying when I lean forward to the ground. For example, I enjoy rinsing [the floor tiles], cleaning the house. But when I lean under the couches or something I get exhausted doing that. Okay, I fasten it well using the belt ((held LVAD bag to waist level)) [pause] I fasten it but I get exhausted from its weight [pause]. Its weight while walking the stairs is annoying as well.”

"إيه هلق مثلاً شغلوات تعربش هيدي فك البرادي ما بقى في .. ليه؟ لأنو هي وزن يعني ... مزعجة شي طب من الأرض مثلاً أوقات بحب إشطف نصف البيت لما بطب تحت الكنباتيات أو شي بتعب للشطف هلق بربطها أنا بربطها ((held LVAD bag)) في إلهها ceinture بحطه .. بربطها معي ((held LVAD bag to waist level)) إيه بس بتعب من وزنها خلص إنو تعبت .. وزنها عالدرج مزعج يعني بيتي عالتالت. "

Caregiver 3: “Yes, we have an issue when the electricity goes off [pause] and the [electricity] generator in our village is not working – we went once to another place at our friends’ house to visit them so we can charge the batteries. This is another problem we face [pause]. Okay, we have a UPS but it does not last for a long [time] just for 5 minutes. It only lasts from when you change from the batteries to the monitor. Sometimes, it works and other times, it does not. This is why we use the batteries more.”

"إيه إيه هلق عنا مشكلة إذا بتروح الكهرباء .. وعنا كتير بيتعطل ال-moteur بالضبعة حاطينه فا مضطرين بدنا نروح - نحن مرة رحنا على مطرح ثاني عند ناس أصحابنا لقعدنا عندهن لشرجنا البطارية يعني كمانه هيدي مشكلة من واجها .. ولتيجي مثلاً صحيح هي في UPS وهيك بس ما بضايين كتير يعني انجأ خمس دقائق يعني من لما تغيري من ال- moniteur على البطارية أوقات لحق وأوقات ما تلحقي من شان هيك منستعمل البطاريات أكثر."

Theme V: Despite the subsequent lifestyle changes, the LVAD brought hope and expectations

1. The lifestyle changes experienced by patients and their caregivers

Patient 2: “I get really annoyed with the shower [pause]. I told her that “I really get annoyed while showering [because of the LVAD]”. I feel annoyed and afraid [for the LVAD] to get in contact with the water [pause]. I hold the shower head [diagonally to avoid water contact with the LVAD].”

"الحمام بضايق.. قتلها " أنا بضايق بالحمام كتير " بضايق بفرع ما يجيها ماي .. بمسك ال-douche بعمل هيك بال-douche. {diagonal position.} "

Patient 5: “One of the things that really annoy me [with the LVAD] is the physical look of the [LVAD] bag with the clothing [pause]. Yes, I can no longer wear everything that I want to. My clothing [consists] mostly of shirts and pants, and I am picky with my choices [pause]. I let go of a lot of items in my wardrobe like dresses and so on [pause]. Yes, they no longer work with me [pause]. You cannot have the cable [driveline] coming out without a two-piece clothing.”

"من الأمور يلي أكثر شي بتضايقني شكل الشنطة باللبس ... إيه ما بقدر اليبس كل شي يلي بيدي إياه أكثر ليسي بنطلون وقميص ما كل شغلة بتعجبني .. قطع من تيايبي كتير روحتها فساتين وما فساتين ... إيه ما بيظبت .. إذا بدك طلعي الشريط ما في طريقة تانية غير ما يكون قطعتين. "

Patient 1: “[my social routine changed] for sure [pause]. When we go by the beach, I wish I am able to swim, I wish these [pointing at the LVAD bag and the driveline] can turn internally so I could return to swimming. I long for the day these [the LVAD bag and the driveline] can turn compact and internal.”

"هلق أكيد .. منروح حد البحر بقول يا ريت فيني اسبح يا ريت هاي ((مؤشراً عالشنطة وأل-driveline)) بتتغير بتصير بالجسم تحتى إرجع اسبح ... بس بيجي يوم بدا هاي ((مؤشراً عالشنطة وأل-driveline)) تصغر يمكن تصير بالجسم. "

Caregiver 2: “At first, we were worried and sad [seeing him unable to walk] but he slowly recovered and improved [pause], he started to sleep, started to – Before [the LVAD], he couldn’t sleep and anything. [there is a huge difference] in his condition before and after [the LVAD].”

"هلق نحن شو اسمو .. دايقنا شوي صار شوي شوي صار وضعه أحسن صار .. صار يقدر ينام صار يقدر هيدا - .. قبل ما يقدر ينام ولا شي إيه وين كنا ووين صرنا. "

Patient 1: “Visits [after the LVAD] of course not [pause]. For sure, I keep my visits [and social activities] limiting them to just the necessary. I delegate all social duties to my wife.”

"زيارات هلق طبعاً لأ طبعاً لأ.. طبعاً المشوار الضروري يعني إذا ما ضروري مية بالمية مرتي بتعمل الواجبات. "

Caregiver 5: “I’m [living everything], seeing everything with my bare eyes [as they say], the one hearing about [something] is different than the one seeing it. Yes, I am seeing with my own eyes [her condition].”

"إنو عم شوفهن بعيني ... أنا ... يلي بيسمع غير يلي بكون عم يشوف بعينه. إيه أنا عم شوف بعيني. "

Caregiver 5: “[I can say] from my personal experience, that the [LVAD] has changed my life [pause]. Yes, the patient is not the only one with the illness as his surroundings share his illness [pause]”.

"إيه من تجربتي غيرلي حياتي .. إيه لكان المريض ما بكون مريض لوحده المريض بكون محيطه كله مريض .."

Caregiver 3: “((sigh)) [I manage everything] with difficulty ((laugh)). I got stressed as well. It affected my blood pressure – I also got ill ((lowered voice)). But I need to stay strong [in control]. You can’t have both [parents] ill within the same family.”

((sigh)) " بصعوبة ((laugh)) يعني كمانه أنا صار عندي stress قوي كمان أثرتلي على ضغطي على - صار في عندي سخونة ((lowered voice)) مضطرة بدي ضلني واقفي على إيجريه ما في تنين يسخنوا بفرض بيت ما. "

Patient 3: "If it was this [LVAD] or even bigger [in size], even if I am mostly staying at home, the important thing is that I can still walk [pause]. I am no longer working but I can walk, go out, go to the bathroom, and go to the beach only to walk as I am not allowed to swim."

"إن كانت هاي {LVAD} أو كانت أكبر منها واللا قاعد بالبيت هي المهم إنو بعدني عم بامشي .. مش عم إشتغل بس عم امشي عم بضره بروح بفوت عالحمام ما تواخذيني بانزل عالبحر بمشي عالبحر ممنوع إتسبح بالبحر. "

Patient 4: "I empowered myself [pause] I empowered myself [pause] in everything even at home. I do the dishes, if I had a small thing to iron, I would do it ((with a pride tone)) I arrange my house [pause]/ I start the washer and then hang the laundry to dry out. [I do] everything everything, life is normal [pause]. Yes ((excited tone)) I get dressed if I want to go out. I close the door and I go out. So, nothing nothing annoys me anymore."

"أنا قويت حالي .. أنا قويت حالي .. بكل شي حتى بالبيت بجلي في عندي شغلة صغيرة بدي كوي بكويها((with a pride tone)) برتب البيت ... بحط الغسالة بغسيل بنشر غسيل كل شي كل شي حياتي طبيعية .. ايه ((excited tone)) اضهر بلبس وبضهر بسكر بابي وبضهر يعني ما ما في شي بضايقتني أبداً. "

Patient 1: "First thing, the [LVAD] gave me hope and the second thing, it [LVAD] made me realize that I was alive anew."

"أول شي عطيتني أمل وتاني شي تاني مرحله يعني أول مرحله عطيتني أمل وتاني مرحله خلنتي فكر إنو أنا إنسان عايش عن جديد. "

Caregiver 4: "Concerning the machine [LVAD], let me start by saying that it would be best if they develop it [LVAD] to avoid external components so everything would be internal. This eases the patient's [life]. If they develop an internal [device] inside the body [pause], the operation would consist of an internal one with nothing to hold and no tubes [driveline coming out [of the abdomen]]."

"أنا كي-machine تا بلش فيها أنا بقول أحسن هي إذا بطوروا هيدا الشي {LVAD} ما يكون عنا شي external .. يعني يكون كل شي انترنال يكون أهون لل-patient .. يعني إذا بيتوصلوا لشي interne بقلب الجسم .. لينعمل عملية وتكون interne لحتالي ما ينحمل شي مع الشريط {driveline} الطالع. "

Theme VI: Patients and their caregivers were provoked by others' perception of the LVAD machine

1. Being singled out

Patient 2: *"I get followed by a lot of people frequently asking me if I am a doctor or a realtor [as I am] holding a bag. I usually reply by "I am sorry [this is not true] this is a heart device".*

"حتى في كثير ناس بيلحقوني ببسألوني حضرتك دكتور حضرتك ... سمسار بيوت سمسار عقارات حامل هألشنتطة ((ضحكة المحاور ٢)) بقلهن " لا عفواً هيدي بطارية للقلب "

Patient 2: *"I get frequently asked "what is your job? And they also monitor my side [where the LVAD bag is placed]. I later found out that realtor hold bags [similar than the LVAD one], where they place their [contact] cards."*

"يفتكروها مصاري أو شي ((ضحك)) يشدوها مني .. بقى كثير بنسأل بالطريق بمشي إنه " انتي شو بتشتغل انتي؟ " براقبولي جنبي لحتى ما عرفت أنا إنه تجار السيارات تجار العقارات بيحملوا منها قال ((مؤشراً عشنطة ال بحطوا بطاقات-LVAD))"

Patient 1: *"I was placing it [LVAD bag] next to me. Someone comes and says, "Why the hell is a big guy holding a bag on his shoulder?" [Pause]. I even told my doctor that I was placed in common situations when people ran away from me and got scared from me. This behavior can be explained as it is scary to see a cable coming out of a person. This perception has even increased nowadays. People seriously wonder that the person might be holding an explosive cable [referring to the driveline]."*

"بيجي واحد بيقول " عمى! شو حامل هيدا شاب ضخم مع (LVAD) بتكوني حاطتيها حدك ((حمل شنطة ال عالنفيزينات affiche شنطة بكتفه " بس أنا يلي بدي قولوا إنو الحكما يلفتوا نظر وزارة الصحة يعملوا شي عنا شي منه ارهابي ولا منه شي هيدا زلمه .. عايش- يعرضوها مفروض يعرضوها أنا قتلته لا -LVAD إنو يلي عامل ال _ مرة كمان قتلته في كثير عالم أوقات بتهرب منك بتقبت منك شو مفكر معلق هيك طالع شريط منك ((مؤشراً على ال وبالأخص-driveline)) ".

Patient 2: *"If they consider [the LVAD] as [a valuable property] like money or anything ((laugh)) and they try to pull it from me."*

"يفتكروها مصاري أو شي ((ضحك)) يشدوها مني .. "

Patient 5: “when I walk on the street, you will find me walking while I [hold the LVAD and tighten the driveline closer to my body] like that.”

"بلزقها هون" ((holding the LVAD bag and driveline closer to her body)) مثلاً أنا بكون ماشية بالطريق بتلقيني ماشية وعاملي هيدي هيكي "

Patient 5: “By the way, you will rarely find someone who knows what an [LVAD is about] in North Lebanon [pause]. They look at you, wondering how you hold an artificial heart [pause]. I usually just explain that it is an artificial heart to ease their understanding [pause]. If you say LVAD or pump, they won't [understand][pause]. I get [people] staring [with wonder] at me like that thinking “what is she holding?” [Pause] This lady asked me: “are you leaving?” but we are coming to visit you and you are leaving”.”

"يعني نادراً ما حدا يفهم عليك .. إيه بيطلعوا فيكي إنو كيف يعني حاملي .. {North Lebanon} _ عفكرة بي pump بتقليلهن LVAD قلب إصطناعي .. أكثر شي بقلهن قلب إصطناعي يعني ليستوعبوا الفكرة .. بتقليلهن ((wondering)) بتقليلهن مضخة ما - ما في شي بقلهن قلب إصطناعي تا يستوعبوا الفكرة .. إيه إنو تطلع فيني هيكي .. إنو شو حاملي هيدي .. في وحدة قالتلي "انتي رايحة؟" نحن جايين لعندك وانتي رايحة ((looks))"

Patient 1: “What I want to convey is that the doctors should inform the Ministry of Health to post educational material on Television. So, they can know that patients with an LVAD are not terrorists. They should raise awareness on this topic.”

"بس أنا يلي بدني قولوا إنو الحكما يلتوا نظر وزارة الصحة يعملوا شي عنا شي affiche عال تلفزيونات إنو يلي عامل ال-LVAD منه ارهابي ولا منه شي هيدا زلمه. "

REFERENCES

- Abshire, Martha, RN, MS, PhD(c), Prichard, R., RN, Cajita, Mia, RN, BSN, PhD(c), DiGiacomo, M., PhD, & Dennison Himmelfarb, Cheryl, RN, ANP, PhD, FAAN. (2016). Adaptation and coping in patients living with an LVAD: A metasynthesis. *Heart & Lung: The Journal of Acute and Critical Care*, 45(5), 397-405. doi:10.1016/j.hrtlng.2016.05.035
- Adams, E. E., & Wrightson, M. L. (2018). Quality of life with an LVAD: A misunderstood concept. *Heart & Lung*, 47(3), 177-183. doi:10.1016/j.hrtlng.2018.02.003
- Akbarin, M., & Aarts, C. (2013). Being a close relative of a patient with a left ventricular assist device. *European Journal of Cardiovascular Nursing : Journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology*, 12(1), 64-68. doi:10.1177/1474515111432996
- Baker, Kathy, RN, MS, Flattery, Maureen, RN, MS, NP, Salyer, Jeanne, PhD, RN, Haugh, Kathryn H., PhD, RN, & Maltby, M., MSW. (2010). Caregiving for patients requiring left ventricular assistance device support. *Heart & Lung*, 39(3), 196-200. doi:10.1016/j.hrtlng.2009.07.007
- Bangerter, L. R., Griffin, J. M., & Dunlay, S. M. (2018). Qualitative study of challenges of caring for a person with heart failure. *Geriatric nursing (New York, N.Y.)*, 39(4), 443-449. <https://doi.org/10.1016/j.gerinurse.2017.12.017>

- Bidwell, J. T., Vellone, E., Lyons, K. S., D'Agostino, F., Riegel, B., Juárez-Vela, R., . . . Lee, C. S. (2015). Determinants of heart failure self-care maintenance and management in patients and caregivers: A dyadic analysis. *Research in Nursing & Health*, 38(5), 392-402. doi:10.1002/nur.21675
- Bidwell, J. T., Lyons, K. S., & Lee, C. S. (2017). Caregiver well-being and patient outcomes in heart failure: A meta-analysis. *The Journal of Cardiovascular Nursing*, 32(4), 372-382. doi:10.1097/JCN.0000000000000350
- Bidwell, J. T., Lyons, K. S., Mudd, J. O., Grady, K. L., Gelow, J. M., Hiatt, S. O., . . . Lee, C. S. (2018). Patient and caregiver determinants of patient quality of life and caregiver strain in left ventricular assist device therapy. *Journal of the American Heart Association*, 7(6), n/a. doi:10.1161/JAHA.117.008080
- Blumenthal-Barby, J., Kostick, K., Delgado, E., Volk, R., Kaplan, H., Wilhelms, L., . . . Bruce, C. (2015). Assessment of patients' and caregivers' informational and decisional needs for left ventricular assist device placement: Implications for informed consent and shared decision making. *Journal of Heart and Lung Transplantation*, 34(4), S336-S336. doi:10.1016/j.healun.2015.01.955
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. SAGE Publications.
- Brouwers, C. J., de Jonge, N., Caliskan, K., Manintveld, O., Young, Q., Kaan, A., . . . Pedersen, S. S. (2014). Predictors of changes in health status between and within

patients 12 months post left ventricular assist device implantation. *European Journal of Heart Failure*, 16(5), 566-573. doi:10.1002/ejhf.75

Buck, H. G. , Kitko, L. & Hupcey, J. E. (2013). Dyadic Heart Failure Care Types. *The Journal of Cardiovascular Nursing*, 28(6), E37–E46. doi: 10.1097/JCN.0b013e31827fcc4c

Buck, H. G., Harkness, K., Wion, R., Carroll, S. L., Cosman, T., Kaasalainen, S., . . . Arthur, H. M. (2015). Caregivers' contributions to heart failure self-care: A systematic review. *European Journal of Cardiovascular Nursing : Journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology*, 14(1), 79-89. doi:10.1177/1474515113518434

Buck, H. G., Hupcey, J., Wang, H., Fradley, M., Donovan, K. A., & Watach, A. (2018). Heart failure self-care within the context of patient and informal caregiver dyadic engagement: A mixed methods study. *The Journal of Cardiovascular Nursing*, 33(4), 384-391. doi:10.1097/JCN.0000000000000465

Casida, Jesus M., PhD, RN, CCRN-CSC, APN-C, Marcuccilli, Linda, MSN, RN, Peters, Rosalind M., PhD, RN, & Wright, Susan, MS, RN. (2011). Lifestyle adjustments of adults with long-term implantable left ventricular assist devices: A phenomenologic inquiry. *Heart & Lung: The Journal of Acute and Critical Care*, 40(6), 511-520. doi:10.1016/j.hrtlng.2011.05.002

- Cené, Crystal W., MD, MPH, Haymore, L. B., MPH, Dolan-Soto, D., LCSW, Lin, F., PhD, Pignone, Michael, MD, MPH, DeWalt, Darren A., MD, MPH, . . . Corbie-Smith, Giselle, MD, MSc. (2013). Self-care confidence mediates the relationship between perceived social support and self-care maintenance in adults with heart failure. *Journal of Cardiac Failure*, 19(3), 202-210.
doi:10.1016/j.cardfail.2013.01.009
- Charlson, M. E., Pompei, P., Ales, K. L., & MacKenzie, C. R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *Journal of chronic diseases*, 40(5), 373–383.
[https://doi.org/10.1016/0021-9681\(87\)90171-8](https://doi.org/10.1016/0021-9681(87)90171-8)
- Cicolini, G., Cerratti, F., Pelle, C. D., & Simonetti, V. (2016). The experience of family caregivers of patients with a left ventricular assist device: An integrative review. *Progress in Transplantation (Aliso Viejo, Calif.)*, 26(2), 135-148.
doi:10.1177/1526924816640648
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage Publications.
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: qualitative, quantitative, and mixed methods approaches*. Fifth edition. Los Angeles: SAGE.
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five approaches*. SAGE Publications.

- Cypress, B. S. (2017). Rigor or reliability and validity in qualitative research: Perspectives, strategies, reconceptualization, and recommendations. *Dimensions of Critical Care Nursing*, 36(4), 253-263. doi:10.1097/DCC.0000000000000253
- Deek, H., Newton, P. J., Kabbani, S., Hassouna, B., Macdonald, P. S., & Davidson, P. M. (2020). The lebanese heart failure snapshot: A national presentation of acute heart failure admissions. *Journal of Nursing Scholarship*, 52(5), 506-514. doi:10.1111/jnu.12583
- Degheili, J. A., Yacoubian, A., Abu Dargham, R., Rkein, G., & Khauli, R. (2020). Cadaveric organ donation in lebanon: Proposed suggestions for improvement. *Transplantation Proceedings*, 52(1), 37-41. doi:10.1016/j.transproceed.2019.11.022
- Doumit, M. A., Abu-Saad Huijer, H., & Kelley, J. H. (2007). The lived experience of Lebanese oncology patients receiving palliative care. *European journal of oncology nursing : the official journal of European Oncology Nursing Society*, 11(4), 309–319. <https://doi.org/10.1016/j.ejon.2007.02.008>
- Doumit, M. A., Huijer, H. A., Kelley, J. H., & Nassar, N. (2008). The lived experience of Lebanese family caregivers of cancer patients. *Cancer nursing*, 31(4), E36–E42. <https://doi.org/10.1097/01.NCC.0000305751.28120.f4>
- Dumit, N. Y. (2008). Perceptions of cardiac self -care among Lebanese patients and their family caregivers

Dumit, N. Y., Abboud, S., Massouh, A., & Magilvy, J. K. (2015). Role of the lebanese family caregivers in cardiac self-care: A collective approach. *Journal of Clinical Nursing*, 24(21-22), 3318-3326. doi:10.1111/jocn.12949

Durante, A. , Paturzo, M. , Mottola, A. , Alvaro, R. , Vaughan Dickson, V. & Vellone, E. (2019). Caregiver Contribution to Self-care in Patients With Heart Failure. *The Journal of Cardiovascular Nursing*, 34(2), E28–E35. doi: 10.1097/JCN.0000000000000560

Egerod, I., & Overgaard, D. (2012). Taking a back seat: Support and self-preservation in close relatives of patients with left ventricular assist device. *European Journal of Cardiovascular Nursing: Journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology*, 11(4), 380-387. doi:10.1177/1474515111435609

Gustafsson, F., & Rogers, J. G. (2017). Left ventricular assist device therapy in advanced heart failure: patient selection and outcomes. *European journal of heart failure*, 19(5), 595–602. <https://doi.org/10.1002/ejhf.779>

Grady, Kathleen L., PhD, APN, FAAN, Naftel, D., PhD, Stevenson, L., MD, Amanda Dew, M., PhD, Weidner, G., PhD, Pagani, Francis D., MD, PhD, . . . Young, J., MD. (2014). Overall quality of life improves to similar levels after mechanical circulatory support regardless of severity of heart failure before implantation. *The*

Journal of Heart and Lung Transplantation, 33(4), 412-421.

doi:10.1016/j.healun.2013.10.017

Ghorbani, F., Khoddami-Vishteh, H. R., Ghobadi, O., Shafaghi, S., Rostami Louyeh, A., & Najafizadeh, K. (2011). Causes of family refusal for organ donation. *Transplantation Proceedings*, 43(2), 405-406.

doi:10.1016/j.transproceed.2011.01.031

Hamdan, R., Fakhri, S., Mohammad, M., Charif, F., Abdallah, H., Safa, S., . . . Saab, M. (2020). The lebanese left ventricular assist device experience, a success story despite the odds. *Journal of Cardiothoracic Surgery*, 15(1), 1-7.

doi:10.1186/s13019-020-01235-7

Hamilton, H. (2016). The Lived Experience of African American Caregivers Caring for Adult African American Patients with Heart Failure. *Home Healthcare Now*, 34(4), 196–202. doi: 10.1097/NHH.0000000000000359

Heidenreich, P. A., Trogdon, J. G., Khavjou, O. A., Butler, J., Dracup, K., Ezekowitz, M. D., Finkelstein, E. A., Hong, Y., Johnston, S. C., Khera, A., Lloyd-Jones, D. M., Nelson, S. A., Nichol, G., Orenstein, D., Wilson, P. W., Woo, Y. J., American Heart Association Advocacy Coordinating Committee, Stroke Council, Council on Cardiovascular Radiology and Intervention, Council on Clinical Cardiology, ... Council on Cardiovascular Surgery and Anesthesia, and Interdisciplinary Council on Quality of Care and Outcomes Research (2011). Forecasting the future of cardiovascular disease in the United States: a policy statement from the American

Heart Association. *Circulation*, 123(8), 933–944.

<https://doi.org/10.1161/CIR.0b013e31820a55f5>

Helman, D. N., & Rose, E. A. (2000). History of mechanical circulatory support. *Progress in Cardiovascular Diseases*, 43(1), 1-4. doi:10.1053/pcad.2000.7194

Institute of Health Management and Social Protection. National health statistics report in Lebanon. https://www.usj.edu.lb/intranet/annonce/files/pdf/175_pdf_1.pdf; 2012

Joo, H., PhD, Fang, J., MD, Losby, Jan L., PhD, MSW, & Wang, G., PhD. (2014;2015;). Cost of informal caregiving for patients with heart failure. *The American Heart Journal*, 169(1), 142-148.e2. doi:10.1016/j.ahj.2014.10.010

Jurgens, C. Y., Hoke, L., Byrnes, J., & Riegel, B. (2009). Why do elders delay responding to heart failure symptoms? *Nursing Research*, 58, 274–282. doi: 10.1097/NNR.0b013e3181ac1581

Kaan, A., Young, Q., Cockell, S., & Mackay, M. (2010). Emotional experiences of caregivers of patients with a ventricular assist device. *Progress in Transplantation* (Aliso Viejo, Calif.), 20(2), 142-147. doi:10.7182/prtr.20.2.h26u0x93puu386w6

Kirkpatrick, J. N., MD, Kellom, K., BA, Hull, Sarah C., MD, MBE, Henderson, R., BA, Singh, J., MD, Coyle, Laura A., MSN, ACNP-BC, . . . Barg, Frances K., PhD, MEd. (2015). Caregivers and left ventricular assist devices as a destination, not a journey. *Journal of Cardiac Failure*, 21(10), 806-815. doi:10.1016/j.cardfail.2015.05.016

Kitko, Lisa A., RN, PhD, CCRN, Hupcey, Judith E., EdD, CRNP, Gilchrist, J. H., BA, & Boehmer, J. P., MD. (2013). Caring for a spouse with end-stage heart failure through implantation of a left ventricular assist device as destination therapy. *Heart & Lung*, 42(3), 195-201. doi:10.1016/j.hrtlng.2012.10.004

Kitko, L. A., Hupcey, J. E., Birriel, B., & Alonso, W. (2016). Patients' decision making process and expectations of a left ventricular assist device pre and post implantation. *Heart & lung: the journal of critical care*, 45(2), 95–99. <https://doi.org/10.1016/j.hrtlng.2015.12.003>

Kurian, M. J., Rentzepis, P. J., Carracher, A. M., & Close, K. L. (2018;). American heart association scientific sessions 2018. *Journal of Diabetes*, 11(4), 261-264. doi:10.1111/1753-0407.12884

Lee, C. S., Riegel, B., Driscoll, A., Suwanno, J., Moser, D. K., Lennie, T. A., . . . Worrall-Carter, L. (2009). Gender differences in heart failure self-care: A multinational cross-sectional study. *International Journal of Nursing Studies*, 46(11), 1485-1495. doi:10.1016/j.ijnurstu.2009.04.004

Lee, C. S., Gelow, J. M., Chien, C. V., Hiatt, S. O., Bidwell, J. T., Denfeld, Q. E., . . . Mudd, J. O. (2018). Implant Strategy–Specific changes in symptoms in response to left ventricular assist devices. *The Journal of Cardiovascular Nursing*, 33(2), 144-151. doi:10.1097/jcn.0000000000000430

Li, C., Chang, S., & Shun, S. (2018). The self-care coping process in patients with chronic heart failure: A qualitative study. *Journal of Clinical Nursing*, 28(3-4), 509-519. doi:10.1111/jocn.14640

Lum, Hillary D., MD, PhD, Lo, D., MD, Hooker, S., MS, & Bekelman, David B., MD, MPH. (2014). Caregiving in heart failure: Relationship quality is associated with caregiver benefit finding and caregiver burden. *Heart & Lung*, 43(4), 306-310. doi:10.1016/j.hrtlng.2014.05.002

Magid, M., Jones, J., Allen, L. A., McIlvennan, C. K., Magid, K., Sterling, J. A., & Matlock, D. D. (2016). The perceptions of important elements of caregiving for an LVAD patient: A qualitative meta-synthesis. *The Journal of Cardiovascular Nursing*, 31(3), 215-225. doi:10.1097/JCN.0000000000000242

Marcuccilli, L., & Casida, J. M. (2011). From insiders' perspectives: Adjusting to caregiving for patients with left ventricular assist devices. *Progress in Transplantation (Aliso Viejo, Calif.)*, 21(2), 137-143. doi:10.1177/152692481102100209

Marcuccilli, L., & Casida, J. (2012). Overcoming alterations in body image imposed by the left ventricular assist device: A case report. *Progress in Transplantation*, 22(2), 212-216. doi:10.7182/pit2012579

Marcuccilli, L., Casida, J. (., Bakas, T., & Pagani, F. D. (2014). Family caregivers' inside perspectives: Caring for an adult with a left ventricular assist device as a destination

therapy. *Progress in Transplantation* (Aliso Viejo, Calif.), 24(4), 332-340.

doi:10.7182/pit2014684

Massouh, A., Skouri, H., Cook, P., Huijjer, H. A. S., Khoury, M., & Meek, P. (2019). Self-care confidence mediates self-care maintenance and management in patients with heart failure. *Heart & Lung*, 49(1), 30-35. doi:10.1016/j.hrtlng.2019.07.008

McIlvennan CK, Jones J, Allen LA, et al. Decision-making for destination therapy left ventricular assist devices: implications for caregivers. *Circ Cardiovasc Qual Outcomes*. 2015;8(2):172-178. doi:10.1161/CIRCOUTCOMES.114.001276

McMurray, J. J., Adamopoulos, S., Anker, S. D., Auricchio, A., Bohm, M., Dickstein, K., . . . Ponikowski, P. (2012). ESC guidelines for the diagnosis and treatment of acute and chronic heart failure 2012: The Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2012 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association (HFA) of the ESC. *European Journal of Heart Failure*, 14, 803–869. doi: 10.1093/eurjhf/hfs105

Metra, M., & Teerlink, J. R. (2017). Heart failure. *Lancet* (London, England), 390(10106), 1981–1995. [https://doi.org/10.1016/S0140-6736\(17\)31071-1](https://doi.org/10.1016/S0140-6736(17)31071-1)

Modica, M., Ferratini, M., Torri, A., Oliva, F., Martinelli, L., De Maria, R., & Frigerio, M. (2015). Quality of life and emotional distress early after left ventricular assist device implant: A Mixed-Method study. *Artificial Organs*, 39(3), 220-227. doi:10.1111/aor.12362

- Morrow, R., Rodriguez, A. and King, N. (2015). Colaizzi's descriptive phenomenological method. *The Psychologist*, 28(8), 643-644.
- Morse, J. M. (1994). Designing funded qualitative research. In Denzin, N. K. & Lincoln, Y. S., *Handbook of qualitative research* (2nd Ed). Thousand Oaks, CA: Sage.
- Morton, G., Masters, J., & Cowburn, P. J. (2018). Multidisciplinary team approach to heart failure management. *Heart*, 104(16), 1376-1382. doi:10.1136/heartjnl-2016-310598
- Moustakas, C. E. (1994). *Phenomenological research methods*. Sage Publications, Inc.
- Mozaffarian, D., Benjamin, E. J., Go, A. S., Arnett, D. K., Blaha, M. J., Cushman, M., . . . Turner, M. B. (2016). Executive summary: Heart disease and stroke Statistics—2016 update: A report from the American Heart Association. *Circulation* (New York, N.Y.), 133(4), 447-454. doi:10.1161/CIR.0000000000000366
- The National Organization for Organ and Tissue Donation and Transplantation (NOOTDT) (2011)
- Nordfonn, O. K., Morken, I. M., Bru, L. E., & Husebø, A. M. L. (2019). Patients' experience with heart failure treatment and self-care—A qualitative study exploring the burden of treatment. *Journal of Clinical Nursing*, 28(9-10), 1782-1793. doi:10.1111/jocn.14799
- Okam, N. A., Ahmad, W., Rana, D., Torrilus, C., Jahan, N., & Sedrakyan, S. (2020). Psychological spectrum experienced by heart failure patients after left ventricular

assist device implantation. *Curēus* (Palo Alto, CA), 12(8), e9671-e9671.

doi:10.7759/cureus.9671

Ottenberg, A. L., Cook, K. E., Topazian, R. J., Mueller, L. A., Mueller, P. S., & Swetz, K.

M. (2014). Choices for patients "without a choice": Interviews with patients who received a left ventricular assist device as destination therapy. *Circulation. Cardiovascular quality and outcomes*, 7(3), 368–373.

Overgaard, D., Grufstedt Kjeldgaard, H., & Egerod, I. (2012). Life in transition: A

qualitative study of the illness experience and vocational adjustment of patients with left ventricular assist device. *The Journal of Cardiovascular Nursing*, 27(5), 394-

402. doi:10.1097/JCN.0b013e318227f119

Park, S. J., Milano, C. A., Tatroles, A. J., Rogers, J. G., Adamson, R. M., Steidley, D. E.,

Ewald, G. A., Sundareswaran, K. S., Farrar, D. J., Slaughter, M. S., & HeartMate II

Clinical Investigators (2012). Outcomes in advanced heart failure patients with left ventricular assist devices for destination therapy. *Circulation. Heart failure*, 5(2),

241–248. <https://doi.org/10.1161/CIRCHEARTFAILURE.111.963991>

Paturzo, M., Petruzzo, A., Bertò, L., Mottola, A., Cohen, M. Z., Alvaro, R., & Vellone, E.

(2016). The lived experience of adults with heart failure: A phenomenological study. *Annali Di Igiene*, 28(4), 263

Ponikowski P, Voors AA, Anker SD, Bueno H, Cleland JG, Coats AJ, Falk V, González-

Juanatey JR, Harjola VP, Jankowska EA, Jessup M, Linde C, Nihoyannopoulos P,

Parissis JT, Pieske B, Riley JP, Rosano GM, Ruilope LM, Ruschitzka F, Rutten FH, van der Meer P; Authors/Task Force Members; Document Reviewers. 2016 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure: The Task Force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC) Developed with the special contribution of the Heart Failure Association (HFA) of the ESC. *Eur Heart J.* 2016 May 20. pii: ehw128. PMID: 27206819

Pressler, S. J., Gradus-Pizlo, I., Chubinski, S. D., Smith, G., Wheeler, S., Sloan, R., & Jung, M. (2013). Family caregivers of patients with heart failure: a longitudinal study. *The Journal of cardiovascular nursing, 28*(5), 417–428.
<https://doi.org/10.1097/JCN.0b013e3182563877>

Riegel, B., Lee, C. S., Dickson, V. V., & Carlson, B. (2009). An update on the self-care of heart failure index. *The Journal of cardiovascular nursing, 24*(6), 485–497.
<https://doi.org/10.1097/JCN.0b013e3181b4baa0>

Riegel, B., Moelter, S. T., Ratcliffe, S. J., Pressler, S. J., De Geest, S., Potashnik, S., ... Goldberg, L. R (2011). Excessive daytime sleepiness is associated with poor medication adherence in adults with heart failure. *Journal of Cardiac Failure, 17*, 340–348. doi: 10.1016/j.cardfail.2010.11.002

Riegel, B., Dickson, V. V., & Faulkner, K. M. (2016). The Situation-Specific Theory of Heart Failure Self-Care: Revised and Updated. *The Journal of cardiovascular nursing, 31*(3), 226–235. <https://doi.org/10.1097/JCN.0000000000000244>

- Rizzieri AG, Verheijde JL, Rady MY, McGregor JL. Ethical challenges with the left ventricular assist device as a destination therapy. *Philos Ethics Humanit Med.* 2008;3:20. doi:10.1186/1747-5341-3-20
- Roston, T. M., Bains, M., Code, J., & Virani, S. A. . (2020). Heart Failure in the Young: The Patient Perspective and Lived-Experience. *Canadian Journal of General Internal Medicine*, 15(SP1), 36-39. <https://doi.org/10.22374/cjgim.v15iSP1.418>
- Sandau, Kristin E., PhD, RN, Hoglund, Barbara A., EdD, FNP-BC, Weaver, Carrie E., BSN, RN, CCRN-CMC/CSC, Boisjolie, Charlene, MA, RN, CCRP, & Feldman, David, MD, PhD. (2014). A conceptual definition of quality of life with a left ventricular assist device: Results from a qualitative study. *Heart & Lung*, 43(1), 32-40. doi:10.1016/j.hrtlng.2013.09.004
- Sandau, K. E., Lee, C. S., Faulkner, K. M., Pozehl, B., Eckman, P., Garberich, R., . . . Cowger, J. A. (2020). Health-related quality of life in patients with a left ventricular assist device (QOLVAD) questionnaire: Initial psychometrics of a new instrument. *The Journal of Cardiovascular Nursing*, doi:10.1097/JCN.0000000000000774
- Schroder, J. N., & Milano, C. A. (2017). A tale of two centrifugal left ventricular assist devices. *The Journal of thoracic and cardiovascular surgery*, 154(3), 850–852. <https://doi.org/10.1016/j.jtcvs.2017.04.033>

- Sedlar, N., Lainscak, M., Mårtensson, J., Strömberg, A., Jaarsma, T., & Farkas, J. (2017). Factors related to self-care behaviours in heart failure: A systematic review of European Heart Failure Self-Care Behaviour Scale studies. *European journal of cardiovascular nursing: journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology*, 16(4), 272–282.
<https://doi.org/10.1177/1474515117691644>
- Seto, E., Leonard, K. J., Cafazzo, J. A., Masino, C., Barnsley, J., & Ross, H. J. (2011). Self-care and quality of life of heart failure patients at a multidisciplinary heart function clinic. *The Journal of Cardiovascular Nursing*, 26, 377–385. doi: 10.1097/JCN.0b013e31820612b8
- Sharp, J., Miller, H., & Al-Attar, N. (2018). Unforeseen challenges of living with an LVAD. *Heart & Lung*, 47(6), 562-564. doi:10.1016/j.hrtlng.2018.08.005
- Smith, D. (2013, December 16). Phenomenology. Retrieved from <https://plato.stanford.edu/entries/phenomenology/>
- Standing, H. C., Rapley, T., MacGowan, G. A., & Exley, C. (2017). ‘Being’ a ventricular assist device recipient: A liminal existence. *Social Science & Medicine* (1982), 190, 141-148. doi:10.1016/j.socscimed.2017.08.016
- Streur, M. M., Auld, J. P., Liberato, A. C. s., Beckman, J. A., Mahr, C., Thompson, E. A., & Dougherty, C. M. (2020). Left ventricular assist device caregiver experiences and

health outcomes: A systematic review of qualitative and quantitative studies. *Journal of Cardiac Failure*, 26(8), 713-726.
doi:10.1016/j.cardfail.2020.05.018

Tatari, S., Soubra, L., Tamim, H., Akhras, K., & Kabbani, S. (2015). The economic impact of patients with heart failure on the lebanese healthcare system. *ESC Heart Failure*, 2(3), 178-183. doi:10.1002/ehf2.12038

Taylor, C. J., Hobbs, F. D. R., Marshall, T., Leyva-Leon, F., & Gale, N. (2017). From breathless to failure: Symptom onset and diagnostic meaning in patients with heart failure—a qualitative study. *BMJ Open*, 7(3), e013648. doi:10.1136/bmjopen-2016-013648

Tedy, G., n.d. History of Heart Transplantation In Lebanon.

Udelson, J. E., & Stevenson, L. W. (2016). The Future of Heart Failure Diagnosis, Therapy, and Management. *Circulation*, 133(25), 2671–2686.

<https://doi.org/10.1161/CIRCULATIONAHA.116.023518>

Van Manen, M. (2014). *Phenomenology of Practice: Meaning-Giving Methods in Phenomenological Research and Writing*. Walnut Creek, CA: Left Coast Press.

Vellone, E., D'Agostino, F., Buck, H. G., Fida, R., Spatola, C. F., Petruzzo, A., . . . Riegel, B. (2015). The key role of caregiver confidence in the caregiver's contribution to self-care in adults with heart failure. *European Journal of Cardiovascular Nursing*:

Journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology, 14(5), 372-381. doi:10.1177/1474515114547649

Wingham, J., Frost, J., Britten, N., Jolly, K., Greaves, C., Abraham, C., . . . REACH-HF research investigators. (2015). Needs of caregivers in heart failure management: A qualitative study. *Chronic Illness*, 11(4), 304-319. doi:10.1177/1742395315574765

Weerahandi, H., Goldstein, N., Gelfman, L. P., Jorde, U., Kirkpatrick, J. N., Meyerson, E., . . . Ascheim, D. D. (2017). The relationship between psychological symptoms and ventricular assist device implantation. *Journal of Pain and Symptom Management*, 54(6), 870-876.e1. doi:10.1016/j.jpainsymman.2017.05.002

Yancy, C. W., Jessup, M., Bozkurt, B., Butler, J., Casey, J., Donald E, Colvin, M. M., . . . Westlake, C. (2017). 2017 ACC/AHA/HFSA focused update of the 2013 ACCF/AHA guideline for the Management of heart failure: A report of the american college of Cardiology/American heart association task force on clinical practice guidelines and the heart failure society of America. *Journal of the American College of Cardiology*, 70(6), 776-803. doi:10.1016/j.jacc.2017.04.025

