AMERICAN UNIVERSITY OF BEIRUT

DEVELOPING A SUPPORT AND BEREAVEMENT BUNDLE FOR INFORMAL CAREGIVERS OF PATIENTS WITH A VENTRICULAR ASSIST DEVICE-DESTINATION THERAPY

by
VANESSA WALID ALHADDAD

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VANESSA WALID ALHADDAD

Approved by:

Angela

Signature

Dr. Angela Massouh, Assistant Professor First Reader
Rafic Hariri School of Nursing

Signature

H Puzantian

Dr. Houry Puzantian, Assistant Professor
Rafic Hariri School of Nursing Second Reader

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ABSTRACT
OF THE PROJECT OF

Vanessa Walid AlHaddad for Master of Science in Nursing
Major: Adult-Gerontology Clinical Nurse Specialist

Title: Developing a Support and Bereavement Bundle for Informal Caregivers of Patients with a Ventricular Assist Device-Destination Therapy

Heart Failure (HF) is a leading cause of mortality globally, posing significant challenges in healthcare, especially in older adults. This review explores the multifaceted impacts of ventricular assist devices (VAD) as a treatment option. The prevalence of HF and the adoption of VADs vary significantly across regions, with countries like Lebanon facing unique challenges. VADs initially used as a bridge to heart transplantation, have shifted into a long-term solution for many patients, including those ineligibles for transplant. This shift has profound implications for patient care and caregiver burden, that may affect the negatively.

The economic burden of VADs is substantial, with costs encompassing device implantation, hospitalization, and ongoing care. Caregivers of VAD patients face significant psychological and emotional stress, often leading to anxiety, depression, and socioeconomic strain. In Lebanon, the scarcity of organ donations and the high cost of VADs present additional challenges. This review also delves into the complexities of end-of-life care for VAD patients' caregivers, underscoring the need for advanced care planning and bereavement support.

Guidelines have highlighted the importance of support and bereavement programs for VAD caregivers, as early as the decision of implantation is made, however, none of the hospitals in Lebanon have adopted one. This document proposes a support and bereavement intervention checklist for informal caregivers, addressing the gap in the Lebanese context. By integrating cultural values and healthcare policies, the study seeks to improve the overall experience of patients and their caregivers, especially during bereavement.

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ABBREVIATIONS

VAD: Ventricular Assist Device
HF: Heart Failure
PC: Palliative Care
AHA: American Heart Association
VAD-DT: Ventricular Assist Device – Destination Therapy
ISHLT: International Society for Heart and Lung Transplantation
WHO: World Health Organization
IMACS: International Mechanically Assisted Circulatory Support
ESRD: End Stage Renal Dysfunction
CMQ: Caregiver Mourning Questionnaire
CINAHL: Cumulative Index to Nursing and Allied Health Literature
NYHA: New York Heart Association
INTERMACS: Interagency Registry for Mechanically Assisted Circulatory Support
CNS: Clinical Nurse Specialist
SIPAT: Stanford Integrated Psychosocial Assessment for Transplantation
ESC: European Society of Cardiology
EMR: Electronic Medical Records
ICU: Intensive Care Unit
HCP: Heath Care Providers
ICD: Implantable Cardioverter-Defibrillator
BMI: Body Mass Index
INR: International Normalized Ratio
HFaST: Heart Failure Symptom Tracker
EUROMACS: European Registry for Patients with Mechanical Circulatory Support

CHAPTER I

INTRODUCTION

A. Background

Cardiovascular diseases are the primary cause of death globally, with Heart Failure [HF] playing a major role in this global pandemic (Savarese et al., 2023). HF, frequently described as the culmination of many cardiovascular diseases, is a concerning indicator of the challenges facing modern healthcare. The disease continues to be highly prevalent among older adults, carrying a significant risk of mortality within one year (Emmons-Bell et al., 2022). About 1% to 2% of the adult population in developing countries are affected by HF (Störk et al., 2016). This percentage increases with age, indicating that more than 10% of those aged 70 and above are affected. In addition to affecting the individual's wellbeing, HF places a significant financial burden on the global healthcare system (Savarese et al., 2023).

The American Heart Association [AHA] estimates that HF costs $5,380 per patient in the United States (Benjamin et al., 2019). In 2012, the total expenditure on HF care in the United States was around $30.7 billion. It is projected to rise by 127% to $69.8 billion by 2030, equating to an additional $244 per HF patient (Savarese et al., 2023). In the United States, there are about 6.2 million adults with heart failure (HF), and in 2018, HF was mentioned as a cause of death on 379,800 death certificates. The prevalence of HF differs across regions. In 2017, Central Europe, Northern Africa, and the Middle East had prevalence rates ranging from 1,133 to 1,196 per 100,000 individuals. In contrast, Eastern Europe and Southeast Asia observed lower rates, varying between 498 to 595 per 100,000 people. (Virani et al., 2020).

In Lebanon, there's a scarcity of published data on HF, but a 2012 study by Tatari et al. found that 1.8% of their sample had HF, with 16% of these cases requiring hospitalization. In the Middle East, Ischemic Heart Disease is believed to be responsible for HF in 50% of patients. It is more frequently linked with HF with reduced ejection fraction and HF with mildly reduced ejection fraction, as opposed to HF with preserved ejection fraction (Virani et al., 2020). Awareness of HF, its risk factors, and early symptoms has been found to be lacking in the Middle East. Patients with HF in this region face high mortality rates and frequent hospital admissions. Although various treatment options are available, the effectiveness of their delivery and implementation has been called into question (Skouri & Dickstein, 2015).

Ventricular Assist Devices [VADs] have become a viable treatment option for many patients with end-stage HF. VADs were initially introduced as a mechanical aid, but they have undergone significant development since then. In the last ten years, significant changes have been made tackling the technology, design, and clinical use of VADs. These devices support or, in some cases, assume the heart's primary role – circulating blood throughout the body (Slaughter et al., 2018). The support provided by VADs is of great value, especially to those waiting for a heart transplant. But beyond this temporary use, VADs have taken on a wider role. VADs have evolved beyond their initial role as a Bridge to Transplant and are now employed as Destination Therapy (VAD-DT) for individuals who may not be eligible for heart transplantation. (Aburjania et al., 2021).

The acceptance and adoption of VADs by the medical community have been reflected in its clinical effectiveness, and the increasing use for efficient HF treatment options. It is highlighted that VAD implantation is a growing need (Hanke et al., 2021). Over the past ten years, VADs have quickly emerged as a trustworthy and secure treatment for patients with end-stage HF. According to the 13th annual report from The Society of Thoracic Surgeons Interagency Registry for Mechanically Assisted Circulatory Support, 27,314 patients in the United States have received this therapy (Yuzefpolskaya et al., 2023). According to the Lebanese sole supplier, 55 HeartMate IIIs have been implanted in Lebanon since 2017.

Guidelines highlight the importance of the presence of a strong social support system for patients undergoing VAD implantation and the need for a primary caregiver in place to facilitate post-surgical care is key (Cook et al., 2017). It is widely known that VADs change the daily lives of both patients and their families, imposing life adjustments to the various challenges associated with the device (Ferrario et al., 2022).

With the rising prominence of VADs for the treatment of end-stage HF, it is important to understand the experiences and troubles of those caring for the VAD recipients. Usually, close family or friends, these caregivers offer both medical supports, like overseeing the device and monitoring medications, and emotional support as patients adapt to the lifestyle changes needed by the device. However, caregivers' profound roles can have a negative impact on their mental health. The complexity of VAD caregiving highlights the fact that caregivers frequently handle technical issues, including the supervision and maintenance of VADs, dispensing medications, addressing potential complications, and coordinating with medical professionals (Marcuccilli & Casida, 2014).

In addition to the technical responsibilities, caregivers also carry a considerable emotional and psychological load. A significant number of VAD caregivers show signs of anxiety and depression, especially during the immediate post-surgery phase when the care demands are highest (Bidwell et al., 2017). The socio-economic outcomes for caregivers are important to note (Kavalieratos et al., 2017). All of these factors, taken together, can damage their overall well-being.

B. Significance and Aims

In Lebanon, from 2010 to December 2019, 53% of patients received a VAD as a bridge to transplant, 42% as Destination Therapy (DT-VAD), and 5% as a bridge to recovery. The likelihood of receiving a heart transplant within six months of VAD implantation was as low as 14%. Consequently, patients who were initially categorized as bridge to transplant have increasingly transitioned to DT-VAD (Hamdan et al., 2020). Because of the shortage in organ donations (Hamdan et al., 2019), bereavement for caregivers should start as soon as the patient is identified as a candidate for VAD therapy.

Although VADs are thought to be a cornerstone in the treatment of end-stage HF, they have a number of drawbacks. These devices’ potential to save lives is frequently weighed against sizable barriers (Miller et al., 2019). The cost of implantation (Silvestry et al., 2020) and the risk of mortality (Brescia et al., 2021) remain key barriers. Death rates among VAD patients, especially in the immediate postoperative period, continue to be an urgent concern for physicians and caretakers. The period following the operation is especially delicate. Even with the advancement in technology and surgical methods, the immediate post-implantation stage is full of possible complications, ranging from infections to equipment malfunctions. VAD recipients face a one-year mortality rate of 14% (Brescia et al., 2021). While this death rate is concerning, it provides some perspective on the critical situation. Sepsis and complications related to the device were the key determinants of mortality. Sepsis in the context of a weakened cardiovascular system puts the patients in life-threatening situations (Mankowski et al., 2019). Device-related complications can range from mechanical failures to thrombosis. Although these complications are infrequent, they can pose immediate risks on the patient’s life, necessitating immediate medical interventions (Mehra et al., 2018).

Moreover, the economic burden of HF extends beyond its initial diagnosis. As the condition progresses and treatments become more advanced, the financial costs increase significantly. While VAD therapy offers a hint of hope to many, it also carries a heavy price tag. The device is the result of extensive research, development, and testing, and its advanced technology comes with a premium cost. The financial implications of VADs also extend beyond the device itself (Silvestry et al., 2020). The surgical procedure, the duration of hospitalization, potential hospital readmissions due to complications, and frequent outpatient check-ups all contribute to the rising costs. The average implantation cost of VADs in the U.S. is around $150,000, and this does not factor in the subsequent costs of post-operative care (Silvestry et al., 2020).

Providing support for informal caregivers of terminally ill patients is an essential aspect of end-of-life care. However, the needs of these caregivers at the end of life are often not adequately addressed. (Bloomer et al., 2022). A life-extending device like VAD actuates some of the most complex healthcare decisions as one approaches the end. After VAD patients have taken the decision of implantation, (McIlvennan et al., 2016), it becomes crucial to achieve and speak about preferences for end-of-life care, and to emphasize patient-centered care.

It's crucial to involve patients with VAD-DT and their caregivers in discussions about advance care planning and end-of-life care options, according to recommendations from the International Society for Heart and Lung Transplantation (ISHLT). These conversations are infrequent during pre-implantation and death. (Husain et al., 2016). Several factors might contribute to this communication gap, one of which is the intricate nature of the decision-making process, and the lack of training on how to facilitate these conversations. It is essential that clinicians be equipped with the necessary resources and training to successfully engage in these important conversations (Chuzi et al., 2021). By integrating cultural values and beliefs into healthcare policy and practice, practitioners can better assist people with heart failure and their families (Alassoud et al., 2020). Despite the improved quality of life and increased longevity VAD recipients may experience, there is still much that is unknown or unexpected about life post-VAD implantation for both recipients and their families. (Friedman, 2020).

Dying with a VAD is a complex and unknown process for patients and their caregivers. Deciding on end-of-life care can be extremely challenging. For many patients, a VAD is the lifeline sustaining them, and the majority of these patients will pass away within 20 minutes of the device being turned off. Consequently, the discontinuation of the device and the ensuing death can be quite dramatic and emotionally intense. (McIlvennan et al., 2016; Chuzi et al., 2019). A decisional regret scale showed low levels of regret among patients with VAD-DT. These patients are often inadequately prepared for end-of-life care. The causes behind these deficiencies are not well-understood (Chuzi et al., 2019). Bereaved caregivers have reported experiencing confusion during the final weeks of their loved one's life, particularly regarding the process of dying with a VAD. They have also noted a shortfall in the integration of palliative care and hospice support services, which are crucial for providing comprehensive care and support during this challenging time (McIlvennan et al., 2017). There has been scarce research on bereavement from the caregiver perspective on end-of-life preparation and care for VAD-DT patients, and no study has been done regarding the Lebanese population.

The World Health Organization (WHO) highlights the significance of support, specifically its need for both patients and their caregivers. Delivering significant end-of-life care necessitates providing grief and bereavement support (Thrower et al., 2023). Informal caregivers often navigate the complex emotions of grief and bereavement as they support their loved ones through their final journey. According to a Canadian study, 42% of people who were grieving used some form of bereavement support (Wilson et al., 2019).

Evidence indicates that many patients with VADs and their families often miss the chance to engage in open discussions about end-of-life preferences until significant complications occur (Delmaczynska & Newham, 2019). This leaves the families distraught after a negative outcome and does not allow healthcare providers the chance to support families in bereavement. The aim of this project is to identify interventions that have been found to be beneficial for the bereavement process in informal caregivers of VAD patients and to develop a bereavement intervention checklist for informal caregivers. This work aims to lay the groundwork for the future development and implementation of culturally appropriate bereavement interventions, with the goal of enhancing outcomes for caregivers of patients with VADs.

CHAPTER II

REVIEW OF LITERATURE

A. Bereavement: General Overview and Theories

In medical care, understanding the concept of bereavement is vital. WHO (2018) acknowledge bereavement as part of palliative care stating, “relatives should be accompanied and supported after patient’s death, if needed”. Bereavement is defined as the objective state or situation experienced by individuals following the death of a significant person in their lives (Stroebe et al., 2008). Bereavement, coping, and grief are intertwined concepts. Coping refers to the thoughts and actions used to deal with challenging situations and how one adapts to external pressures (Algaroni & Gupta, 2023) while grief is an intricate emotional response experienced on multiple fronts: social, psychological, behavioral, and physical (Stroebe, et al., 2017). Bereavement, on the other hand, is the feeling of loss after a loved one's death (Merriam-Webster, 2023).

In Freud's Grief Theory, he suggested that mourners should sever emotional ties with the departed. The core idea is that holding onto memories can prevent people from looking ahead, establishing new relationships, and stepping into roles left by the departed. The pain stems from the continuous, yet mistaken sense of the deceased's presence. Thus, it's reasonable to distance oneself from the departed to reclaim personal freedom and a clear state of mind (Gravesen & Burkelund, 2021). Even after a loved one's physical departure, feelings, memories, and acquired knowledge remain. Psychologists point out that latent learning, a concept introduced by Blodgett (1929), might not show immediately but stays hidden, ready to emerge even without external cues (Wang & Hayden, 2021). People can respond based on their beliefs, attitudes, and evolving situations, like a loved one's absence (Ledoux, 2021).

Contemporary theories on bereavement stress that people can progress after a loss without forgetting the departed. A person's emotional state shifts from mourning, allowing them to adjust to the departed's physical absence (Baker, 2001). Research, including that by Klass et al. (2014), endorses the notion of a positive, continuous bond with the departed. Excessively persistent connections with the deceased may indicate abnormal mourning. However, others warned against quickly deeming such bonds as abnormal, noting that for many, this connection maintains their identity and helps them restructure their lives with purpose. Complicated or lingering grief could suggest a disruption in this adjustment process (Shear, 2015).

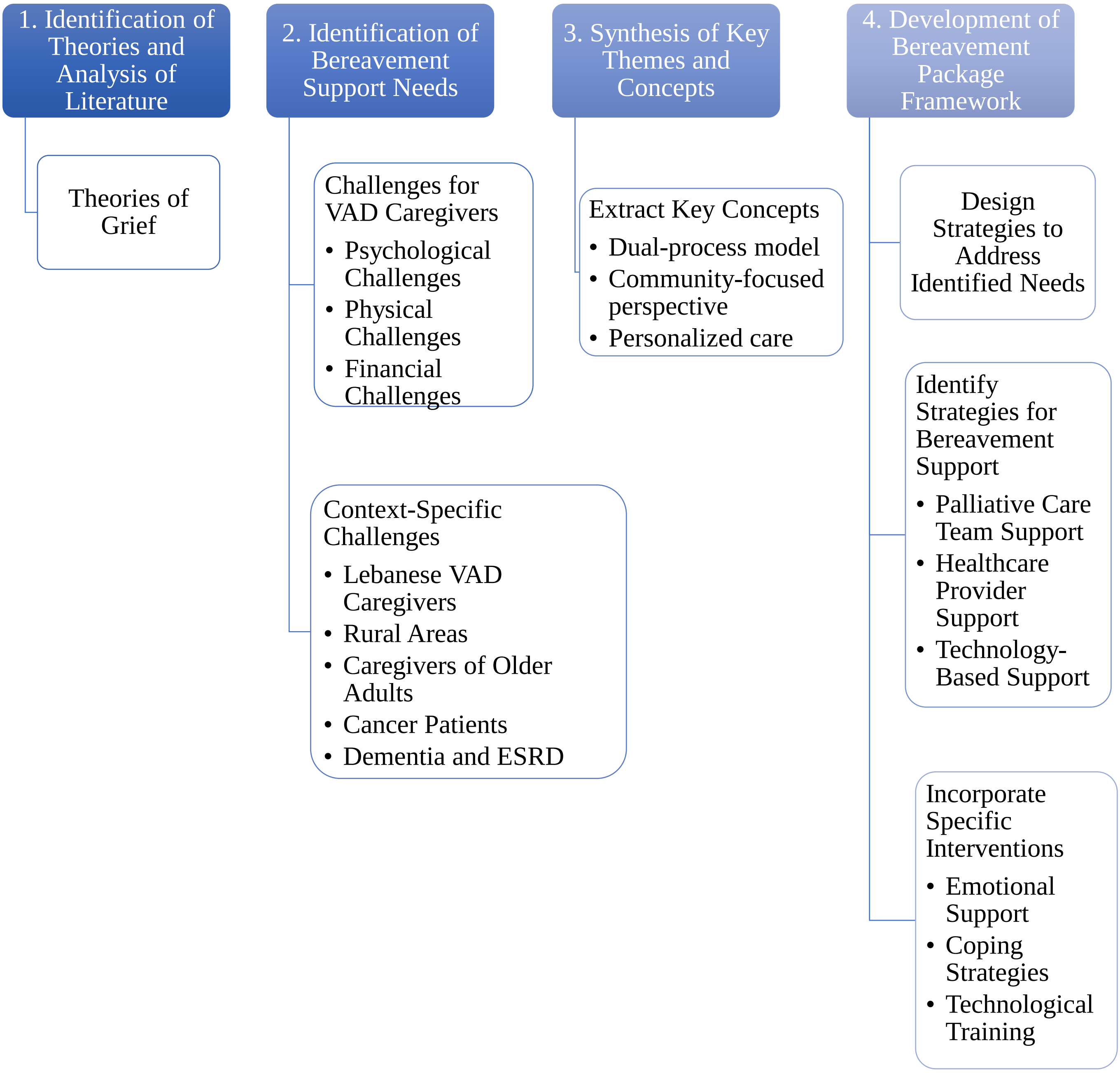

Figure 1 Literature Review Overview

B. Challenges Specific to VAD Caregivers

Family caregivers, often the unsung heroes of the healthcare system, are typically unpaid yet provide invaluable support. They assist individuals facing physical or mental challenges, particularly the elderly and those nearing the end of their lives, offering essential care and comfort (Hampton et al., 2018). The caregiving journey is marked by many different trajectories, and adjustments to the situation, and can have a significant impact on the caregivers' well-being and quality of life (Sittler et al., 2020). Some of the challenges that VAD caregivers face is psychological, physical (Auld et al., 2023) and financial (Bruce et al., 2017).

1. Psychological Challenges

The importance of caregivers becomes even more apparent as society shifts toward in-home care. But there are difficulties on their journey. They frequently experience intense feelings of fear or inadequacy and frequently feel unprepared to manage the challenges of caregiving (Totman et al., 2015). VAD caregivers encounter considerable stress, which is linked to feeling less prepared, experiencing more depressive symptoms, and having a lower quality of life. Despite receiving education in the hospital, they often feel inadequately prepared for their caregiving roles. These caregivers face significant challenges in adjusting to their responsibilities once they are back at home with the patient (McIlvennan et al., 2021). A picture of the profound impact caregiving can have on a person's overall well-being is due to the emotional strain of providing care, along with the potential financial repercussions and changing family dynamics (Akpinar & Yutsever, 2018). They fear suffering, loss of dignity, and death in hospice because they see it as accepting impending death and saying goodbye to their loved one (El Jawhari et al., 2017).

A common concern is the feeling of being under-informed, leading to unpreparedness for potential issues. The lack of information not only affects practical care but also has psychological implications (Ferrario et al., 2022). Some caregivers note patients’ struggles with self-image post-VAD, reflecting possible shared emotional challenges. The daily demands of VAD care can lead caregivers to feelings of regret and guilt. Despite these challenges, caregivers recognize the benefits of VADs, noting improved patient health and longevity. Yet, the emotional and physical toll on caregivers is evident, with many reporting health issues, fatigue, and feelings of isolation (Ferrario et al., 2022).

VAD Caregivers face challenges like limited personal time and emotional stress, including feelings of uncertainty and sadness. They also report difficulty in social life and self-care (Ferrario et al., 2022). Caregivers and patients face shifts in personal and societal perceptions, particularly in intimate relationships. The emotional and psychological well-being of VAD patients and their caregivers are deeply interconnected, with each significantly impacting the other. Both patients and caregivers have reported experiencing moderate levels of anxiety, depression, and caregiver strain. They also exhibit behaviors like denial of the illness and deliberate avoidance. Furthermore, the demands of caregiving can profoundly affect mental health, intensifying feelings of responsibility, loneliness, frequent confrontations with death, and the pursuit of meaning in their experiences (Applebaum et al., 2022).

The connection between the mental health of the caregiver and the psychological well-being of the patient is evident and significant, indicating that the condition of one directly affects the other. It is crucial to use holistic care strategies that address the mental and emotional requirements of both patients and caregivers. Interventions that give caregivers the necessary training and information can greatly increase their preparedness and confidence, which ultimately benefits both the patient and the caregiver (Ratkowski et al., 2015). The interconnections between stress, evaluation, emotion, and coping, which suggests that a dynamic interplay between these factors has an impact on the health and wellbeing of caregivers. In particular, the theme of coping highlights the flexibility and adaptability of caregivers, emphasizing the necessity of ongoing cognitive and behavioral adjustments in response to shifting demands and challenges (Magan et al., 2020).

This condition can lead to substantial alterations in family dynamics, roles, and interactions. The overwhelming distress experienced by caregivers can adversely affect their quality of life and their capacity to fulfill their caregiving responsibilities effectively (Bruinsma et al, 2022).

2. *Physical Challenges*

VAD caregivers revealed adaptation to technological demands and loss of independence. Caregivers were able to address the requirements of their patients while also efficiently incorporating the demands of VAD therapy into their everyday life. However, the capacity to manage and adapt necessitated caregiver sacrifice and going above and beyond (Cicolini et al., 2016). Caregivers in low-income households are younger, female, married, and live in the same home as those in higher-income households (Abdel-Malek et al., 2019). Family members, particularly spouses and adult children, find themselves at the forefront of caregiving as the preference for end-of-life care at home grows. Their motivations for taking on this role can range from personal commitment to the scarcity of specialized in-home care services to cultural and familial obligations (Kilgour et al., 2015). With age, the difficulties of providing care increase. Compared to their younger counterparts, older caregivers frequently struggle with their own health problems while providing care. The value of preventive clinical services is heavily emphasized, particularly for older adults. These services are essential for managing chronic illnesses as well as controlling healthcare costs (Mendez-Luck et al., 2016).

Caregivers and patients face shifts in personal and societal perceptions, particularly in intimate relationships. The emotional and psychological well-being of both VAD patients and their caregivers are deeply interconnected, influencing each other significantly. Both groups have reported experiencing moderate levels of anxiety, depression, and caregiver strain, along with tendencies towards illness denial and deliberate avoidance of the situation. Additionally, many couples have expressed that the presence of the VAD disrupts their sleep patterns and affects their emotional and sexual connections. (Ferrario et al., 2022).

3. *Financial Challenges*

When analyzing the effects of VAD therapy on caregivers, financial hardship, increasing demands on caregivers' personal time, and a detrimental impact on social and occupational performance must all be addressed (Bidwell et al., 2017). Concerns regarding unstable finances are prevalent for every caregiver. In addition to their caregiving responsibilities, they often have to undertake employment to help pay off financial debts. This financial burden is frequently due to the patient's inability to maintain long-term employment following the implantation of a VAD (Neo et al., 2021).

Job instability is important because being employed provides financial stability, boosts self-esteem, and keeps the patients actively engaged. Frequently, patients have to miss work to visit the hospital. Because of the stigma associated with having a VAD, some patients are forced to conceal their condition. Frequent clinic visits and recurring hospital stays are frequently a financial burden. Caregivers often find themselves compelled to take on the role of the primary breadwinner, especially when financial needs arise due to the patient's health condition. Those seeking financial assistance from the community face challenges, as many social organizations are not familiar with what a VAD is, making it difficult for caregivers to obtain the necessary support. (Neo et al., 2020).

C. Challenges Specific to Lebanese VAD Caregivers

There have been little studies on Lebanese caregivers of patients with VAD. This knowledge gap is especially noticeable considering the essential role caregivers play in their management and well-being. This scarcity of studies is especially worrisome in the Lebanese context, where cultural, social, and healthcare variables might profoundly impact caring experiences. Little research has been discovered so far that particularly tackles the experiences and problems of Lebanese VAD caregivers. This highlights the urgent need for more extensive research in this field to better understand and assist these caregivers in their critical role.

The challenges that DT-VAD therapy in Lebanon include its high cost, delays in patient referrals to specialized units, and a significant shortage of organ donations, affecting heart transplant options. While comparing Lebanon’s VAD experiences with global standards, notably the IMACS data, the article reveals that despite these challenges, VAD outcomes in Lebanon match international results (Hamdan et al., 2020). Communication, or the lack thereof, plays a pivotal role in shaping the VAD journey, especially for caregivers.

In 2021, a qualitative study was conducted in Lebanon related to the lived experience of VAD patients and their caregivers (Chehade et al, 2021). The detailed examination of the experiences of individuals with VADs and their caregivers revealed five main themes: 1) Adapting to Life Post-VAD: Patients and caregivers perceive the VAD as a necessary, life-saving intervention. They report improvements in health and functionality over time, viewing the VAD as an opportunity for a new beginning. 2) Embracing the VAD: Patients develop a profound trust in their VAD, which becomes an essential part of their identity. They personalize the device, integrating it fully into their life experience. 2) Self-Determination, Coping, and Adjustment: Dyads learn to live with the VAD, navigating through various stages of grief to reach coping and acceptance. They successfully incorporate VAD into their daily lives, despite initial challenges. 3) Hope and Future Expectations: The VAD brings hope and new expectations for the future, despite necessary lifestyle changes. Dyads view these changes as a collective experience, akin to receiving a second chance at life. 4) Public Perception of the VAD: Dyads are impacted by societal views of the VAD. They encounter privacy issues due to public curiosity and labeling, feeling singled out and sometimes fearing for their safety. This highlights a lack of public awareness about VADs. These insights underscore the importance of ongoing, comprehensive assessments of grief and the need for individualized support for those living with VADs (Breen et al., 2020).

D. Experiences and Bereavement of Caregivers

1. Experiences and Bereavement of Caregivers with Chronic Illnesses

The experience of bereaved caregivers is marked by a distinct mix of problems and resources. The nature of relationships and the context of caregiving are two major themes that can be broadly used to categorize caregiver experiences. The caregiver's experience is greatly influenced by their relationships, whether they are with the patient, their loved ones, friends, or other healthcare professionals. The dynamic nature of the caregiver-patient relationship, which is affected by the progression of dementia, presents both difficulties and chances for closer relationships. Significant changes, like the patient's admission to a care facility, can, however, have a profound effect on these relationships, resulting in emotions of loss and guilt as well as a redefining of roles (Broady et al., 2018).

The dual-process model of bereavement offers a comprehensive understanding of the grieving process. This model encompasses two types of coping: loss-orientation coping and restoration-orientation coping, along with the oscillation between these two coping mechanisms (Supiano et al., 2015).

2. Experiences of Caregivers within Rural Areas

The challenges that come with bereavement are particularly difficult in rural areas. Even if they are not specifically created for bereavement, community support groups can be a lifeline in these trying times. After a loss, people may experience intense emotional upheaval, including waves of unanticipated grief, isolation, and a variety of physical and mental health issues (Kilgour, 2015; Marsh et al., 2019; Applebaum et al., 2022; Kilty et al., 2019). An observed trend shows that as they approach the end of their lives, older people actively withdraw from their communities. The limited role that communities currently play in providing end-of- life support for the elderly is highlighted by caregivers’ expressions of a lack of support from the larger community (Gott et al., 2018). Despite the prevalence of caregiving challenges in general, rural areas are especially impacted due to a scarcity of resources, lower income levels, and inadequate internet connectivity. Telehealth and the internet, among other electronic strategies, have the potential to provide efficient caregiver support (Hicken et al., 2017).

3. *Experiences of Caregivers with Older Adults*

The caregiver’s journey is a complex tapestry of emotions and difficulties that extends from diagnosis to post-bereavement. Because of the emotional toll, many caregivers develop symptoms resembling burnout, including emotional exhaustion and a pervasive sense of being overwhelmed (Diefenbeck et al, 2018). Caregiving and bereavement are journeys filled with multifaceted challenges that impact caregivers both emotionally and practically. These experiences, often intense and demanding, highlight the complexities of providing end-of-life care and the subsequent period of mourning. Recognizing these challenges is essential for identifying and addressing the support needs of caregivers both during and after their caregiving journey.

Caregivers experience tremendous challenges in understanding complicated pathophysiology and therapy, sometimes considering the information supplied to be overly complex. Many caregivers have a tremendous feeling of bewilderment and unpreparedness, especially when death arrived abruptly and unexpectedly (Poor et al., 2022). They feel unprepared for the impending death, highlighting how common this problem is. This lack of readiness is closely related to problems in understanding the illness, accepting the death, and having a difficult time grieving (Supiano et al., 2022).

Another stage where caregivers encounter a wide range of emotional and practical difficulties is the post-bereavement period. When a loved one passes away, caregivers frequently experience a void that is filled with reflections and, occasionally, regrets about their caregiving journey (Binjsdorp et al., 2022). The physical, emotional, and financial challenges that come with caregiving don't simply disappear following the patient's passing. Rather, they often persist, casting a shadow over the bereavement process (Diefenbeck et al, 2017). When healthcare providers review with caregivers the decision to provide care at home; they should support caregivers to assume leadership roles, ensure that they have sufficient knowledge regarding who to contact for help; and provide post-bereavement support to caregivers (Mckinlay et al, 2021). End-of-life care for patients at home requires advance preparation, emphasizing the importance of proactive advance care planning (Mogan et al., 2022).

Caregivers provide a level of individualized care and emotional support that is frequently outside the purview of trained healthcare professionals. However, the magnitude of their obligations can cause severe stress and burnout. Research has focused on unraveling the complex connection between a caregiver’s sense of competence and the stress they feel. These studies highlight the significance of providing caregivers with the necessary tools and assistance to help them on their journey (Hampton, 2018).

4. *Experiences of Caregivers with Cancer Patients*

Research has shown that preparing and discussing death have eased the transition to hospice care, whereas avoidance made it difficult to address the reality of a terminal illness and impending death (Waldrop et al., 2016). The rapid expansion of outpatient palliative care is a response to the increasing number of individuals with cancer and other chronic illnesses. While nurses and other palliative care professionals provide significant support to patients and their families, there has been limited research specifically focusing on the needs of family caregivers of cancer patients in outpatient palliative care settings. It's important to address the needs of these caregivers in various areas, including understanding, self-efficacy, finding meaning, informal support, formal support, access to resources, and self-care (Washington et al., 2021). Cancer caregivers have identified the sources of their distress as: (1) inadequate and delayed information; (2) uncertainty; (3) caregiving roles and responsibilities; (4) absence of family-focused services; (5) practical difficulties; and (6) the effects of distress (Taylor et al., 2021).

For some cancer diagnoses, the absence of active disease leads to anxiety about recurrence, uncertainty about post-treatment life quality, and adjustments in family roles for caregiving. This constant anticipation can cause dread, making it difficult to cope with the illness's various challenges. In contrast, inherited diseases often have a well-known progression within families, unlike sporadic cancers. This family-shared knowledge helps interpret uncertainties related to disease risk (Werner-Lin et al., 2020). The difficulties may have a significant impact on their wellbeing and their level of satisfaction.

5. *Experiences of Caregivers with Dementia and End-stage renal disease*

Similar to caregivers of dementia patients, end-stage renal disease (ESRD) patients face a variety of challenges. These caregivers frequently find themselves juggling competing personal and professional obligations as the disease worsens. Many people give up important things, like their jobs, to provide around-the-clock care. While navigating a sea of emotional, practical, and financial difficulties, they watch as their loved ones' physical health deteriorates. Consistent with the palliative care model, the medical community has recognized the importance of including caregivers in the decision-making process. This approach focuses on holistic well-being, considering the patient and family as one integrated unit of care (Maddalena et al., 2018).

Family members, particularly spouses and adult children, find themselves at the forefront of caregiving as the preference for end-of-life care at home grows. Their motivation for taking on this role can range from personal commitment to the scarcity of specialized in-home care services to cultural and familial obligations (Kilgour et al., 2015). For families, the behavioral form of frontotemporal dementia, a neurodegenerative disease, presents a distinct set of difficulties. Significant changes in family dynamics, roles, and interactions may result from this condition. Excessive distress can detrimentally affect caregivers' quality of life and their capacity to fulfill caregiving responsibilities. In light of these challenges, tailored support and interventions can be highly beneficial in fostering understanding and strengthening family relationships (Bruinsma et al, 2022).

E. Bereavement and Bereavement Support in VAD Caregivers

Caregivers of VAD patients face challenges, especially during end-of-life stages. The unexpected realization of a patient's imminent death and the complexities of managing the VAD device at home can be overwhelming. Recent caregiving interventions have been developed with a focus on enhancing caregiving abilities, providing emotional support, and anticipatory guidance about dementia's progression (Wolff, 2016; Hicken et al., 2017). Several strategies and interventions can significantly improve the experiences of caregivers and those grieving. Addressing the emotional, practical, and technological needs of caregivers is crucial in facilitating a more manageable and healing relationship. In addition, adopting a person-centered approach to care is crucial, rather than solely depending on existing organizational structures. For many, witnessing the progression of a disease is a prolonged and profoundly distressing experience (Orlowska et al., 2018).

The UK National Institute for Health and Clinical Excellence organizes bereavement intervention strategies into a structured three-tier model, as outlined by Higgins et al. (2023). This model encompasses the distribution of general information to all bereaved individuals; the provision of selected or targeted non-specialist assistance for those identified as having the potential to develop complex bereavement issues; and the availability of professional, specialized support for those experiencing a high level of complicated bereavement needs. Evaluating fundamental outcomes is crucial, particularly in areas like the experience of profound and intense grief, understanding and finding meaning in bereavement, and ensuring access to adequate support. These elements are significant in assessing how caregivers manage grief and their overall mental health (Moss et al., 2021). This tiered approach to bereavement intervention, as outlined, and the emphasis on key outcomes in grief management by Moss et al. (2021), pave the way for a broader, more community-focused perspective on bereavement support. The transition from individual-focused interventions to a more inclusive, community-engaged strategy represents a significant shift in how we address the needs of the bereaved. This shift is crucial in understanding the wider implications of bereavement support, not just for the individual but for the community as a whole.

1. ***Bereavement Support from Palliative Care Team***

Many caregivers feel unprepared for post-VAD complications and their concern about hospice teams (Wingate, 2016). There is also a main concern in understanding the VAD’s role during the dying process, its ethical implications, and navigating the fragmented palliative care system (McIlvennan et al., 2016). Consequently, in the event of the deactivation of VAD, in hospital, when patients are dying, palliative care is frequently included. Interviews with grieving family members have shown a greater need for emotional assistance and disease state information during this time (Singh et al., 2021). As the end-of-life approached, caregivers of VAD patients often experienced considerable confusion and frustration, feeling that their questions about what to expect during this phase remained unanswered (Broglio et al., 2015; Thompson, Moser, 2020). Healthcare professionals are hesitant to recommend palliative care due to unfamiliarity with its benefits and discomfort discussing it. Payment systems also limit comprehensive palliative care access. The importance of integrating palliative care into the overall treatment plan emphasizes effective communication, holistic patient care, and family involvement (Braun et al., 2016). There is a strong emphasis on the importance to recognize the value of planning for death, the difficulties in communicating uncertainties, the varying views on VAD withdrawal, and the challenges healthcare professionals face in defining their roles at the end of life (Chuzi et al., 2020). Engaging communities in the development of grief support capacity can help bereaved persons and perhaps alter views around dying and death more broadly. This approach is consistent with the notion of compassionate communities, in which end-of-life care is a shared obligation (Breen et al., 2017). Adult family caregivers who get bereavement assistance experience much less sadness, despair, and anxiety. The need of grief support in palliative care, emphasize its role in enhancing caregivers' psychosocial outcomes (Kustanti et al., 2021). This implies that caregivers may require various sorts of assistance depending on where they are in the grief process (Moss et al., 2021). It is critical to encourage engagement in jobs, social activities, and preserving relationships with friends and family. This contributes to the overall enhancement of bereaved people's welfare and quality of life (Harrop et al., 2020). The inclusion of a spiritual care practitioner on the palliative care team is advantageous for providing additional grief-related resources and support. Many caregivers value this spiritual element during the grief process (Thrower et al., 2023).

Throughout the DT-VAD trajectory, there’s limited knowledge about caregiver attitudes towards discussing and preparing for end-of-life care. Both caregivers and physicians find it challenging to determine the appropriate timing and approach for end-of-life conversations with DT-VAD patients and their caregivers, complicated by uncertainties about disease progression and life expectancy (Chuzi et al., 2021). As the use of VADs becomes more common, it becomes increasingly important for healthcare providers and caregivers to recognize the unique challenges associated with end-of-life care. One recurring idea is the need to involve palliative and hospice care teams in the care of VAD patients, underscoring the importance of a comprehensive and collaborative approach to their treatment (McIlvennan et al., 2018).

2. ***Bereavement Support from Various Healthcare Providers***

Literature provides elements that are deemed essential for bereavement support programs. One such element was the use of a condolence letter (Kentish-Barnes et al., 2017). The handwritten sympathy letter was delivered 15 days after the patient's death and addressed several topics, including acknowledging the deceased, sharing personal impressions, offering condolences to family members, and expressing grief. Meanwhile, other researchers implemented grief support programs that included providing a booklet to the bereaved family upon the patient's death. This booklet contained information on bereavement, funeral preparations, financial arrangements, obtaining death certificates, and accessing bereavement support services (McAdam et al., 2018). The family received a sympathy card and a practical resource kit a week after their loved one's passing. After 4 to 5 weeks, they received a follow-up phone call to check on their well-being and assess any additional needs. Six months later, the family was contacted again, and a handwritten condolence message was sent one year after the loss. Additionally, a card was sent on the patient's birthday to commemorate the occasion.

White et al. (2020) employed the Four Supports intervention as bereavement assistance, which involved a professionally trained nurse or social worker providing emotional, communicative, decisional, and, if appropriate, anticipatory grieving support. A nurse-led intervention for difficult mourning, anxiety, depression, and posttraumatic stress disorder can be tested. Such intervention can increase the quality of bereavement care while also decreasing symptoms of difficult grieving and accompanying mental health issues (van Mol et al., 2020). This intervention is created in partnership with intensivists, spiritual service providers, social workers, and nurses, resulting in a comprehensive and compassionate approach to bereavement care (van Mol et al., 2020). Professionally led support interventions, such as those conducted by healthcare practitioners skilled in bereavement management, are more successful. Group assistance is also successful in alleviating bereavement, but resolving depression requires a combination of individual and group methods (Näppä, Björkman-Randström, 2020). More than six sessions of grief support tend to be more helpful, and the effectiveness of the assistance must be evaluated within six months following the intervention. This shows that caregivers require continuing and timely help (Kustanti et al., 2021).

In therapeutic settings, a variety of therapies aimed for bereaved caregivers are routinely used, including psycho-educational techniques, risk assessments for extended mourning disorder, and specialized care for people with complicated needs (Laranjeira et al., 2022). Psychologists, psychiatrists, therapists, and nurses are critical in providing these therapies. Individual assistance can be offered via phone or online sessions, acknowledging that the freshly bereaved may not be ready for group sharing right away (Laranjeira et al., 2022). It is critical to provide psychoeducation bereavement resource packages for informal caregivers. These packages provide information about grieving, the domains of loss, and how to address them, which assists caregivers in understanding and effectively managing their grief (Eyre, 2019). Spiritual, social, physical, and psychological care are all included in the package. It covers important topics including sharing last moments with loved ones, self-care during sorrow, and assisting oneself in healing after a loss (Eyre, 2019). According to the Caregiver Mourning Questionnaire

(CMQ), caregivers suffered health issues, sleeping disorders, eating disorders, fatigue, and loneliness. These physical and emotional health difficulties should be addressed as part of bereavement assistance (Ferrario et al., 2016). Adapting bereavement therapies to each participant's specific needs, preferences, and resources, is more beneficial than a one-size-fits-all strategy (Caserta et al., 2016). These bereavement resource packages lay a foundational understanding of the multifaceted needs of caregivers in bereavement.

3. *Bereavement Support Using Technology*

Technology can be a key component of helping caregivers, particularly Facebook groups where caregivers can discuss unexpected and anticipated events that spark intense grief. The group frequently experiences emotional outbursts in response to these triggers, whether they were recollections, anniversaries, or other somber reminders (Wittenberg-Lyles et al, 2015). The emergence of online venues can help caregivers with grieving support. These platforms allow caregivers to share their experiences, advise, and support with other caregivers in similar situations (Wittenberg-Lyles et al., 2015). Caregivers of VAD patients may suffer difficult grief, emphasizing the significance of early intervention and ongoing support throughout the caring and bereavement process (Thrower et al., 2023). Rolbieck et al (2021) examined the effectiveness of the "Caregiver Speaks" intervention, which employs a digitally mediated storytelling method, especially via a private Facebook group. Photo-elicitation storytelling is part of the intervention, in which caregivers share images that capture their thoughts, feelings, and reactions to caring and mourning. This innovative strategy can assist caregivers in expressing and processing their feelings. The intervention is unusual in that it follows caregivers from active caregiving to grief, addressing the obstacles and emotional requirements of both periods.

The public health approach to bereavement support suggests that everyone who is grieving should have access to essential information and local resources for coping with their loss. Volunteer grief workers and community mourning groups should give a lower proportion formal opportunity for reflection, whereas only a tiny fraction may benefit from specialized assistance (Breen et al., 2017).

Family members have a desire for greater involvement in care and for their opinions to be heard throughout the care process. They also seek support to deal with the difficulties of caregiving and bereavement, both emotionally and in terms of resources (Naoki et al, 2018; Yu et al., 2022).

While the majority of grieving individuals do not require professional therapy, they might all benefit from adequate information and compassion. To assist grieving caregivers, this information might be distributed through booklets, posters, and websites (Breen et al., 2017). It is critical to give grief information and to refer people to other resources if necessary. This method assists caregivers by assisting them in understanding the bereavement process and navigating their emotions (Harrop et al., 2020). The provision of grief information and resources emphasizes the importance of accessible and compassionate support for all bereaved individuals, particularly caregivers. These approaches not only address the informational needs of caregivers but also offer practical and emotional tools to help them process their grief more effectively.

Emotional and practical assistance provided to the caregivers is of great importance. Goal-of-care talks lead to a sense of pleasure in fulfilling end-of-life preferences. Personalized condolences from the healthcare team, such as phone calls and handwritten cards, play a vital source of comfort and closure for the grieving caregivers (Poor et al., 2022).

CHAPTER III

METHODS

A. Literature Review Section

To examine the impact of Ventricular Assist Devices (VADs) on caregivers' bereavement and support, a systematic search was conducted across multiple databases, including PubMed, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Cochrane, and Medline. The search strategy was crafted to incorporate terms related to VADs and those pertinent to caregivers, their well-being, and the challenges they face. Keywords such as "bereavement," "grief," "VAD caregivers," "family caregivers," "challenges," and "adaptations" were utilized. This approach aimed to combine these terms in various combinations to create a comprehensive search.

The inclusion criteria for articles were as follows: they had to be published between 2015 and 2023, focus on the adult population, be peer-reviewed, in English, and specifically address bereavement, as well as the experiences, challenges, and adaptations of patients and their caregivers, providing insights into their physical, mental, and social well-being. Conversely, articles were excluded if they were not available in full text, were not published in peer-reviewed journals, were not in English, or focused on the pediatric population.

The search yielded diverse results across the databases. In total, 761 articles were initially identified from all the databases. After a thorough review of titles and abstracts, 79 articles were selected for a full-text review based on their direct relevance to the research topic. question. These selected articles were then thoroughly reviewed, and their findings were synthesized to comprehensively answer the aim of this project.

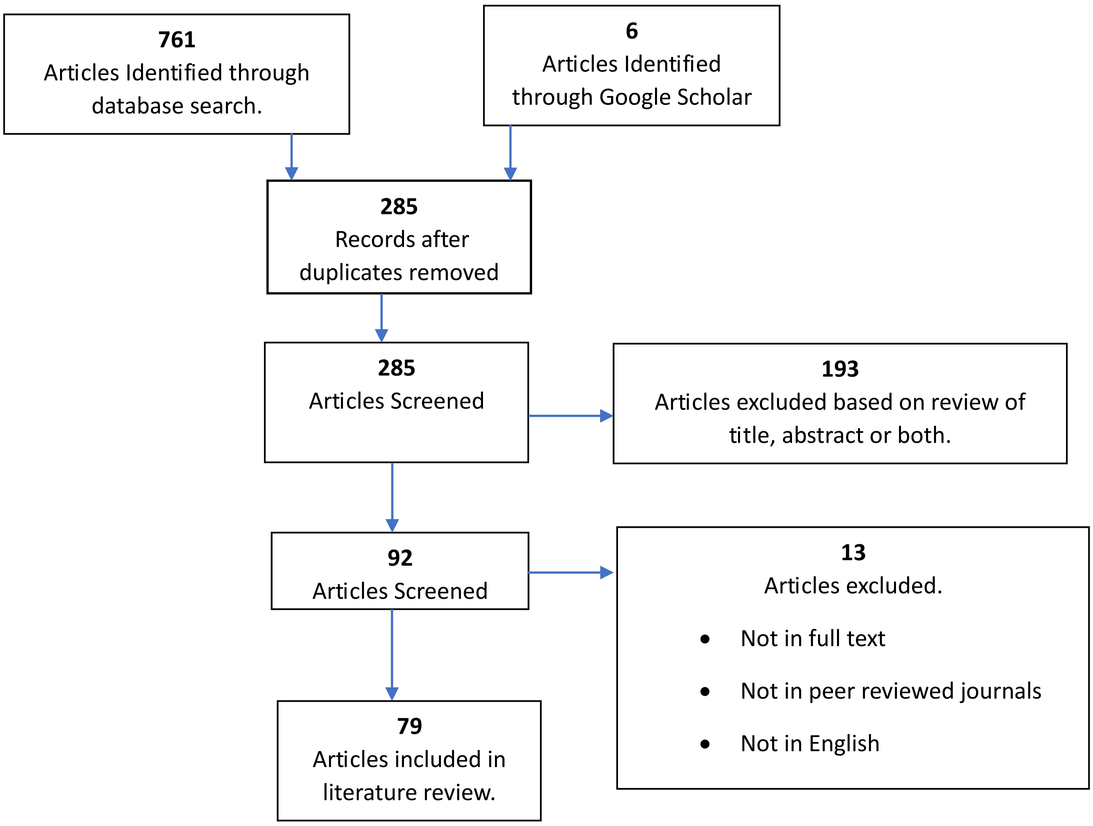

Figure 2 Article Inclusion Decision Tree

B. Appendices Section

This section outlines the process through which Appendices A-R were identified and obtained. These appendices comprise various questionnaires and checklists intended for the support and bereavement package designed for caregivers of VAD patients. The identification and collection of these appendices followed a systematic approach, ensuring a comprehensive and relevant selection of questionnaires and checklists. The process was guided by the research question, focusing on tools that assess and support the bereavement and support needs of VAD patient caregivers.

Table 1 Bereavement Package Questionnaires

Appendix	Title	Brief Description	Reference
A	Markers of Advanced HF [I NEED HELP]	The American and European Heart Failure Guidelines and Consensus Statements recommend using the “I Need Help” acronym to define advanced heart failure since it includes many of the essential elements.	Baumwol, J. (2017). “I Need Help”—A mnemonic to aid timely referral in advanced heart failure. The Journal of Heart and Lung Transplantation, 36(5), 593–594. https://doi.org/10.1016/j.healun.2017.02.010
B	INTERMACS Profile Descriptions in Patients with Advanced HF Profile	INTERMACS is a North American database that collects information on adults with advanced heart failure who have received FDA-approved mechanical circulatory support devices.	Stevenson, L. W., Pagani, F. D., Young, J. B., Jessup, M., Miller, L., Kormos, R. L., Naftel, D. C., Ulisney, K., Desvigne-Nickens, P., & Kirklin, J. K. (2009). INTERMACS profiles of advanced heart failure: The current picture. The Journal of Heart and Lung Transplantation: The Official Publication of the International Society for Heart Transplantation, 28(6), 535–541. https://doi.org/10.1016/j.healun.2009.02.015
C	Preparedness for caregiving	Initially developed in the United States, this assessment tool is designed to evaluate the readiness of caregivers. It comprises eight items, and each item is rated on a 5-point Likert-type scale, ranging from "not at all prepared" (0) to "extremely well-prepared" (4). The total score, obtained by summing the responses to all eight items, ranges from 0 to 32, with a higher score indicating a higher level of preparedness.	Gutierrez-Baena, B., & Romero-Grimaldi, C. (2022). Predictive model for the preparedness level of the family caregiver. International Journal of Nursing Practice, 28(3), e13057. https://doi.org/10.1111/ijn.13057
D	Pre-VAD evaluation by	This questionnaire serves as a semi-structured script and is designed to minimize	Nakagawa, S., & Blinderman, C. D. (2019). Palliative Care Consultation Before

	palliative care team	variations in the approach of Palliative Care physicians in such consultations.	Ventricular Assist Device Implantation. Journal of pain and symptom management, 57(3), e9–e11. https://doi.org/10.1016/j.jpainsymman.2018.11.027
E	Social worker standardized questions	Social workers standardized questions to evaluate VAD patients	Bruce, C. R., Minard, C. G., Wilhelms, L. a., Abraham, M., Amione-Guerra, J., Pham, L., Grogan, S. D., Trachtenberg, B., Smith, M. L., Bruckner, B. A., Estep, J. D., & Kostick, K. M. (2017). Caregivers of Patients with Left Ventricular Assist Devices. Circulation: Cardiovascular Quality and Outcomes, 10(1), e002879. https://doi.org/10.1161/CIRCOUTCOMES.116.002879
F	Psychiatry consult questions	The SIPAT score is a validated tool used to assess behavioral and psychosocial risks in patients who are undergoing evaluation for organ transplantation.	Sperry, B. W., Ikram, A., Alvarez, P. A., Perez, A. L., Kendall, K., Gorodeski, E. Z., & Starling, R. C. (2019). Standardized Psychosocial Assessment Before Left Ventricular Assist Device Implantation. Circulation: Heart Failure, 12(1), e005377. https://doi.org/10.1161/CIRCHEARTFAILURE.118.005377
G	Post Surgery Complications	This list comprises of complications that may happen post VAD surgery.	Agrawal, A., Alexy, T., Kamioka, N., Shafi, T., Stowe, J., Morris, A. A., Vega, J. D., Babaliaros, V., & Burke, M. A. (2021). Outflow graft obstruction after left ventricular assist device implantation: A retrospective, single-centre case series. ESC Heart Failure, 8(3), 2349–2353. https://doi.org/10.1002/ehf2.13333 Han, J. J., Acker, M. A., & Atluri, P. (2018). Left

			Ventricular Assist Devices. Circulation, 138(24), 2841–2851. https://doi.org/10.1161/CIRCULATIONAHA.118.035566 Saeed, D., Feldman, D., Banayosy, A. E., Birks, E., Blume, E., Cowger, J., Hayward, C., Jorde, U., Kremer, J., MacGowan, G., Maltais, S., Maybaum, S., Mehra, M., Shah, K. B., Mohacsi, P., Schweiger, M., Schroeder, S. E., Shah, P., Slepian, M., … D'Alessandro, D. (2023). The 2023 International Society for Heart and Lung Transplantation Guidelines for Mechanical Circulatory Support: A 10-Year Update. The Journal of Heart and Lung Transplantation, 42(7), e1–e222. https://doi.org/10.1016/j.healun.2022.12.004
H	Self-Care of VAD Patients	The VAD Self-Care Behavior Scale comprises 33 items that assess three components: self-care maintenance, self-care monitoring, and self-care management. Responses are recorded on a 5-point Likert scale, ranging from 1 (never) to 5 (always). A higher mean score of the items indicates a greater level of self-care behavior	Melnikov, S., Avraham, B., Zadok, O., Shaul, A., Abuhazira, M., Yaari, V., Jaarsma, T., & Ben-Gal, T. (2023). Self-care behaviours of patients with Left ventricular assist devices in Israel: Changes during the COVID-19 pandemic. ESC Heart Failure, 10. https://doi.org/10.1002/ehf2.14376
I	Post-Op Orientation of The Informal Caregiver	The objective of this list is to provide healthcare executives and interprofessional healthcare teams with a set of systematically informed best practices for Family-Centered Care (FCC) in the ICU. The aim is to encourage family presence, offer support to	Schwartz, A. C., Dunn, S. E., Simon, H. F. M., Velasquez, A., Garner, D., Tran, D. Q., & Kaslow, N. J. (2022). Making Family-Centered Care for Adults in the ICU a Reality. Frontiers in Psychiatry, 13, 837708.

		family members, and enhance effective communication with families.	https://doi.org/10.3389/fpsyt.2022.837708
J	Guide to ICU Stay at the American University of Beirut Medical Center	It includes detailed information on how to navigate the complexities of an ICU stay, supporting both patients and caregivers.	American University of Beirut, Medical Center
K	VAD discharge checklist for patients and caregivers	Discharge instructions that are easy to understand address important themes and may improve patient education.	Ozdemir Koken, Z., Sezer, R. E., & Kervan, U. (2019). Caring for Patients With Ventricular Assist Devices: A Mini-Review of the Literature. Transplantation Proceedings, 51(7), 2492–2494. https://doi.org/10.1016/j.transproceed.2019.03.046 Colin-Ramirez, E., Sepehrvand, N., Rathwell, S., Ross, H., Escobedo, J., Macdonald, P., Troughton, R., Saldarriaga, C., Lanas, F., Doughty, R., McAlister, F. A., & Ezekowitz, J. A. (2023). Sodium Restriction in Patients With Heart Failure: A Systematic Review and Meta-Analysis of Randomized Clinical Trials. Circulation: Heart Failure, 16(1), e009879. https://doi.org/10.1161/CIRCHEARTFAILURE.122.009879 Fick, A., Tymkew, H., Deters, M., Martin, K., Ratermann, J., Reilly, A., Lohbeck, B., & Liu, Y. (2022). Functional Status and Discharge Location of Patients Post–Left Ventricular Assist Devices Surgery in the Acute Care Setting. Cardiopulmonary Physical Therapy Journal, 33(3), 116. https://doi.org/10.1097/CPT.0000000000000193

			Han, J. J., Acker, M. A., & Atluri, P. (2018). Left Ventricular Assist Devices. Circulation, 138(24), 2841–2851. https://doi.org/10.1161/CIRCULATIONAHA.118.035566 Kugler, C., Meng, M., Rehn, E., Morshuis, M., Gummert, J. F., & Tigges-Limmer, K. (2018). Sexual activity in patients with left ventricular assist devices and their partners: Impact of the device on quality of life, anxiety and depression. European Journal of Cardio-Thoracic Surgery: Official Journal of the European Association for Cardio-Thoracic Surgery, 53(4), 799–806. https://doi.org/10.1093/ejcts/ezx426 Piña, I. L., Di Palo, K. E., Brown, M. T., Choudhry, N. K., Cvengros, J., Whalen, D., Whitsel, L. P., & Johnson, J. (2021). Medication adherence: Importance, issues and policy: A policy statement from the American Heart Association. Progress in Cardiovascular Diseases, 64, 111–120. https://doi.org/10.1016/j.pcad.2020.08.003 Saeed, D., Feldman, D., Banayosy, A. E., Birks, E., Blume, E., Cowger, J., Hayward, C., Jorde, U., Kremer, J., MacGowan, G., Maltais, S., Maybaum, S., Mehra, M., Shah, K. B., Mohacsi, P., Schweiger, M., Schroeder, S. E., Shah, P., Slepian, M., … D'Alessandro,

			D. (2023). The 2023 International Society for Heart and Lung Transplantation Guidelines for Mechanical Circulatory Support: A 10-Year Update. The Journal of Heart and Lung Transplantation, 42(7), e1–e222. https://doi.org/10.1016/j.healun.2022.12.004 Scott, A. R., Sanderson, C. J., Rush, A. J., Alore, E. A., Naik, A. D., Berger, D. H., & Suliburk, J. W. (2018). Constructing post-surgical discharge instructions through a Delphi consensus methodology. Patient Education and Counseling, 101(5), 917–925. https://doi.org/10.1016/j.pec.2017.12.004 Schlöglhofer, T., Zapusek, L., Wiedemann, D., Riebandt, J., Wittmann, F., Dimitrov, K., Angleitner, P., Haberl, L., Laufer, G., Moscato, F., Zimpfer, D., & Schima, H. (2021). International Normalized Ratio Test Frequency in Left Ventricular Assist Device Patients Affects Anticoagulation Quality and Adverse Events. ASAIO Journal (American Society for Artificial Internal Organs: 1992), 67(2), 157–162. https://doi.org/10.1097/MAT.0000000000001206 Tan, N. Y., Sangaralingham, L. R., Schilz, S. R., & Dunlay, S. M. (2017). Longitudinal Heart Failure Medication Use and Adherence Following Left Ventricular Assist Device

			Implantation in Privately Insured Patients. Journal of the American Heart Association, 6(10), e005776. https://doi.org/10.1161/JAHA.117.005776 Wilcox, J. E., Cameron, K. A., Harap, R. S., Shanklin, K. L., Grady, K. L., Cohen, E. R., Abicht, T. O., Adler, E. D., Alexy, T., Alonso, W., Beckman, J., Bjelkengren, J., Cagliostro, B., Cogswell, R., Colombo, P. C., Cotts, W., Haglund, N. A., Haverstick, S., Kiernan, M. S., … Barsuk, J. H. (2019). Ventricular Assist Device Driveline Dressing Change Protocols: A Need for Standardization. Journal of Cardiac Failure, 25(8), 695–697. https://doi.org/10.1016/j.cardfail.2019.06.009 Xu, Y., Zheng, X., Li, Y., Ye, X., Cheng, H., Wang, H., & Lyu, J. (2023). Exploring patient medication adherence and data mining methods in clinical big data: A contemporary review. Journal of Evidence-Based Medicine, 16(3), 342–375. https://doi.org/10.1111/jebm.12548
L	Symptom Tracker Checklist of VAD patients	This checklist includes alarming signs of HF exacerbation, specifically using the HF symptom tracker (HFaST), signs of driveline infection, and signs of bleeding.	Lewis, K. B., Harkness, K., Hummel, A., Leung, J., & MacIver, J. (2021). The relational dynamics of caregivers of patients with a left ventricular assist device for destination-therapy: A qualitative investigation. Heart & Lung, 50(3), 375–381.

			https://doi.org/10.1016/j.hrtlng.2021.01.008 Leuck, A.-M. (2015). Left ventricular assist device driveline infections: Recent advances and future goals. Journal of Thoracic Disease, 7(12), 2151–2157. https://doi.org/10.3978/j.issn.2072-1439.2015.11.06 Perna, E., & Wettersten, N. (2021). Evaluation and Management of LVAD Complications. In U. Birgersdotter-Green & E. Adler (Eds.), Case-Based Device Therapy for Heart Failure (pp. 111–137). Springer International Publishing. https://doi.org/10.1007/978-3-030-70038-6_7
M	VAD Alarms	This checklist includes all VAD alarms, as a reference for patients and their caregivers.	Chaudhry, S., DeVore, A. D., Vidula, H., Nassif, M., Mudy, K., Birati, E. Y., Gong, T., Atluri, P., Pham, D., Sun, B., Bansal, A., Najjar, S. S., & null, null. (2022). Left Ventricular Assist Devices: A Primer For the General Cardiologist. Journal of the American Heart Association, 11(24), e027251. https://doi.org/10.1161/JAHA.122.027251
N	Psychosocial Assessment of the Informal Caregiver	Identifying when a stressed-out family caregiver may require support is a critical public health topic. This questionnaire is an easily available instrument that can assist in determining whether extra assessment is required.	Epstein-Lubow, G., Gaudiano, B. A., Hinckley, M., Salloway, S., & Miller, I. W. (2010). Evidence for the validity of the American Medical Association's caregiver self-assessment questionnaire as a screening measure for depression. Journal of the American Geriatrics Society,

			58(2), 387–388. https://doi.org/10.1111/j.1532-5415.2009.02701.x
O	Predictors of Mortality in VAD patients	Predictors of 90 days and 5 years mortality rate in VAD patients.	Akin, S., Soliman, O., de By, T. M. M. H., Muslem, R., Tijssen, J. G. P., Schoenrath, F., Meyns, B., Gummert, J. F., Mohacsi, P., & Caliskan, K. (2020). Causes and predictors of early mortality in patients treated with left ventricular assist device implantation in the European Registry of Mechanical Circulatory Support (EUROMACS). Intensive Care Medicine, 46(7), 1349–1360. https://doi.org/10.1007/s00134-020-05939-1 Nayak, A., Hall, S. A., Uriel, N., Goldstein, D. J., Cleveland, J. C., Cowger, J. A., Salerno, C. T., Naka, Y., Horstmanshof, D., Crandall, D., Wang, A., & Mehra, M. R. (2023). Predictors of 5-Year Mortality in Patients Managed With a Magnetically Levitated Left Ventricular Assist Device. Journal of the American College of Cardiology, 82(9), 771–781. https://doi.org/10.1016/j.jacc.2023.05.066
P	Signs and Symptoms of Complicated Grief	This questionnaire helps providers to identify caregivers who are at risk of developing complicated grief. Score 0 to 2: Low Risk; Score 3 to 5: Moderate Risk; Scores of 5+ are High Risk. Those with a high score are referred to the appropriate providers, and those at risk are provided with support and counseling.	American University of Beirut Medical Center (2022). Bereavement policy (Policy No: PCT-001)

Q	Post Death-Caregiver Standardized Questions	A set of open-ended questions that can assess complicated grief and provide appropriate recommendations based on standardized questions.	American University of Beirut Medical Center (2022). Bereavement policy (Policy No: PCT-001)
R	Brief Grief Questionnaire	A brief grief questionnaire evaluation to identify caregivers at risk of developing complex sorrow. If positive, they are referred to appropriate providers.	American University of Beirut Medical Center (2022). Bereavement policy (Policy No: PCT-001)

CHAPTER IV

THE CAREGIVER AND BEREAVEMENT PACKAGE

The Caregiver and Bereavement Package presents a comprehensive exploration of the multifaceted aspects of caring for patients and their informal caregivers in the context of VAD implantation, primarily focusing on the critical role of education, timely referral to palliative care, preimplantation psychiatric evaluation, and timely referral to social services. Such activities are expected to support both the patient and informal caregiver and might help prepare the informal caregiver for any negative outcome (Heidenreich et al., 2022).

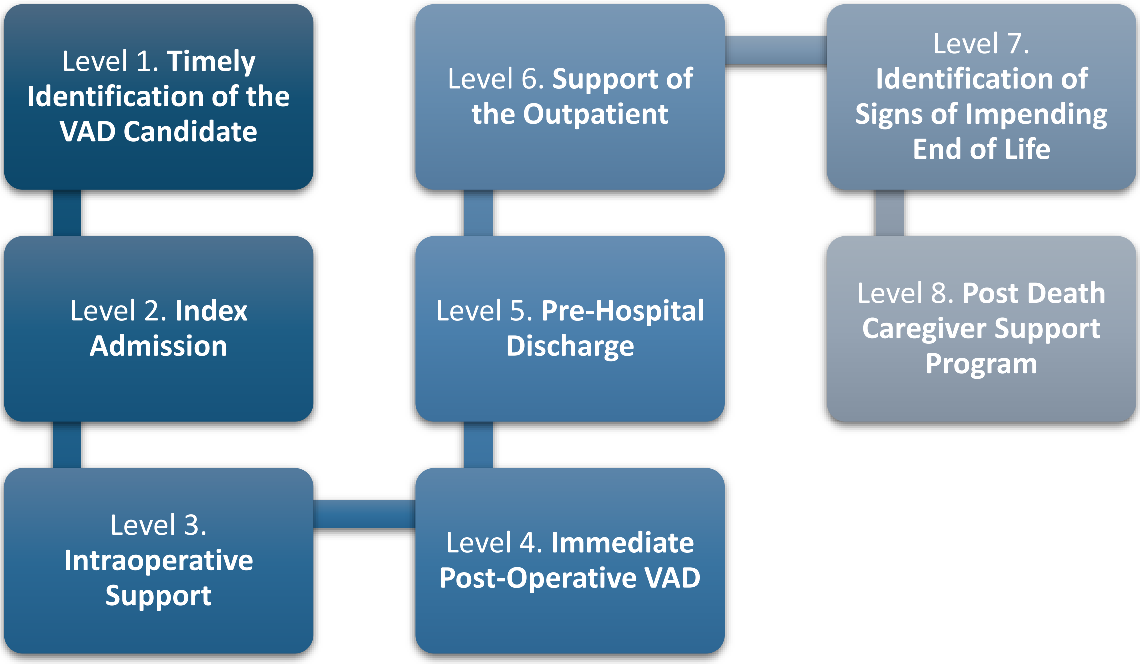

Figure 3 The Caregiver and Bereavement Package

A. Level 1. Timely Identification of the VAD Candidate

Under level one support, it is essential to ensure timely identification of the VAD candidate. VAD surgery outcomes are better when the surgery is planned, and ample time is given to prepare patients and their caregivers (Croke, 2021). In this level, we suggest development of 1. Candidacy Checklist, 2. Guidelines for Palliative Care Team Consult, 3. Guidelines for Social Worker Consult, 4. Guidelines for Psychiatry Consult, and 5. Procedures for identification of the Informal Caregivers.

1. Development of a Candidacy Checklist

While VAD therapy offers clear benefits for patients living with advanced HF, many don't receive timely referrals due to the challenge of identifying patients' transitioning from stage C to stage D HF (Herr et al., 2021) [Refer to Appendix A. Markers of Advanced HF]. This preparation will give both patients and caregivers time to be mentally, emotionally, and logistically prepared. l provides patients and their caregivers with ample time to accept the VAD and its effect on their lives (Hui et al., 2022). Classification systems like the New York Heart Association class and the Interagency Registry for Mechanically Assisted Circulatory Support [INTERMACS] classification provide a detailed assessment. Our focus should be on patients that fit profile 4 to 7 as they have time to decide and process all information given to them, however, patients in profile 1 to 3, are in a critical situation and VAD should be inserted within few hours to few days. Cardiopulmonary exercise testing can further evaluate and stratify the risk (Chaudhry et al., 2022) [Refer to Appendix B. INTERMACS Profile Descriptions in Patients with Advanced HF Profile].

Observable indicators of advancing to stage D heart failure (HF) encompass diminishing exercise capacity, decreased doses of neurohormonal antagonist medications, persistent symptoms despite treatment, recurrent hospitalizations, heightened reliance on diuretics, notable enlargement of the left ventricle (with left ventricular size exceeding 7 cm), lack of improvement with medical therapy, or initial signs of organ damage. It is critical to educate patients about the advantages, potential risks, and necessary lifestyle adjustments related to Ventricular Assist Devices (VADs) during this stage (Heidenreich et al., 2022).

In this transition, the role of nurses and clinical nurse specialists in patient education is paramount. As frontline caregivers, nurses have the unique opportunity to empower patients and their caregivers, promote health literacy, and provide vital educational and informational support. This is more crucial when patient symptomatology increases such as in deteriorating cases of advanced HF. Nurse-led HF self-care education significantly reduced the likelihood of hospital readmission for any reason, specifically HF-related readmissions, and readmissions or deaths due to any cause (Son et al., 2020). Given the complexities involved in managing VAD post-surgery, a comprehensive nurse-led educational strategy is essential. This approach ensures patients are well-informed, competent, and adequately prepared for the surgery and the subsequent aftercare. Such education plays a critical role in reducing complications and hospital readmissions, thereby improving patient outcomes. Notably, a research study demonstrated a reduction in the 30-day readmission rate; patients who underwent the education program had a 15% readmission rate compared to the center’s average of 21%. This highlights the significance of thorough patient education in enhancing outcomes and reducing hospital readmissions (Sesay et al., 2021).

2. Identification of the Informal Caregivers

A safe environment for the patient is crucial and it starts with the availability of a caregiver. After identifying the VAD candidate, an informal caregiver must be identified as well. The measurable worth of volunteer support and services provided by caregivers to patients is significant. In the context of HF, this reliance on caregivers is particularly pronounced, as they play a crucial role in delivering intensive care at home following left ventricular assist device implantation and transplantation. Caregivers also play a vital role in transitional care programs aimed at preventing costly hospital readmissions (Kitko et al., 2020).

The ISHLT's latest guidelines recommend assessing caregiver burden during pre-implantation screening for VADs and consider significant caregiver burden as a relative contraindication for implantation (Saeed et al., 2023). The latest guidelines from ISHLT recommend evaluating caregiver burden as part of the pre-implantation screening for VADs. Additionally, they identify significant caregiver burden as a relative contraindication for VAD implantation (Baird et al., 2023).

Many scales can be used so the cardiology CNS can determine if the caregiver is fully prepared for this job. One of them can be the Caregiver preparedness scale [Refer to Appendix C: Preparedness for caregiving]. It was initially created in the United States for the purpose of evaluating caregivers' readiness, as described by Archbold et al. in 1990. This scale consists of eight items, each assessed using a 5-point Likert-type scale that ranges from 'not at all prepared' (0) to 'very well-prepared' (4). To derive a total score, the responses to all eight items are summed, resulting in a score that can range from 0 to 32. A higher score on this scale indicates a higher level of preparedness among caregivers (Gutierrez-Baena et al., 2022).

3. *Palliative Care Team Consult*

The European Society of Cardiology (2021) outlines key components of PC services for patients with advanced HF. These components include a focus on maintaining or improving the quality of life for patients and their families until the end of life. There should be regular assessment of symptoms, such as dyspnea and pain, related to advanced HF and associated conditions, with a focus on symptom relief. Furthermore, the Centers for Medicare and Medicaid Services mandated in 2013 that all patients undergoing DT-VAD implantation must have access to a palliative care team before the surgery. Despite this requirement, there is limited understanding regarding the quality and content of these consultations (Chuzi et al., 2019).

The Joint Commission International requires preimplantation PC consultations (Salomon et al., 2018). Integrating PC services into the workflow of both the cardiothoracic and palliative care teams can improve advanced care planning and enhance care coordination for all VAD patients (Salomon et al., 2018). PC consultations before VAD implantation help identify potential challenges. A single PC session before VAD surgery is insufficient to ensure comprehensive readiness, planning, and a precise understanding of patients' preferences and goals. More timely and possibly ongoing palliative care consultations are imperative (Chuzi et al, 2019). To address this issue, a semi-structured script for pre-VAD evaluation was developed [Refer to Appendix D. Pre-VAD Evaluation by the Palliative Care Team]. This script, which covers questions ranging from patient comfort to likely outcomes, ensures that all key components of the consultation are addressed (Nakagawa & Blinderman, 2018). The semi-structured screenplay emphasizes knowing the patient’s quality of life and what makes life important for them. This strategy shifts the focus away from particular medical procedures and toward circumstances that would constitute a meaningful existence for the patient (Nakagawa & Blinderman, 2018). As highlighted earlier, a risk factor for lack of successful post VAD care is an unavailable caregiver, therefore, one of the important parts of the Pre-VAD Evaluation by the Palliative Care Team checklist is to educate the patient on the importance of identifying an informal caregiver (Rodriguez et al., 2018).

4. *Social Worker Consult*

VAD eligibility examinations should include both medical and social concerns, according to the International Society of Heart and Lungs Transplant (ISHLT) recommendations. Prior to VAD, there should be a full psychosocial evaluation that encompasses neurocognition, mental health, behavior, coping, knowledge, social support, and VAD preparation, providing each patient an overall score (Sperry et al., 2019).

The need for psychological support services for both patients and caregivers and the importance of their crucial role in the rehabilitation process is highlighted in ISHLT 2023 guidelines (Saeed et al., 2023). Social workers play a crucial role in evaluating potential candidates for VADs, taking into account factors like adherence, caregiver support, substance use, home environment, learning abilities, and financial resources. This holistic approach is essential in ensuring that patients have established support systems and can access community services (Saeed et al., 2023).

During the social interviews, social workers gather information about caregiver support and assess various aspects of the patient's self-sufficiency. This is achieved through a set of standardized questions that cover a range of topics [Refer to Appendix

E. Social Workers Standardized Questions]. This thorough and standardized approach ensures that social workers gather essential information consistently and comprehensively when evaluating VAD candidates (Bruce et al, 2017).

In Lebanon, a significant challenge for VAD patients is the financial burden associated with medications, equipment, and follow-up care. Only two national healthcare providers in the country cover the cost of VAD procedures: the national social security fund and the Lebanese army fund, which collectively serve approximately 40% of the Lebanese population (Hamdan et al., 2020).

5. *Psychiatry Consult*

The role of psychiatry in the pre-implantation phase of VAD therapy is a crucial aspect that has been explored in various studies. ISHLT (2023) recommendations highlight a vital role in addressing the mental health needs of patients before VAD installation. They offer a structured approach to patient selection, which includes psychosocial evaluation. This is particularly relevant in the broader context of grief among VAD caregivers. Psychosocial evaluations are crucial in assessing patient eligibility for VAD implantation. These evaluations take into account factors such as the presence of social support, coping mechanisms, and mental health status. These factors have predictive value for postoperative outcomes, including the risk of infection and readmission (Saeed et al., 2023).

The Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT) is a reliable tool for evaluating psychosocial impairment pre-VAD insertion [Refer to Appendix F: Psychiatry Consult Questions]. This assessment tool has been linked to adverse medical and psychosocial outcomes following transplantation, therefore, its use by the psychiatry team may help the cardiology team in better choosing VAD candidates (Sperry et al, 2019).

The interplay between a patient's psychological state and the caregivers' experience, including their grief process, is a significant area of concern. The ESC (2021) highlights that decreased social support not only increases the risk of unfavorable outcomes for the patient but also imposes higher stress and challenges on the caregiver. Caregivers form an integral part of the psychological support for VAD patients, and their ability to cope with care demands is heavily influenced by the patient's emotional stability and readiness for VAD implantation.

B. Level 2. Index Admission

1. Pre-VAD Implantation Checklist

Under level two support, ensuring timely readiness of the VAD candidate and caregiver is essential. Preoperative readiness measures the patient and caregiver's ability to take in information, weigh potential consequences, and make an informed decision to have surgery (Torres et al., 2021). In this level, we suggest checking: 1. Home Readiness, 2. Patient Psychological Readiness, 3. Financial Readiness, and 4. Patient and Informal Caregiver VAD Education (What to expect, Immediate post-op and out of the hospital complications, and Self-care).

2. Home Readiness

It is important to inquire about certain aspects when assessing patients, including the presence of grounded electric outlets, telephone accessibility, the absence of clutter or hazardous conditions in their surroundings, and their proximity to emergency medical services (Hamdan et al., 2020; Saeed et al., 2023). Therefore, during the social worker visit, questions about the readiness and safety of the house should be asked, and any deficiency will be communicated with the CNS.

3. *Patient Psychological Readiness*

ISHLT advocates for a careful and complete psychosocial examination prior to heart transplantation or VAD, including formal consultation if there is a risk for psychiatric disease. It is necessary for a patient to provide informed consent, follow instructions, have enough social support, and display adequate cognitive and behavioral abilities in order to get compliant treatment. However, it is up to the institution to interpret and apply these guidelines (Saeed et al, 2023).

Psychosocial assessment prior to VAD implantation is critical in selecting individuals for advanced surgical treatment. This would be useful for giving post-implant psychotherapy assistance as well as customizing lifestyle changes for higher-risk individuals (Yost et al., 2016). Patients who have a high psychosocial risk tend to have higher incidence of device-related infections, gastrointestinal bleed, pump thrombosis and readmission (DeFilippis et al., 2020). A significant number of patients scheduled for VAD implantation often exhibit traits that are commonly associated with an elevated psychosocial risk level. These traits may include the lack of a dependable caregiver, limitations in health literacy, challenges with medication adherence, dietary concerns, and difficulties in keeping appointments (Rodriguez et al, 2018).

Along with the assessment of any psychiatric disease, the ISHLT (2023) recommends the assessment for any substance use (alcohol, tobacco, marijuana, cannabinoid). Every patient scheduled for VAD implantation should be provided with education emphasizing the significance of quitting smoking and understanding the implications of second-hand smoke exposure. Patients with a history of substance abuse involving marijuana, alcohol, or cannabis should undergo counseling and regular follow-up sessions. And Those with no history should receive education to never try them. We suggest, after identifying the VAD candidates, that the CNS re-evaluate the patients. If the SIPAT scores are high, they should be referred to a psychiatrist for further management before VAD implantation. And for the patients with normal scores, we suggest education on stress management, tobacco and alcohol abstinence, and seeking help if needed.

4. *Financial Readiness*

For individuals with limited medical coverage, depending on the country, there should be a mechanism in position to provide financial assistance or aid for postoperative care. This support can come from government programs, insurance providers, or even family members (Saeed et al., 2023).

Financial problems are a major concern for patients and their caregivers. The cardiology CNS will assess the financial situation for each VAD candidate. The substantial economic expenditures that families must bear, financial strain is prevalent, many of whom are forced to deplete their savings. Buying equipment, employing specialists, and the added financial strain that the disease imposes on families all add to the stress in family life. Financial concerns frequently impair the caregiver's capacity to satisfy the individual's healthcare demands, adding stress to their life (McMullan et al., 2022).

5. *Patient and Informal Caregiver VAD Education*

Discussions between the cardiology team [clinical nurse specialist and HF specialist], cardiothoracic team, and patient as well as informal caregivers should commence on concepts of VAD expectations, immediate postoperative and late complications after VAD implantation, and self-care.

6. *What to Expect*

Patients and caregivers should be familiar with what to expect after a VAD implantation. Websites can be used to help them read other patent and caregiver stories of living with a VAD. One such websites, www.myLVAD.com, uses simplified medical explanations. It explains to the patient and the caregiver what they should be expecting post VAD insertion: Immediately after surgery, coming off the ventilator, and recovering.

7. *Immediate Postop and Out of The Hospital Complications*

Adverse events pose a significant challenge to the long-term sustainability and durability of VADs. Patients in a state of cardiogenic shock during implantation have been found to have a higher occurrence of these events. Surprisingly, even among otherwise healthy patients who did not require IV inotropic support during implantation, there is a substantial morbidity rate, with an 80% readmission rate within one year of follow-up (Han et al., 2018).

Guidelines have shown that adverse events are common in VAD patients [Refer to Appendix G. Post VAD Complications]. Incidence may vary depending on the device generation (Agrawal et al., 2021; Han et al., 2018; Saeed et al., 2023).

8. *Self-Care*

As per the American Heart Association (AHA) in 2022, several health and socioeconomic factors have been linked to unfavorable clinical outcomes, necessitating a fundamental shift in how education and support are provided. Depression has been connected to inadequate self-care, higher rates of rehospitalization, and increased all-cause mortality among HF patients. Interventions designed to improve self-care have demonstrated the potential to decrease hospitalization and the risk of death, particularly in individuals dealing with moderate to severe depression (Heidenriech et al., 2022).

Patients must engage in a comprehensive regimen of self-care activities, such as self-care maintenance, self-care monitoring, and self-care management [Refer to Appendix H. Self-care of VAD patients] (Melnikov et al., 2023). Cardiology CNS alongside the HF specialist have to educate patients and caregivers about self-care and its components (device handling, exit site care, and infection prevention) (Spielmann et al., 2021).

C. Level 3. Intraoperative Support

Under level three support, ensuring intraoperative support for the caregiver is important. Better communication skills between caregivers and care recipients may lessen caregiver stress and frustration in light of the growing complexity of healthcare (Smith et al., 2018). In this level, we suggest improving communication between healthcare providers and informal caregivers during surgery, to ease their stress.

Clear communication is essential. Family members have a desire for greater involvement in care and for their opinions to be heard throughout the care process. They also seek support to deal with the difficulties of caregiving and bereavement, both emotionally and in terms of resources (Naoki et al, 2018; Yu et al., 2022). A need for healthcare professionals to be open and proactive in their communication is highlighted by the fact that ambiguities or a lack of information can reduce patients' confidence in their ability to make decisions. The humanistic approach is just as important to the quality of care as medical procedures. Caregivers demand compassion in addition to information, indicating that the emotional component of communication is just as crucial as the content (Durieux et al., 2022).

For better satisfaction, there is an emphasis on better communication and information from the healthcare providers side towards the informal caregivers. A study conducted at university hospitals in Norway and Denmark identified two primary themes: the absence of preoperative information and the role of caregivers in actively seeking communication while in the hospital. The findings highlight the critical need for a more inclusive approach to communication in healthcare settings, especially for significant procedures like open heart surgery (Hojskov et al., 2023). Therefore, there are few options that can be adopted to ease the caregivers anxious state during the surgery.

Mignault et al. (2022) investigates the benefits of automatic intraoperative SMS updates as a quality improvement program. The purpose of this study, which was carried out in a big tertiary care hospital, was to increase communication between surgical teams and caretakers by using SMS messaging. The effort aims to boost caregiver satisfaction while decreasing anxiety. During the research period, caregivers for more than 75% of procedures chose to receive SMS updates, with 34,129 texts sent in total. The survey findings revealed great caregiver satisfaction and a considerable decrease in anxiety. This effort emphasizes the need for digital health care technologies in improving family-centered communication. Wieck et al. (2017) explored the utilization of an electronic medical record (EMR)-integrated communication system to enhance perioperative communication with families. Implemented at Doernbecher Children's Hospital, Oregon, this system allowed for the sending of customized or standardized text messages to families, improving patient satisfaction, and efficiency. The system was well-received by families, nurses, and surgeons, indicating its effectiveness in improving intraoperative family communication.

D. Level 4. Immediate Post-Operative VAD

Under level four support, a smooth transition to the Intensive Care Unit (ICU) setting may lessen the stress and anxiety of the caregivers. Transitioning presents a number of challenges for both patients and caregivers, including conflicting emotions about the change, worrying about the new atmosphere, and looking for new support, which can leave them experiencing care shock (Ghorbanzadeh et al., 2021). In this level, we suggest guides to improve the caregivers stay in the ICU.

Intensive care units are dedicated to caring for patients facing life-threatening illnesses or critical events. The environment can be intimidating for both the patient and their family, leading to feelings of stress, anxiety, uncertainty, and even post-traumatic stress disorder. Regardless of the family's educational background or cultural differences, the primary requirement is to have a clear understanding of the patient's clinical condition. Effective communication significantly impacts the satisfaction of families during their loved one's admission. Since patients are often too ill to actively participate in communication and decision-making, their families play a crucial role in discussions and choices regarding their treatment (Kynoch et al., 2016).

Although hospitals adapt Patient-Centered Care, however, a new model Family-Centered Care may also show better outcomes in terms of satisfaction for caregivers in the ICU setting, where most patients cannot advocate for themselves [Refer to Appendix I. Post-Op Orientation of The Informal Caregiver] (Schwartz et al., 2022). This model comprises five key practices, with the first practice being to encourage and facilitate family presence. Recognizing that families play a crucial role in the care of their loved ones in the ICU, this practice emphasizes their involvement and support (Ning & Cope, 2020). And the second being supporting the informal caregiver and their family. Supporting the caregiver so he/she feels less overwhelmed and anxious is important (Davidson et al., 2017). Third is prioritizing communication with the family. Healthcare providers should be aware of the importance of empathic, respectful, and supportive communication with caregivers (Goldfarb et al., 2017). Fourth, consultation. In order to reduce psychological distress among caregivers, some consults may be necessary: palliative, social services, psychiatry teams… (Davidson et al., 2017). Lastly, it's important to maximize operations in the ICU environment. This involves integrating quality improvement initiatives focused on monitoring and evaluating family satisfaction with care, as well as understanding healthcare providers' perspectives on the support and resources needed for such care. Policies should be developed to facilitate caregivers' stays, ensuring they have adequate time for rest, sleep, and meals (Nin Vaeza et al., 2020).

To further understand the practical application of these practices, Appendix J provides a comprehensive guide. Titled "Guide to ICU Stay at the American University of Beirut Medical Center", this appendix offers valuable insights into the real-world implementation of Family-Centered Care in a hospital setting. It includes detailed information on how to navigate the complexities of an ICU stay, supporting both patients and caregivers.

E. Level 5. Pre-Hospital Discharge

Under level five support, high-quality patient education materials are critical for providing patients with relevant and practical information. Patients and caregivers expressed that the benefits of a comprehensive home transition are: (1) feeling that medical professionals genuinely care about them; (2) clear accountability from the health care system; and (3) feeling ready and able to carry out care plans (Mitchell et al., 2018). In this level, we suggest educational discharge checklists that healthcare providers can use to ensure that caregivers and patients are ready for discharge, and safe to handle the VAD.

1. Patient and Informal Caregiver Education

It is stated that surgical discharge instructions are frequently devoid of evidence-based information and are instead focused on surgeon preferences or training procedures. There is room for improvement in post-surgical patient education, with an emphasis on developing high-quality materials that are both relevant and communicative (Scott et al., 2018). A discharge checklist [Refer to Appendix K. VAD Discharge Checklist for Patients and Caregivers] is a valuable tool to follow up on discharge planning.

According to ISHLT (2023) guidelines, daily driveline dressing changes using chlorhexidine swabs are recommended as the primary aseptic method. Once the driveline has healed, the dressing change frequency can be reduced to three times a week. To ensure that patients and caregivers are properly prepared before discharge, it is recommended that both parties engage in an exit interview where they demonstrate their acquired skills and knowledge (e.g., dressing change procedures, battery replacement to support safe VAD patient discharge) (Saeed et al., 2023). There is no standard procedure for driveline care, however, patients and caregivers should be taught about the frequency of dressing change, patient's position while changing the dressing, how to clear the surface, in a sterile technique, type of dressing to be used, how to manage the driveline during dressing change and discarding used materials (Wilcox et al., 2019). Infection is a frequent adverse event and an independent predictor of death. Though it can develop anywhere on the VAD apparatus, from the soft tissues surrounding the outlet to the driveline, driveline infection is the most prevalent, occurring in 15.4% to 23.8% (Han et al, 2018). Patients and caregivers should receive thorough education on recognizing the signs and symptoms of driveline infection, and should understand the critical importance of promptly reporting any symptom to their healthcare provider (Saeed et al., 2023). Once sufficient wound healing has been verified, the patient should be educated in the proper bathing method. Driveline dressing should not get wet, controller and batteries should be placed within reach, but away from any water, so they don't pull on the driveline, bathing is not advised (www.myLVAD.com).

Education for patients, caregivers, and medical staff regarding device alerts is crucial to enable prompt diagnosis and intervention. Until monitor device parameters become accessible, the evaluation of VAD alerts requires a review of the patient's clinical history and an examination of device data. While minor device issues can sometimes be resolved through telephone assistance or during a clinic follow-up, substantial device alarms mandate in-person assessment by qualified VAD specialists (Saeed et al., 2023). It is critical to keep with the patient and the caregiver an information card of all the healthcare providers needed in case of emergencies (Scott et al., 2018).

Patient and caregiver education includes batteries maintenance and electrical safety. A per ISHLT (2023), batteries should show charge maintenance, and devices with battery clips should show secure battery attachment, as well as clean battery connections. The home environment should be safe post discharge, and this includes the availability of grounded electrical outlets and an uninterrupted power supply (Saeed et al., 2023). Educate on daily maintenance routines, including checking battery life, changing batteries, and managing the power source (Ozdemir Koken et al., 2019).

Various factors, such as reduced atmospheric pressure, lower humidity levels, the expansion of gases, limited mobility, and heightened physical and mental stress, can collectively affect cardiovascular health during air travel (Saeed et al., 2023). Education should focus on transporting spare VAD batteries in carry-on luggage and that people carrying lithium-ion batteries remain a safety risk for airlines. External backups should be accessible at all times, especially during long-distance trips (Saeed et al., 2023). Driving poses dangers not only to the driver, but also to any passengers and bystanders, making it a public health problem. The risks associated with driving for VAD patients primarily center around the possibility of sudden loss of consciousness or loss of control of the vehicle. These events can be triggered by device malfunctions, power loss, arrhythmias requiring ICD intervention, or stroke. Therefore, ISHLT (2023) does not recommend it.

Post device implantation, sexual activity has been seen as better due to improved cardiovascular health, and as worse due to the device itself and the batteries (Saeed et al., 2023). Long-term adaptation counseling should serve as a resource center for information about illness-related changes in the quality of sexual activity (Kugler et al., 2018). Physical activity starts as early as possible post-surgery and must continue at home. There is major emphasis on the significance of early physical rehabilitation and mobilization following VAD surgery (Fick et al., 2022). The study dwells on the need of patient education, especially in terms of enhancing functional mobility and preparation for discharge. Patients who have undergone VAD surgery frequently arrive with a poor degree of physical function, which is aggravated by immobility and hospital-related tasks. Early mobilization, supervised by a physical therapist, is critical for improving patients' functional results. According to the study, the optimal techniques for teaching LVAD patients and caregivers entail early engagement in physical therapy. The educational approach should be comprehensive, addressing each patient's specific requirements. This might involve actual demonstrations, customized instruction from therapists, and frequent progress reviews. It is critical for patients' rehabilitation that they comprehend the necessity of early mobility and are equipped to participate in these activities (Fick et al., 2022). According to ISHLT (2023) guidelines, VAD patients should strive to maintain a BMI (Body Mass Index) below 30 Kg/m^2. Current data does not provide strong support for dietary salt restriction as a means to reduce mortality or hospitalization, although it may have a role in alleviating symptoms and improving the quality of life for HF patients. Despite the absence of statistical significance, stricter sodium restriction (2000 mg/d) was related with poorer outcomes when compared to less rigorous sodium restriction (2-3 g/d) (Colin-Ramirez et al., 2022). VAD patients may appear to be in good health, but they should be reminded that they are still vulnerable and should be urged not to consume alcohol or tobacco, to check up on a regular basis, and not to discontinue their HF medications (Saeed et al., 2023).

VAD patients have poor medication adherence (Tan et al., 2017). There are certainly numerous challenges when it comes to medication adherence. These challenges exist not only at the patient-provider interaction level but also within the healthcare system as a whole and extend to issues involving insurers and payment systems (Piña et al., 2020). WHO (2003) claimed that adherence to long-term medicines was 50% in industrialized nations (Piña et al., 2020). Medication education, effective patient-provider communication, simplified medication regimens, the use of electronic reminders, and other similar interventions have been found to be effective strategies for improving medication adherence among older populations (Xu et al., 2023). VAD patients are given warfarin to keep their INR within the ranges advised by the device manufacturer (Saeed et al., 2023). Post discharge, patients with a well-controlled INR have fewer adverse events related to bleeding (Schlöglhofer et al., 2021). Therefore, it is very important to teach patients the importance of anticoagulant adherence, and frequent INR checking.

As a part of the protocol adopted by medical teams, it is essential to engage in discussions about the advantages and disadvantages of each medication option. Providers should also address factors such as cost disparities between brand and generic versions, potential side effects, and the recommended daily dosage. Effective communication, characterized by empathy and an understanding of the challenges associated with medication adherence for both acute and chronic conditions, can enhance compliance. Additionally, compliance can be further improved when patients are informed about the consequences of not adhering to their healthcare provider's instructions regarding medication use (Aremu et al., 2022).

F. Level 6. Support of the Outpatient

Under level six support, supporting the caregiver during follow up visits is important. VAD caregivers experience significant stress, which is linked to reduced preparedness, increased depressive symptoms, and a diminished quality of life (Mcllvennan et al., 2021). In this level, we provide checklists and educational materials to ease the caregivers’ responsibilities at home.

The number of visits to the healthcare providers varies according to the VAD program, but they are typically weekly for the first month, then bi-weekly for 2 months, and then every four to eight weeks for as long as the VAD is active. Each visit will cover the following topics: vital signs, VAD parameters, physical exam, medication review, functional capacity evaluation, laboratory data, VAD supply, and follow-up visits and testing (Yousefzai & Urey, 2021). At first, the adjustment period may be difficult. Patients and caregivers must learn to adapt to daily routines in order to accommodate the device. This includes sleep disturbances, changes in hygiene, wardrobe habits, as well as the home environment and psychological adaptations such as adopting new routines, managing stress, and changes in interpersonal interactions. Patients may also worry about being a physical or financial burden on their caregiver (Smith & Franzwa, 2015).

VAD caregivers often feel underprepared for their roles despite receiving education in hospital. They face challenges in adapting to caregiving responsibilities once at home (McIlvennan et al., 2021). Therefore, preparing the caregivers to see warning signs will help decrease their stress and anxiety. A symptom tracker checklist [Refer to Appendix L. Symptom Tracker Checklist of VAD patients] is very important. This checklist will include alarming signs of HF exacerbation, specifically using the HF symptom tracker (HFaST) (Lewis et al., 2019), signs of driveline infection (Leuck, 2015), and signs of bleeding (Perna & Wettersten, 2021), and VAD alarms [Refer to Appendix M. VAD Alarms] (Chaudhry et al., 2022). Every program should designate an on-call individual who can provide assistance in troubleshooting, resolving issues, and planning the next steps necessary to provide optimal care for the patient (Chaudhry et al., 2022).

The emotional and psychological well-being of caregivers is of utmost importance. It is crucial to incorporate routine psychosocial assessments into the outpatient care of VAD patients to effectively address the emotional and psychological needs of caregivers (Smith & Franzwa, 2015). The American Medical Association has developed and assessed the Caregiver Health Self-Assessment Questionnaire. This questionnaire serves as a tool for caregivers to assess their own behavior and potential health risks. It aids healthcare practitioners in identifying and offering preventive interventions to a potentially overlooked at-risk group. The questionnaire has the potential to enhance communication and foster a healthier partnership between healthcare providers and caregivers [Refer to Appendix N. Psychosocial Assessment of the Informal Caregiver] (Epstein-Lubow et al., 2010). There is a huge emphasis on the importance of supporting caregivers in the outpatient setting by focusing on the interdependency within the family. This approach involves not just addressing the patient but also supporting caregivers through peer support, personal time for self-care, and discussing their worries with the cardiology CNS (Andersen et al., 2020). Effective communication, with patients and their caregivers, is one of the main aspects of adequate care. It also involves long-term collaboration with the multi-disciplinary team (Ben Gal et al.; 2021).

Caregivers also play an essential role in palliative care discussions and decisions. It is important to include caregivers in these conversations to address their concerns and provide necessary support (Plőthner et al; 2019). The CNS cardiology can introduce caregivers to the website www.myLVAD.com, where the VAD caregivers have formed a community to share their thoughts and questions. Home-based specialist palliative care with the patient-caregiver dyad as the primary unit of care, highlights the need of managing both patients' and caregivers' suffering simultaneously. It can enhance mental health and mitigate other harmful impacts of caring (Von Heymann-Horan et al., 2018). This intervention significantly reduces caregivers' anxiety and sadness symptoms both before and after mourning (Von Heymann-Horan et al., 2018).

G. Level 7. Identification of Signs of Impending End of Life

Under level seven support, identifying early signs of impending death, is important, as it changes the course of care planning. While it is generally impossible to anticipate the date of death, the capacity of healthcare personnel to detect clinical signs and symptoms of near death in terminally ill patients may lead to earlier prediction of care requirements and better planning to deliver care that is personalized to the individual's needs, resulting in better end-of-life care and a better bereavement transition experience for the caregivers (Ijaopo et al.; 2023). In this level, we provide a list of signs and symptoms of near death.

While it is generally impossible to anticipate the date of death, the capacity of healthcare personnel to detect clinical signs and symptoms of near death in terminally ill patients may lead to earlier prediction of care requirements and better planning to deliver care that is personalized to the individual’s needs, resulting in better end-of-life care and a better bereavement transition experience for the families (Ijaopo et al.; 2023).

As we look further into the parameters impacting mortality in VAD treatment, we see that both pre-operative and post-operative features have an impact on patient outcomes. Being healthy enough to complete cardiopulmonary exercise tests and not getting dialysis during the hospitalization are pre-operative factors associated with a greater risk of dying outside of the hospital. Bleeding, infection, device malfunction, and mental episodes are all post-operative correlations with an increased risk of dying outside the hospital. In contrast, respiratory failure, neurologic dysfunction, and renal dysfunction shows a lower risk of dying outside of the hospital (Mcllvennan et al., 2018).

According to the EUROMACS registry, one out of every five patients die within 90 days following VAD implantation (Akin et al., 2020). Pump technology advancements have resulted in a significant reduction in hemocompatibility-related adverse effects (Nayak et al., 2023). Predictors of 5 years mortality rate differ than those of early mortality in VAD patients [Refer to Appendix O: Predictors of Mortality in VAD patients].

H. Level 8. Post Death Caregiver Support Program

Under level eight support, providing caregivers with post death support programs, will ease their grief. Interventions can stop caregivers from experiencing more serious issues following a patient’s death, like painful grief and psychological problems (Bergman et al., 2017). In this level, we provide a bereavement program led by the PC team.

It is impossible to overstate the importance of bereavement programs for informal caregivers. Even when these programs include only short-term interventions, they remain essential in preventing chronic grief or the onset of mental illnesses in caregivers of deceased patients (Wilson et al., 2021). It has been demonstrated that a variety of program combinations for bereavement can effectively address conditions like anxiety, depression, post-traumatic stress disorder, and complex or protracted grief. Effective communication with informal caregivers plays a critical role in these programs (Brekelmans et al., 2022) and will outline our brief intervention.

After the unfortunate death of a VAD patient, we plan to have the PC team provide bereavement support to caregivers. Communication that is sensitive, transparent, and compassionate between the team and the informal caregivers is required to assist caregivers in understanding and preparing for what to anticipate, as well as come to terms with their loss and sadness. The process is systematic, it begins when a patient is likely to die in the hospital and continues for up to one year after death. PC physicians, nurses, social workers, and psychologists are core members of this intervention. If any of the informal caregivers are found to be at risk of having complicated grief, during assessment, counseling and support are offered, and they are referred to the appropriate care provider if indicated [Refer to Appendix P. Signs and Symptoms of Complicated Grief]. The bereavement program consists of the following:

The PC nurse designated to do the follow-up communication shall call the designated caregiver in line with the bereavement follow-up plan or as needed. From the moment of the patient’s death, the grief follow-up program will be initiated as follows:

1. ***Within a week of death***
    - Express sympathy to the primary caregiver.
    - Introduce the bereavement support program.
    - Inform the primary caregiver about the frequency of phone calls.
    - Request permission from the primary caregiver to continue calling them.

2. ***At 40 days***
    - Conduct assessments and provide appropriate recommendations based on standardized questions [Refer to Appendix Q. Post Death- Caregiver Standardized Questions].
    - Explain the natural grieving process and what to expect when a loved one dies

3. ***At 6 months***
    - Conduct a brief grief questionnaire evaluation to identify caregivers at risk of developing complex sorrow [Refer to Appendix R: Brief Grief Questionnaire].
    - Refer if the screen for complex grieving is positive.

4. ***One year***
    - Conduct an evaluation using the short grief questionnaire to identify caregivers at risk of developing complex sorrow.
    - After one year, discharge the patient’s caregiver from the program.

CHAPTER V

DISCUSSION AND IMPLICATIONS

A. Discussion

The initiation of a bereavement support program for caregivers of DT-VAD patients prior to the patient’s death is a critical aspect of comprehensive patient and family care. VAD caregivers report a significant level of bewilderment toward end of life, including misunderstanding regarding the nature of the death, medical decisions to be made, palliative care and hospice treatments given (McIlvennan et al., 2016). The implementation of a bereavement support program for caregivers of DT-VAD patients, as early as the decision of implantation, is a key component for the caregivers’ well-being. This discussion synthesizes current literature to emphasize the importance of such initiative.

There is a lack of research on end-of-life planning for DT-VADs patients and caregivers. Although caregiver perspectives have been explored, the majority of publications have been about VAD deactivation (McIlvennan et al., 2016; McIlvennan et al., 2017; Nakagawa et al., 2020) care delivered to patients with VADs in the final weeks before death (McIlvennan et al., 2016), or caregiver stress, strain, and decision making (Streur et al., 2020). Little is known about adopting a bereavement support program for DT-VAD caregivers as early as the decision is made for implantation.

Informal caregivers frequently feel anticipatory grief, a type of mourning that happens before the patient’s death (Nielsen et al., 2016). This sort of grieving may be as profound as bereavement, affecting the caregiver’s mental health and quality of life. Anticipatory grief is directly correlated with caregiver burden. Reducing burden among caregivers of older cancer patients, improved family functioning, and enhanced resilience all have significant benefits in alleviating caregivers’ anticipatory sadness (Li et al., 2022). A pre-death bereavement support program can equip caregivers with coping methods and emotional support, thereby minimizing the negative consequences of anticipatory grieving (Kirby et al., 2017).

Early bereavement support assists caregivers in developing effective coping methods to decrease grieving and providing vital support. Emotional assistance is one of the most requested forms of help (Cacciatore et al., 2021). Support given to caregivers before the patients’ death can improve their psychological adaptation and strength. These programs may provide counselling services, peer support groups, and educational resources to caregivers, giving them the tools needed to manage their emotional and psychological well-being (Aoun et al., 2018). Palliative care providers benefit more from focusing their efforts on assessing and supporting family caregivers prior to grief, as well as creating community capacity and referral routes for bereavement care (Aoun et al., 2017). This lack of comprehensive care is also present in other disease processes. Though there are specialized services like daycare centers, training programs, and respite care available to assist caregivers, the majority of interventions focus on reducing caregivers’ stress levels and improving their capacity for coping. But these actions frequently fail to address the intense grief and guilt caregivers experience prior to a dementia patient’s physical passing (Chan et al., 2020).

Caregiving and eventual mourning can have a long-term psychological impact. Caregivers who do not receive enough support are more likely to experience protracted bereavement disorder and depression (Wu et al., 2022). Complicated mourning encompasses the more intense and long-lasting symptoms that interfere with social and vocational functioning. It has been linked to an increased risk of mental illnesses, sleep disturbances, suicidality, cardiovascular and cancer diseases, and a lack of social support (Pereira et al., 2016). Caregivers' powerful and conflicted feelings indicated the significance of health care professionals following up to ensure caregivers have access to social support and health/mental health care options to work through the post-caregiving experience (Orzeck, 2016). Grief support provided as an early intervention, within the context of a bereavement support program, can help to reduce the likelihood of these long-term psychological impacts.

Bereavement support programs can also help caregivers, patients, and healthcare practitioners have essential end-of-life talks. Such interactions are critical for ensuring that the patient's end-of-life desires are honored and can offer caregivers a feeling of closure (Sutherland, 2019). These discussions can help relieve caregivers of some of the decision-making duties during a difficult time. Aside from the time of end-of-life communication, some non-palliative care professionals acknowledged uneasiness and ambiguity about how to handle death (Chuzi et al., 2021). Conversations regarding prognosis and advance care planning occur infrequently in regular care, including cardiology practices (Hafid et al., 2021) and that many practitioners avoid these talks for fear of shattering hope or inflicting harm (Hamilton, 2016). One possible explanation for such discussion avoidance is that few cardiologists get formal communication or palliative care training (Berlacher et al., 2017).

Many caregivers find it difficult to adjust to life following the patient's death. Early bereavement assistance can help caregivers rethink their identity and find new meaning in their lives (Johnson, 2016). Changes and transformations in female caregivers' identities occurs during the active caring phase. This has an impact on them after-caregiving, as the women had put caring over all of their other ambitions, abandoning several hobbies in the process (Orzeck, 2016). According to Alves et al. (2022) about one-fifth of caregivers left their jobs within a year after the care receiver passed away, indicating the sizeable percentage of people who experience bereavement. Remarkably, mental health improved for caregivers who continued their work, but declined for those who stopped working. Therefore, assistance in adjusting is critical in reducing social isolation and encouraging caregiver reintegration into social and vocational situations.

B. Implications for Practice

Caregiving adds a dimension to bereavement that can make the post-caregiving experience more challenging, even though not everyone needs bereavement support. Healthcare providers should follow up to make sure that caregivers have access to social support and healthcare resources to help them navigate the post-caregiving experience, as highlighted by the strong and contradictory emotions experienced by caregivers.

There is a need for better support for caregivers of patients with DT-VADs. This includes training to enhance communication about end-of-life care, making such discussions more common, and providing ongoing, specialized palliative care throughout the patient's treatment journey to help caregivers prepare for end-of-life situations (Chuzi et al., 2021). There is a need for increased assistance during the grieving process. Furthermore, recommendations to modify practices and policies will be important, to better assist caregivers in situations involving both continuous care and bereavement. Though preliminary and requiring additional investigation, the results underscore the intricate dynamics of caregiving and the noteworthy influence of bereavement on the psychological well-being of caregivers (Alves et al., 2022).

Future studies should concentrate on the creation and assessment of these programs to fine-tune and personalize support to the unique requirements of this demographic. New policies could concentrate on the broad adoption of these initiatives, acknowledging not only the vital role caregivers play but also the unique difficulties they encounter while providing palliative care.

C. Conclusion

The establishment of bereavement support programs for informal caregivers of DT-VAD patients prior to the patient's death is not only humane but also a required strategy. Such programs target the special issues that these caregivers experience, such as improving their capacity to cope with anticipatory loss, promoting healthy psychological adjustment, and assisting them in making the transition to post-caregiving life.

In palliative care, the bereavement phase presents a unique and profound challenge, particularly for informal caregivers who are frequently unprepared for the intense emotional and psychological toll it can take. This stage is characterized by a complex mix of emotions that can be overwhelming, including grief, loss, and sometimes relief. It is critical to provide caregivers with targeted support during this phase so that they can process their experiences and find a new sense of normalcy after the loss of a loved one.

If health care practitioners consider caring as a continuum that extends beyond the death of the care-recipient, they will be able to create supportive treatments for caregivers during active caregiving that extend into grief. This might eventually be viewed as a prophylactic measure.

Bereavement support programs for informal caregivers of DT-VAD patients should be incorporated into the healthcare system as a compassionate approach and an essential step. These initiatives ensure a more comprehensive approach to care, which benefits our healthcare system long-term while also meeting the immediate needs of carers. A more resilient, encouraging, and compassionate healthcare environment can be cultivated by acknowledging and assisting caregivers as vital partners in the healthcare process.

APPENDIX A

Table 2 Markers of Advanced HF [I NEED HELP]

I	Inotropes	Previous or ongoing use of Dobutamine, Dopamine, Milrinone, or Levosimendan
N	NYHA Class/Natriuretic Peptide	Persisting New York Heart Association Class III/IV and/or persistently high ProBNP
E	End-Organ Dysfunction	Worsening renal or liver dysfunction
E	Ejection Fraction	Left Ventricular Ejection Fraction <20%
D	Defibrillator Shocks	Recurrent defibrillator shocks
H	Hospitalizations	More than 1 hospitalizations in the last 12 months
E	Edema/Escalating Diuretics	Persisting fluid overload and/or increasing diuretic demand
L	Low Blood Pressure	Systolic Blood Pressure <90 mmHg
P	Prognostic Medication	Inability to up-titrate medications

APPENDIX B

Table 3 INTERMACS Profile Descriptions in Patients with Advanced HF Profile

Patient Profile	**Time Frame for Intervention**
Profile 1: Critical Cardiogenic Shock Patients with life-threatening hypotension despite rapidly escalating inotropic support, critical organ hypoperfusion, often confirmed by worsening acidosis and/or lactate levels. “Crash and burn.”	Definitive intervention is needed within hours.
Profile 2: Progressive Decline Patient with declining function despite intravenous inotropic support, may be manifest by worsening renal function, nutritional depletion, inability to restore volume balance. “Sliding on inotropes.” Also describes declining status in patients unable to tolerate inotropic therapy.	Definitive intervention is needed within a few days.
Profile 3: Stable but Inotrope-Dependent Patient with stable blood pressure, organ function, nutrition, and symptoms on continuous intravenous inotropic support (or a temporary circulatory support device or both) but demonstrating repeated failure to wean from support due to recurrent symptomatic hypotension or renal dysfunction. “Dependent stability.”	Definitive intervention elective over a period of weeks to few months.
Profile 4: Resting Symptoms Patient can be stabilized close to normal volume status but experiences daily symptoms of congestion at rest or during ADL. Doses of diuretics generally fluctuate at very high levels. More intensive management and surveillance strategies should be considered, which may in some cases reveal poor compliance that would compromise outcomes with any therapy. Some patients may shuttle between 4 and 5.	Definitive intervention elective over a period of weeks to few months.

Profile 5: Exertion Intolerant Comfortable at rest and with ADL but unable to engage in any other activity, living predominantly within the house. Patients are comfortable at rest without congestive symptoms, but may have underlying refractory elevated volume status, often with renal dysfunction. If underlying nutritional status and organ function are marginal, patients may be more at risk than INTERMACS 4, and require definitive intervention.	Variable urgency depends upon maintenance of nutrition, organ function, and activity.
Profile 6: Exertion Limited Patient without evidence of fluid overload is comfortable at rest, and with ADL and minor activities outside the home but fatigues after the first few minutes of any meaningful activity. Attribution to cardiac limitation requires careful measurement of peak oxygen consumption, in some cases with hemodynamic monitoring to confirm severity of cardiac impairment. "Walking wounded."	Variable depends upon maintenance of nutrition, organ function, and activity level.
Profile 7: Advanced NYHA class III A placeholder for more precise specification in future, this level includes patients who are without current or recent episodes of unstable fluid balance, living comfortably with meaningful activity limited to mild physical exertion.	Transplantation or circulatory support may not currently be indicated.

Kittleson et al., 2019

APPENDIX C

Table 4 Preparedness for Caregiving

Question	**Not At All Prepared**	**Not Too Well Prepared**	**Somewhat Well Prepared**	**Pretty Well Prepared**	**Very Well Prepared**
1. How well prepared do you think you are to take care of your family member’s physical need?	0	1	2	3	4
2. How well prepared do you think you are to take care of his/her emotional needs?	0	1	2	3	4
3. How well prepared do you think you are to find out and set up services for him/her?	0	1	2	3	4
4. Ho well do you think you are for the stress of caregiving?	0	1	2	3	4
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your family member?	0	1	2	3	4
6. How well prepared do you think you are to get help and information you need from healthcare providers?	0	1	2	3	4
7. Overall, how well prepared do you think you are to care for your family member?	0	1	2	3	4
8. Is there anything specific you would like to be better prepared for?					

Gutierrez-Baena et al., 2022

APPENDIX D

Table 5 Pre-VAD Evaluation By the Palliative Team

Preferences for decision making and information sharing	Ask the patient. • Who is your informal caregiver? • Have you discussed the above with that person?
Patient and Caregiver Comfort	Assess patient level of comfort in terms of • Comfort with the care • Comfort with symptom management • Ease with the decision Assess caregiver level of comfort in terms of • Comfort with the care • Acceptability of the commitment • Ease with the decision
Patient and Caregiver Understanding of VAD Therapy	Ask patient and caregiver • When did they hear about VAD? • How did they feel about VAD as a treatment option?
Patient Goals and Expectations	Ask patient • What makes his/her life meaningful? What is his/her current quality of life? • What is he/she hoping to achieve by getting a VAD? • What are things he/she is looking forward to doing after getting the VAD?

Spiritual Needs	Ask patient and caregiver • Are they a spiritual person? Are they religious? • How important is it? • What role do their beliefs play in regaining health? Are they part of a spiritual or religious community? • How would they like the health care provider to address these issues in the patients' health care?
Possible Complications and Exploration of Unacceptable Conditions	Emphasize that having a VAD can cause problems, such as stroke or infection. What if things don't go well? These complications can cause significant disability and keep you from achieving your goals. Ask patient • What is the condition he/she would find unacceptable? • Ask about debilitative comorbid conditions: conditions that are not associated with the VAD but rather caused because of its presence and the fact that the VAD prolonged survival.

Nakagawa & Blinderman; 2018

APPENDIX E

Table 6 Social Workers Standardized Questions

1	Social, psychological, behavioral, and cognitive coping abilities.
2	Patient’s comprehension of the proposed intervention.
3	History of adherence and compliance with medical recommendations.
4	Availability of familial and social support systems (e.g., marital status, presence of children, availability of caregivers).
5	Substance use history.
6	Evaluation of financial resources and other support systems.
7	Living Arrangements [proximity of family members, post-VAD implantation arrangements].
8	Caregiver’s understanding of VAD and its role (e.g., What is a VAD? Does it replace the patient’s heart? Duration of VAD use).
9	Assessment of any psychopathological factors within the patient’s family.
10	Identification of conflicting caregiving obligations.
11	Housing-related issues.

Bruce et al., 2017

APPENDIX F

Table 7 Psychiatry Consult Questions

SIPAT Core Components	
Readiness for VAD	• Knowledge and understanding of medical illness. • Knowledge and understanding of VAD. • Willingness for treatment. • Treatment compliance. • Lifestyle factors.
Social Support System	• Availability of social support system. • Functionality of social support system. • Appropriateness of physical living space and environment.
Psychosocial Stability and Psychopathology	• Presence of psychopathology. • Assessment of depression. • Assessment of anxiety. • History of neurocognitive impairment. • Influence of personality disorders. • Effect of truthfulness vs. deceptive behaviors. • Overall risk for psychopathology.
Lifestyle and Effect of Substance Abuse	• Alcohol use/ abuse/ tendency. • Substance use/ abuse/ tendency. • Nicotine use/ abuse/tendency.

Sperry et al., 2019

APPENDIX G

Table 8 Post-VAD Complications

Adverse Events, Incidence Rate, Timeline		
Adverse events	**Incidence**	**Timeline**
Pump thrombosis	1.1 to 12.1%	Varied
Gastrointestinal bleed	15 to 30%	Varied/ recurrent
Stroke	13 to 30%	Varied
Aortic insufficiency	30% - 2 years	Chronic
Driveline infection	15 to 24%	Varied
Arrythmias	42%	Varied
Outflow graft obstruction	4 to 9%	Varied
Device failure	36 to 51%	Varied

Agrawal et al., 2021; Han et al., 2018; Saeed et al., 2023

APPENDIX H

Table 9 Self-Care of VAD Patients

Self-Care Maintenance			
	I clean the controller, batteries, and battery connection		I avoid kinking, pulling, or moving of the driveline at the exit site
	I check that the electric and battery power source are available and work properly		I keep the exit site and the driveline clean and dry
	When I go to sleep, I keep the driveline, controller, and power supply secured		I follow the steps/instructions in changing the sterile dressing on the exit site of the driveline
	I keep back up battery and controller with me, wherever I go		I inspect all cable connectors and the driveline for dirt or damage every day
	I can talk to someone about coping with the LVAD or with my health condition		I take my medicines as prescribed every day
	I perform regular exercise		I eat a heart healthy diet
	I follow the daily recommended fluid intake		I limit my alcohol intake to 1 unit/day for females and 2 units/day for males
	I avoid cigarettes and tobacco smoke		I get enough sleep
	I come to scheduled clinic visits		
Self-Care Monitoring			
	I evaluate and monitor my driveline exit site for evidence of infection and drainage as instructed		I monitor myself for signs of infection including fever, chills, and night sweats
	I monitor myself for any signs of blood in my nose, urine (color change), or blood in my stools		I check my INR regularly as instructed
	I monitor myself for the development or increase in leg swelling		I monitor myself for worsening shortness of breath
	I monitor myself for worsening fatigue		I weigh myself every day
Self-Care Management			
	I contact the VAD team in case of alarms or equipment issues		I talk with VAD team or someone when I am feeling sad or worried
	I adjust my physical activities according to my symptoms		I contact the VAD team in case of symptoms

Melnikov et al., 2023

APPENDIX I

Table 10 Post-Op Orientation of The Informal Caregiver

1	Encourage and facilitate family presence	An open-door policy to the informal caregiver should be adopted, as well as open access to information, whenever needed
2	Supporting the informal caregiver and their family	Healthcare providers to introduce themselves when entering the room, nurses explain the tasks they are about to do
3	Prioritizing communication with the family	Post operation, caregivers must be oriented, by the nurse, to the ICU setting, lines, tubes, medications given. The cardiology CNS, along with the HF specialist should report daily updates regarding VAD patient to the caregiver. Multidisciplinary meetings should be held on a weekly basis, and whenever a major event happens with the patient, to keep the family informed at all times.
4	Consultation	To reduce psychological distress among caregivers, some consults may be necessary: palliative, social services, psychiatry teams…
5	Maximize operations and environment	Building a part of the electronic health record in which HCPs record information exchanged with the family, goals of care talks, family input in and arguments regarding choices.

Schwartz et al., 2022

APPENDIX J

Table 11 Guide to ICU Stay at the American University of Beirut Medical Center

Visiting Regulations	• Please enter the patient’s room one person at a time and limit your visit to five to ten minutes for each visitor. This will allow us to provide uninterrupted care for the patient. • It is preferable to restrict visitors to close family members only. • Visitors are not allowed to stay or sleep inside ICU rooms. • Children under 12 years of age are not allowed to enter the ICU.
Unit Regulations	• Only the identified key person has the right to receive information over the phone. • Cellular phones should be turned off or left outside the ICU since they may interfere with our monitors. • Food, drinks, flowers, or plants are not allowed in the ICU. • Do not assist a patient before calling the nursing staff. • Taking pictures is not allowed. It violates our patient’s privacy, dignity and confidentiality. • Smoking is strictly prohibited. • Religious figures are welcome at any time. • Home medications are not allowed unless informed otherwise. • Beverage and snack machines are available in the waiting area.
Infection Control Guidelines	• Wash your hands with soap and water or antibacterial solution before and after you enter the patient’s room to prevent the spread of infections. Antibacterial solutions are available near to each room. • If the patient is under isolation, visitors should wear protective clothes (such as a gown, gloves and a mask) before entering the patient’s room. Remove these clothes before leaving the patient’s room and discard them in the wastebasket.
Transferring Outside ICU	• Your patient will be transferred from the ICU into a regular room when his/her condition improves and does not require intensive care and close monitoring.

	• Only the attending ICU doctors decide on the best time for transfer. • The ICU team will collaborate with multiple services within the medical center to make the patient's transfer smooth.
Complaints and Compliments	• We strive to make your stay at our hospital smooth and pleasant. • However, things do not always go the way that we like.

American University of Beirut Medical Center, 2016

APPENDIX K

Table 12 VAD Discharge Checklist for Patients and Caregivers

Competency	Caregiver and Patient Status	
Dressing Change with Return Demonstration		Demonstrate step-by-step dressing change procedure.
		Emphasize hand hygiene and use of sterile gloves.
		Discuss frequency of dressing changes.
		Discuss proper disposal of used materials.
Signs of Infection		Educate about infection signs: REEDA.
		Discuss the importance of daily inspection of the incision site.
		Discuss when and how to report symptoms to providers.
		Understand the potential risks of untreated infections.
Emergency Procedure		Get familiar with different alarm sounds and their meanings.
		Keep emergency contact numbers easily accessible.
		Regularly review and practice the emergency plan.
Battery and Equipment Maintenance		Demonstrate how to charge and change batteries.
		Teach how to check for battery life and equipment functionality.
		Discuss storage and care of spare batteries and equipment.
Medication Management and Adherence		Review each medication, its purpose, dosage, and timing.
		Discuss the importance of adherence to medication schedules.
		Discuss the use of medication organizers and reminders.
		Discuss potential side effects and interactions.
Physical Activity		Outline safe and recommended exercises post-VAD implantation.
		Highlight the importance of regular, moderate physical activity.
Follow-Up Appointments		Provide a schedule of upcoming appointments and tests.
		Discuss the importance of each appointment for ongoing care.
Diet and Fluid Management		Discuss specific dietary restrictions or recommendations.
		Discuss the importance of monitoring and recording daily fluid intake.

		Weight monitoring.
		Smoking and alcohol cessation.
INR Management		Explain the purpose and importance of INR monitoring.
		Discuss the impact of diet and medications on INR levels.
Bathing and Personal Hygiene		Give instructions on waterproofing and protecting the device during bathing.
		Discuss frequency and duration of bathing that is safe.
Travel Considerations		Discuss plans for medical emergencies while traveling.
		Discuss plans for managing medications during travel.
		Discuss plans for transporting equipment during travel.
		Discuss travel insurance and healthcare access.
		Discuss tips for airport security and travel with a medical device.
Electrical Safety		Understand the electrical requirements of VAD equipment.
		Understand the needed precautions during power outages.
Emergency Contact Information		Share a comprehensive list of emergency contacts.
		Ensure easy access to this list for all family members.
		Regularly updating contact information.
		Carry emergency contact information when outside the home
Sexual Activities		Discuss when it’s safe to resume sexual activity.
		Communicate with partners about fears and expectations.
		Address potential changes in sexual function or libido.
Pet Care		Understand potential infection risks from animals.
		Keep pets away from surgical sites and equipment.
		Ensure regular pet hygiene and vaccinations.
Driving and Transportation		Assess readiness to resume driving post-surgery.
		Understand limitations and precautions for driving.

Colin-Ramirez et al., 2022; Fick et al., 2022; Han et al., 2018; Kugler et al., 2018; Ozdemir Koken et al., 2019; Piña et al., 2020; Saeed et al., 2023; Scott et al., 2018; Schloglhofer et al., 2021; Tan et al., 2017; Wilcox et al., 2019; Xu et al., 202

APPENDIX L

Table 13 Symptom Tracker Checklist of VAD patients

Symptoms	**Yes**	**No**
Fatigue or low energy level when performing everyday activities.		
Fatigue or low energy level even while sitting or lying down.		
Shortness of breath at rest		
Shortness of breath when performing everyday activities		
Shortness of breath while lying down or reclining (for example, needing to add pillows or move to a recliner to sleep)		
Sudden attacks of shortness of breath that wake you from sleeping.		
Cough.		
Swelling of feet, ankles, legs, or abdomen; shoes or waistband feeling tight		
Heart palpitations—rapid, fluttering, or pounding heartbeat.		
Gained more than 1 Kg during the past 24 h or more than 2.5 Kg during the past 72 h		
Fever, erythema at the driveline, hot to touch, pus.		
Focal weakness, sensory deficits, speech difficulties, vision loss, or loss of coordination.		
Headache, confusion, or altered mental status.		

Leuck, 2015; Lewis et al., 2019; Perna & Wettersten; 2021

APPENDIX M

Table 14 VAD Alarms

VAD Alarms	
Heart Ware	**Heart Mate II and III**
High Priority Alarms • VAD Stoppage • Controller Failure • Critical Battery Medium Priority Alarms • High Watts • Low Flow Alarms • Controller Faults Low Priority Alarms • Suction Events • Increased Afterload • Impaired VAD Filling	Alarms with these devices include messages and active symbols on their controller screen. Hazard Alarms • Pump Off • Low Flow • Driveline Disconnect • Double Power Disconnect • Critical Battery

Chaudhry et al., 2022

APPENDIX N

Table 15 Psychosocial Assessment of the Informal Caregiver

During the past week or so, I have…	**Yes**	**No**
1. Had trouble keeping my mind on what I was doing….		
2. Felt that I couldn't leave my relative alone		
3. Had difficulty making decisions		
4. Felt completely overwhelmed		
5. Felt useful and needed		
6. Felt lonely		
7. Been upset that my relative has changed so much from his/her former self		
8. Felt a loss of privacy and/or personal time		
9. Been irritable		
10. Had sleep disturbed because of caring for my relative		
11. Had a crying spell(s)		
12. Felt strained between work and family responsibilities…		
13. Felt ill (headaches, stomach problems or common cold)		
14. Had back pain		
15. Found my relative's living situation to be inconvenient or a barrier to care		
16. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress		
17. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year.		
18. Found my relative's living situation to be inconvenient or a barrier to care		
19. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress		
20. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year.		

Epstein-Lubow et al., 2010

APPENDIX O

Table 16 Predictors of Mortality in VAD patients

90 Days Mortality Predictors	**5 years Mortality Predictors**
Age	Elevated BUN
Female sex	Infected driveline
INTERMACS profile 1 to 3	Prior CABG, or surgical valve procedure
ECMO	GFR < 60 ml/min/1.73m^2 at discharge
Laboratory results (Increased Creatinine, total bilirubin, lactate, Decreased hemoglobin)	Serious ventricular arrhythmias
Hemodynamic predictors (elevated RA-to-PCWP ratio, pulmonary vascular resistance, and low systemic vascular resistance).	Hemocompatibility related adverse events

Akin et al., 2020; Nayak et al., 2023

APPENDIX P

Table 17 Signs and Symptoms of Complicated Grief

Caregiver Characteristics			
	Caregiver under 18 years of age		Caregiver was a twin
	Caregiver is a young spouse		Caregiver is an elderly spouse
	Caregiver has no social network		Caregiver is isolated
	Caregiver was dissatisfied with help available during illness		Caregiver was financially dependent on deceased patient
	Caregiver was fully dependent on deceased patient		
Illness Characteristics			
	Lengthy and burdensome		Inherited Disorder
	Stigmatized disease in the family/community		
Death			
	Significant cultural/social burdens as a result of the death		Traumatic circumstances associated with death
	Sudden		
History of Loss			
	Caregiver has had cumulative losses		Caregiver has previous mental health illness
	Caregiver has current mental health illness		Caregiver has other significant health issues
Relationship with the Deceased			
	Lifelong Partner		Highly Dependent
	Antagonistic		Deeply Connected

Score 0 to 2: Low Risk; Score 3 to 5: Moderate Risk; Scores of 5+ are High Risk

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APPENDIX Q

Post Death- Caregiver Standardized Questions

1. Are you sleeping well at night?
2. Are you eating well?
3. Do you have a family and/or friend with whom you feel comfortable talking to?
4. Do you feel you are well surrounded by your family/friends?
5. Did you go back to work? If not, why?
6. How are you feeling since the death of Mr. or Mrs. …?

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APPENDIX R

Table 18 Brief Grief Questionnaire

Question	Not At All	Somewhat	A Lot
1. How much are you having trouble accepting the death of ---?	0	1	2
2. How much does your grief still interfere with your life?	0	1	2
3. How much are you having images or thoughts of --- when s/he died or other thoughts about the death that really bother you?	0	1	2
4. Are there things you used to do when --- was alive that you don’t feel comfortable doing anymore, that you avoid? Things like going somewhere you went with him/her, or doing things you used to enjoy together? Or avoiding looking at pictures or talking about ---? How much are you avoiding these things?	0	1	2
5. How much are you feeling cut off or distant from other people since --- died, even people you used to be close to like family or friends?	0	1	2

A score of 5 or more may be suggestive of the presence of the syndrome of Complicated Grief, but full evaluation by a clinician is necessary to make this diagnosis.

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